Experiences of People with Multiple Sclerosis and their use of Assistance Dogs: An Interpretative Phenomenological analysis

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Abstract

In this thesis, findings are reported from a qualitative study of eleven people living with multiple sclerosis (MS) who between them have used nineteen assistance dogs for more than two decades.

The first recorded use of dogs specifically trained to help people living with physical impairments undertake practical tasks aimed at increasing their independence and quality of life was in North America in 1975. In recent decades, the use of such dogs by people living with a wide range of physical, sensory, and intellectual disabilities and mental illness has rapidly expanded in many countries of the global north. Research from the field of human-animal interactions and disability studies raises issues concerning both the quality and quantity of evidence in this area. Recently, this has led researchers to urge caution regarding the benefits and challenges of assistance dog use by those living with disabilities. In this study, participants were recruited from two of the four accredited charities who train assistance dogs for people with physical disabilities across the United Kingdom (UK). Single in-depth, semi-structured interviews were undertaken. Interpretative Phenomenological Analysis (IPA) was applied to the data resulting in three super-ordinate themes: VISIBILITY, (UN)CERTAINTY and IDENTITY.

Key findings were that the use of an assistance dog was perceived to transform participants' self-identity to one which was shared with their dog. Experiences of interactions between participants and society in which their assistance dog served to misdirect negative public gaze away from visible impairment were understood to amplify shared human-ness and minimise difference. This interspecies relationship was however, revealed to be vulnerable to the uncertainties of ageing (human and canine) intertwined with the unpredictability of living with a degenerative condition. The findings and conclusions offered in this thesis enhance and inform both critical disability studies and human-animal interaction studies through its exploration of new understandings of identity.

Dedication

To the memory of my parents

Sean and Deirdre '*Tiocaidh ár lá'.*

Not forgetting Sparky, Ragnor, Mumby, Fionn and Quigley.

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Glossary

Literature in the field of Anthrozoology uses a variety of terms to describe studies of human-animal interactions (HAI) and the resultant human-animal relations (HAR) and human-animal bonds (HAB). In the interest of clarity and consistency for the purposes of this thesis I will be using the term human-animal interaction (HAI) by which I mean the "mutual and dynamic relationships between people and animals, and the ways in which these interactions may affect physical and psychological health and well-being" (Griffin et al., 2012, p. 3).

Abbreviations

AAA	Animal Assisted Activity
AAT	Animal Assisted Therapy
AD	Assistance Dog
ADI	Assistance Dogs International
ADUK	Assistance Dogs UK
HAB	Human-Animal Bond
HAI	Human-Animal Interaction
MS	Multiple Sclerosis
OTAD	Owner Trained Assistance Dog

PPMS	Primary Progressive Multiple Sclerosis
RRMS	Relapsing Remitting Multiple Sclerosis
spss	Secondary Progressive Multiple Sclerosis

Chapter 1

This chapter introduces the thesis, establishing its context and locating it in the overlapping spheres of disability studies and the study of human-animal interactions. It outlines the overarching aim and objectives of the study and indicates its significance to both areas of academic enquiry. My personal motivations and position as an 'insider researcher' are also described. The content of the thesis draws from two different fields of academic enquiry, those of disability studies and those of human-animal interactions. It is acknowledged that the reader may not be familiar with abbreviations or meanings of field specific words in both areas. For this reason, both a list of abbreviations and a glossary (above) are provided to aid with clarity and understanding of these interdisciplinary materials. It further serves to maintain the use of consistent terminology throughout the thesis.

1.1   Rationale for the study

The primary purpose of this research is to explore the lived experiences of people with multiple sclerosis (MS) who use an assistance dog. It aims to provide insight into experiences of what is a uniquely modern, rapidly expanding but significantly under-researched, phenomenon. The concept of assistance dog use for and by people with MS appears to be culturally situated and less than fifty years old. However, it speaks to a purposeful connection and symbiotic relationship between humans and dogs occurring across many diverse cultures which has existed for millennia. This research further aims to illuminate an emergent, interdisciplinary field of inquiry which is

located at the confluence of research into experiences of living with chronic conditions, disabilities studies and human-animal interaction.

There are known to be over 7,000 disabled people in the UK who use an assistance dog, that has been trained and accredited by an organisation called Assistance Dogs UK (ADUK). This includes some disabled people who have gained recognition from the Department of Work and Pensions (DWP) of their assistance dog's formal contribution to meeting some of their identified needs, but this is limited. The DWP's guidance for carrying out assessments for Personal Independence Payment (PIP) (DWP, 2020), defines assistance dogs as 'dogs trained to help people with sensory impairments.' (DWP, 2020, p. 72) acknowledging the additional costs and potential barriers incurred by people who use a guide, hearing, or dual sensory dog. Within the guidance however, acknowledgement of the role potentially played by assistance dogs used by people living with physical disabilities is conspicuous by its absence.

However, there is no easy way of knowing, as the extract from the freedom of information (FOI) request I made shows:

- What are the numbers of Department of Work and Pensions (DWP) claimants with MS, and/or with another disability, reporting they use an assistance dog in their claim for Personal Independence Payment (PIP) since its introduction in 2013 (replacing Disability Living Allowance (DLA), which was introduced in 2008)?

- What are the numbers of DWP claimants with MS and/or other disability who use an assistance dog, applying for a Personal Budget and allocating a proportion of that (for example, Direct Payments) for the care and additional cost that an Assistance Dog may entail?

This FOI request yielded a disappointing response, an extract of which is quoted below:

> The Department is unable to provide any of the information requested as this information is not collated centrally and the only way to establish these numbers would be to look at individual claimant records, therefore this information could only be obtained at disproportionate cost.
>
> (DWP, 2019, personal communication)

In addition, there are an unknown number of owner trained assistance dogs or those trained by a private/commercial trainer, often for many thousands of pounds who have subsequently ceased trading leaving vulnerable families with an assistance dog who was unfit for the purpose it was trained for, but that they may be emotionally attached to. Equally, demand for assistance dogs far exceeds supply with every assistance dog organisation around the UK and internationally reporting the need to close waiting lists, which can exceed two years in length. The demand for dogs to assist owners with psychiatric or emotional issues is also a cause for concern. Assistance Dogs UK do not currently accredit assistance dog charities who train assistance dogs for those whose primary issue is one related to mental health. This situation has led to unscrupulous companies exploiting vulnerable families, or people passing their pet dogs off as 'fake' assistance or emotional support dogs. This can result in issues regarding the welfare of the dogs, the safety of the public and/or the

well-being of the owner. In part, this is due to the lack of a national register of assistance dogs and a legislative anomaly whereby any dog can be called an assistance dog regardless of how well or inadequately it has been trained or looked after. On occasion, this has caused incidents involving 'fake' assistance dogs causing problems in public places. Consequently, feelings of distrust by the public generally of genuine assistance dogs have increased, threatening the opportunities for participation and service provision for genuine ADUK and non ADUK trained assistance dog partnerships (ADUK, 2017, 2020).

In the following section, the current evidence supporting the use of assistance dogs is examined. The section narrows the focus to the context of the current study which, aims to add to the body of knowledge about assistance dogs and **providep** insight into their use.

1.2 Thesis Context

This study explores the lived experience of eleven people in the UK, with the degenerative neurological condition Multiple Sclerosis (MS), who use an assistance dog to help them with practical tasks in their daily lives. This includes the activities of daily living which are made difficult or impossible by the impairment effects and disabilities that MS can cause. The use of animals, predominantly dogs (Canis lupus familiaris), in an assistive capacity by humans has increased dramatically in the last fifty years (see Table 1, below) (DeMello, 2012; Fine, 2019; Parenti et al., 2013). The relative speed of the increase in both the number and variety of these interspecies partnerships in recent decades has resulted in the development of a somewhat un-

coordinated field of academic enquiry, spread across a multitude of disciplines. This appears to be out of step with the enthusiastic uptake and use by people, mainly those in the Global North, of these animals (ADI, 2020) for support with a multitude of physical, emotional, psychiatric and therapeutic roles (Fine, 2019; Parenti et al., 2013). Participants in this study make up a discrete but small proportion of the more than 7,000 disabled people in the UK who rely on accredited assistance dogs for support in living with their MS (ADUK, 2019). Four of the eight accredited assistance dog charities in the UK train dogs for people with physical disabilities. They have reported that people living with MS make up between 20-22% of their service users (Brewer, 2012; Canine Partners, 2016; Dog A.I.D, 2016; Support Dogs, 2017).

Table 1 Taxonomy of Assistance Dogs Associated with Current Human Animal interactions in the UK (adapted from Parenti et al., 2013)

Human Animal Interaction – Dogs			
Assistance Animals	Animal Assisted Intervention (AAI)	Public & Military Service	Human Companion Animals
Owner protected by equality act 2010	Owner not protected by equality act 2010		
Guide Dogs	Animal Assisted Therapy Dogs	Police Dogs	Pet Dogs
Hearing Dogs	*Occupational Therapy Dogs*	Military Working Dogs	Emotional Support Dogs
Medical Detection Dogs (Bio-Detection)	*Global Developmental Delay Dogs*	Search and Rescue Dogs	
Medical Detection Dogs (Medic Alert	Animal Assisted	Bomb Detection Dogs	

Dogs)	Activity Dogs	Drug Detection Dogs	
	e.g. *Hospital visiting*		
Seizure Alert Dogs	*dogs*	Conservation Dogs	
	e.g. Reading Dogs		
Autism Dogs			
Disability Assistance			
Dogs (Service Dog)			
ADUK / Owner /			
Commercially trained			

1.3   Researcher positionality and biographical context

This study is concerned with exploring the perceptions, understandings and meaning that the participants in this study make of their experiences of living with MS and using an assistance dog. My status as an 'insider researcher' has brought to the fore a variety of personal and methodological considerations that I will address both in the current section, and in greater depth in Chapter 3 (section 3.4.6), where I discuss reflexive and reflective activity undertaken before and during the research process. This both informs researcher positionality and contributes to overall 'trustworthiness' (Yardley, 2008) of the research. Reflexivity informs researcher positionality and constitutes   what Kingdon (2005, p.622) describes as the ' ongoing process of self-awareness adopted by researchers in an attempt to demonstrate the trustworthiness of their findings.' This includes maintaining an awareness of how I may transform or impact the research. One element of this included providing a biographical account for the reader which now follows.

1.3.1 Professional (Outsider) knowledge and personal biography

I am a Caucasian female in my early fifties. I grew up in Ireland, the daughter of Irish parents and, like countless Irish economic migrants before me, moved to the UK after completing university, to train as a Registered General Nurse (RGN) in South West London, England at the beginning of the 1990s. As a health professional I was familiar with MS, having cared for patients with the condition in an acute hospital setting (Chapter 2 provides in-depth information on the condition multiple sclerosis relevant to this study). These professional experiences were largely confined to nursing patients who were undergoing an acute exacerbation (relapse) in their condition, requiring hospital admission for treatment, for example, the administration of intravenous steroids or having further tests such as a lumber puncture and an MRI scan to aid diagnosis. The other category of MS patients I was familiar with were those admitted onto the medical ward in the final stages of their life with MS. Often they were suffering from complications such as overwhelming infections, at times requiring unplanned end of life care on a usually busy general medical ward. This outsider (professional) experience of MS was influential in shaping my beliefs and opinions about the condition. It left me with the impression that all those living with MS were, in my experience, either wheelchair users or bedbound.

Later in my professional career, working in the community as a health visitor, this perspective changed little. On two occasions I was directly involved in the child protection process which necessitated the removal of young children from the care of their mothers whose cognitive impairment, because of their MS, was such that they could not safely care for their children or indeed themselves. These experiences

were ones that I found profoundly distressing. I was heartbroken for those mothers and for their children. I vividly recall the sister of one of those women remarking that they 'would rather be dead than have MS' and in my more reflective, private moments I would probably have agreed.

1.3.2 Experiential (Insider) knowledge

My personal transition from professional outsider, observing others with MS, merged into that of an insider when I (now married with two children under the age of five and working full-time) was diagnosed with relapsing remitting multiple sclerosis (RRMS). The process of receiving the diagnosis was relatively straightforward and timely. From the onset of symptoms to hospital admission, tests and diagnosis was approximately four months.

Over the next decade, my visible MS symptoms were minimal, and work and family life continued 'normally', including a move further north for work. Accommodations in lifestyle and activities, for self-administered injections of disease modifying drug therapies (DMTs) three times a week to reduce the incidence of relapses, became the norm; the deterioration engendered by MS only thrown into focus in yearly consultant appointments and infrequent trips to the physiotherapist.

It is fair to say my identity was based around that of being a mother and health professional. Apart from gradually increasing disability, I was rarely ill and never missed work because of MS. Very few people in my professional life knew I had MS

and physically it was relatively easy to hide without the need for walking aids. I was able to both 'pass' (Goffman, 1963, p. 73) and 'cover' (Goffman, 1963, pp 102-104; Leary, 2018) impairment effects for many years. However, inexorably for me, living with MS over time, the hidden became visible when a major relapse resulted in impairment effects necessitating the permanent and very visible use of walking aids, and latterly the additional use of an assistance dog. This insider/outsider perspective of living with multiple sclerosis potentially influences my role as a researcher in this study (see Chapter 3, section 3.5), as does my previous experiences with both pet dogs and an assistance dog (outlined next).

1.3.3 Canine connection

I would consider myself an animal lover and grew up with a succession of both pet dogs and cats, all mixed breeds and never purchased or officially trained. They just seemed to appear and stay until they died many years later of old age and were buried in the back garden. As a family we have owned pet dogs of various types, some with questionable personal habits and most with a somewhat laissez faire attitude to the meaning of obedience. Considered as a member of the family we mourned each of their deaths, scattering their ashes in favourite rivers and woodland walks, recalling their quirks, and regaling their adventures. Until we were ready to welcome their successors. Scenes no doubt familiar to the nine million plus pet dog owners in the UK today. My assistance dog is an ADUK accredited charity trained black Labrador with a very conscientious attitude to obedience and (mostly) acceptable personal habits.

Some years before my own diagnosis, I had a chance encounter with a wheelchair user who used a disability assistance dog. A casual remark she made sparked my interest in the use of assistance dogs (other than guide dogs for deaf or visually impaired people, of which I was familiar). Describing how she had only left her home on six occasions in the entire year before she got her assistance dog, becoming disabled had made her unwilling to face the stares of strangers and the struggle of inaccessible shops. Consequently, she had stopped going out more or less, completely. With tears in her eyes, she was keen to convey how this assistance dog had 'transformed' her life; describing mundane tasks he was trained to do for her, like picking up dropped keys, helping to take her socks off, fetching the phone and accompanying her to the supermarket. This dog, she remarked, 'makes the unbearable bearable'. This left me with a number of unanswered questions that I was curious to find answers to. These included:

- How can a dog trained to assist with the most ordinary of tasks, to pick-up dropped keys or take socks off, be described in such extraordinary terms?
- What makes an assistance dog different from a pet dog?

And perhaps most intriguingly, I wanted to understand,

- What is happening in the relationship between a person with an impairment/s and their assistance dog and then in their subsequent relationships with others that can be understood to transform the experience of living with a disability?

My personal experiences of living with MS and in using an assistance dog play an intrinsic part in undertaking this PhD thesis. Chapter 3 (section 3.4.6) contains further details of how I addressed issues of reflexivity throughout the research process when, as an insider researcher I have undertaken research with participants whose medical condition I also share. As Greene (2014) writes:

> As qualitative researchers, what stories we are told, how they are relayed to us, and the narratives that we form and share with others are inevitably influenced by our position and experiences as a researcher in relation to our participants.

Greene (2014, p. 1)

Those personal experiences afforded me greater understanding of the topic which, in combination with these unanswered questions, allowed me to identify the current study's aims and objectives. The following section now outlines the overall structure of the thesis.

1.4   Organisation of the thesis

The thesis has eight chapters in total. Following this introductory chapter, Chapter 2 situates the study and its overarching research questions in the context of the existing literature relating to the dual concerns of living with MS and the use of an assistance dog. It also establishes the need for an investigation into the experiences of this under examined group of disabled people.

Chapter 3 sets out a detailed examination of the methodology employed in this study, that of interpretative phenomenological analysis (IPA). In addition, the overall aims of the research, research questions and description of the research paradigm are

presented. Methods used in the application of IPA to investigate the experiences of people with MS who use an assistance dog are outlined: the processes of sampling, recruitment, data collection and data analysis are described. Ethical considerations are addressed along with measures used to ensure issues of trustworthiness and quality of the findings.

Chapter 4, the first of three findings chapters, examines the experiences of people with MS who use an assistance dog, around the theme of VISIBILITY. Experiences of becoming invisible with the acquisition of visible physical impairments in public situations are explored. Notions of the multifaceted nature of visibility in the social context are illuminated – participants who are at times made to feel invisible, at others hyper-visible and always understood to be enacted through the prism of the presence or absence of the person's assistance dog.

Chapter 5 on (UN)CERTAINTY explores the unique additional issues and experiences of living with MS and using an assistance dog when they intersect with those events over the life course that many others may/will experience, such as the death of a companion animal and our own aging.

IDENTITY is the concern of Chapter 6, the final findings chapter, which examines participants' experiences of transition from the taken-for-grantedness of the 'normal' able identity through to the identity of 'becoming disabled'. This identity is then perceived to shift again, when the experience of living with an assistance dog

overtime sees the development of a shared, unique identity which ultimately

participants must inevitably lose.

Chapter 7, the Discussion chapter, draws together the findings in relation to the

literature of disability studies and human-animal interactions. Here I interpret the

significance of the findings and explain the insights they offer into the experience of

living with MS and using an assistance dog.

In Chapter 8, Conclusions and Recommendations drawn from the thesis are

presented and their contribution to the fields of disability studies and human-animal

interactions research explained. This chapter also includes an evaluation of the

strengths and limitations of the study in addition to suggestions for future research in

both areas.

Chapter 2 Literature review

This review brings together distinct bodies of literature in seemingly disparate fields. In doing so, it situates this research study and its overarching research questions in an interdisciplinary context. Existing literature in the fields of human-animal interaction research (HAI) and those of disability studies, medical sociology and social psychology, extant knowledge relating to living with multiple sclerosis (MS) and the phenomenon of assistance dog use is brought together and examined. This synthesis delineates the scope of the study, establishing the need for continued investigation into this uniquely modern and culturally situated aspect of the experiences of people living with MS. It also serves to indicate how gaps identified by the literature review are addressed within this study.

After a brief description of the literature search strategy employed in the review, the chapter divides into three main sections. It begins with an exploration of the empirical literature around the neurological condition of MS. Firstly, I describe the key mechanisms underlying the condition. The latest estimates indicate that there are over 130,000 people in the UK currently diagnosed with MS, suggesting around 1:500 of the population is living with this acquired, degenerative, but rarely fatal, disease (MS Society, 2020). Contextualising how its sequelae can impact those who develop it, across multiple bodily systems, often simultaneously and in a uniquely unpredictable manner, serves to situate the reader. It further allows for clarification of those elements that distinguish MS from other long-term conditions and disabilities. However, this purely biomedical approach to the literature is set aside in the following

section of the chapter. The discussion moves on from the complex functional impacts of having MS and focusses on research literature related to the wider aspects of living with its impairment effects. In keeping with the underpinning phenomenological epistemology of this study, which I discuss in Chapter 3, research literature adopting an approach which foregrounds the lived experiences of people with MS, where it exists, is highlighted. I then consider the place MS may occupy within the wider field of disability studies. Here, I set out some of the tensions that exist within the academic literature between chronic illness and disability. Differing perspectives with which to view the impairment/disability divide are appraised and contemporary thinking relevant to this current study are examined.

It is at this juncture that the third and final main section of the chapter begins by introducing a very different lens through which to view the experiences of people with MS. Encompassing contributions from anthrozoology to occupational therapy, ethology to psychology, and sociology to veterinary science, the field of human-animal interactions research introduces a kaleidoscope of perspectives relating to the myriad relationships between humans and animals. In the case of this study the relationships between people with MS and their assistance dogs are brought into focus. Firstly, literature pertaining to the origins of how humans and dogs came to form interdependent, interspecies alliances over millennia is introduced. Importantly, the evolution of the role of assistance dogs as we see them today - a highly trained specialist, a living sentient, assistive technology/auxiliary aid is also explored in some depth. To end the final section of the chapter, the threads of these literatures are drawn together providing a coherent whole. Thus, an account of the human-animal

interactions in disability (HAI-D) research, such as it is - culturally situated, rapidly

expanding and under researched - is presented, revealing gaps in knowledge that

this study seeks to address.

The literature review concludes with a summary and signposts the reader to the

subsequent Methodology and Methods section of this thesis in Chapter 3. However,

first, as alluded to earlier, there follows a description of the literature search strategy

employed in the present study. This includes a consideration of how the literature

review in an IPA study may be revisited and extended post data analysis.

2.1 Search Strategy

Searches were restricted to texts written in the English language and no date limits

were applied. Keywords and phrases were inputted using Boolean operators as

follows into several data bases (listed in alphabetical order below). These included:

'multiple sclerosis AND experiences of living with', 'multiple sclerosis AND personal

perspective', 'multiple sclerosis AND service dog', 'multiple sclerosis AND assistance

dog', 'dogs AND disabled persons', service dog*, assistance dog*, dog* AND (disab*

OR handicap*). In addition, reference lists from relevant systematic reviews were

hand searched and the search subsequently widened to include keywords, including

'human animal bond', 'human animal interaction', 'human animal relations', 'human-

animal bond', 'human-animal interactions', 'animal-human relations', 'Anthro*',

'anthro-zoology'. Care was taken using the words 'dog' or 'canine' which yielded

numerous false hits.

The following data bases were searched:

- Cambridge University Press
- Emerald
- IEEE Explore
- JSTOR
- Oxford University Press
- PsychInfo
- Sage
- ScienceDirect
- Scopus
- Springer
- Taylor Francis
- Web of science

This was complemented with citation searches using Google Scholar.

Grey literature searched included:

- Monthly publications of ADUK charities
- Quarterly publication of the International Association of Assistance Dog Partners (IAADP)
- Resources from the Multiple Sclerosis Society
- Resources from the MS Trust
- Equality and Human Rights Commission (2017) leaflet 'Assistance dogs: A guide for businesses'

2.1.1 Literature reviews and IPA

The place of literature reviews in IPA studies is influenced by its underpinning

theoretical foundations of phenomenology, hermeneutics and idiography (see

Chapter 3 for an in-depth look at IPA as an approach to qualitative research). It aims

to focus on those 'key objects of concern' for each individual participant (Smith, 2009,

p. 46). It is recognised that researcher fore-conceptions (for example, a preliminary

literature review of the field, researcher preconceptions and previous experiences)

through the iterative process of interpretative activity, both influence and are

influenced by participants' experiential claims and sensemaking of their lived

experiences. Hence, it is usual for the findings section (Chapters 4-6 in this thesis) of

an IPA study to be

> discrete in the sense that the interpretative account provided is a close
> reading of what the participants have said. This is done without
> reference to the extant literature
>
> (Smith, 2009, p. 112).

Whilst acknowledging that a proportion of the literature reviewed will feature before

the data analysis, Smith (2009) maintains it is the unexpected themes that emerge

through the IPA research process that often necessitate additional literature

searching after analysis is completed. This is undertaken to frame any new

perspectives that were unanticipated in the original interview schedule. Thus, it is

considered acceptable to introduce for the first time some new literature in the

discussion (Chapter 7 in this thesis). Where this has proved to be the case in the

present study, the readers' attention is drawn to it. The review now moves to an in-

depth look at MS and the key mechanisms underlying this complex condition.

2.2   Multiple Sclerosis: A biomedical perspective.

> MS is relentless, painful, and disabling
>
> (MS Society, 2019)

Multiple Sclerosis (MS) is a chronic neurological disorder of the central nervous

system (CNS). The CNS is made up of the brain and the spinal cord. Although the

condition has been described for at least the last 160 years, there are historical

accounts of what is recognisable as MS, as we understand it today, as far back as 1421 (Finlayson, 2013). MS is prevalent in every region of the world, although it is more common in temperate countries (MS Trust, 2011; MSIF, 2013; Burgess, 2010). In 2008 the World Health Organisation (WHO) and the Multiple Sclerosis International Federation (MSIF), a network of 44 member MS organisations from around the world, published its first 'Atlas of MS'. By the time their Atlas of MS 2013 was published, 'ninety-two countries (accounting for 79% of the world's population) provided prevalence data' (MSIF 2013, p. 8). Of these, nearly half referred to reports of local or national studies that were peer reviewed. The study compares the global prevalence of MS and confirms that it is rising (2.1 million people worldwide in 2008 to 2.3 million people in 2013). However, the report concedes that this increase may be a result of better reporting and/or medical advances leading to an increase in diagnosis, rather than an increase in prevalence. As discussed earlier in the chapter, more than 130,000 of those people with MS live in the UK, with another estimated 6,500 - 7,000 new cases being identified each year (MS Society, 2020).

MS is predominantly diagnosed between the ages of 20 and 40. Children and people over 65 can, and are, diagnosed with MS but this is considered atypical (Pena & Lotze, 2013; Compston, 2008; MSIF, 2013). In the UK, as elsewhere, women are more affected than men in a ratio of approximately 3:1, the reasons for which are not yet fully understood (MS Trust, 2011, MSIF, 2013, MS Society, 2020). With the peak incidence of diagnosis being at around the age of 30, MS develops at an age when, arguably, most able-bodied people are at their most productive economically. They may be building a career, working to provide for their family, raising children, buying

property, or seeking to experience what 'normal' able-bodied life has to offer. In the UK, the Work Foundation published a report on the impact of MS on employment (Work Foundation, 2011). Their research findings paint a gloomy picture, revealing that within 15 years of diagnosis, up to 80% of people with the condition will have stopped working. In 2020, the MS society estimate that people with MS will lose on average 19.4 working years and, according to one estimate, cost the UK £2.3 billion a year (Bevan et al., 2011). Though rarely considered fatal, MS is thought to have an impact on life expectancy (MS Society, 2020; Sadovnick et al., 1992; MS trust, 2011; Compston & Coles, 2008) with estimates of a reduction of between five and ten years, in comparison to the general population. This suggests that people with MS can expect to live upwards of 50 years with symptoms which, as described earlier, can be varied, unpredictable and disabling.

For 85% of people with MS these symptoms will be acutely experienced during a relapse (also called an exacerbation or attack), lasting for weeks or months, followed by a period of full or partial recovery (remission). Of those people with MS who begin with this relapsing-remitting (RR) pattern of disease, three quarters will go on to develop secondary progressive MS (SPMS), where there is continued deterioration even without defined relapses. For a further 10% (approximately), the disease will be progressive from the outset, known as primary progressive or PPMS. The remainder will have a benign form of the condition characterised by relapses separated by many years. It is usually diagnosed retrospectively after a decade or more, but it too will culminate in more frequent relapses, leading possibly to SPMS (MS Trust, 2011; Coles, 2005).

The reason why the body's own immune system begins to attack the CNS is unknown (Compston, 2005; MS trust, 2011; Finlayson, 2013). Current empirical research in the field has revealed that both genetic susceptibility and environmental factors are involved but do not provide a definitive answer (Compston & Coles, 2008; MS Society, 2020). The nerves in the CNS are coated with a fatty substance called myelin which acts like the insulation on an electrical wire. It allows the electrical impulses to be transmitted along the nerve faster. In MS, inflammation (triggered by the body's own immune system) leads to damage of the myelin and the axon (nerve fibres) of the nerve which results in the loss or disruption of the electrical signals. Initially the body can repair or remyelinate the affected nerves leaving plaques or sclerosis, but this is not substantial or hard-wearing enough. Over time this leads to extensive, chronic degeneration or death of the affected nerve cell. This manifests clinically as a progressive accumulation of disability (Compston & Coles, 2008; MS Trust, 2011).

Which symptoms a person with MS experiences relates to which nerves of the CNS are damaged and in which of the body's systems these nerves are located. Symptoms can include, pain, fatigue, visual disturbance (double vision, loss of visual acuity), difficulty swallowing, muscle weakness, poor balance, bladder and bowel dysfunction, cognitive impairments, anxiety, depression/euphoria, sexual difficulties, temperature sensitivity, muscle spasms, sensory issues and many more. Finlayson (2013) cites the work of El-Moslimany and Lublin (2008), which has identified more than 62 different signs and symptoms now known to be associated with MS, although

some symptoms, such as seizures or blindness, would be considered rare.

Symptoms vary between different people with MS, as well as within the same person

with MS (for example, between different times of day) (MS Society, 2020; Finlayson,

2013).

Many of the symptoms mentioned above are considered invisible, any and each of

these symptoms could provide huge challenges for the person experiencing them.

White et al. (2008) argue that the invisible symptoms experienced by people with MS,

such as pain, fatigue, and depression, may cause them more difficulty and distress at

times than visible symptoms like mobility issues. The following discussion takes a

closer look at some of the hidden impairment effects of MS - pain, 'unpleasant

sensations' (MS Society, 2018) and fatigue - commonly experienced by those with

the condition. Pain in MS is caused in different ways, by the damaged nerves of the

CNS directly or more indirectly because of living with disability or as a side effect of

medication. Within the label 'pain' there are different types and effects of pain as

described below.

Acute (short-term but can reoccur) or Paroxysmal pain (occurring suddenly),

examples of which include:

- Painful muscle spasms
- Optic neuritis causing blurred or double vision and eye pain
- Lhermitte's sign (sudden electrical buzzing sensation running down the neck
  and spine)

- Trigeminal neuralgia (sudden, severe facial pain (maybe triggered by things that lightly brush the persons face, eating, being outside when there is a breeze or brushing their teeth
- Muscle cramps or spasms

Chronic (enduring or persistent) pain experienced in MS, examples of which include:

- Pain caused by light touch where sensitised skin finds the slightest touch (brushing hair, pulling bed covers up over one's self) unpleasant or painful
- Pins and needles or numbness, prickling/tingling or itching sensation or the feeling of crawling insects under the skin
- Painful abnormal sensations in the body which can feel like stabbing, electric shocks, or aching
- Squeezing or the sensation that there is a tight band around the chest 'MS Hug'
- Musculoskeletal pains in shoulders, neck, arms, hips and back caused by posture

(MS Society, 2018)

Whilst it is true to say that not every person with MS will experience all these symptoms, fatigue is reported by two thirds of them (Opara et al., 2010; MS Society, 2014). Fatigue in MS is reported by those who experience it as the most difficult symptom to live with. Opara et al. (2010) report that attempts to evaluate fatigue in MS have resulted in 30 different scales being developed. Personal accounts of fatigue in MS describe feeling much more than the tiredness normally experienced after exertion or missing a night's sleep. It can cause people to feel weak, nauseous, dizzy, unable to concentrate or even hold a pen. For some people it can affect their

eyesight, cause their speech to slur, and is significantly exacerbated by heat (Milne et al., 2012; MS Society, 2013).

Exploring a range of visible and invisible impacts of MS here, albeit briefly, can foster a greater understanding of the complexity of the condition, beyond the visible effects such as mobility issues. In addition, a more fine-grained appraisal of the impairment effects experienced when living with MS helps to place this disabling condition within the impairment/disability debate. This is explored in the next section of this chapter which follows. It also informs the interpretation of participants' decision to use an assistance dog to mediate the impairments effects of MS. Thus, providing useful insights into their self-management and understanding of the embodied experience of living with chronic illness and disability.

2.3   Multiple Sclerosis: The wider literature.

> the chief curse of the illness…I must ask constant services of people I love most closely…it is an illness accompanied by frustration…it is an illness that inflicts awareness of loss… sporadically it is, in its manifestations, a disgusting disease
>
> (Brigid Brophy, 1929-95)

Previous areas of research on MS, addressed by the academic literature, mainly concentrate on adapting to the diagnosis of MS, coping, quality of life, social support, psychosocial factors and physical disability (Buchanan et al., 2009; Olsson et al.,

2011; Finger, 1998; Mitchell et al., 2005; Sprangers et al., 2000; Kirkpatrick Pinson et al., 2010; Feinstein, 2004; Morales Gonzales et al., 2005). Devins et al. (1993) and Sprangers et al. (2000) suggest that people with MS experience a lower quality of life than others living with chronic long-term conditions because MS has a greater effect on daily life. This is perhaps unsurprising given the extensive list of potential symptoms of MS and their unpredictability, as outlined earlier. In this section of the chapter I discuss a selected sample of relevant research in more detail. For example, research that has adopted a similar methodology or method to that employed in the present study, or reveals an aspect of interest relating to lived experiences of MS.

Irvine et al. (2009) explored the experiences of seven individuals who had been living with MS for at least five years. Using IPA, which employed the use of a semi-structured focus group interview, the study explored participants' experiences of coping with the changes brought about by MS. Findings suggest that common reactions to diagnosis were denial and attempts at concealing their condition from others. The same study also explored the psychological impact of MS on identity. The authors noted that common initial negative reactions to diagnosis were accompanied by loss of confidence, covering of impairments and experiences of uncertainty. These psychological challenges were somewhat ameliorated over time as an increased appreciation for life and spirituality led to identity redefinition associated with adjustment to MS. Irvine et al. concluded that interventions focussing on role/identity re-examination would assist people with MS to better manage their condition and enjoy life more fully.

A study by Dennison et al. (2010) undertook telephone interviews of 30 people with MS who had been purposively selected to obtain maximum variation in sample demographics and illness characteristics. Participants were interviewed about their experiences of MS using broad open-ended questions, the data obtained was analysed using inductive thematic analysis and adopted aspects of grounded theory methodology. As with Irvine et al.'s (2009) study, Dennison and colleagues' work highlighted that participants regarded as highly stigmatising anything that would visibly identify them as impaired (such as the use of mobility aids or attendance at support groups for people with MS, which were described by some as 'cripple clubs'). Dennison et al.'s work focused on people with MS considered to be in the early stage of adjustment to living with the condition and the authors acknowledged that participants' attitudes may change over time should their health deteriorate. In their research, Irvine et al. and Dennison et al. allude to the temporal nature of the participants' experiences of 'passing' and 'stigma,' when in the early stages of living with MS. Irvine et al. (2009) found that although initial self-management involved concealment and fear of stigma, this gave way in time to positive changes, both in terms of appreciation for life and future outlook. More recently, Silverman and colleagues (2017) conducted a qualitative study using four different focus groups (two with people living with MS (n=6 men, n=6 women), one group with partners with MS (n=11) and one with 'community stakeholders serving those with MS' (n=9)), to explore what resilience meant to them. They were also asked what facilitators and barriers to resilience they perceived. The purpose of the study was to describe the meaning of resilience in MS from the participants' perspectives. Data were analysed for emerging themes and sub-themes. Findings identified facilitators of resilience, which were perceived in terms of concepts such as life meaning, social connection,

psychological adaptation to MS and physical wellness. Conversely, barriers were understood to be social stigma, physical fatigue, negative thoughts and feelings, and perceived social limitations. The authors concluded that unpredictability inherent in MS 'present a challenge' to developing resilience in those with MS as they get to middle age. However, they expressed optimism that perceived facilitating factors were achievable, despite those challenges, as they were receptive to interventions within a rehabilitation setting. Positioning the making sense of life events, such as illness or disability, as central to the adjustment process, Pakenham (2008) used mixed methods to investigate the nature of sense making in MS, from a psychological perspective. He contends that the response of those diagnosed with MS may be an endeavour to adjust to the reality of their new way of living with their long term-condition.

Drawing on the work of theorists concerned with recovering and adjusting to loss and trauma, and stress and coping, Pakenham considers Janoff- Bulman's (1992) description of how a person's 'assumptive world' is shattered by the development of such adverse events which throw everything that once was meaningful into a state of tumult and uncertainty. This disruption of a person's meaning structures engenders distress; however, through the processes of meaning making, a sense of order, predictability and certainty may be re-established. Developing the concept further, Janoff-Bulman and Yopyk (2004) suggest that the rebuilding of one's assumptive world involves two types of meaning making processes: sense making (meaning-as-comprehensibility) and benefit finding (meaning-as-significance). Elsewhere, Park and Folkman (1997) (see Park (2010) for a useful review of research into meaning

and meaning making, in the context of experiencing stressful life events) propose a meaning making model, the main tenets of which include:

- people possess a sense of global meaning (beliefs, goals, and a subjective sense of meaning or purpose) which act as a framework wherein they interpret their experiences.
- when people undergo stressful life events, they assign meaning to them.
- it is the discrepancy between these global beliefs and these situational ones that cause distress and trigger a search for meaning.

Pakenham's (2008) study on the nature of sense making in MS, in which participants completed a questionnaire relating to illness, adjustment (life satisfaction, anxiety, depression, positive states of mind) and spiritual/religious beliefs, revealed that half of the sample (n=408) generated sense making explanations for their conditions which varied between participants. A further third could not make sense of their MS but anticipated they would be able to comprehend it in the future and this anticipation was related to greater life satisfaction. Other findings of significance included participants being more likely to report sense making where they also stated they held a religious or spiritual belief in comparison to those who did not. After controlling for illness effects and spiritual/religious beliefs, sense making in MS was found to have a beneficial direct effect on both depression and 'positive adjustment outcomes' (Pakenham, 2008, p. 93).

A review of the literature on living with MS indicates that many of the studies fall within the domain of rehabilitation and health psychology. This foregrounds the medical professional as expert who can advise and direct interventions that facilitate 'positive adjustment outcomes' so that the disabled service user can live life to the

full. Recently, Goodley (2020) addresses this meeting of psychological perspectives and disabilities, describing the 'troubling and troubled status of psychology' (2020, p. 362) within the field. The place of MS between the rehabilitation, therapy, biomedical model, individualised, treatment focused approach and the disabilities studies politicised approach, focused on the exclusion, stigma, dis/ableist discourses, can appear stark and these form the basis of the next section of this chapter.

As this study examines the experiences of people living with MS who have chosen to use an assistance dog, it is apposite to conclude this section with a quote from Michalko (2002, p.30), a disabled scholar who has written frequently about living with blindness with his guide dog Smokie. It encapsulates the tensions traditionally held between these two perspectives and moves the review on to the next stage of the discussion.

> What shall we do now that you are disabled?
> *We shall cure you.*
> How shall you live when our cure fails,
> and you are now permanently disabled? You shall adjust.

2.4 Multiple Sclerosis: A contested terrain

MS is categorised as a long-term neurological condition (NHS England, 2019) by which is meant it lasts for more than a year and does not have a cure, but its symptoms can be controlled by medical means (DOH, 2012). However, as Wendall

(2013) argues, the 'relationship between disability and illness is a problematic one'

where chronic conditions such as MS can:

> behave like recurring acute illnesses, with periods of extreme debility
> and periods of normal (or nearly normal) health, or they can have
> virtually constant symptoms (such as fatigue and pain) and/or be
> characterized by recurring acute episodes that leave behind permanent
> losses of function (such as paralysis…)
>
> (Wendall, 2013, p. 163)

Describing those with long-term disabling conditions as the 'unhealthy disabled,'

Wendall admits they do not fit the paradigmatic 'healthy disabled,' who have static

disabilities with a relatively stable and predictable course to their impairment.

Shakespeare (2014) concurs, asserting that to tell those with long-term conditions

like MS that they are not disabled would be unfair, citing the inclusion of multiple

sclerosis as one of the chronic conditions automatically protected against

discrimination under the Equality Act 2010, as the right thing to do. The

disability/illness/impairment debate is not confined to MS, it is heard around the globe

and across different nations:

> Disability is part of the human condition… Every epoch has faced the
> moral and political issue of how best to include and support people with
> disabilities… Disability is complex, dynamic, multidimensional, and
> contested.
>
> (World Health Organisation, 2011, p. 3)

To address this, the World Health Organisation (WHO) produced (in partnership with

the World Bank) a World Report on Disability (WHO, 2011). This report was based

'solely on facts: no opinion, no 'advocacy', but simply the scientific evidence'

(Shakespeare, 2014, p. 6). It reports that globally nearly 200 million people

experience difficulties in functioning and when children are included it is estimated that 15% of the world's population, or over one billion people, were living with disability.

Early in the report it is acknowledged that many researchers over recent decades (from both health sciences and social sciences) have identified the role of barriers in disability. What became known as the medical model of disability, which regarded disability as a biological problem, a personal tragedy or individual failing (Thomas, 2007; Barnes & Mercer, 2010), was largely overtaken by the social model of disability wherein people are regarded as 'being disabled by society rather than by their bodies' (WHO, 2011, p. 4). The social model however has not been without its critics. Shakespeare (2006, 2014) draws attention to the fact that over several decades the model remained unchanged, unlike other theoretical approaches such as the feminist social movement which has developed over time. The adherence to a clear disability/impairment divide, which was so radical when first proposed in the 1970s, was seen by some to be no longer fit for purpose.

Writers in the field of disability studies, including those advocating from both within the social model (but calling for its expansion or renewal) and those opposed to it, acknowledged the tremendous contribution that the model made to the lives of disabled people in the UK and around the world (Barnes & Mercer, 2010; Thomas, 1999, 2007; Shakespeare 2006, 2014; Goodley, 2011, 2014). However, the WHO report is clear that disability should no longer be viewed as either exclusively medical or social in nature. Hence its world report on disability adopts what has become

known as the bio-psycho-social approach to disability, using a conceptual framework for its report the International Classification of Functioning, Disability and Health (ICF) (WHO, 2002, 2011). The ICF maintains that there are three interconnected areas of human functioning from which problems may arise:

- **Impairments:** problems in body function, alterations in body structure - for example, paralysis or blindness
- **activity limitations:** difficulties in executing activities - for example, walking or eating
- **participation restrictions:** problems of involvement in any area of life - for example, facing discrimination in employment or transportation

Disability is referred to by the WHO in the ICF as 'difficulties encountered in any or all three areas of functioning' and crucially, that disability arises from the interaction of health conditions with contextual factors – environmental (support and relationships, natural and built environment, attitudes, policies, systems and services) and personal factors (including motivation and self-esteem and other personal factors not yet classified) (WHO, 2011, p. 4). Criticisms of the ICF by disability scholars has been advanced (for example, among others, Barnes and Mercer, 2010; Barnes, 2006; Goodley, 2017) connecting it with the medical model of disability. An in-depth analysis of the ICF is beyond the scope of this thesis, however, Bickenbach's (2020) close examination of the ICF 'from a stance within disability studies' contends, rather pragmatically, that despite its imperfections 'the short answer as to why disabilities studies researchers should be familiar with and apply the ICF is that it is the only game in town' (2020, p. 59). Bickenbach calls for scholars in the field to use their skills:

> to craft even-handed critiques of the ICF that will not only reveal its inherent flaws but will provide a way to move beyond them so that the full potential of the ICF might be realised
>
> (Bickenbach, 2020, p. 68).

Examining more closely the place of long-term conditions (LTC) such as MS within disability studies, Scambler (2016; 2020) observes that despite being the most common cause of disability in the developed world, long-term conditions are frequently side-lined to 'a token chapter on chronic illness' (Scambler, 2020, p. 172) in mainstream texts in disability studies. Describing the position of impairment within the field as 'unique, ubiquitous and constantly troublesome,' Sherry (2016, p. 1) acknowledges the power of studying impairment through a sociological lens which 'helps to explain the identities, politics, and experiences of disabled people' (Sherry, 2016, p. 1). Scambler's (2020) useful description of the five broad areas of theoretical approaches to the sociological study of chronic illness provides a selective review of key themes this vast area of scholarship has developed over the last sixty years. Scambler further advocates a 'move to medical sociology' if an exploration of the experiences of living with long-term conditions is required which 'seeks to lay out a more oppression aware approach to the sociological study of disabled people' (2020, p. 180) citing the work of Carol Thomas (2007, 2010) as an obvious example of such an approach.

At this stage in the discussion, I would like to spend some time exploring the potential psychological and social impacts of disability by drawing more heavily on the work of feminist writers such as Thomas (1999, 2007, 2012) and Reeve (2008,

2013, 2014), whose work in the field of medical sociology has done much to influence the academic landscape across the impairment/disability divide, with Thomas' development of the concept of psycho-emotional disablism. Reeve (2008, 2013, 2014) has done much to clarify and deepen our understanding of what the experience of psycho-emotional disablism might look like in the daily lives of disabled people. She further divides the sources of psycho-emotional disablism in two: indirect psycho-emotional disablism and direct psycho-emotional disablism. The former is aligned to structural disablism and its psycho-emotional consequences. For example, on being faced with a structural barrier (such as, a broken lift, an inaccessible bus, or a restaurant toilet which is upstairs), a disabled person is once more reminded that they are different. Emotional reactions to this physical exclusion may include anger, frustration, rejection and hurt. Ironically, according to Reeve, the Equality Act 2010 can lead to indirect psycho-emotional disablism, whereby the requirements for reasonable adjustments, for example, the use of a back entrance for disabled patrons, may engender feelings of humiliation or feeling like a second-class citizen.

By contrast, the concept of direct psycho-emotional disablism focusses on the relationship a disabled person has with themselves or with others. Thomas (1999) is careful to emphasise that she was not referring to impairment effects (pain, fatigue, disorientation and similar) here, although they too have psycho-emotional effects. It is the psycho-emotional disablism that can involve those close to us – partner, parent, friend, or sibling – or complete strangers and health and/or social care professionals. The hurtful words or actions of these non-disabled people when

interacting with people with impairments, may be intended or unintended, but their effects on psychological and emotional pathways can be profound. Included in this definition is the experience of living every day in a society suffused with negative stereotypes and 'denigrating images of people with impairments' (Thomas, 2007, p. 72).

Both Reeve and Thomas are clear that psycho-emotional disablism is not experienced by everybody and will vary in its intensity. For example, there may be some days in which a person with impairments feels that they are able to cope with stares or gaze avoidance, invasive questions or thoughtless comments, and other days when they may not have the emotional/psychological resources to deal with them. Their effect is as real and as powerful as any structural barrier. Reeve (2014) is in agreement with Keith (1996) when she ascribes this effect of psycho-emotional disablism to the fact that 'there is a lack of agreed rules of cultural engagement and social interaction between disabled people and others' (Reeve, 2014, p. 94). She argues that a consequence of a lack of such rules may require the disabled person to do a good deal of 'emotion work' in an attempt to alleviate a potentially awkward or difficult social situation. As such it becomes an attempt to avoid exclusion and facilitate inclusion (Reeve, 2008, 2014). Working from a symbolic interactionist approach, Goffman's (1963) seminal work explored how the 'stigmatised' (disabled person) adopted identifiable behavioural responses in their social interactions with 'normals' (able-bodied person). He argues that stigmatised individuals employ a range of management strategies when in the presence of 'normals'. These include withdrawal, whereby individuals simply absent themselves from avoidable social

encounters completely or, more commonly, engage in managing 'the presentation of self'. This involves either attempting to 'pass' as 'normal' (which involves a degree of secrecy or disguise of impairment) or 'covering' when the individual acknowledges that there is a stigmatised feature but then works hard to minimise its significance. It is behaviour that requires considerable emotional and physical investment (Reeve, 2011; Thomas, 2008). The concept of 'self-presentation (or impression management) refers to the process of controlling how one is perceived by other people' (Leary, 2018, p. 15), and is explored more later in the thesis, in relation to the findings of this study.

Thomas and Reeve, in their writing on psycho-emotional disablism, acknowledge the fact that a great many impairments are hidden. For those who may have a hidden disability a lot of their energy may be used up in trying to pass as normal. Those for whom 'passing' is an option, are not subject to the disablism the people with visible impairments can experience. However, they do live with the constant threat that their difference may be revealed (Morris, 1991). Structural disability may feature in their day-to-day experience of living with disability on occasion, but it is the experience of psycho-emotional disablism which may play the greater part and have the most influence in their daily lives (Thomas, 1999, 2007; Reeve, 2008). As Thomas says (emphasis in the original):

> Social barriers 'out there' certainly place limits on what disabled people *can do, but* psycho-emotional disablism places limits on who they *can be* by shaping individuals' 'inner worlds', sense of 'self' and social behaviour.
>
> (Thomas, 2007, p. 72)

Thus far this review has interwoven the threads of the biomedical and Disability studies perspective of MS to enhance the understanding of the complexities and nuances of both the 'out there' dimension and the private, personal 'inner worlds' of living with MS. This study moves beyond the boundaries of the 'presentation of self' in this way. Notions of 'passing' and 'covering' are consigned to the past, as, once visibly disabled, these options are no longer available. Using an assistance dog is a choice, it precedes the disabled person, declaring 'an anomaly of […] embodiment' to all (Whitburn and Michalko, 2020, p. 228). This necessitates a refocusing of the discussion to encompass academic literature which examines the disabled person in relation to others (non-human animals, others, technology), before moving on to a consideration of the literature specific to human-animal interactions in disability.

When writing in 1985, Donna Haraway developed the concept of the cyborg (originally coined in 1960 by Clynes in the context of advances in technology around the time of the space race) - the enmeshing of the human and the machine in the modern technological age. It is Reeve's (2012) reflections on Haraway's essay 'The Cyborg Manifesto' (Haraway, 1985) that expands this review to now consider the disabled human/non-human relationships and other ways of being, explored in this research. Reeve (2012) is critical of Haraway's key work in which she introduced the notion of the cyborg, a hybrid of machine and human. Although disabled people who use technology such as prosthetics, wheelchairs, cochlear implants or indeed assistance dogs may be considered cyborgs, it is worth cautioning that the association of technology with rehabilitation, normalisation and cure is problematic (Goodley, 2010). It speaks to a hierarchy of impairments regarding who should

benefit from the technology, exposing inequalities in healthcare across cultural and

economic divides. That being said, notions of hybridization and posthuman ways of

being (Goodley et al., 2020; Braidotti, 2019; Michalko, 1998) which explore the

concepts of human/non-human, human/animal alliances between disabled people

and assistance dogs are an accepted feature in critical disability study literatures

now. Goodley (2017, p.203) writes:

> The cyborg is very much a figure of dis/ability studies because of the
> way in which it extends both the disabilities of a human being whilst
> also foregrounding disability as the community to think critically about
> human-non-human relationships […].Both disability and the cyborg urge
> a moment of human reflection – how do we interconnect with one
> another (with human or non-human)?

Returning briefly to the WHO's world report on disability (2011), it is of note that the

use of assistance dogs by those with impairments is universally recognised in its

chapter on support and assistance for people with disabilities for more than

undertaking practical tasks. Citing the United Nations Convention on the Rights of

Persons with Disabilities' (CRPD) (2008), the WHO assert that:

> support and assistance not as ends in themselves but as a means to
> preserving dignity and enabling individual autonomy and social
> inclusion. Equal rights and participation are thus to be achieved, in part
> through the provision of support services […]. Some of the more
> common types of assistance and support services [are] assistance
> animals – such as dogs…
>
> (WHO, 2011, p. 139).

Haraway herself, 'having worn the scarlet letters, "Cyborgs for earthly survival!" for

too long' (Haraway, 2003, p. 5) altered course briefly to further explore her personal

passion for human-canine relationships in 'The Companion Species Manifesto'

(2003) and again in 'When species meet' (Haraway,2008), attempting to write the story of dogs, not as:

> an alibi for other themes; dogs are fleshy material-semiotic presences in the body of technoscience. Dogs are not surrogates for theory; they are not here to think with. They are here to live with. Partners in the crime of human evolution […] a species in obligatory, constitutive, protean relationship with human beings.
>
> (Haraway, 2003, p. 5)

In 'When species meet', Haraway (2008, p. 3) goes on to proffer two questions which guide her thinking:

1) Whom and what do I touch when I touch my dog?
2) How is "becoming with" a practise of becoming worldly?

In this study, an exploration and interpretation of the experiences of people with MS and their partnerships with assistance dogs, touches on both questions.

In the final section of this review which follows, I turn to selected literature exploring the intentional and considered relationship between humans and animals.

2.5 Humans and animals: Some we love, some we hate, some we eat

This section begins with an exploration of the connection between humans and animals generally, and then humans and dogs specifically. As with the previous section, there are three main parts within this section of the literature review. The first examines relevant literature in the field of human-animal interactions, providing context and exploring key concepts, such as the culturally and biologically mediated responses of humans to animals, globally and historically. Reference is also made to technological and scientific advances which are revealing insights into the human

and canine brain, enhancing those anecdotal accounts of human-animal interactions, relationships, and bonds (HAI/HAR/HAB) which, some would argue, have always instinctively been known but lacked scientific evidence. The chapter concludes with a final section, bringing together the threads of literature focused on the role and use of assistance dogs by disabled people today.

This study focuses on a dimension of disability experience where it purposely intersects with dogs. Exploration of the experiences of disabled people and assistance dogs purely from a disability perspective, as an isolated phenomenon, risks producing a superficial account of those experiences. Extant knowledge on the co-evolution of dogs and humans has a great deal to offer in this investigation. How and why some human cultures choose to pair their disabled people with domesticated dogs, enshrining in law their right to access restricted areas, such as hospitals, restaurants, and even the cabins of planes, is extraordinary and fascinating. This explication forms the middle part of this section which is given over to a consideration of the origins, development, and current state of relevant human-animal interaction research today.

It is nearly a decade since the first systematic review on the use of assistance (service) dogs by people with 'mobility-related physical impairments' was published by Winkle in 2011. The review, written from an occupational therapy/rehabilitative perspective, described a nascent field of study beset with methodological confusions and inconsistent use of terminology. The passing of time has seen an exponential

growth in scholarship in this area (Fine, 2020; Wells, 2019; Rodriguez et al., 2018) and a review of progress in the last decade is also addressed here.

Within this middle section, I argue however, that the proliferation of research focussing on a more quantitative approach, whilst welcome, has led to a dearth of HAI studies using a standardised qualitative approach (Rodriguez et al., 2019; Whitney et al., 2020; Eatough and Smith, 2017). This study seeks to address this disparity, thereby building on previous work and providing additional insights into the field of human-animal interactions and relationships in disability.

The section heading borrows from Herzog's (2010) book, and encapsulates the complicated relationships humans have had, and continue to have, with animals. It was E. O. Wilson, a biologist from Harvard, who, in 1984, first described an innate tendency for humans to seek connections with nature and other lifelike processes, suggesting it has, in part, a genetic basis. This hypothesis (Biophilia) is one of the most frequently cited to explain why humans have an inherent affinity for other living things (Kellert & Wilson, 1993). This is not limited to animals but to all of nature. The hypothesis has been further reappraised over time, resulting in one which asserts that biophilia contains a wide variety of emotional reactions to living things. Some of these will be positive, peaceful, even reverent, or conversely negative, fearful, or aversive. More recently studies undertaken in the fields of psychology and neuroscience lend support to the theory, including that of Mormann et al. (2011) who found that specific cells in the right amygdala of the human brain respond to images

of animals. This is in addition to research which found that the human mind thinks differently about animals than it does about inanimate objects (Amiot & Bastian, 2014).

Humans interact with animals of every kind and in a wide variety of ways daily. They have done so throughout the history of humankind (Serpell, 2010). In the present day, billions of animals are farmed or managed worldwide by humans every year, hundreds of millions of visits to zoos and aquariums are made by people annually and millions of animals are used in laboratories (Hosey & Melfi, 2014). Accurate figures for total global wildlife tourism (wildlife-watching tourism, captive-wildlife tourism, hunting tourism, fishing tourism) are not collected. It is however an area of human-animal interactions that is rapidly expanding globally and contributes significant amounts to individual countries' economies (Higginbottom, 2004). People have written about, sung about, drawn, painted, and talked about animals throughout history. Beck explains that the relationship between humans and domesticated animals is 'rooted in evolutionary, psychological and physiological processes' (2014, p. 1). People selected desirable characteristics and encouraged the breeding of those animals. This led to animals being bred who possessed characteristics which people sought. Animals became 'tamer, fatter or cuter'. In particular, a preference for neoteny – where adult animals retain features associated with younger individuals occurred over time and remains apparent today. The juvenile characteristics, such as large eyes and infant like general appearance, are thought to promote nurturing behaviours. This effect is frequently utilised in animated films and charity fundraising campaigns. Beck (1999) comments that the concept of a human-animal bond echoes

that used to describe the bonding between a parent and a child. The term human-animal bond (HAB) was first officially used in 1979 and its use was initially pioneered by three influential figures – Konrad Lorenz (ethologist), Boris Levinson (psychotherapist) and Leo Bustad (founder of the Delta Society (now known by the name Pet Partners), an organisation devoted to the promotion of animal assisted interventions - AAI) (Fine and Beck, 2020). While there is not a universally accepted definition of HAB, there are aspects of human-animal relationships which are thought to exemplify its meaning. Hence, the American Veterinary Medical Association's Committee (JAVMA, 1988, p.1675) has defined the human-animal bond (HAB) a

A mutually beneficial and dynamic relationship between people and other animals that is influenced by behaviours that are essential to the health and well-being of both. This includes, but is not limited to, emotional, psychological, and physical interactions of people, other animals, and the environment.

In keeping with this is Serpell's (2002) perspective that it is our innate propensity to anthropomorphise animals, because they benefit human health and quality of life, which explains why companion animals are considered to provide us with social support. Advances in the study of biochemistry in HAI have found that oxytocin, a neuropeptide released by the hypothalamus in all mammals, including dogs and humans, has a significant role in enhancing feelings of intimacy, pair bonding and attachment after childbirth, and increases feelings of well-being. Studies indicate when a dog's owner gazes into their dog's eyes oxytocin is released and vice versa, enhancing this bi-directional bonding and attachment between dogs and humans (Fine, 2020).

2.6 Human-animal interaction research: History and development

An understanding of the history of the field of HAI research is important. It clarifies

how research in the area has developed and the continuing direction of travel it is

taking, which ultimately influences research into human-animal interaction in disability

(HAI-D).

Friedman et al.'s (1980) seminal work on increased survival rates post heart attack of

pet owners, in comparison to non-pet owners, opened the floodgates for research on

the health benefits of pet ownership (Friedman, 2020). There are studies which

assert that stroking a friendly dog or cat can reduce both a person's blood pressure

and stress levels (Allen et al., 2001, Allen, 2003). Pets are shown to be connected to

their owners' physical and emotional well-being in studies indicating they are less

lonely, more active, have higher self-esteem, visit their GP less, enjoy greater life

satisfaction and sleep better than non-pet owners (El-Alayli et al., 2006; Gilbey et al.,

2007; Gillum, 2010). Equally however, there are also some reports that claim the

opposite effect or no effect (Parker et al., 2010, Wright et al., 2007).

Herzog's work looks at this phenomenon, the so called 'pet effect', and the possible

reasons why things may not be as conclusive as they would first appear (Herzog,

2010, 2011). Herzog suggests that no effect or negative effect studies may be more

likely to remain unpublished or not widely disseminated in the media. He refers to this

as the "file drawer effect" to mean those studies that remain in the researcher's filing

cabinet. Ioannidis (2005) argues that areas of research that typically contain small homogeneous sample sizes, small effect sizes and a wide diversity of research designs (such as those in HAI research), will exhibit conflicting results. Herzog (2011) further asserts that as research participants know whether they are interacting with an animal or not, methods such as single or double blind experimental and control groups are not appropriate. This makes it at the very least, extremely difficult to eliminate placebo effects in studies looking at the impact of pets on human health.

More recently, Wells (2019) reviewed the state of research on the implications for human health of human-animal relations, concluding it remains a mixed picture. Wells is in agreement with Herzog (2011) with regards to the causes of conflicting research findings and adds that the wide variety of variables, different research designs and a failure to control for confounding variables, such as gender balance or differences in owner pet attachment, persist.

Hines (2003) offers useful insights into the field and an explanation of how HAI became an interdisciplinary area of research. She notes that in the 1970s and early 1980s, the UK, France, Australia, and the USA had established organisations devoted to the study of the human-animal bond (HAB). Initially groups of scholars held international conferences on HAI. By 1989, representatives from six of these organisations opted to formalise their international, interdisciplinary working relationship by establishing a formal organisation – the International Association of Human Animal Interaction Organisations (IAHAIO). Now with members from 22 countries, IAHAIO describes itself as a global umbrella organisation which seeks to

provide international leadership to associations from any discipline working in research or education in the field of HAI (IAHAIO, 2015). Initially based in Europe, the International Society for Anthrozoology (ISAZ) was formed in 1991 to foster the mutual support of researchers in the field of HAI. It now boasts a membership of over 300, representing nearly 30 countries. ISAZ began producing Anthrozoos, a quarterly, peer reviewed journal with scholarly articles from across the field of HAI in a wide variety of disciplines (ISAZ, 2015). Both organisations, IAHAIO and ISAZ, as well as many of the researchers within the field, acknowledge that the study of human-animal interactions has been beset with challenges for a variety of reasons.

To begin with, the literature is scattered across many disciplines, including those of Veterinary Science, Animal Behaviour, Ethology, Anthrozoology, Psychology, Sociology, Human-Animal Interaction, Arts, Culture and Human Medicine (including Neuro-science, Rehabilitation Medicine, Nursing & Occupational Therapy), amongst others. Each discipline has its own terminologies, methodologies, and theoretical perspectives. Initially with no agreed index terms and little consistency in terminology, it was difficult for search engines to find or compare research across the different disciplines (Griffin et al., 2012; Wilson, 2010). James Serpell (2012), a founder member of ISAZ and Professor of Humane Ethics and Animal Welfare, writes about some of the challenges and barriers the field of HAI has encountered in its development over the previous thirty years or more. Serpell (2012) cites the biggest barrier to the development of Anthrozoology as the lack of funding. In addition, Anthrozoology had developed from the idea that interactions with animals are predominantly beneficial for us, an idea that attracted a mix of scholars and scientists

from a wide range of disciplines. Consequently, HAI research lacked a coherent body of knowledge, concepts, and theories to underpin it. The result of this is that much of the research in the field of HAI has been, and continues to be, funded by the pet food industry (McCune et al., 2020). Dependence on short-term funding has restricted the scope of the research undertaken. This has strongly influenced the type of human-animal interaction research carried out, which is largely focused around companion animals (pets).

In the UK there are an estimated 65 million pets in 13 million (45%) of our homes, costing pet owners approximately £5.4 billion a year, of which £3 billion goes on pet food and accessories. It is an industry that has flourished and continued to grow despite the economic downturn (Pets at Home, 2014). This is not restricted to the UK; Serpell (2012) goes on to state that most HAI/HAB literature relates to Western culture and our interactions with companion animals. By which he means predominantly, but not exclusively, with dogs; the numbers of which are estimated to be 8.5 million in the UK – 24% of households (PFMA, 2014), in Europe over 75 million dogs (FEDIAF, 2012) and 83 million in the USA (ASPCA, 2015). Hines (2003) acknowledges the millions of dollars provided by the pet food industry since its very beginning. She asserts that:

> to the credit of the industry, the millions of dollars that have supported research, conferences, and community programs globally have for the most part been awarded on the basis of merit and without undue interference from the industry in the research study design and publication, in the conference content, or in program activities

(Hines. 2003, p. 13)

This source of funding must be considered when critically analysing the results of research in the field (Serpell, 2012). Initially, this was compounded by virtue of the intermittent, short term nature of corporate funding, leading new, young researchers to be dissuaded from entering the field.

Human-animal interaction research in the last decade however has made significant progress, mostly due to a public private partnership (PPP) between the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and Waltham Centre for Pet Nutrition (Waltham) who are a part of Mars Incorporated.

> As global funders of HAI research we are often the first to be aware of new studies, methods, and trends in HAI research developments that we believe are of particular significance
>
> (McCune et al., 2020, pp. 487-488).

A decade of sustained funding has resulted in significant improvements in the field, such as an increase in the use of a single keyword to index publications (human-animal interaction) (IAHAIO, 2014), greater use of genetic and biomarker assays such as cortisol and oxytocin, and other standardised measures, in a bid to increase methodological rigour. As mentioned earlier the focus of the research in HAI supported by the PPP is along the HCAB route ('pets are good for us') (Wells, 2019) or the AAI field (see below for more details of this area of HAI research). The PPP is increasingly developing an interest in research around service dogs for US military service men with PTSD (LaFollette et al., 2019); and AAI for children with Autism Spectrum Disorder (McCune et al., 2020).

The topic of children with Autism Spectrum Disorder (ASD) and animal interactions has seen a surge in research studies such that there have been two rapid cycle systematic reviews (O'Haire, 2013, 2016) undertaken in recent years. The inclusion of animals in the lives of children with ASD and their families is a useful example because it shows the complexities of the human-animal interaction in disability continuum. The inclusion of dogs as an animal-assisted intervention (AAI) for children with ASD is undertaken widely (Fine, 2020) but it has also developed as a branch of assistance dog use (Dogs for Good, 2020; Support Dogs, 2020). One, as an assistance dog working partnership, is included as an 'auxiliary aid' under the Equality Act 2010 and is afforded access to restricted public places (see section 2.6.1 below), the other if the human-animal interaction is deemed part of AAI (animal-assisted therapy (AAT), animal-assisted activity (AAA), or animal assisted education (AAE)) does not; as the following paragraphs explain in more detail.

The study of the human companion animal bond (HCAB or HAB) reviewed earlier may intersect with the lived experiences of many people with disabilities and their families and allies. Equally, the emergence of the field of AAI overlaps with the area of HAI which encompasses assistance dog use, but it is fundamentally different. Turning first to AAI, the literature is further divided into those related to Animal Assisted Therapy (AAT) and Animal Assisted Activities (AAA). AAI, as defined by Kruger and Serpell (2010), encompasses 'any intervention that intentionally includes or incorporate animals as part of the therapeutic or ameliorative process' (2010, p. 36). LaJoie (2003), in a review of the literature, reported at least 20 different definitions of animal-assisted therapy. Inconsistencies in terminology such as this

prompted the Delta Society (now known as Pet Partners) to publish the following definitions which are now widely accepted:

- Animal-Assisted Therapy (AAT): AAT a goal direct intervention in which an animal, meeting specific criteria is an integral part of the treatment process. AAT is directed and/or delivered by a health/human service professional with specialised expertise, and within the scope of practice of his/her profession. Key features include specified goals and objectives for each individual and measured progress. Examples of AAT would be the use of animals (usually but not always dogs and has included birds, reptiles, small mammals) as a part of goal directed psychotherapeutic programme, or by occupational therapists in rehabilitation programmes for stroke patients or children with global developmental delay.

- Animal-Assisted Activities (AAA): AAA provides opportunities for motivational, educational, recreational, and/or therapeutic benefit to enhance quality of life. AAA's are delivered in a variety of environments by specially trained professionals, paraprofessionals, and/or volunteers, in association with animals that meet specific criteria. Key features include absence of specific treatment goals; volunteers and treatment providers are not required to take detailed notes; visit content is spontaneous. Examples of AAA would be casual visiting of hospital patients or care home residents by suitably qualified dogs or visiting schools with dogs who 'listen' to children read.

For a comprehensive account of this exponentially increasing area of HAI research and practise globally, see Fine et al., 2020.

This study focuses on the use of specially trained dogs which, although they may incorporate elements of all of the above, are considered to be neither a companion animal (pet) nor as a part of AAI; that is the Assistance Dog.

2.6.1 Assistance Dogs

The earliest example of a dog leading a blind man comes from a mural dating from first century Roman Herculaneum (Guide Dogs, 2014). However, it was not until around 1780 that attempts to systematically train dogs to guide blind people in Paris was reported (Guide Dogs, 2014). The first use of the term 'Service Dog' to describe a dog trained to assist people with physical disabilities, was in 1975. It was coined by Bonita Bergin, a canine researcher who went on to found the Bergin University of Canine Studies in California in 1991. Since then, the concept has been adopted enthusiastically throughout the western world, predominantly in North America and the UK (Walther et al., 2017). Prior to this the only assistance dogs working in the UK were guide dogs for blind and visually impaired people which have been in this country since 1931 (Guide Dogs, 2019). The term 'assistance dog' is the umbrella term encompassing guide dogs for blind and visually impaired, hearing dogs for deaf and hearing-impaired people, and service dogs (any assistance dog not trained as a guide or hearing dog). Assistance Dogs International, Inc. (ADI) was founded in 1986 and is now a worldwide coalition of 134 member organisations. In 2017, its European member organisations (ADEU) (including ADUK) placed 10,845 assistance dogs, and in 2018 over 16,000 assistance dogs were placed in other parts of the world (ADI, 2020).

There follows a brief overview of the current landscape of assistance dog use in the UK and the literature on the topic. Currently there are seven charities in addition to Guide Dogs who train dogs to assist people with a range of impairments. These are: Hearing Dogs for Deaf People, Canine Partners, Dogs for Good (Previously Dogs for the Disabled), Support Dogs, Medical Detection Dogs, Dog A.I.D.(Assistance in Disability), and The Seeing Dogs Alliance. These specially trained dogs assist their owners with impairments, including Physical Disabilities, Epilepsy, Autism, and life-threatening conditions (for example, Cancer, hypoglycaemia, Addisonian crisis, severe allergic reactions, and narcolepsy). All of the charities mentioned are members of Assistance Dogs UK (ADUK). There are no ADUK accredited assistance dog charities who train dogs for people where mental health issues are their primary condition.

As previously discussed, currently over 7,000 disabled people in the UK use an assistance dog trained by a member organisation of ADUK. This means they will have been assessed as adhering to strict standards of assistance dog training, welfare and in the administration of their individual organisations (ADUK, 2020). Accredited assistance dogs have been specifically trained and assessed to be:

- fully toilet trained
- healthy and monitored over time to ensure they are not a hygiene risk
- regularly checked by veterinarians
- well-behaved in public
- safe and have a reliable temperament
- accompanied by a disabled handler who has been trained to work their assistance dog

- recognisable by a member organisation specific coat, lead slip, harness, and identification tag on their collar

A review of the literature regarding Assistance Dogs, also known as Service Dogs, disability or mobility assistance dogs, reveals a paucity of research evidence generally in this area. There is no evidence, to the author's knowledge, of qualitative research on the impact of an assistance dog on a person with the complex, degenerative condition of Multiple Sclerosis on its own. People with MS who use an assistance dog do feature in research as part of a general sample, consisting of people with many different causes of their mobility problems, both acquired and congenital in nature.

Two large reviews of the literature which looked at the benefits of assistance dogs have been undertaken. Sachs-Ericsson et al. (2002) reviewed studies of both service dogs/assistance dogs for people with physical impairments and hearing dogs for deaf people. The authors considered the available research on the benefits of having an assistance dog within a 'model of functioning disability' similar to the World Health Organisation (WHO)'s International Classification of Impairments, Disability, and Handicap (ICIDH-2) categories (WHO, 1999). This viewed the study of disability and functioning at three levels: body, activity, and participation, as well as discussing how these three levels can be facilitated or hindered by features externally in the environment or within the individual themselves. Research studies that showed immediate physiological consequences from physically touching an animal were reported and included findings such as a decrease in blood pressure and

physiological arousal (Katcher, 1985, Katcher, Friedmann, Beck & Lynch, 1983),

decreased heart rate and slower rates of breathing (Lynch, Fregin, Mackie & Monroe,

1974). A review of large-scale general population studies also found a positive

relation between pet ownership and health benefits, with owners being found to have

lower blood pressure, lower triglyceride levels, and lower cholesterol (Anderson, Reid

&, Jennings, 1992). Other studies reviewed by Sachs-Eriksson addressed the

benefits of assistance dogs for individuals who require help with their activities of

daily living (ADL). They cite the work of Fairman and Hubner (2001) which examined

retrospectively participant's reports of the amount of care they needed from paid and

unpaid assistance to carry out the ADLs. Participants reported that they had used two

fewer hours of paid assistance and six fewer hours of unpaid assistance each week

since having an assistance dog. A cross-sectional study which compared individuals

with an assistance dog to those that were on a waiting list, found no significant

differences in paid and unpaid care required (Hackett, 1994). However, Sachs-

Eriksson and colleagues do note that this study did not report actual data and there

was no assessment of what an unpaid assistant was. The final section of the review

considered the benefits of having an assistance dog at the level of society and in life

situations. It acknowledges that participation in society relies on both access and

participation in social roles. The authors considered the literature on the

psychological benefits obtained from having an assistance dog. These included

feelings of safety when using community resources or in the home (Valentine et al.

1993); accessing employment (Fairmount & Hubner, 2001); increases in social

acknowledgement and friendly communication with strangers (Eddy, Hart & Boltz,

1988; Hart & Bergin, 1987). Overall, their review supported the conclusion that

assistance dogs 'have a positive impact on individuals' health, psychological well-

being, social interactions, performance of activities and participation in various life roles at home and in the community' (Sachs-Ericsson, 2002, p. 270). However, methodological weaknesses resulting from a reliance on retrospective, cross-sectional studies, subjective researcher ratings and single interviews with participants after obtaining an assistance dog, meant support for the efficacy of assistance dog use was less convincing.

Winkle's (2011) systematic literature review of service dogs and people with physical disabilities concluded that although findings from the review were limited and inconclusive, they were promising. As with Sachs-Ericsson (2002), methodological issues were highlighted as being problematic. Of the 371 published articles viewed only 12 met the authors' criteria for methodological soundness. The review did conclude that assistance dogs positively influence their human partner's socialisation and community participation (Lane et al., 1998; Valentine et al., 1993). In addition, they provide functional assistance and several psychological benefits. These benefits included increases in self-esteem, confidence and having the capability to be in control of one's life (Valentine et al., 1993; Allen and Blascovich, 1996; Morey et al., 2010). Recommendations for future research included

> additional qualitative studies examining the meaningfulness of service dog use, caregiver perspectives, perceived independence, health maintenance, and prevention of further disability should be considered.
>
> (Winkle, 2011, p. 65)

Crowe et al. (2014) examined the effects of the partnerships between women with disabilities (spinal cord injury, muscular dystrophy, and cerebral palsy) (n=3) and service dogs on social interactions and functional performance. Researchers

designed forms (The Social Interaction Form and The Functional Performance Form) and used an alternating-treatment design to research the effects with and without their service dogs on time and effort to complete two tasks (such as grocery shopping and picking up dropped objects), and effects of service dogs on social interactions in the community, measured by levels of satisfaction and amount of interaction. Results indicated that all participants had increased levels of satisfaction with social interactions, increased social interactions for two participants and decreased performance time in 4/6 tasks and decreased effort for 5/6 tasks. Recommendations for future research included examining social interactions in a variety of different settings, with a variety of participants (adult men and children), including a qualitative component focusing on 'expanding understanding of participant satisfaction' and studying the transition of participants from having no dog to using an assistance dog.

Lundquist et al. (2018) conducted a longitudinal interventional study with pre-post design of 55 owner-dog dyads. Participants with their own pet dog completed health related quality of life (HRQOL) scales (EQ-5D-3L, EQ-VAS and RAND-36) a well-being scale (WHO-5) and one for self-esteem (Rosenberg Self-Esteem Scale). Data was collected before training the dogs to assist participants: 30 physical disability dogs (disability not reported), 20 diabetes alert dogs, two epilepsy seizure alert dogs, and three hearing dogs, and again three months after the dogs were certified. Findings indicate that health related quality of life (EQ-VAS), well-being, and level of physical activity had improved significantly. The authors claim the study is the largest to explore potential consequences for HRQOL, physical activity and well-being with an ADEU (including ADUK) certified service or hearing dog. In addition to which it used validated generic scales to measure HRQOL (Rodriguez et al., 2018; Fine,

2020). Weaknesses of the study were acknowledged as lack of a randomised control group, a lack of control for confounders such as disease progression, and a short follow up period of three months. The study acknowledged that disabled person-assistance dog relationship develops over time, and therefore recommended that future research explore more longitudinal designs.

Recent studies with a focus on assistance dog use include Hall et al., 2017, Rodriguez et al., 2019a, 2019b and Whitney et al., 2020. Firstly, Hall et al. (2017) used a case control survey design with an adaptation of the Flanagan Quality of Life Scale (QOLS) with deaf and hearing-impaired participants (n=141). 111 participants had a Hearing Dog for the Deaf and 30 were on the waiting list for one. The study also included people with disability assistance dogs (n=72) and 24 on the waiting list. Of the 96 participants in the disability assistance dog group, 18 had MS. The type of MS, time since diagnosis, length of time partnered with an assistance dog, age, and gender of those with MS, age of their assistance dog, and demographic status were not given. Five participants with MS were on the waiting list. Participants were recruited from ADUK charity Dogs for Good. Results from participants' completed questionnaires indicate that those with service dogs showed higher quality of life scores than those on the waiting list, particularly around 'understanding yourself,' reporting increases in pleasure and/or ability to partake in recreational activities. The study, while controlling for age and gender as mentioned earlier, did not specify how many of those participants with MS were men, they did find that generally male participants scored higher on the life satisfaction scale, higher than both the control group and the female participants.

Two papers from Rodriguez et al. (2019a, 2019b) explore different aspects of

assistance dog use among a sample (n=154) of individuals with physical disabilities

or chronic conditions, of which 20 had a 'neuromuscular' condition. The first study

looked at the effects of service dogs on the psychosocial domains of health and well-

being. Participants (n=97 with assistance dog, n=57 on waiting list) completed a

cross- sectional survey using standardised measures of psychosocial health and a

standardised scale to quantify the human-dog bond (Monash Dog-Owner

Relationship Scale). Findings suggest that service dogs may have measurable

effects on some aspects of participants' psychosocial health and well-being, including

higher social, emotional, and functioning at work/school. It further found no significant

effect on measures related to anger, sleep disturbance or companionship. Authors

cite that limitations of the study included inability to infer causation between variables

because of the cross-sectional design and potential for results to be due to changes

over time, rather than having an assistance dog as the treatment group which was

not randomised. Recommendations for future research included using a longitudinal

design to explore patterns of change which may develop over time for participants as

their relationship with their assistance dog develops.

In a related study, Rodriguez et al. (2019b) analysed the expectations and

experiences of participants with an assistance dog (n=64) and on a waiting list (n=24)

using a cross-sectional open-ended survey. Qualitative content analysis was

employed to identify over one hundred codes which were then summarised into the

themes of physical benefits, psychosocial benefits and drawbacks of assistance dog

use. Findings suggest those on the waiting list were more likely to anticipate physical benefits but those who had an assistance dog highlighted psychosocial benefits. Those on the waiting list were also found to have not anticipated negative effects of assistance dog use, such as experiences of public discrimination. Assistance dog owners identified drawbacks, including dog behaviour, lifestyle adjustments, public access issues and the need to educate the public about access rights, and care of the assistance dog.

Moving from research carried out in the United States to recent research from the UK, the literature review concludes with an examination of research undertaken in partnership with ADUK accredited organisation Canine Partners and the University of Sheffield (2020). The Canine Care Project was funded by the Economic and Social Research Council (ESRC) and was made up of a disabled co-researcher who is also an assistance dog user, academic researchers from the University of Sheffield and staff from Canine Partners. The study built on previous early findings from an associated project (Living Life to the Fullest Project) which had established the importance of assistance dogs to young people with 'life limiting' and 'life threatening' impairments. The research entailed the administration of an online questionnaire to 58 young adults (aged 18-35) who used an assistance dog trained by Canine Partners, with a key aim of the research being to produce a quantitative analysis of the data, exploring the impacts of an assistance dog on the lives of respondents in a variety of life domains. Detailed information on the demographics of the sample, including length of time they had been with their disability assistance dog, questionnaire design and development, ethical considerations and researcher

positionality were made explicit. Analysis of the findings was carried out using descriptive statistics. This was then combined with the qualitative data derived from eight pre-existing case studies from Canine Partners clients, and two further accounts from young people arising from the Living Life to the Fullest sister project.

Findings from the project were overwhelmingly positive concerning the impacts of an assistance dog on the lives of the young people in the following areas of experience: physical well-being and personal safety, emotional well-being, areas of relationships and emotional support, independence, care, social inclusion, motivation, confidence and embracing new challenges. Most participants in the research agreed that their assistance dog met or exceeded their expectations. Verbatim extracts enhanced the emotional power and impact of the findings. They, in concert, provided evocative accounts of lived experiences of interspecies connections and synergetic relationships in HAI-D.

Key recommendations from the authors include:

1) Enabling every young person with physical impairments to be aware of the possibilities and benefits of canine care
2) Develop future research to engage the views of the wider Canine Partners client base across the life-course ensuring attention is paid to the myriad of intersections of disability in terms of age, race, class, ethnicity, sexuality, and poverty
3) More research should be undertaken about the ways inter-species relationships are a fundamental element of rethinking future human relationships – especially for those who are marginalised and displaced

(Whitney et al., 2020, p. 7).

In conclusion, the literature on human-animal interaction predominantly focuses on human-companion animal relationships/benefits/bonds or on animals (predominantly dogs) as part of animal assisted interventions (AAI) (Griffin et al., 2019; O'Haire, 2013, 2016). However, the study of human-animal interactions can help us to understand the possible reasons why some people with impairments might benefit (or not) from the use of assistance animals. It can also ensure training and welfare requirements of assistance dogs are founded on the most appropriate evidence-based methods available (O'Haire and Rodriguez, 2018; Crossman and Kazdin, 2015).

The limited literature specifically related to research on assistance dog use fails to acknowledge, for the most part, what is to be learned from human-animal interactions (HAI) scholarship. Instead, it focuses ostensibly on the role of an assistance dog as an assistive technology, with the bonus of increased social and emotional benefits. In addition, available literature reporting on research in the field of assistance dog use mostly groups disabled people with mobility impairments together, regardless of the impairment type which, in the light of previous discussions on the complexity of impairment effects, including age of onset, is of limited use.

A review of the literature revealed that, to the author's knowledge, there appear to be no qualitative research studies addressing what the experiences of living with a long-term condition such as MS is like, before and after acquiring an assistance dog. The use of assistance dogs has gained recognition as a legitimate source of physical, psychological, and social support for people with disabilities (WHO, 2011). This,

coupled with the encouraging findings from an ever-increasing amount of human-animal interaction studies, strengthens the case for ongoing research into assistance dog use by people with disabilities. It is in this current gap in the research that this work is situated.

2.7   Summary of the chapter

In this literature review chapter, I have addressed distinct bodies of published research in the fields of disability studies, multiple sclerosis, human-animal Interaction (HAI) and assistance dog use. Both the fields of disability studies and studies on MS contain extensive bodies of work. I have focused in this review on current thinking in the field, as well as introducing some studies that employ the same methodological approach that was used within my thesis, that of IPA. In contrast to the former two fields of study addressed herein, I have also examined two fields of study with a more recent history and a considerably smaller body of academic literature. All four bodies of literature come together in the current study which explores the experiences of people living with multiple sclerosis before and after they become assistance dog partners. This review of the literature highlighted that some have cast doubts on the appropriateness of traditional positivist, quantitative approaches to researching people's interactions with non-human animals, including the phenomenon of assistance dog use (Ioannidis, 2005; Herzog, 2011). In addition, the literature review further revealed a call for more qualitative research to be undertaken (Winkle, 2011). The contribution of studies utilising mixed methods has much to offer the field of HAI-D (Whitney et al., 2020). However, uppermost is the clarion call for the greater use of consistent, established research methods

underpinned by standardised evaluation and outcome measures (Winkle, 2011; Rodriguez et al., 2019; Fine, 2020). In addition to which, I would argue for the use of qualitative methods, with established procedures and evidence of indicators of validity and quality (Yardley, 2008; Smith, 2009), in recognition of the small sample sizes characteristic of some HAI research studies (Ioannidis, 2005), and the known benefits of qualitative research. Of equal consideration are the calls for more qualitative research concerning the 'ways inter-species relationships are a fundamental element of rethinking human relationships – especially for those who are marginalised and displaced' (Whitney, et al., 2020, p.7).

This is coupled with a greater move towards the use of shared terminology (IAHAIO, 2018), epistemological and ontological transparency and interdisciplinary working (Fine, 2020; O'Haire, 2018; Herzog and Wells, 2018). It is apposite then to consider the approach taken to the research described in this thesis. Therefore, it is to an in-depth examination of the methodological underpinnings of this research study to which we now turn.

Chapter 3 Methodology and Methods

The preceding chapters introduced the topic area of living with multiple sclerosis

(MS) and having an assistance dog and, through reviewing the literature, the need

for further exploration of the topic, and its importance were established. Commencing

with a description of the aims of the research and identifying its primary and

subsidiary research questions, this chapter then divides into two constituent parts. In

the first part - the methodology section - both the epistemological and ontological

assumptions guiding this study are set out. These along with the methodology and

methods constitute the research paradigm that guides the design of this study and

how it was conducted. Theoretical justification for the choice of the research

methodology employed in this research - that of Interpretative Phenomenological

Analysis (IPA) is also addressed. IPA is an approach to qualitative research which

developed within the field of psychology in the mid 1990's. Its commitment to

examining how people understand and give meaning to significant life experiences

has contributed to IPA's rapid expansion beyond its initial disciplinary boundaries.

Allied disciplines such as management, education, health, and social sciences

(Smith, 2009, 2017; Bailey, 2011; Holland, 2016, Borkoles, 2008) now utilise IPA as

an approach to qualitative inquiry. Alongside a detailed account of IPA – its origins

and theoretical underpinnings, two further approaches to qualitative research

Thematic Analysis (TA) and Grounded Theory (GT) are discussed. Both of which

were considered but ultimately rejected as unsuitable. The methodology section also

considers the concept of experience in relation to IPA.

Part two of the chapter then follows, in which the application of IPA as a means of exploring the experiences of people with MS using an assistance dog is examined in detail. As such, it sets out how a purposive sampling strategy was developed, which facilitated the recruitment of a homogenous sample of eleven participants. This is followed by a description of the data collection process using semi-structured interviews. The consequent application of IPA procedures is described using illustrative examples with which to highlight the distinct stages of analysis.

This part of the chapter also addresses ethical considerations and describes how steps taken to ensure the quality and validity of the findings were achieved. Including an explication of the 'audit trail' within the thesis. Finally, I return to the issue of positionality including my own reflexive engagement with the present research.

3.1 Research aims

Choosing to research the topic of assistance dog use by people living with disabilities out of personal interest and experience, as discussed in Chapter 1, led to a review of the literature. This resulted in the identification of a gap in the research which this study sought to address – the use of assistance dogs by people living with MS. Acknowledging my orientation to exploring and understanding others lived experiences focused the development and articulation of the overall aims of this research study which as set out below.

The aims of the study were:

- To explore the perceptions and experiences of people living with multiple sclerosis who have used an ADUK accredited disability assistance dog for a minimum of two years.
- To contribute to research and existing knowledge concerning the use of assistance dogs by disabled people generally, and those with multiple sclerosis specifically.

3.2   Research questions

Research questions in studies which use interpretative phenomenological analysis (IPA) 'focus on peoples experiences and/or understanding of particular phenomena' (Smith, 2009 p 46). The primary research question in this study was:

What are the experiences of people living with multiple sclerosis who have used an assistance dog for two years or more?

The primary research question generated these secondary questions:

- What can existing theories in human-animal interaction research tell us about the perceptions and understandings of participants of their lived experiences of using an assistance dog as distinct from the experiences for example of interacting with a pet dog or living with MS without any dog?
- What can existing theories in disability studies tell us about the experience of living with MS as a long-term, degenerative condition in the UK thus increasing understanding of the social and cultural situatedness of participants?

Smith et al., (2009) acknowledge the usefulness of such 'second tier' research questions as a way to explore 'theory-driven questions' in IPA but, the authors caution that it is impossible to predict if they will be answered given the open nature of data collection methods in qualitative research. They go on to cite Flowers et al.,

(1997) who, describe how analyses of the data resulting from these second-tier

questions can be:

'used as a lever to evaluate existing theories and models…by comparing the fit between
'understandings utilised by participants'…and 'constructs in the literature' …but this does need to be
done cautiously, and at the interpretative end of the analysis'

(Smith et al., 2009, p.48)

3.3 Determining a research strategy

This study concerns the exploration of the experiences of people living with MS who

have chosen to use an assistance dog rather, than to discover facts about it. The

research paradigm situates the 'reality' of assistance dog use by people with MS as

a phenomenon experienced and understood by the individual, as well as being

something that was jointly constructed through social interaction (Gergen, 2015). In

addition, it sought to interpret the meanings those people ascribed to their

experiences rather than to describe them. As such, a qualitative approach was

adopted for this study due to its flexibility, and its exploratory nature with regards to

data collection and analysis (Denzin and Lincoln, 2017; Willig and Stainton-Rodgers,

2017). Research questions that require an explanation or seek to understand social

phenomena and their contexts are applicable to qualitative research methods (Ritchie

and Lewis, 2014). Hence the use of a qualitative methodology in this study offered an

appropriate means of achieving the aims of this study as outlined earlier in Section

3.1. However, qualitative research is a general term covering a range of

methodological approaches which are influenced by different guidelines for ensuring

methodological rigour and by different beliefs (Ritchie, 2014; Leavy, 2014). The next

section looks in at some alternative approaches considered for this study. Focusing

on two approaches (of several) to conducting qualitative research within the

qualitative paradigm; those of thematic analysis (Braun and Clarke, 2006; Clarke et

al., 2015) and grounded theory (Charmaz, 2006, 2015), a rationale is given as to why they were not utilised in this study.

3.4 Alternative qualitative approaches that were considered

Thematic Analysis

Thematic Analysis (TA) is an approach to qualitative research that provides a method – a set of tools - for analysing qualitative data which is independent of pre-determined guiding theoretical assumptions (Braun & Clarke, 2006; Braun et al., 2015). This well-established qualitative approach was initially considered for this study.

 The term 'thematic analysis' in relation to the analysis of qualitative data has described numerous methods and many discrete meanings over the forty years since it first materialised (Braun et al., 2015). Confusion about what exactly thematic analysis is and inconsistent advice on how it should be applied resulted in the application of the term to describe a range of methods utilised in the analysis of qualitative research.   However, with Braun and Clarke's (2006) systematic outline of the six recursive phases of data analysis, thematic analysis has developed into one of the most widely recognised and used method that utilises themes, in health, social sciences and psychology (Braun et al., 2015). Described as possessing flexibility as its hallmark, thematic analysis can be utilised in diverse ways and within a broad spectrum of theoretical frameworks such as critical realist or constructionist. Additionally, thematic analysis can be used to grapple with most types of research question and deployed to analyse most types of qualitative data from interviews to focus groups, diaries to secondary sources. Due to its inherent flexibility, the researcher must take an active part in the design of a research study which uses

thematic analysis as an approach (Braun and Clark, 2006; Braun et al., 2015). Thematic analysis can assist researchers in the identification of patterns in the data through the process of identifying themes relevant to the research question posed. Although it has been argued that once extracted, the researcher must then make the decision as to what the themes represent thereby revealing their adopted theoretical and epistemological perspective (Willig, 2012).

Yardley (2000) sets out a core set of principles for demonstrating the validity of qualitative research which are drawn upon in this thesis, (see Chapter 3, Section 3.7.6), one of which is 'coherence and transparency' (Yardley, 2000; Smith et al., 2009). The extent to which a study makes sense as a whole is argued to be somewhat influenced by the fit between the theoretical approach the researcher adopts, the type of research question, the methods used and the subsequent interpretation of the data (Yardley, 2015). Willig (2001), describes 'fit' as important in research design wherein each different element is conceptually compatible. However, Braun et al. (2015) concede that thematic analysis does not provide a good fit with research questions with an idiographic focus or concerned with the in-depth examination of individual participants' narratives. Its emphasis on patterns across the whole data set made it a less suitable fit for this study which explored data from a small homogeneous sample. This decision was informed by initial enquiries with all four assistance dog charities regarding the percentage of their service users that had a diagnosis of MS. Once it was established that the potential pool of participants who met the inclusion criteria (see Chapter 3, Section 3.5.1) was likely to be few in number, given the relatively new and uncommon phenomenon of assistance dog use by people living with MS in the UK, the use of thematic analysis which favours larger

sample size was deemed inappropriate. Overall, my focus in this study concerned the lived experiences of individuals which called for an approach more suitable for undertaking 'in-depth scrutiny of the narratives of individual participants' (Clarke et al., 2015, p.226), for which ultimately, thematic analysis is not (Smith et al., 2009).

In making an informed choice about a research approach that matched both my interests, my epistemological and ontological perspective and my research questions, a more cohesive approach to this study was sought. I wanted to use a more theoretically informed framework with a goal of achieving a more fully conceptualised study within which to answer my research questions.

Grounded Theory

With the aim of developing 'a clear, systematic and sequential guide to qualitative fieldwork and analysis' (Smith et al., 2009, p.202) two sociologists, Glaser and Strauss, (1967) challenged the dominant quantitative paradigm rooted in positivism, with their development of Grounded Theory (Charmaz, 2015). In doing so , grounded theory countered many of the prevailing assumptions that qualitative research was unsystematic, was unable to generate theory or should be conducted utilising the criteria for quantitative research. However, early versions of grounded theory were revised following a schism between Glaser and Strauss. And the subsequent publication of Strauss and Corbins' book *Basics of Qualitative Research* (1990,1998) saw a significant revision of grounded theory. Further revisions followed with the next major constructivist revision of the theory first articulated by Charmaz (2000). Constructivist grounded theory, in Charmaz's words

continues the iterative, comparative, emergent and open-ended approach of Glaser and Strauss's (1967) original statement; adopts the pragmatist emphasis on language, meaning and action; counters mechanical applications of the method; and answers criticisms about positivistic leanings in earlier versions of grounded theory.

(Charmaz, 2015, p.56)

Smith et al., (2009) contend that constructivist grounded theory (Charmaz, 2006) is now the most commonly utilised version of grounded theory in psychology and is viewed as the 'main alternative method for someone considering IPA for a research study' (Smith, 2009, p.201). Constructivist grounded theory and IPA share similarities, with both having an inductivist approach to qualitative inquiry and both concerning the individual as their focus. However, grounded theory seeks to generate theoretical-level explanatory account (impacts, influences, factors) involving the phenomenon/complex social process that is being researched (Larkin, 2015). Though Charmaz (2015) acknowledges that most researchers undertaking grounded theory research never actually construct formal theory rather they

construct conceptual analyses of a particular experience…They emphasize analytic categories that synthesize and explicate processes in the worlds they study rather than tightly framed theories that generate hypotheses and make explicit predictions.

(Charmaz, 2015, p.80)

These aims are achieved with the use of larger sample sizes employing theoretical sampling whereby the researcher moves between sampling, data collection and analysis until reaching a point where no new information is collected (saturation). Neither of these (use of large sample size and theoretical sampling) could be deemed a good fit for this study in view of the size of the potential pool of participants available (as discussed previously) and also, for pragmatic reasons of time constraints on the duration of the project. Of primary concern however, in choosing or rejecting a qualitative methodology centred on achieving the research aim to explore

individual perceptions and understandings of participants hence, grounded theory

was also discounted as a methodology for this study.

The section concludes with an in-depth discussion of why Interpretative

Phenomenological Analysis (IPA) was ultimately deemed to be the best

methodological fit for this study considering my epistemological and ontological

stance as the researcher and the aims of the research study.

3.5   Epistemology and Ontology

Acknowledging how I as a researcher understand the ontological (nature of the social

world, reality) and epistemological (nature and scope of knowledge) beliefs when

undertaking research is essential in order to ensure academic rigour and research

validity (see Chapter 3, Section 3.4.6). The importance of being aware of these

perspectives is because they represent, as Kivunja and Kuyini (2017, p. 26) suggest

'the lens through which a researcher looks at the world'. By providing a philosophical

foundation for the study, both beliefs can influence the design and conduct of the

research (Bryman, 2008). They formed (along with the methodology and methods

used) an underlying set of assumptions that guided and underpinned the whole

research process (Guba and Lincoln, 1994; Creswell, 2014).

3.5.1 Phenomenological Ontology

Phenomenology is the philosophical study of human experience and of how things

are experienced. It seeks to express the essential meanings phenomena hold for the

people who are experiencing them (Smith, 2016; Giorgi, 1985). 'Reality' is made up of phenomena (events and things) as people perceive them and then they are understood by the consciousness rather than existing as objects that are independent of the human consciousness (Smith, 2016). It was this phenomenological ontology (understanding of the social world) which guided this study, in concert with the adoption of a social constructionist epistemology, which views the world as being constructed through the language and interactions of the people in situ.

Experienced from a social constructionist perspective, what is considered the 'truth' or 'reality' are merely concepts about the social world, existing within a certain culture, at a certain time, and which depend on those social relationships which reinforce what is socially agreed (Gergen, 2015). In relation to this study for example, these interpretations of the social world collided early on when I (and my assistance dog) shared a conference table with a colleague from Africa and a delegate from Korea. One lives in a country which still eats dogs, one grew up where it was normal for there to be a village dog that no individual person owned and would scavenge for food scraps, never to be allowed inside to sleep. And myself, an assistance dog user who had been upgraded to first class on the Eurostar train from the UK, to allow the two of us (human and dog) to have more room. Neither of the three interpretations of the social world is more 'true' or 'real' than the other. They are merely as Schwandt (2000, p. 197) describes, peoples' constructions of the social world, each against a different 'backdrop of shared understandings, practices, language and so forth'.

3.5.2 Phenomenological research

Explorations of the human experience have been a concern of philosophers throughout the eighteenth and nineteenth centuries. Originating in the 1890s with the philosopher Edmund Husserl (1859 – 1938), the philosophical approach to the study of human experience is known as phenomenology (Kaufer & Chemero, 2015). Husserl wanted to find a system whereby someone could accurately know their own experience of a particular event or phenomenon. He reasoned that by identifying the essential features of an experience, the set of conditions connected to their appearance might be transcended, thereby illuminating that given experience for others too (Smith et al., 2009). In order to do this, we have to suspend our 'natural attitude' where we take for granted or 'accept our experience as veridical' (Kaufer & Chemero, 2015, p. 48). Husserl developed a method through which the essential features of an experience would be revealed. Primarily Husserl suggested we must 'bracket, or put to one side, the taken-for-granted world in order to concentrate on our perceptions of the world' (Smith et al., 2009, p. 13). This was to be followed by a series of 'reductions' involving different ways of thinking about the experience with the ultimate aim of establishing its essence. The descriptive (eidetic) approach to phenomenological research first developed by Husserl, is concerned with understanding social reality, believing that experience (as the human conscious perceives it), can be investigated and was of value. Furthermore, research questions viewed from a Husserlian perspective place an emphasis on the provision of a 'thick description' of the experience or the particular phenomenon (Smith, et al. 2009). Giorgi (2012) suggests that everything to do with the subject of the phenomenological inquiry is as it shows itself which, essentially can be summarised

from a participant's accounts. Hence, from a descriptive phenomenological

perspective - for example, the relevance of Jo's experience of temporarily losing

the ability to walk while crossing the road (see Chapter 3, Section 3.7.5) - is only

related to what her experience means for the experience of living with MS generally

as a phenomenon. The essential feature of that individual experience that makes

living with MS, living with MS. However, overtime descriptive phenomenology

evolved due to the influence of philosophers such as

Heidegger (a student of Husserl) whose concept of 'Dasein' or there-being,

emphasises that our knowledge of the world is always in the context of a person's

lived personal experiences situated in their world. This differs from the Husserlian

tradition which is considered to have a more descriptive and transcendental

perspective (Smith et al., 2009). Heidegger (1962/27), and later Merleau-Ponty

(1962), assert that as people experience the world from a position of being situated

somewhere (there-being or being-there), it is impossible to completely bracket out

our taken for granted perceptions of the world as Husserl advocates, but we should

do so as much as possible. Heidegger (2010) argued that, peoples engagement with

the world is through interpretation. This marks the beginning of what Caputo (2018)

considers is meant by 'contemporary or postmodern hermeneutics' (p. 25), which I

discuss in more depth below, in relation to IPA which aligns itself with this more

hermeneutically orientated phenomenological approach.

3.6 Interpretative Phenomenological Analysis (IPA)

Moving on from the historical and philosophical background of phenomenology upon

which IPA draws, the following section looks in some depth at how its key theoretical

underpinnings – Phenomenology, (postmodern) Hermeneutics and Idiography apply to the exploration of the experiences of participants in this study. It begins by examining what is meant by the term 'experience' within an IPA study and offers a rationale for how participants' sense-making of their experiences proceeded to then be interpreted by me as a researcher. This includes a closer look at the role and degree of bracketing of previous experiences which IPA subscribes to and how I as a researcher enacted this throughout. And finally, the section concludes with an examination of the third major influence on IPA, and one of the reasons IPA provided the best fit as the qualitative methodological choice for this study, its concern for the particular – Idiography.

Experience

IPA, as a phenomenological approach is concerned with the study of lived experiences and its aims to make sense of the sense-making that participants' are engaging in of those experiences. It recognises that ways of thinking around what exactly an experience is in this context, can assist in clarifying what may be happening when participants engage in thinking about the experiences they have in life. In this study this entails an in-depth analysis and interpretation of the sense-making of the participants around their experiences of having an assistance dog with them as they experience living life with a longterm condition. Smith et al., (2009) reference the strong phenomenological underpinnings of IPA in framing the development and application of in the approach. Acknowledging that much phenomenological writing concerning what was termed by Husserl as our 'natural

attitude' (Smith et al., 2009, p.12) meaning ones every day, unselfconscious, taken-for-granted immersion in daily life. This is a pre-reflective state and exists within the 'everyday flow of experience', however, once we become conscious of the thing that is happening, it is then that it becomes 'an experience' rather than merely experience (Smith et al., 2009, p.2). IPA is predicated on the assumption that people are fundamentally sense-making by nature and the authors cite Dilthey's (1976) description of how once we turn our attention to 'an experience', this may become either a discrete 'unit in the flow of time' or, when it includes many other aspects of something which are all connected by a common meaning. These constitute a 'more comprehensive unit' of experience even when the parts are separated by interrupting events' (p. 210) such as the passage of time. When something important happens in a person's life, they are predisposed to reflect on its significance for them in their life world. The aim of the IPA researcher is firstly to try to understand a participant's attempts at making sense of their significant life experiences through the participants 'reflecting, thinking, and feeling as they work through what it means' (Smith et al., 2009, p.2). However, the accounts provided by the research participants in an interview depend on what a participant chooses to tell the researcher about an experience of major significance. As such, it is then the domain of the IPA researcher to interpret the participants interpretations of those more 'comprehensive units of experience' by facilitating their recall, highlighting the connections between aspects of those experiences, and revealing their meaning, which may not be apparent to the participants themselves. This involves substantial interpretative activity on the part of the researcher and in the following sections I discuss how IPA as a phenomenological hermeneutical approach utilises the systematic and detailed analysis of the eleven participants' verbatim accounts of assistance dog use in this

study by employing the two other theoretical underpinnings of IPA, Hermeneutics and Idiography.

3.6.1 Hermeneutics

One of the key theoretical underpinnings of IPA is that of hermeneutics – the theory of interpretation. In particular, this involves the use of the hermeneutic circle whereby the meaning of the 'whole' (for example, the research project, complete text or sentence) depends on meanings of the 'parts' (such as the interview, a single extract or a single word) and vice versa (Smith, 2009). In IPA, the researcher is interpreting the meaning making that the participant is making of the event that is happening to them, of their personal lived experience. As such, IPA is engaged in a double hermeneutic (Smith & Osborn, 2015).

Smith et al. (2009) emphasise two key elements of the interpretative activity involved in IPA as an interpretative phenomenological approach as articulated by Heidegger in his key text Being and Time (1927/1962). Firstly, this asserts that if some phenomena is interpreted, this interpretation is always interpreted through the lens of previous experiences of the interpreter. Secondly, the relationship between this interpretative activity and 'the fore-structure of our understanding necessitates a reconsideration of the role of bracketing' (Smith et al. , 2009, p.25) in the analysis of data generated in qualitative research adopting IPA as their methodology such as this one. Gadamer (1990/1960) concurs and although predominantly concerned with hermeneutics in relation to historical texts, acknowledges the complexity of the relationship between the reader/interpreter and the interpreted (Smith et al., 2009).

As such, bracketing is regarded as dynamic and 'a cyclical process and as something which can only be partially achieved' (Smith et al., 2009, p.25). This returns us to the perspective of an Interpretative Phenomenological Analysis which employs a double hermeneutic as a key theoretical influence wherein I, as the interpreter interpret the participants' narratives in which they are interpreting – making sense of their experiences of living with MS and using an assistance dog. Dixon (2010) contends the role of the researcher is crucial in an IPA study in which the researcher's own fore-conceptions, understandings and previous knowledge interact with the participants' lifeworld. This dynamic role of the researcher is considered central to the effectiveness of the analytic process (Smith and Eatough, 2007; Smith and Osborn, 2015), with the resultant final analysis a 'co-construction' between the participants and myself as researcher (Osborn and Smith, 2006, p. 218).

3.6.2 Idiography

IPA is committed to understanding phenomena from the perspective of particular individuals, in particular contexts (Finlay, 2011). As such, IPA requires the detailed examination of a particular case as an entity in its own right before moving on to more general claims. It is therefore committed to idiographic inquiry (Smith et al., 2009; Smith and Osborn, 2007). It focuses on meanings at a personal level (Hamill et al., 2010), generating rich and detailed descriptions of how individuals experience the phenomena under investigation and emphasising the importance of the individual as a unit of analysis (Eatough and Smith, 2017). It is this concern for the particular, rather than the general or nomothetic (Smith, 2009), that makes IPA idiographic in its

focus. IPA seeks to examine each case, each participant, in context and explores their personal perspective before moving on to the next.

Committed to examining how people make sense of major life experiences, IPA is highly appropriate for this research study as it aims not to find the essence of what it means to live with MS and use an assistance dog. Rather, it aims to capture the particular experiences of living with MS and assistance dog use for particular people – 'they represent a perspective, rather than a population' (Smith et al., 2009, p. 49). IPA, as an idiographic process privileges the minutiae of participants' lived experiences. Detailed accounts of the nuances, subtle differences and quirks of each of the nineteen assistance dogs participants used over more than two decades combined with the highs and lows of living with a progressive neurological disease, elucidate the findings facilitated by a detailed analysis (Smith and Osborn, 2007; Findlay, 2011). This application of an interpretative hermeneutic analytic process in IPA helps with understanding the experiences of what Gadamer (1900-2002) conceptualised as 'a horizon of understanding' of the lived experiences of the participants in this study (Clark, 2008, p.2). A fusion of horizons between participants and researcher who is trying to understand must 'learn to look beyond what is close at hand – not in order to look away from it but to see it better' (Gadamer, 2004) (See Chapters 4-6).

 The thesis now moves from an overview of the theoretical and philosophical underpinnings of IPA to an examination of the research methods it informed which were employed within in this study.

3.7 Methods

This section describes the qualitative research methods used to explore and examine the experiences of people with MS who have chosen to use an assistance dog. Detailed examination of the application of IPA to the data collected is presented. The section begins with a description of how the use of IPA as an approach to qualitative research, with its firm theoretical underpinnings (Smith et al., 2009) and its 'detailed procedural guide' (Brocki & Wearden, 2006, p. 4), informed the development of the sampling strategy employed and hence the participants recruited.

This is followed by a description of how the single semi-structured, in-depth, interviews were planned and conducted. As a method of data collection, semi-structured interviews are consonant with the qualitative paradigm in general and for IPA research studies in particular (Smith et al., 2009; Eatough and Smith, 2017). I then set out my process for data analysis in which illustrative examples from the data are used to describe the various stages of IPA undertaken, aiding transparency, and elucidating the interpretative processes underlying the research. Ethical considerations within the study are also addressed in this part of the chapter, along with further examination of researcher reflexivity, its role in informing positionality and issues of trustworthiness and quality. Finally, a summary of the key points contained within the chapter, and an introduction to the subsequent three findings' chapters, (Chapters 4-6) conclude the methods and methodology chapter.

3.7.1 Sampling

Robinson (2014) states that sampling is an essential part of qualitative research design, but it has not featured as prominently in the literature, when compared to data collection and data analysis. His four-point approach to sampling is a useful guide and provides a practical and theoretically informed framework with which to undertake sampling in qualitative approaches such as IPA. Robinson suggests that these points in the sampling approach (outlined below) are not 'sequential steps in a linear process, for decisions pertaining to each point can iteratively affect the other three and vice versa' (2014, p. 15).

The approach to sampling employed in this study is that suggested by Robinson, (2014) and is outlined below:

- Define sample universe
- Select sample size
- Devise sampling strategy
- Source sample

The adoption of this four-point approach to sampling also serves to enhance the validity and quality of the research (Robinson, 2014; Smith, 2009) as outlined and evaluated by Yardley (2000). Issues of quality and validity in this thesis are addressed later in the chapter but first, the next section of the chapter utilises Robinson's framework to explicate the sampling approach used in the thesis in greater detail.

The sampling strategy utilised in this research study was that of purposive sampling

(Barbour, 2014; Smith, 2009). The rationale for using this approach to sampling was

to recruit those participants 'for whom the research question [would] be significant'

(Smith & Osborne, 2007, p. 56). Robinson (2014) reminds us that:

> maintaining a measure of sample homogeneity, IPA studies remain
> contextualised within a defined setting, and any generalisation from the
> study is made cautiously to that localised sample universe, and not
> beyond at any more speculative or abstract level

(Robinson, 2014, p. 27)

To this end, all four ADUK registered assistance dog charities, who train disability

assistance dogs for people with multiple sclerosis across the UK (excluding Northern

Ireland), were contacted by email. They were: Canine Partners, Dog A.I.D., Support

Dogs and Dogs for Good (previously Dogs for the Disabled). In my communications

with the charities, the broad aim of the research was shared, the inclusion/exclusion

criteria given, and the data collection method described. Offers to visit each individual

charity, to speak further to staff about the research, were made. This was with the

intention of explaining face to face, the information sheets for participants (Appendix

B), the consent form to take part in the research (Appendix C) and to discuss how the

individual charity could or would be prepared to facilitate the process of identifying

clients who met the inclusion criteria for the study and passing on my contact details.

In addition, it was anticipated that staff would be able to raise any concerns or

questions they may have had about the research at an early stage. Equally it served

to aid in building positive, collaborative relationships between myself as a researcher

and the assistance dog charities as gatekeepers. Ultimately it was hoped that this

personal contact with a researcher who is an ADUK trained assistance dog user – a

perceived 'Insider researcher' – may increase the likelihood that the assistance dog

charities would identify clients who met the inclusion criteria for the study. Thereby

acting as trusted go-betweens to facilitate contact between researcher and potentially

vulnerable participants (Greene, 2014; Corbin Dwyer & Buckle, 2009).

A description of the rationale behind the inclusion and exclusion criteria that were

established now follows, including the provision of a table (Table 2, below) to aid with

clarity, consistency, and transparency of the study.

As discussed previously, ADUK registered organisations were exclusively

approached for the following reasons. IPA requires a small, homogeneous group of

participants who will, as far as possible, have had similar experiences. By recruiting

participants who have obtained/trained their assistance dog through an ADUK

registered organisation, it was clear that all participants will have had a minimum of

the following similarities of experience:

- A confirmed medical diagnosis of their physical disability (multiple sclerosis).
  Eligibility criteria for both ADUK organisations recruited from stipulate that
  applicants for disability assistance dogs must have a diagnosed physical
  disability and must provide medical reports from their GP/Consultant.
- Undergone similar training to the same high standards as described in the
  previous section.
- Adhered to the same standards of welfare and hygiene of their assistance dog
  required of an ADI/ADUK accredited assistance dog working partnership.
- Received their assistance dog without charge and inclusive of ongoing support
  and training for the working life of the dog.

- Undergone a re-certification assessment as a working assistance dog partnership annually.

Table 2 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
Person with MS (PwMS) over 18years	PwMS Under 18 years
Assistance dog Trained by ADUK accredited organisation	PwMS with OT or commercially trained assistance dog
PwMS-AD partnership 2 years minimum	PwMS-AD partnership less than 2 years

Below is a more detailed explication of the inclusion/exclusion criteria applied in this study.

Exclusion criteria

Without a national register of assistance dogs in the UK, this research is situated in a landscape where an unknown number of owner-trained assistance dogs (OTAD) and assistance dog partnerships trained by the commercial sector (CSTAD), are working in this country, indeed this is true globally (ADI, 2018). Exclusion of owner trained/commercial sector trained assistance dogs of people living with MS does not imply per se that they are trained to a lesser standard or their assistance dog maybe subject to inadequate hygiene or lower welfare standards, by comparison to an ADUK assistance dog partnership (ADUK, 2020). It does however reflect the potential challenges in identifying, gaining access to and recruiting participants with an owner trained assistance dog/an assistance dog trained in the commercial sector.

However, when recruitment of participants proved initially slow, this option was cautiously considered. On further reflection however, it was felt the risk of potential inconsistencies in the level of training, and standards of behaviour and welfare of non-ADUK accredited assistance dogs may diminish the homogeneity of the sample. Therefore, the inclusion/exclusion criteria remained unchanged, adhering to one of the tenets of IPA research methods to, where possible and practicable, use a homogenous sample.

Inclusion criteria

Further inclusion criterion established was that participants were people with MS who had had their assistance dog for two years or more. This was designed to capture data from partnerships that were well established and stable. In line with IPA's idiographic commitment, this allowed the interviews to yield a richer, deeper level of data from participants and further informed the development of questions on the interview schedule (Appendix D), as well as yielding data which contained accounts of uniquely personal experiences from participants. This approach shifted narratives beyond the more superficial, perhaps wholly positive, descriptive accounts of this phenomenon, commonly encountered in literature, media, and organisational fund-raising material, to a more nuanced, balanced, and in-depth treatment of the topic.

A final criterion guiding the sampling strategy was that all participants were adults over the age of eighteen. This was informed by the literature which reports that between 2-5% of people with MS will be diagnosed under the age of eighteen. It is now established that people under eighteen with MS have different support needs to

adults and they also require different medical treatment (MSIF, 2013). IPA's requirement for a homogeneous sample of people for whom the research questions will be meaningful meant that the inclusion of participants under 18 years was not appropriate for this study.

3.7.2 Ethical considerations

Ethical approval was granted by The Open University's Human Research Ethics Committee (HREC) prior to commencing data collection (see Appendix A. Memorandum of a favourable opinion: HREC Ref.: HREC/2015/2170). Cognisant that as a researcher I was obligated to ensure the protection of both the participants' interests and their identities (Social Research Association (SRA), 2003), I put a variety of safeguards in place before, during and after the study which are described in the following section. The study followed both the OU Code of Practice for Research at The Open University (2014, 2017), guidelines on research ethics and the SRA (2003) guidelines on ethical research. In addition, an enhanced DBS check was obtained from the Disclosure and Barring Service prior to commencing fieldwork with participants who were 'adults in certain circumstances' as they were in receipt of healthcare or personal care and thereby considered a vulnerable group (ESRC, 2015; Disclosure and Barring Service, 2017).

Details of individual assistance dog charities to which participants were associated were presented in the text of this thesis as 'assistance dog charity', and each participant assigned a pseudonym. This meant a participant's identity could not be disclosed or inferred from the text. Participants' real names were not used or stored

with data collected. In addition, participants were informed in writing, and in accessible and understandable terms, of the benefits, obligations, risks, or possible inconveniences of participating in the research. Participants were given an information sheet about the research, as well as oral explanations (see Appendix B). Furthermore, participants were given enough time (48 hours or more) to consider whether they wished to participate in the research before consent was obtained and a consent form signed. Signed consent forms were stored in a locked filing drawer, in a locked office located in an OU building in Milton Keynes.

Participants were informed that they remained free to withdraw at any time (up to the point of analysis) and the data collected from them would be destroyed. None of the participants wished to take up this option but three expressed an interest in receiving a summary of the study's results once the project was completed.

In the accompanying literature review (Chapter 2) there is detailed description concerning the range of possible hidden and visible impairment effects of MS. With these in mind I built into my data collection accommodations that would, as far as possible, mitigate potential impairment effects of MS. This ensured that any participant's specific requirements which maybe a hidden impairment effect of MS (fatigue, discomfort, memory and concentration problems, bladder/bowel dysfunction and so on) were considered and accommodated. For example, participants were reminded that they were free to take rest breaks throughout the interview. Choice of interview location and preferred time of day were honoured, acknowledging that each participant with MS may have times of the day where they feel better or less well and

this may alter during any given day. A letter was sent to each participant the week of the interview reminding them of the date and time of the interview and reassuring them that should their circumstances alter they could cancel/reschedule their interview at any time. One participant initially identified as meeting the criteria was unable to proceed with the interview due to a significant relapse in their MS. Another participant cancelled the morning of the interview as she was feeling too fatigued but was able to proceed ten days later when she was feeling less fatigued.

I followed the OU guidance regarding lone working (Lone-Working-Operational-Standards-HSOS014.doc) for those interviews conducted in a participant's own home. Procedures were put in place should a participant disclose information of significant risk of harm to themselves or another person (or assistance dog). In this situation I was aware that participant safety superseded any assurance of confidentiality. Participants were made aware (verbally and in writing) of who they may contact in the OU should they have issues with any aspect of the conduct of the study. Furthermore, participants were informed that findings from the study would be disseminated via peer reviewed documents and presentations. This would include a PhD thesis, academic posters, peer reviewed papers and conference abstracts and presentations, as well as a brief report that would be sent to the assistance dog charities involved in training them. Finally, in this section outlining ethical considerations in this thesis, I briefly address how researching people's experience of living with MS and the use of an assistance dog might cause me personal psychological or emotional distress. Consequently, I was careful to put in place resources that could provide appropriate support should it be required. This was

done without disclosing confidential fieldwork information. Resources included

obtaining information on support available from the MS Society, The Open University

(Supervisors and student support team), regular attendance at post-graduate

fieldwork support group and peer-to-peer support with fellow trusted PhD students

(Disabled and able-bodied) undertaking 'insider' research.

3.7.3 Recruitment

Whilst all four of the relevant ADUK registered charities contributed information on

the percentage of their clients living with MS and using an assistance dog, only three

of the four ADUK registered organisations went on to offer access to potential

participants meeting the inclusion criteria outlined in the section above. I travelled to

each of those three organisations, in one I gave a formal talk to the whole staff group

and met with the CEO and some instructor level senior dog trainers at the other two.

All three of the organisations agreed to review their client list to identify appropriate

clients who, as well as meeting the inclusion criteria, were also close to their routine

re-accreditation assessment or aftercare input. This meant they would not need to

make a separate journey to undertake the interview. Clients who expressed an

interest in participating were passed a Participant Information letter, which also

contained my contact details (Appendix B) and a Consent Form (Appendix C).

Initially planned for between March and September 2016, the recruitment period was

extended by three months due to participants' various difficulties with arranging

interview dates over the summer period (a point to consider in future research and no

doubt a contributing factor in the slow recruitment to the study initially). Seven women

and four men who were clients of two of the four ADUK registered charitable

organisations (who train and supply disability assistance dogs to clients throughout

the UK, excluding Northern Ireland) were recruited to the study. One other person

who met the inclusion criteria was recruited from a third ADUK accredited charity, but

shortly thereafter she suffered an exacerbation of her MS. The deterioration in her

health caused by this relapse necessitated her withdrawal from the study. This left a

sample size of eleven participants (Table 3) which is consistent with IPA studies

where, as Smith and Osborn (2007) assert,

> there is no right answer to the question of sample size. It partly
> depends on several factors: the degree of commitment to the case
> study level of analysis reporting, the richness of the individual cases,
> and constraints one is operating under (2007, p. 56).

More recently, Spiers et al. (2018), in their interpretative phenomenological analysis

of ten general practitioner partners living with distress, described the sample size as

'large enough to include an enlightening variety of convergence and divergence, yet

small enough to allow for the in-depth analysis characteristic of IPA' (2018, p. 3).

Table 3 Participant details

Participant Pseudonym	Gender	Age at Diagnosis/ Interview	Type of MS at Diagnosis/Interview	Social Situation	Number of Assistance Dogs
P1 Helen	F	43/65	RRMS/SPMS	Lives with partner	1
P2 Amanda	F	33/44	RRMS/RRMS	Divorced	1
P3 Maggie	F	29/60	RRMS/SPMS	Lives alone	2
P4 Roy	M	45/64	PPMS/PPMS	Married	2

P5 June	F	32/67	RRMS/SPMS	Divorced lives alone	3
P6 Richard	M	36/52	RRMS/SPMS	Married	1
P7 Anne	F	36/58	RRMS/RRMS	Married	1
P8 Steve	M	26/52	RRMS/SPMS	Divorced lives alone	3
P9 Jo	F	47/63	RRMS/SPMS	Married	1
P10 Elaine	F	26/41	RRMS/SPMS	Lives with partner	2
P11 Sean	M	38/55	PPMS/PPMS	Married	2

Nine of the eleven participants were interviewed alone (apart from their own assistance dog). Two of the participants, 'Roy' and 'Steve', the most severely physically affected people interviewed, were accompanied for all (Steve) or part (Roy) of the time by a paid carer or spouse. Both participants were unable to speak for an extended period of time due to the effect that MS had on their speech and energy levels. Whilst it is acknowledged that having an additional person in the interview may have inhibited participants from speaking freely, the pragmatic demands for Steve and Roy to receive support (having a drink safely or on occasion interpreting an inaudible or unintelligible word/phrase), was on balance a necessary compromise. Having discussed the sampling strategy, recruitment, and characteristics of the eleven participants in the study, the focus now turns to the method of data collection employed.

3.7.4 Data collection

Pilot study

A small pilot study of two people, one with MS who uses an assistance dog and a carer for a different person with MS who used an assistance dog, were undertaken before the data collection phase of this study began. This was done to make sure the questions flowed, and the data collected was 'IPA friendly,' by which is meant it connected to meaning making and moved beyond description. Thus, 'allowing the researcher to get a sense of emergent themes including the most salient extracts that support them before moving on' (Holland Personal Communication, 2018). In addition, doing the pilot interviews allowed for the identification of any issues which would necessitate an alteration or refinement of the interview schedule questions or prompts. Interviewing a carer allowed a more fine-grained consideration of potential objects of concern for people living with MS. It revealed some aspects of living with MS and the use of an assistance dog, such as the intensity and extent of the fear of retirement of the dog, which influenced the interview schedule theme of loss and grief. It was possible that without specifically addressing this in the interviews, participants may have avoided the topic, finding it too painful.

Undertaking the pilot interviews allowed me to begin to focus on perceived 'objects of concern' (Smith et al., 2009, p. 83); for example, the key events, people, and processes for people with MS who use an assistance dog (as distinct from those people living with MS with a pet dog or those living with a different disability with a pet/assistance dog). Taken as a whole, and implicitly informed by the research question, data from the pilot interviews, along with preliminary reading around the subject, went on to inform the broad topic areas covered in the interview schedule (Appendix D). Further refinement of questions was undertaken in collaboration with

the project supervisors and a close reading of Smith et al.'s (2009) description of the

construction of a schedule for an in-depth interview. Examples of the kinds of

questions, adapted from Smith and colleagues (2009), are shown in Tables 4 and 5

(below). These were employed with the 'aim to set the interview as an event which

facilitates the discussion of relevant topics, and which will allow the research question

to be answered subsequently, via analysis.' (Smith et al., 2009, p. 57). A full version

of the interview schedule can be found in Appendix D of this thesis.

Table 4 Interview themes

Broad themes covered by the semi-structured, in-depth interviews
1. Living with MS/ a long term condition (diagnosis, impairment effects, impact on self)
2. Society (perception of reactions before and after assistance dog and when with/without assistance dog)
3. Understanding of the benefits/challenges of using an assistance dog when living with MS
4. Experiences of loss and grief, imagined futures or 'what if's …'

Table 5 Question types

Question type	Examples of Interview questions
Descriptive	How does MS affect you day to day?
Narrative	Can you tell me about when you were first diagnosed with MS?
Structural	What does your assistance dog do for you?
Comparative	How do you think your life would be without your assistance dog?
Evaluative	Do you find any aspects of having an assistance dog challenging?
Circular	What did your family/friends think of your decision to apply for an assistance dog?

(Adapted from Smith et al., 2009, p. 62)

Participant Interviews

All participants lived in England and were spread geographically across the regions.

Three participants chose to be interviewed at the location where they had initially

trained with their assistance dog. This was for their convenience because they were

attending the centre that day as part of their yearly re-assessment. The remaining

eight interviews were conducted at the participants' homes, at their request. Their

annual re-accreditation assessment usually took place at their home. At three of the

home-based interviews, and three of the training centre ones, I was accompanied by

my own assistance dog (with the participants' and training organisation's consent).

The remaining five interviews I attended without my assistance dog, at the request of

one of the charities, who had put me in touch with those participants.

Those recruited to the study took part in a single in-depth, semi-structured interview

to explore their experience of living with MS and the use of an assistance dog/s over

time. As discussed earlier, in-depth, semi-structured interviews are the most

frequently used method of data collection in IPA studies; though there are studies

that have used other methods such as participants' essays, personal diaries or focus

groups (Smith, 1999; Palmer et al., 2010; Brocki & Wearden, 2006). Each individual

interview was recorded digitally and lasted between 50-90 minutes. Interviews were

transcribed verbatim by an Open University approved transcription service who had

an agreed confidentiality agreement in place. An interview schedule was used to

guide the interview process (Appendix D). This allowed me to prepare for the

interview and plan contingencies in case of difficulties. Questions on the schedule

were open and the participants encouraged to speak at length about their experiences.

As mentioned earlier, recordings of the interviews were transcribed by an Open University approved transcription service. This was a source of anxiety initially, given that I had previously undertaken transcription of qualitative interviews some years earlier and found the process to be extremely valuable. It increased greatly my familiarity with the data and allowed me to begin forming initial responses to it, effectively the process of transcribing formed part of the nascent analysis of the data. Any anxiety about a lack of familiarity or closeness to the data proved unfounded when I listened to the original audio tape of each interview while reading the written transcript. This helped me to become familiar with the data (again), especially as there was a gap in sending tapes for transcription and the return of the verbatim transcripts from the approved transcription service, with other interviews conducted in between. Further immersion in the data was achieved by listening and re-listening to the audio tapes between episodes of analysis, such as on long commutes. Smith et el. (2009) advocate listening to the audio tape of each interview on at least one occasion while initially reading the transcript, advising that this is helpful because 'Imagining the voice of the participant during subsequent readings of the transcript assists with a more complete analysis' (2009, p. 82). Listening to audio recordings is a key recommendation from Rodham et al. (2013) as a way of self-monitoring if researchers' interpretations of the data are biased or superimposed on the data and that themes are 'actually represented in the transcripts being analysed' (2013, p. 60).

3.7.5 Data Analysis

Committed to an idiographic approach to inquiry means that it is usual in IPA studies to analyse the first case in detail before moving on to the next case or making more general claims (Smith and Osborn, 2007). Smith et al. (2009) provide a detailed six step process by which the data generated in IPA studies may be analysed. This is described by Smith (2007,2009) as an inductive and iterative process which employs a variety of strategies moving from a descriptive to the interpretative, and the idiographic (particular) to that which is shared (nomothetic). This involves adhering to the underpinning commitment to understanding experiences from the participants perspective with a focus on the meaning they make of that experience in their particular context or life-world.

The steps of the interpretative phenomenological analysis applied to the data in this study guided the analysis process and are outlined below:

- The first step of the IPA analysis applied to the data involved reading and re-reading the first verbatim transcript of the semi-structured interview. The aim of this step is to encourage immersion in the data. This meant undertaking 'a line-by-line analysis of the experiential claims, concerns and understandings of each participant' in turn (Smith et al., 2009, p.79). This was followed by the first level of analysis which entails the use of descriptive exploratory comments. Eatough and Smith (2006) suggest that each reading facilitates a deeper engagement with the data thus the researcher's receptiveness to what the participant has said is increased.

- This initial noting employed three processes which guided the exploratory comments made. These were recorded on the right margin of the transcript and differentiated by using:

  - Descriptive comments that describe the content of what the participant said written in normal font
  - *Linguistic comments written in italics and focused on the participants use of language*
  - <u>Conceptual comments underlined, focusing on a more conceptual exploration of the participants' narrative</u>

These three different readings of the same text are presented on the single transcript because it allowed me and thus the reader to see the connections and links between the levels of analysis and engagement with the individual participant's lifeworld (Smith et al., 2009). Table 6 provides an example of how these three levels combine to offer what Smith et al. (2009, p.83) consider a researcher 'engaging in deep data analysis'.

- This then allowed for the third stage of the analysis to take place where I was able to analyse the exploratory comments to identify emergent themes (usually expressed as phrases), identifying convergence and divergence across the themes. Appendix E shows an extract based on June's transcript showing emergent themes identified from my exploratory comments expressed in phrases. Below three related utterances from June are put together which speak to what goes on to become the super-ordinate theme of

IDENTITY along with my exploratory comments on that section of the transcript:

- Professional identities   1:6   am a nurse/ was a nurse
- Misdirection, visibility, validity   23: 317   not drunk something she's got, attention on AD
- AD assisting in adaptation in progression   23:326   in a wheelchair now June,… back to Max

Reflections on identities - past, post diagnosis, throughout   I used to be…. a nurse, midwife, manager, social worker, athlete, Alan's wife, 'drunk', Not socialising, nightmare, not wanting to be seen/not being seen Max's owner, social, healthy person,

At this stage of the analysis when developing the emergent themes, I move from working with the whole transcript to, in this example, the initial noting on one aspect of June's narrative around her perceptions of herself overtime. Smith et al. (2009, p.91) note two elements of the analysis that are involved in this interpretative activity. Firstly, the use of key words or phrase to the right of the page which 'speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual'. Secondly, and most importantly, though seeming to break up June's experiences into fragments, this process constitutes a use of the hermeneutic circle whereby June's whole interview becomes a series of parts. These then come back together as a new cohesive and plausible narrative of June's experiences and my interpretations of the meaning she ascribes to them. The part, (in this example) 'in a wheelchair now June…then (the conversation returns) to

Max' (23:326) is related to the whole interview where she speaks about her previous professional identities, her ascribed identity as drunk falling in public and putting off moving to use a wheelchair because of embarrassment and stigma, an acquired identity as disabled person; and the whole is interpreted in relation to the part demonstrating the perception by June of her assistance dog as integral to her IDENTITY as a legitimate disabled person versus a drunk. Max is understood to misdirect the focus from June becoming a wheelchair user to himself smoothing the transition to her becoming more visibly disabled.

- Once the themes were established, they were ordered chronologically, and patterns were identified between emergent themes. Some were classed as super ordinate themes or as recurrent themes. Being classified as super-ordinate signifies a theme's recurrence across 'at least a third, or a half, or, most stringently, in all the participant interviews' (Smith et al., 2009, p. 107). These emergent themes were recorded in the left margin.

- I was then able to move on to analysis of the next case and so on, keeping in mind IPA's commitment to idiography, as well as the phenomenological approach to bracketing which meant, as far as possible, I sought to put aside ideas emerging from the first case before working on the next.

- The final stage of the analysis involved identifying patterns across cases. Results from the analysis of the transcripts were turned into a narrative account in which verbatim extracts from participants are presented with the researchers in depth interpretations (Smith et al., 2009).

By way of illustrating the stages involved in the IPA process, the following sub-sections use extracts from selected transcripts. The first extract highlights the process of developing initial exploratory comments in response to the data after my reading and re-reading of Jo's interview transcript. This analysis was undertaken in a systematic way and was guided by the application of three levels of interpreting the data, at the descriptive, linguistic, and conceptual level. This allowed me to address IPA's intrinsic concern with meaning making and its commitment to an idiographic examination of those events in peoples' lives, in this example Jo, which become an experience because of the significance that she granted them. I could focus on her concerns and experiential claims mindful of IPA's position with regards to interpretation. This meant utilising two interpretative positions: a hermeneutics of empathy, where I sought to adopt an insider perspective to see what it is like from Jo's perspective, but also exploring a hermeneutics of questioning, where I was free to 'stand alongside the participant, to take a look at them from a different angle, ask questions and puzzle over what they saying' (Smith et al., 2009, p. 36).

Smith (2018) developed a typology of meaning by which to extend the theoretical positioning of IPA in relation to meaning making by both the researcher and the participant. Smith devised a useful classification through which to examine

participants' accounts of their experiences. In the following extract Jo's account demonstrates her attempts to understand a particular event where a seemingly acute exacerbation of her MS resulted in a temporary loss of function in her legs. The 'experiential significance' (Smith, 2018, p. 4) of this frightening event was amplified by its occurrence as she was crossing the road, and coming as it did out of the blue, with no pre-warning that she was experiencing a relapse. Combining, as Smith (2018) does, this notion of experiential significance with Taylor's (1985) definition of experiential meaning as being 'for a subject' (Jo), of something (crossing the road and experiencing a sudden loss of function in her legs), in a field (in relation to other things, for example, her perception of her previous self as able-bodied, or her 'decline' since that event). Jo is recounting an experience of significance which occurred eight years previously when she was already eight years post diagnosis of MS and before she began to use an assistance dog. Smith (2018) goes on to suggest that it is here where a participant reflects on an experience of major import, that IPA 'comes into its own'. Describing the consequences of such attempts at sense-making as engendering 'much cerebral activity and that cognition is emotionally laden' (Smith, 2018, p. 2). These experiences can be current or ongoing, as is the case for those living with chronic illness. Despite having a condition for many years, they may still be grappling with aspects of it. Jo demonstrates this in the extract with her use of a temporal aspect of the experience and its impact, 'it is a shock' and 'was the shock'. What is apparent on a deeper level is Jo's bestowal of significance to this experience as a major turning point in living with MS after which her perception of herself was no more, it marked her 'demise'.

Table 6 Transcript extract demonstrating initial exploratory comments

Original Transcript Participant 9 - 'Jo'	Initial exploratory comments Descriptive comments - Normal text Linguistic comments – I*talics* Conceptual comments - <u>Underlined</u>
Jo: My demise, well my ability to walk declined really within the last, I would say, eight years. I started to get different signs and one particular day, about it would be eight years ago, I went to cross the road when we were living in XXX and my legs just stopped, just dead in the middle of the road and if I had been on a busy road I would have been knocked over and I had to flag a car down. G: Gosh. Jo: And the couple in the car, I had to explain the gentleman and I should say the lady as well, that I had got MS and my legs had just packed up and then they had to take me home, which I only lived a few roads down, but the thing was the shock. You see, I just couldn't move my legs, anything, anyway I got to the top and my own front door in floods of tears and then I was able to walk a little bit. Whether it had been just sitting down in the car having that break. G: Having that rest, yeah. Jo: I was alright, but it shook me up and it made me realise how severe MS can be and is with some people because I'd had no pre warning of anything happening like that and just, your legs just wouldn't work in the middle of the road. G: It must have been very frightening? Jo: Yes it is a shock, and I think it	*Use of the word Demise – literal meaning death but using it to express the loss of the ability to walk combined with other symptoms of MS signify the metaphorical death of who Jo (able-bodied) was and is no more.* <u>MS results in the death of self, of identity</u> Describing how MS can be unpredictable from one minute to the next and it can affect the body in dramatic ways without warning but also in more minor ways 'different signs' which are perceived to be more like sliding backwards <u>'was the shock'</u> Realisation of how severe MS can be. Sudden onset, relapse no pre warning eight Years after diagnosis Unpredictable from one moment to the next and significant enough to destabilise Jo's lived experience of MS prior to that incident as one of gradual decline and less severe magnitude

was just tears of relief that I had got home, so lucky that I had not been knocked down or anything. Then after that, as I say, eight years ago my ability to walk and my arms and everything tended to decline somewhat. I didn't have the ability to do the things that I once did, but that was the first sign, being in the middle of the road. When we moved, after living in XXX, I think it was the year, a year and a half after this episode, that we will lived near XXX or we lived in the village, XXX just up the road and my husband bought me a big buggy and he bought a fold up one that would go in the car, so I would still be able to get out and do my shopping and meet people, but I knew things were sort of sliding, I was taking backward steps and it is quite a shock because when you have been able bodied and everything that you know, you realise everything is just coming to a stop. You are not the, you feel yourself, you are not the person that you once were, but you are fighting against it. You find that things that you found simple to do were taking a lot longer to do.	Yes it is a shock' – relapse event was eight years ago. Jo mixes present and past tense. Does the introduction of this temporal aspect of her experience signify she is still working through the shock of the sudden relapse rather than slower decline or gradual accumulation of disability?

Uses the word 'you' rather than 'I' – is she distancing herself from the person she has become? emphasising the hermeneutic circle- the part 'my demise' with the whole extract amplifying who Jo perceives she was. If she is no longer herself who is she? |

Jo (1: 17-58)

The initial noting of exploratory comments stage of the IPA of the data, allowed me to

develop a collection of what Smith et al. (2009, p. 91) describes as 'potentially

important, yet still provisional notes' which increased the data set. The comments

were a reflection of my initial responses to Jo's words and represented my attempt to

identify and describe the 'key objects of concern' for her as well as what Smith et al.

(2009, p.46) describe as her 'experiential claims' in relation to her experiences of living with MS prior to getting her assistance dog. In doing so, my aim was to develop a hermeneutic account of Jo's experiences aiding the explanation of the meaning Jo ascribed to them. Care was taken to maintain a clear phenomenological focus in my commenting for example by noting Jo's description of the lived experience of an acute exacerbation of her MS causing her to lose power in her legs midway across a road. Simultaneously, I also sought to remain close to Jo's explicit meaning ' it shook me up and made me realise how severe MS can be and is'.

The analysis of these exploratory notes became the focus of the next stage of the data analysis which sought to identify emergent themes. This next process denotes 'a higher level of abstraction' (Smith and Osborn, 2006) involving a re-reading of the transcript focusing on similarities and differences in the text and the initial exploratory comments to establish patterns. These patterns developed into specific themes utilising phrases or succinct statements capturing the core essence of Jo's experience. As with the extract from Jo's transcript selected above, this process of identifying emergent themes is applied to discrete sections of the transcript. Initially this felt counterintuitive, being the converse of the participant-led data collection method via the use of semi-structured interviews and the subsequent use of exploratory comments. It marked, as is usual in IPA, a moving away from the transcript as a whole and represents 'one manifestation of the hermeneutic circle' (Smith, 2009). Whereby, the text is broken down into parts and, through the process of my interpretation of Jo's understanding of her experiences of living with MS, results ultimately in a collaborative analysis which is still 'participant close' capturing phrases from Jo's own words. These are combined with my interpretative analysis and thoughts, influenced by both the part of the interview in relation to the whole

interview and the whole interview in relation to the part. Emergent themes were

recorded in the left-hand margin of the transcript and Table 7 provides an example of

this in relation to the extract in Table 6 taken from Jo's transcript.

Table 7 Example of Identification of emergent themes

Emergent theme	Original transcript **Participant P9 - 'Jo'**	**Initial exploratory comments** Descriptive comments - Normal text Linguistic comments – I*talics* Conceptual comments – <u>Underlined</u>
Impact of MS on self-identity *Unpredictable loss of bodily* Control Unreliable body Public admission of disability, loss of function to strangers MS results in dependency having to ask for help – relying on the kindness of strangers 'the gentleman' & 'the lady'	Jo: My demise, well my ability to walk declined really within the last, I would say, eight years. I started to get different signs and one particular day, about it would be eight years ago, I went to cross the road when we were living in XXX and my legs just stopped, just dead in the middle of the road and if I had been on a busy road I would have been knocked over and I had to flag a car down. G: Gosh. Jo: And the couple in the car, I had to explain the gentleman and I should say the lady as well, that I had got MS and my legs had just packed up and then they had to take me home, which I only lived a few roads down, but the thing was the shock. You see, I just couldn't move my legs, anything, anyway I got to the top and my own front door in floods of tears and then I was able to walk a little bit. Whether it had been just sitting down in the car	*Use of the word Demise – literal meaning death but using it to express the loss of the ability to walk combined with other symptoms of MS signify the metaphorical death of who Jo (able-bodied) was and is no more.* <u>MS results in the death of self, of identity</u> Describing how MS can be unpredictable from one minute to the next and it can affect the body in dramatic ways without warning but also in more minor ways 'different signs' which are perceived to be more like sliding backwards <u>'was the shock'</u>

Experiences of a continuum of impairment effects from gradual to sudden, permanent and temporary	having that break. G: Having that rest, yeah. Jo: I was alright, but it shook me up and it made me realise how severe MS can be and is with some people because I'd had no pre warning of anything happening like that and just, your legs just wouldn't work in the middle of the road. G: It must have been very frightening? Jo: Yes it is a shock, and I think it was just tears of relief that I had got home, so lucky that I had not been knocked down or anything. Then after that, as I say, eight years ago my ability to walk and my arms and everything tended to decline somewhat. I didn't have the ability to do the things that I once did, but that was the first sign, being in the middle of the road. When we moved, after living in XXX, I think it was the year, a year and a half after this episode, that we will lived near XXX or we lived in the village, XXX just up the road and my husband bought me a big buggy and he bought a fold up one that would go in the car, so I would still be able to get out and do my shopping and meet people, but I knew things were sort of sliding, I was taking backward steps and it is quite a shock because when you have been able bodied and everything that you know, you realise everything is just coming to a stop. You are not the, you feel yourself, you are not the person that you once were,	Realisation of how severe MS can be. Sudden onset, relapse no pre warning eight years after diagnosis Unpredictable from one moment to the next and significant enough to destabilise Jo's lived experience of MS prior to that incident as one of gradual and less severe magnitude <u>'Yes it is a shock' – relapse event was eight years ago. Jo mixes present and past tense. Does the introduction of this temporal aspect of her experience signify she is still working through the shock of the sudden relapse rather than slower decline or gradual accumulation of disability?</u> <u>Uses the word 'you' rather than 'I' – is she distancing herself from the person she has become? emphasising the hermeneutic circle- the part 'my demise' with the</u>
MS as a journey with notable signs at points only recognised in retrospect as turning points Inevitable decline		
Attempts to maintain independence using assistive technology to facilitate social interaction		

	but you are fighting against it. You find that things that you found simple to do were taking a lot longer to do.	whole extract amplifying who Jo perceives she was. If she is no longer herself who is she?

These two stages of analysis were repeated for the remaining ten transcripts. The close interpretative engagement with the data this stage of the analytic process engenders is aimed at capturing plausible meanings of each participants' lifeworld rather than revealing a single 'true' meaning (Smith, 2009; Lopez and Willis, 2004). Using, for example, Jo's experience of the impact of MS on her self-identity – the 'demise' of her taken-for-granted self-identity as able-bodied reflected the idiographic approach to the data analysis. This in concert with the other similarly in-depth examination of the other transcripts led to the identification of the emergent theme across cases of Identity. It also demonstrated another analytic process used in IPA, that of 'subsumption' (Smith, 2009, p.97) whereby an emergent theme 'itself acquires super-ordinate status as it helps bring together a series of related themes'. Thereby moving from the exploration of individual themes to the next stage of the data analysis process involving the identification of emergent themes across cases. This meant establishing the overall representation of those themes by examining their recurrence. When a theme was identified as emergent in half of the transcripts (Smith, 2009) it was categorised as recurrent, with those themes emerging in less than half of transcripts as non-recurrent. Establishing patterns and points of commonality across recurrent themes served to bring together connected themes and resulted in the development of what became a thematic structure, clustering them as seemed appropriate. Finally, these thematic clusters were reduced to three

super-ordinate themes resulting from the process of further analysis characterised by moving back and forth between the analytic stages.

 This was undertaken with the aim of developing a coherent and plausible account of participants experiences. Whilst acknowledging IPA does not claim to produce an analysis which is 'more true than the claims of […] research participants' (Smith, 2009, p. 23) concerning the experience of living with MS and using an assistance dog, but to reveal insights 'which exceed and subsume the explicit claims of participants' (ibid.). The analysed data were drawn together within a framework which maintained a close connection to the original accounts of participants throughout the process of data collection and analysis. This shaped the organisation of those accounts through to the identification emergent themes, to thematic clusters and ultimately the three superordinate themes (VISIBILITY, (UN)CERTAINTY and IDENTITY) which form the basis of the findings Chapters (Chapters 4-6).

Appendices E-G present extracts of worked examples of these stages of the data analysis process in order to increase transparency within the research. They demonstrate how I developed one of the superordinate themes - IDENTITY from beginning with the identification of the emergent theme containing different aspects of IDENTITY demonstrated in June's transcript, an extract of the analysis of which is provided in Appendix E. It details the emergent themes in chronological order represented by a concise phrase and bearing a record of the page and line number of its location in June's full transcript which means it can be re-examined in context at a later date if required.

Appendix F – follows with a thematic framework developed displaying the process

from identifying recurring emergent themes across cases to their further data

reduction into thematic clusters based on overall representativeness across all of the

participants accounts. In Appendix F I have provided a table showing emergent

themes around VISIBILITY which were counted and considered a recurring theme if

it emerged in more than half of the transcripts analysed (n.6) . Conversely, if a theme

was identified in less than half of the transcripts it was considered non-recurrent.

Appendix F details those recurrent themes which were then explored seeking

connections or patterns across the whole data set and clustered appropriately. In the

example provided 21 recurring emergent themes were collapsed into three thematic

clusters encompassing the most notable descriptive label or 'higher order theme title'

(Eatough and Smith, 2006, p. 487). These three thematic clusters were (INVISIBLE,

HYPERVISIBLE and VISIBLE). The non-recurrent theme TRANSLUCENT SELF was

retained due to its partial reflection of the INVISIBLE thematic cluster and its potential

to reveal an unexpected and novel aspect of the super-ordinate theme. The inclusion

of which echoes the strength of IPA as a uniquely creative and flexible method of

analysis. Here, idiographic details from individual cases 'consonant with the

hermeneutic phenomenological perspective' (Smith et al, 2009, p.166) and where

the participants are considered the experiential experts are fore grounded. This in

turn speaks to the subsequent second-order cross case analysis 'prompted by rather

than pre-empting , the researcher's response to the material in individual cases'

(Smith et al, 2009, p.165).

By moving back and forth between the analytic stages described above, the thematic clusters were further analysed. This involved returning regularly to the original transcripts and discussing the coherence and plausibility of the analysis within supervisory meetings. This culminated, in the example shown (Appendix F) in the broad super-ordinate theme of VISIBILITY. The final analysis of all the data to which interpretative phenomenological analysis was applied resulted in three broad super-ordinate themes, each of which retained a connection to its associated emergent themes, recurrent themes and thematic clusters within the dataset as a whole. Appendix F shows an example of this resulting framework consisting of emergent theme, thematic cluster, super-ordinate theme which formed the basis of the related findings chapter.

Lincoln and Guba (1985, p. 290) ask, 'how can an inquirer persuade his or her audiences (including self) that the findings of an enquiry are worth paying attention to, worth taking account?' The need for academic rigour in qualitative research is well established (Yardley, 2000, 2008, 2017; Baillie, 2015; Lincoln and Guba, 1985). As such, the need to establish confidence in the findings of this study was of paramount importance and therefore, prior to moving on to the findings themselves, the following section addresses issues of academic rigour and quality within this thesis.

3.7.6 Validity and Quality

There is no prescribed framework for assessing validity and quality in IPA (Smith et al., 2009), therefore criteria applied to evaluating these requirements in qualitative research were employed in this study. Firstly, by using Yardley's (2000, 2008) criteria for assessing quality and validity in qualitative research and secondly, by describing the measures I employed to facilitate reflexivity throughout the research process. Yardley uses four broad principles in her assessment; I will discuss each of them relating to this thesis and how I have addressed them.

Sensitivity to context:

Sensitivity to context was shown through an awareness of the existing literature and its relatedness to the topic of investigation. Recognising the interdisciplinary nature of the topic meant reviewing literature across disciplinary boundaries to obtain a comprehensive understanding of the area. This ensured the concerns and understandings of participants were situated in the whole socio-cultural milieu of human/non-human relationships as well as the biopsychosocial world around dis/ability. This sensitivity to context continued in the discussion (Chapter 7) where there is a dialogue with literature not referenced in Chapter 2 of the study. Equally, the choice of IPA as a methodology and the rationale for its adoption was based upon the perceived need for sensitivity to context through close engagement with the particular and to the idiographic.

Secondly, sensitivity to this context (that of an IPA study) was demonstrated by the use of purposive sampling, which was made possible by a sustained engagement, in

terms of establishing rapport with key gate-keepers and was essential to the viability of an IPA project.

Thirdly, sensitivity to context is also demonstrated through an 'appreciation of the interactional nature of data collection within the interview situation' (Smith, 2009, p. 179). Care was taken to maximise the potential for participants to share their perceptions and understandings of their lived experiences with their assistance dog/s. This required close awareness of the interview process - showing empathy and consideration for the potential for impairment effects to negatively influence participants and putting in place accommodations and adjustments to mitigate these (see Chapter 3, section 3.7.2). The participants' awareness that they were assured anonymity and confidentiality, including the knowledge that what was discussed would not be fed back directly to the assistance dog charities or attributable to them individually, was, I argue, significant. It allowed participants to share, if they wanted, experiences of a less positive or a more challenging nature without feeling they must be wholly positive. There is potentially a power imbalance involved between an assistance dog charity and a client with a disability because ultimately the charity retains ownership of the assistance dog legally and can exercise the right to remove the assistance dog/ADUK accreditation at any time. I feel that sensitivity with regards to this context, and my conduct of the interview process, put participants at ease and encouraged the sharing of experiences and perceptions that moved beyond the potentially superficial snapshot of a 'happy, grateful disabled person with a cute, perfectly behaved assistance dog'. This resulted in a more nuanced analysis that engages with the subject of living with MS and assistance dog use for these participants on a deeper level.

This sensitivity to context continued into the data analysis phase and presentation of findings from this study, which have 'a considerable number of verbatim extracts from the participants' material to support the argument being made, thus giving participants a voice in the project and allowing the reader to check the interpretations being made' (Smith, 2009, p. 182). Finally, sensitivity to context is demonstrated in the making of 'claims appropriate to the sample which has been analysed. Interpretations are presented as possible readings and more general claims are offered cautiously' (2009, p. 181).

Commitment and rigour

In this study, commitment was shown in the degree of attentiveness to the participants during data collection and the care with which the analysis of each case was carried out. Here, there is an overlap in how this IPA study addresses Yardley's criteria whereby a demonstration of commitment can be synonymous with a demonstration of sensitivity to context.

Rigour refers to the thoroughness of the study, for example by ensuring the sample is appropriate to the research questions. The sample was selected carefully to match the research question and to be homogeneous, according to the principles described in Smith (2009, pp. 48-51).

I was careful to keep the balance between closeness and separateness as an insider researcher when conducting the in-depth interviews (see sub-section below on

reflexivity), and to be consistent in probing issues, picking up on important cues from the participant and digging deeper.

Thorough and systematic analysis with sufficient idiographic engagement was undertaken, evidenced by extracts of verbatim transcripts analysed on different levels (descriptive, linguistic, and conceptual), thereby moving beyond a simple description of what is there, to an interpretation of what it means. In line with Smith's (2009) advice regarding writing up the findings, I sought to 'select good and appropriate illustrations for each theme to be supported with quotes from a number of participants and that, in the overall narrative, participants' accounts will be drawn on pretty even-handedly' (2009, p. 114).

Transparency and Coherence:

Transparency was achieved in this study in the following ways, by carefully describing:

- how participants were selected (section 3.7.1)
- how the interview schedule was constructed (section 3.7.4)
- how the interviews were conducted (section 3.7 .4)
- what steps were used in analysis (section 3.7.5)
- how transparency was further enhanced with the inclusion of tables, showing detail of each these features: the participants, Table 3.2; the schedule, Tables 3.3 and 3.4, Appendices A-G and Tables 6 & 7; elements of the analytic process, Tables 3.5 and 3.6.
- Inclusion of Appendix G – Original Full Transcript of P3 'Maggie' allows the reader to compare their own interpretation of Maggie's phenomenological account of her experiences and my interpretation of her interpretation of her perceptions and understanding of her experiences.

Coherence in relation to this study was addressed firstly in the use of an approach to the research which was a good fit with aims of the research, the interests of the researcher and the choice of methodology and methods used in its conduct (Yardley, 2000, Smith et al., 2009) .

Impact and importance:

This principle is covered in the final chapter of the thesis Chapter 8, Sub Section 8.1 'Contribution to knowledge', pp. 280 -281.

3.7.7 Reflexivity

Smith and Eatough (2007) acknowledge the inherent difficulty of setting aside personal knowledge and presuppositions within qualitative research studies involving IPA, which regards research inquiry as a dynamic process in which the researcher takes an active role. That does not mean the requirement for reflexivity within an IPA study is any less. Brocki and Wearden (2006) contend that a rigorous examination of the researcher's dynamic role in IPA is essential. Hofmann and Barker (2017) examined those aspects of reflexivity that arise in a research project that the researcher has personally experienced. They outline two set of concerns and possible issues for insider researchers, highlighting the advantages and disadvantages of the researcher's experiential knowledge of the topic. These include the possibility for greater empathy with participants, the false assumption of similarity, the need to bracket one's expectations and whether or not to disclose one's condition to participants. The second set concerns the researcher's emotional reactions to the content of the research; for example, increased knowledge and awareness of the potential harmful consequences of one's condition, feeling a sense of connectedness

with the participants, learning from the experiences and challenges they have faced, and potentially benefitting personally from conducting the research.

Explication of these issues is important. Firstly, because they may affect the trust-worthiness of the findings and, secondly, because of the ethical imperative to evaluate the potential impact of the research on both the participants and the researcher.

I used several strategies specifically aimed at demonstrating reflexivity within the research process. Pillow (2003) contends that reflexive listening and writing may be used as tools to help the researcher situate him/herself and be aware of how their personal history can influence the research process, thus yielding more 'accurate' and more 'valid' research. These included, providing autobiographical details (see Chapter 1, Section 1.3.1-1.3.3) to enable the reader to understand my personal background in relation to the study. This was done to enact transparency about my personal and professional experiences both in relation to multiple sclerosis and as an assistance dog user. In addition, to enhance self-reflection during data collection, I maintained a reflective diary of my responses to the interviews (Ortlipp, 2008). Regular discussions were held with my research supervisors about the interviews, how they had been conducted and my emotional reactions to the data. Doucet (2008) maintains, we confront the difficulty of determining where our own stories end and theirs begin as we interview participants, and this is perhaps more so for an insider researcher studying a condition they also have. I sought throughout the research process to be mindful of these potential factors described above and employed the

measures described to minimise my influence on the research. Having discussed the measures employed to address issues of quality and validity within the thesis, the discussion moves to the three findings chapters themselves.

The following three chapters present the findings of the interpretative phenomenological analysis (IPA) of eleven semi-structured interviews undertaken with participants living with MS who use an assistance dog. In IPA studies, findings are generally presented without reference to the literature (Smith et al., 2009), and hence consideration of the findings in relation to the literature, will be discussed in chapter 7. Those findings presented in the following three chapters (4-6) reflect the dialogue between myself as a researcher and the participants I interviewed. Verbatim extracts from participants are combined with my own interpretative analytic commentary on their sense-making of their lived experiences. This interweaving of perspectives provides a comprehensive and convincing account of the data obtained across participants. Attention is also focused, where relevant, on findings of divergence and convergence across the sample and across individual cases, evidenced by idiographic accounts from individual participant's interviews to further enrich the IPA narrative. 'Doing IPA with larger numbers of participants constantly involves negotiating this relationship between convergence and divergences, commonality and individuality' (Smith et al., 2009, p. 107).

Each of the following three chapters takes as its focus one of the super-ordinate themes and their component thematic clusters, identified in the analysis. As discussed earlier in the chapter, a super-ordinate theme's designation relates to its

recurrence across 'at least a third, or a half, or, most stringently, in all the participant

interviews' (Smith et al., 2009, p. 107). Smith et al. (2009) go on to suggest that

counting these recurrences may also serve to enhance the validity of the findings of

larger IPA studies such as this one. A table (Table 8) is presented at the end of the

findings' chapters identifying which participant's data revealed accounts related to

each of the three super-ordinate themes, and, if they have had more than one

assistance dog, which dog it was in connection with. For reasons of clarity and to

reduce confusion for the reader, I have adopted the convention of writing in capital

letters the names of the super-ordinate themes and thematic clusters identified,

where the words are embedded in the text.

Chapter 4 VISIBILITY

Firstly, I commence with a super-ordinate theme that was apparent in every participant's interview in some manifestation, that of VISIBILITY. Participants' descriptions of their experiences around VISIBILITY were multifaceted and temporal, fluctuating between experiences of feeling invisible, hyper-visible, translucent, or visible. This involved constant negotiation and re-negotiation of relationships evident in the manifestly different expressions of the themes within this super-ordinate theme. For some, this was demonstrated by a desire to make themselves and their seen disability INVISIBLE by attempting to pass as 'normal'. However, when this was no longer possible participants responded by social withdrawal. As will be discussed later in the chapter, when accompanied by an assistance dog, participants attempted at times, to re-direct the negative 'gaze' of others and render their impairment invisible, at least for a time. This *participant-led* INVISIBILITY, this misdirection, contrasts with the experience of being *made to feel* INVISIBLE by others (including health professionals and society in general).

Conversely, the theme of the HYPER-VISIBLE SELF as experienced by most participants, was viewed in both its positive and negative aspects and was experienced as being fundamentally shaped by the presence of an assistance dog. A further state of TRANSLUCENCY was identified for some which was revealed to elicit differing responses from those individuals. At times, the response could be interpreted as an act of resistance, at other times as acceptance. Whichever

response it elicited this liminal state was experienced as being preferable to reverting to a former state of the INVISIBLE SELF.

Ultimately participants described a state where they experienced feeling that they were VISIBLE. However, this was no longer in isolation as an 'I' but as a 'We'; in which they are inextricably bonded with their assistance dog, becoming their VISIBLE SELVES. The chapter concludes with consideration of those participants who expressed fears and anxieties about the future, as it relates to the super-ordinate theme of VISIBILITY. For some, the thought of being without an assistance dog, through the retirement, illness, rehoming, or death of their assistance dog would mean they would once again become INVISIBLE. Many anticipated that they would stop going out or that they may remain alone and unseen in their homes.

4.1 INVISIBILITY

The following extracts describe how, for some participants, the transition to experiencing feelings of INVISIBILITY started at the diagnosis stage, when they first sought medical advice for some of the problems they were starting to experience.

When I interviewed Helen, I asked her to speak about when she was first diagnosed with multiple sclerosis. She shared that her journey to diagnosis was far from straightforward. Helen described that although officially diagnosed with multiple sclerosis (MS) some 15 years previously, when she was 50; she had been experiencing 'more or less' the same problems on and off since she was in her 20s.

After another bout of facial pain 'suddenly they decided' to do an MRI scan to exclude a stroke. When the images came back, she recalled, '(my) brain looked like […] Brussels lace'. Helen's description of her brain scan, with its visible hyper-intense white or grey/black areas denoting plaques (areas of scar tissue), caused by her immune system attacking different areas of her own brain over decades, is poignant. She goes on to recount how she did not really feel any relief when she was diagnosed because many years earlier, whilst working as a social worker, she had gone to her GP asking if she might possibly have multiple sclerosis. This was because she had a client who had many of the same symptoms as her and that is what she was told the client had. Decades later Helen clearly recalls her GP's response:

> ...he said 'don't be ridiculous you are far too young, go away' nicely, because he was a kindly man…
>
> Helen (16-17)

Helen had continued to be treated at the same GP surgery for both arthritis and rheumatism, but her MS was left undetected and untreated for many years. On reflection, her sense-making of the events around her diagnosis of MS have led her to the conclusion that:

> I think they thought I would one-day stop being a nuisance and go away, you know, I felt very much that way as if I was being tiresome…thought to be tiresome anyway
>
> Helen (23-25)

Her attempts to get a diagnosis were dismissed out of hand, erased from the conversation. When Helen was told by the GP that she was too young to have MS it

is as if she had, for all intents and purposes, been rendered invisible. The lace

metaphor transforming from a representation of sclerotic plaques in her brain

accumulated over years, to that of a net through which she has slipped unnoticed,

undiagnosed, invisible.

Similarly, June, diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) 35

years previously, recalls the encounter with her consultant when she started to lose

feeling in her leg:

> JUNE: ...I am a nurse, or was a nurse, and I realised I had got it a little
> before that because I started losing the sensation in my leg and I was
> sure I had got it, then it was okay and then I had it again and then I had
> a really bad relapse and then I was diagnosed then, so that was 35
> years ago.
>
> G: So, it wasn't a big shock when the diagnosis came?
>
> JUNE: No, it wasn't, no, no, in fact I walked into the neurologist and
> stupidly said 'I think I have got MS' and he said 'I will be the judge of
> that', but I had yes.
>
> June (6-15)

Both June and Helen recall their experiences with medical professionals initially as

being dismissed or not believed. In making sense of their experiences, it appears that

until a medical professional makes visible a diagnosis, it does not exist; the patient's

own embodied experience remains invisible to others. The journey from an

autonomous decision-making adult towards the experience of invisibility is achieved

in the length of the consultation. Sean, whose initial symptoms included foot drop

(where the person cannot lift their foot sufficiently due to damage or paralysis to the

nerve, causing them to have an abnormal gait), and episodes of faecal incontinence

(caused by damage to the nerves of the spinal cord from MS), was told by one doctor

'don't be silly it's not MS, only women get that' (52). Elaine experienced numbness intermittently throughout her 20s. She recalls at one point the GP saying the numbness she was experiencing down her arm was 'because you are leaning on it and it wasn't designed to be leaned on' (22-25). She was eventually diagnosed five years later after further relapses.

In the absence of visible physical evidence for their emerging condition, the psychological dimension of their experience was brought into focus for some. As a condition, MS can take many months and sometimes years to diagnose and between the onset of the condition and the diagnosis many are left 'in limbo,' a state of non-existence or, as in Anne's case, felt 'as if I was going mad'. After some years of inconclusive tests to establish the reason for her symptoms Anne was told she was probably depressed and asked if she would like to see a psychiatrist. Intermittent signs and symptoms were characteristic of some participants' experiences of living with MS that was yet to be diagnosed. This, when combined with a medical professional who, for whatever reason, could not recognise the physical cause of their distress, impacted negatively on the experience of living with the condition, even before it had a name. When the diagnosis of MS came there was initially elation:

> (I was) ecstatic… I finally had reassurance that something was wrong… Maybe with a more concrete diagnosis, it would open doors to get the help I needed
>
> (Anne, 70-75)

Medical professionals were regarded by some as gatekeepers to services, granting or denying access to them. If they legitimised the condition, those participants

reported that their levels of distress immediately lessened, at least initially. However, as I move on to examine participants' experiences once they have a diagnosis, the data suggests that a different aspect of VISIBILITY seems to come into play, the experience of becoming HYPER-VISIBLE, which is discussed further in section 4.2.

In this extract from Maggie, she reveals that the impetus to keep her disability concealed once diagnosed may have arisen from within herself. However, once known, concealment or covering visible signs and symptoms of the impairment effects of her MS was also encouraged or reinforced from without - be it health professional, her workplace, or strangers in public places.

> …and then gradually of course, I started to get ill you know, all kinds of different things that I didn't quite know what was going c on you know and typical me I did nothing about it for ages... I am very good at putting up with things and did that, but I did that for quite a long time and then gradually got referred to a neurologist and that and the diagnosis was given. I was told by a neurologist not to mention it, he said so... that I had to, absolutely had to (not mention it) because in his experience I would probably find that I would lose my job or you know, how things that sort of... So, it was you know locally, the place I work in is designed for people with physical disabilities, it should have been the perfect sort of work set up, erm but unfortunately at that time the head that I had worked with had retired and a new one came along, but obviously I was in no position…everybody thought I would take over and erm, … well I, to put it mildly, she had no sympathy whatsoever with anybody and things got pretty bad…
>
> Maggie (18-34)

Maggie starts to make sense of her experiences and describes them initially in terms of self-blame, 'typical me', whereby it was somehow her fault for putting up with things and not doing anything about it sooner when she was first experiencing problems with her health. At this point in her interview Maggie presented as being

passive, either to blame for not seeking help sooner, or as powerless to exert any power over her experiences of VISIBILITY. Her use of language suggests an external locus of control - the neurologist told her 'absolutely' not to mention it at work because she was likely to lose her job. The unsympathetic new head teacher made life miserable at her work, which should have been a place where her changed circumstances and additional needs were acknowledged and easily accommodated; an unnamed authority told her the best option was for her to retire early. She is given permission, even encouraged, to disappear. The message perceived by Maggie from both her workplace and her physician was that disability was to be hidden, remaining undisclosed – INVISIBLE.

4.2 HYPER-VISIBLE SELF

Although Maggie expressed feeling INVISIBLE, she simultaneously described feeling HYPER VISIBLE in public. This is a common feeling for visibly disabled people, and it forms the focus of this section. Reactions to Maggie's visible disability in public places further reinforces this view:

> I was told if I didn't retire and take early retirement then I would be you know, I would… go really downhill very quickly. So I made the decision to take early retirement and erm, but I was still very determined that I wasn't going to let my condition get the better of me, but I erm, very self-conscious, I always tried not to draw attention and suddenly finding myself going out, very wobbly you know, I found people's comments and people asking me things and people, not quite knowing how to react, 'oh it is a bit early to have been hitting the bottle' or 'you should put more water with it', oh they were meaning it in good fun, but you know it got to the point where I was getting – one more person makes a comment like that to me I am frightened I might just be a little bit cross and I just you know, felt so vulnerable that (was) the end of going out... At that time, I had to go out shopping, I mean the idea of shopping on the internet or something was totally unfamiliar to me at that time… and so I didn't... that was really it. I didn't go out… I had got neighbours… a

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very young girl that helped me and had a community physio… and she
used to come to the house and visit me every week

<div align="right">Maggie (39-62)</div>

Despite her best intentions to not let her MS get the better of her, Maggie

acknowledges that once her disability was visible to others, she experienced HYPER-

VISIBILITY. Her staggering gait is misinterpreted as public drunkenness during the

day; strangers' comments and intrusive questions are internalised and cause her to

retreat to her home. Maggie's self-definition as 'very self-conscious' and a person

who 'always tried not to draw attention' to herself presents a picture of a demure,

self-effacing individual who was overwhelmed. Her reaction to the experiences she

describes manifest in her altering her behaviour (rarely going out) to become

INVISIBLE once more. When strangers in public places exhibited hostility and a lack

of sensitivity, Maggie ends up feeling exposed and fearful, as she says, 'I am

frightened, and I might just be a little bit cross and I just you know felt so vulnerable'.

Maggie however is not the only participant in the study who reports experiencing the

feeling of being at once INVISIBLE and yet HYPER-VISIBLE. June recalls:

> [there were] sort of trolleys in there and all that, it is an indoor market
> and I try to avoid them, knocked into this elderly fellow and said sorry
> and he said 'you shouldn't be drunk at this time of day', because I was
> staggering. So, you get that sort of thing […] and several people with
> MS told me that, people saying they are drunk...

<div align="right">June (294-297)</div>

And similarly, Jo:

> I mean I was falling and I remember one person, he told me I was a
> disgusting creature because I was drunk at half past nine in the
> morning.

For some, in the initial stages of their condition, the desire to pass as 'normal' for as long as possible, is foregrounded. Disability aids which would draw attention to visible aspects of their disability were eschewed, made INVISIBLE by the participant themselves:

> JO: …few years after that when I had some really bad patches that it became more difficult and I did struggle a bit, you know, I wouldn't use a walking stick. I'd fold it up and put it in my bag.
>
> G: What made you do that?
>
> JO: I just wanted to appear normal… Erm, yes it was much later on, and then you know a walking stick was sort of a erm, putting a label on me and people started talking, not all, but some people talked to me differently and then I didn't take to a wheelchair, it was just a manual one and it would get kicked in the shed

Jo (91-95)

For most, their acquired status as INVISIBLE came, ironically, when they could no longer conceal the inevitable accumulated burden of visible disability that MS can bring. In making sense of their lived experiences every day in society, participants absorbed the message that they (able-bodied, productive, included, 'normal') were no longer VISIBLE as themselves but in their HYPER-VISIBLE wobbling, foot-dragging, twitching state. At once experiencing the INVISIBILITY of their perceived self (see Chapter 6 for in-depth analysis of the related but distinct super-ordinate theme IDENTITY), and at the same time living with the HYPER-VISIBILITY afforded by being just another visibly disabled body that threatens to overshadow what they feel is the real them. In/Hyper- visibility became two sides of the same coin.

Thus far the description and interpretation of the data has highlighted participants'

sense-making of their experiences of VISIBILITY (IN/HYPER-VISIBILITY) whilst

living with MS before diagnosis, and for some years after. Participants also

experienced both HYPER-VISIBILITY and INVISIBILITY once they started to use an

assistance dog. However, as the following accounts demonstrate, the quality and

impact of these human-assistance dog partnership encounters were perceived and

understood by the participants very differently.

4.3   VISIBILITY -Transformed

In this section, accounts of how participants' interactions with society were perceived

by them as transformed, in the shared presence of an assistance dog, are examined

and interpreted. This transformation is described in a variety of ways by every

participant and formed a key feature of their sense making of living with MS and

using an assistance dog. When they are in public with their assistance dog, the

perceived negative gaze of others illuminating their impairment is redirected, their

impairment overlooked, and the assistance dog becomes the focus of the interaction.

In addition to which, and seemingly occurring simultaneously, the working partnership

is understood to achieve a legitimisation or acknowledgement, even what some

participants experience as a degree of celebrity.

In the following extended extract, Richard - like June, Jo and Helen previously -

mentioned the idea of people misinterpreting slurred speech and unsteady gait as the

person with MS being drunk. Unlike the previous extracts, Richard introduces the

idea that how he perceives his assistance dog influences the dynamic of that

potentially difficult social interaction. Richard speaks about the fact that he personally

has never been accused of being drunk, but he has been sensitised to the possibility

by the reactions to a workmate with visible impairments. Richard also introduces one

of the other themes nested within the superordinate themes of both VISIBILITY and

later in the thesis (Chapter 6 IDENTITY), that of Legitimisation of Status and his

perceived 'permission' to be visibly different in a public place, to exhibit behaviour

perceived as being outside the norm.

> RICHARD: MS makes you look drunk, so people would react very differently. When he (referring to Noah his assistance dog) is there it is obvious that there is something seriously wrong with me, this was before the wheelchair and they look at you differently when there is a dog there than when there isn't.
>
> G: So, did people actually comment to you
>
> RICHARD: No, they just, I used to work with a man who had brain damage from a building accident, he had the same reaction because his speech was slurred, and he wobbled, people would assume he was drunk and go around him and not take anything he said seriously. So, it was a similar, I recognised how I was affecting other people, you know, and now that I twitch rather a lot, I do get odd reactions, but if I have got a[n assistance] dog with me, people react very differently, very differently.
>
> G: Right, so do you feel it helps people to come to...
>
> RICHARD: Yes, it certainly bridges the gap, especially if you are having a bad speech day, they don't know how to treat you because they don't know whether you are mentally disabled or physically disabled, they don't know, but if there is a[n assistance] dog there they will often talk about the dog, assess you by your response and then change their behaviour in [line] with that response… Yeah, instead of becoming a problem, you become well it is the opposite, you become an attraction, which has its own problems, but they are not the same as if they thought you were drunk. So, it is a different you know, you have got this official dog with you, it is it changes the dynamics of the whole relationship. Some people or when you are slurring your speech, the cognition slows down with MS sometimes, if you have got a dog there it softens the whole situation. It is amazing.

> Richard (233-261)

Richard's understanding reveals he uses his own internal perceptions of a hierarchical dimension to his experiences in social situations. He lives within a bounded understanding, a greyscale of his own making between the black/white – 'normal'/abnormal previous state of 'becoming a problem' where he could be mis-identified as 'mentally disabled' (234). Perhaps reflecting how he himself thought about others with visible impairments and diverse abilities before he became disabled.

Fortunately, his assistance dog, Noah, is understood to act as a kind of prism, focusing the glare of public attention away from his atypical body movements and communication difficulties, towards a shared identifiable human characteristic – having a dog. Richard perceives that others see him differently because is perceived as having the mental capacity to manage a dog's behaviour in a public setting. Through the prism of his assistance dog, he arrives on the other side of the public gaze on a spectrum of otherness - not 'normal' but closer to 'normal' than someone who is 'mentally disabled'; because in society 'normal' people, one of which he used to be, 'they don't know how to treat you' without being able to assess which of the two you are.

> It was more challenging [being out in public before he had an assistance dog] in that you had to explain to people much more thoroughly, [but] when he is with me they will almost ignore the MS and all the weirdness, the twitching and dropping things, they will ignore it and focus on him. So, he is like a shield really… the fact that he is there means that they don't notice me, which can be good.
>
> Richard (334-343)

In Richard's sense-making he uses the metaphor whereby his assistance dog Noah is described as his 'shield,' attracting people to interact with him and Noah, yet deflecting the potentially negative 'othering' of Richard as 'mentally disabled' or 'physically disabled'. He further perceives that being with Noah confers a sense of legitimacy on him as being a genuinely disabled person with all the rights and protections our society affords to them as a working partnership. He is not drunk, he is not 'mentally disabled', he is not a fraud. In fact, instead of 'becoming a problem' he is re-becoming human; but this human-ness is contingent on having his assistance dog with him.

Similarly, Steve experienced the impact of his assistance dog on his interactions with others in public situations. He makes sense of how the experiences of interactions (or deliberate non-interactions) played out for him prior to using an assistance dog:

> people just ignored me. You are just another person and the fact that you are in a [wheel]chair, they usually just ignore you, but with a dog with you on a lead on the side… All of a sudden worth talking to, because people are interested.
>
> Steve (164-169)

Helen is pragmatic in her articulation of her experiences:

> When I don't have Alfie, I am invisible and that is a fact, people look through you… Oh yeah, I am very much a non-person when I don't have the dog, or I feel that I am not. I feel that I have got a more social presence when he is with me, which I definitely have because people find him attractive and want to say hello or are a bit curious about what is happening.
>
> Helen (546-593)

The appeal of the assistance dogs to members of the public permeated all the

participants' interviews. It also had the effect of encouraging participants to embrace

this new aspect of VISIBILITY, with some proactively seeking opportunities to be out

in public with their assistance dog:

> G: [when you are in public] without a dog, how did that go?
>
> ELAINE: You're just kind of invisible, I don't know, it is weird.
>
> G: You feel you are invisible?
>
> ELAINE: But it is, you can't go into a shop or anywhere without
> people having to open doors and stuff, but you are just a disabled
> person, but I find with a dog it is like walking with a celebrity everywhere
> because they want to stroke and say, what is your dog? and where did
> you get her from? what does she do around the house? and all this, so I
> just feel like her PA really.
>
> (Elaine; 729-737)

By way of further illustration, I return to Maggie's interview, which typifies this effect.

Living with MS and using an assistance dog appears to have resulted in some

significant changes in how Maggie relates to the outside world. Instead of retreating

to the isolation of her own home, she relishes opportunities to leave the house as she

describes in the following extract:

> I thought If I can take my dog with me, I will go out again, and obviously
> got on to (the) training process. I must say, by this time I didn't realise
> just how much I had lost confidence you know, I was very apprehensive
> at going out, wasn't doing things and so was Ella (first assistance dog),
> because I live in a village and obviously, she was used to going in the
> fields all the time, but not really busy areas. So, in a way both of us
> together learnt again to go out and meet people, and I just, I mean
> Rose (Dog Trainer) says she still uses [Maggie &Ella] as an example,
> she trained Ella, she was you know the first person that I had contact in
> for that Rose and she says that you know, she used to phone me and I
> was always at home and then suddenly when I had this dog, when she
> qualified, she used to phone and I was never in, she started leaving
> messages for me and so, you know, that just made, just made such a
> tremendous difference and it takes a while […] to actually, adjust to
> having this dog and suddenly when she was qualified and I could go

out on my own… but it was just the beginning and people got to know us and talk to us...

<div align="right">Maggie (83-93)</div>

In the following extract, Maggie (like Richard previously) describes how she perceives her assistance dog redirects the gaze of people she meets so that the 'real her' can be expressed 'through her dog'. In the same few lines, she also tells how having an official assistance dog with her also results in a certain legitimisation of her social identity as person with a bone fide disability. Maggie has permission to be 'wobbly' and slow. As a partnership, they are perceived to need, and are afforded, additional space:

> …because obviously I am a lot slower at doing things. It takes me a lot longer to do things and you know, that little bit extra space as well I think too you know, if I am crowded then I feel not used to it, I feel very vulnerable and worried because I am capable of falling over very quickly, and with a dog first of all for me, the very good thing is people notice the dog and not me, which suits me down to the ground. That is what I want, the fact that people will say 'hello Ella' 'hello Sunny' (successor dog to Ella) and not even know who I am, to some people they would find that offensive, for me, that was absolutely ideal. I could work through my dog sort of thing you know. People give you space and they might not have any idea what is the matter, they might not even know you, but they know that if you have got an assistance dog you have got it for a reason, so there is something wrong

<div align="right">Maggie (305-318)</div>

For all participants, the feeling of HYPER-VISIBILITY when they are out with their assistance dog, evoked a range of responses, which participants recalled in their sense-making in diverse ways. The data suggests that the dyad of participant and assistance dog partner becomes, in some social interactions (albeit temporarily), a triad with others, whereby each party affects and is affected by the encounter.

In the following extract, Roy recalls an incident in which he was out in his wheelchair going to his mother's house on his own, except for Millie, his first assistance dog and he fell out of his wheelchair. Concerned passers-by called an ambulance, two ambulances attended:

> Roy: …but they had the back door open, they put me in... she (Millie) wouldn't go in the other ambulance, she came in with me.
>
> G: Why did they send two?
>
> ROY: Suppose the chair and me and the dog, you know. (When) I have been up the hospital and all the nurses always would be there and it's been all the dog, ferrying this water to them. Then I said, 'I had just fallen on the road' and they said, 'oh, would you like a drink of water?'
>
> G: How does that make you feel like in that hospital situation there?
>
> ROY: I thought it was alright.
>
> G: It doesn't upset you?
>
> ROY: No, no.
>
> G: As long as the dog is looked after, you are fine?
>
> ROY: Oh yeah...
>
> <div align="right">Roy (481-496)</div>

Roy relates the story as an amusing anecdote, the absurdity of the situation where, in an accident and emergency department, different staff foreground the assistance dog's perceived needs (a drink of water) whilst backgrounding Roy's – he is there but not there. The novelty of the assistance dog appears to influence the behaviour of the nurses who temporarily forget Roy is their patient and register surprise when he reminds them that he might also be in need of basic human care, 'oh, would you like a drink?'

Roy is not upset or hurt by this encounter; he has not internalised the event in a negative way. However, other participants report similar experiences whereby the hyper-visibility of their highly trained, impeccably behaved, assistance dog, and the resultant increase in social acknowledgement/interaction, is perceived more negatively. There follow some examples where participants sense-making has been of a different, less positive kind:

> Well I started to tell people now, it has been going on for some years, but you know I wish he (was) fat and ugly and I mean, and then they wouldn't bother, they wouldn't bother him you know, or me. I would be, keep nice and calm and happy and, but because he loves people and the more they touch him, he looks for it you see and it annoys me when he solicits attention
>
> Helen (76- 80)

Helen is highlighting a more challenging aspect of being HYPER-VISIBLE using an assistance dog when, despite written instructions on the dog's jacket or lead-slip not to distract the assistance dog when they are working, some members of the public insist on touching or interacting with the dog without the permission of the handler. In Helen's case, she is expressing frustration that her assistance dog has been trained to not solicit attention, to be as unobtrusive as possible when out in public places. She has found however that her assistance dog Alfie really enjoys fuss and attention and, if he gets it when he is working, it interferes with his training and he behaves inappropriately. Elaine also spoke about this aspect of being HYPER-VISIBLE when she is out in public with her assistance dog Meg. She uses humour in her recounting of the sometimes, exasperating situations that she encounters daily:

> …but if you need her to concentrate, she changes gear with her jacket on anyway. It is quite eerie at times, you put the head thing on as well and she is with you all the way and she concentrates if people don't

distract and good grief, I don't know why they bother to put 'don't distract' on her back because nobody takes any notice. I am like, don't make me hit you, leave her alone, but people can be quite forceful 'now I am going to give your dog a treat'. You are not, I will punch you don't make me do it… Well you are not allowed to punch them; I did ask on training.

Elaine (662-673)

Maggie recounts experiencing occasions where the HYPER-VISIBILITY and attractiveness of her assistance dog threatens to overshadow her rehabilitation needs. She does, however, take ownership of the situation. This would appear to be in divergence with her initial demure, self-effacing, persona, described earlier in the chapter, before she had her assistance dog.

(I went) for physio, which is quite recently actually and they were more than happy for her (second assistance dog Sunny) to go, but we didn't do anything because everybody was so [laugh], she was the life and soul of everything, you know, and it was, it was …what do you call it, rehabilitation or something neurologic rehabilitation I think it was or, so it was a big open room and there were other people and nobody did anything because everybody wanted to talk to her, even all the physios wanted to come and talk to her. So, I just think perhaps you know, it would be a good idea if I leave her in the car, which is actually, Sunny has never been left at all, but she is happy to stay in the car for short spells you know… so that is, but that is the physiotherapy sessions I have been to, anything like that she always comes with me. I am kind of on my own accord, stay away from endless visits to neurologists. It is just depressing that you are not getting anywhere.

Maggie (446-462)

Not only is Maggie leaving her house with her assistance dog to access physiotherapy services, rather than have them visit her, she appears to proactively manage the encounter. Her account suggests that over time living with MS and using an assistance dog have resulted in changes in how she lives with and manages the condition. There is an acceptance that MS is a long-term condition and 'endless visits

to neurologists' are not beneficial to her, there is no cure to be found. She asserts her right to withdraw from the system, in part 'I am kind of on my own accord, stay away', choosing to access the services she does feel she benefits from (physiotherapy); however, it is an engagement on her terms. She has 'come out' as being disabled. It is okay to have impairments that have no medical 'cure'. If her assistance dog is with her (and now even for short times when she is not), Maggie appears accepting of being seen to be different, in fact she embraces it.

In the extract above, Maggie acknowledges the positive impact of having Sunny with her in physiotherapy sessions and the feedback she gets from staff and other patients. At the same time, she is now confident to put her assistance dog in the car for the duration of the physio session so that she can be treated (made VISIBLE) without the distraction of her (HYPER-VISIBLE) assistance dog. In this situation she is no longer satisfied with, 'the very good thing is people notice the dog and not me, which suits me down to the ground,' because it potentially results in health professionals and other patients only focussing on her assistance dog, which may serve to render her rehabilitation needs less visible or possibly unmet.

The findings thus far suggest that experiences of living with MS when using an assistance dog impacted on aspects of participants' sense making of their perceived VISIBILITY in society. Experiences of feeling INVISIBLE and/or HYPER-VISIBLE however were not static but occurred in a fluid, dynamic lifeworld. Sometimes the HYPER-VISIBILITY of the assistance dog was welcomed, perceived to redirect negative public scrutiny of VISIBLE disability. Whilst simultaneously allowing those

they encountered to see the 'person at the other end of the lead'. At other times, the

effect of their HYPER-VISIBLE assistance dog was made sense of by participants as,

on occasion, making them subject to intrusive, unwelcome attention, threatening to

destabilise their working partnership or the quality of services they received.

4.3   TRANSLUCENT SELVES

In addition to these states that I have explored above, a small number of participants

appeared to also experience a facet of VISIBILITY which I have interpreted as one of

TRANSLUCENCY.

For some participants, this additional aspect of their experience of VISIBILITY was

revealed when they and their assistance dog were accompanied by an able-bodied

person. These participants described that although they were present, physically

attached to the assistance dog and in full control of the dog, they experienced being

overlooked, barely seen by those they encounter who defer to their able-bodied

human companion. Participants diverged in their responses to this TRANSLUCENT

state, with some emboldened, empowered even, to assert their right to be seen. For

others it was accepted – preferable to their previous experience of total INVISIBILITY

as a visibly disabled person in public without an assistance dog. However, it was not

clear cut:

> Maggie: I think they are genuinely interested in what (I have to
> say), it is a difficult one to answer because if I have somebody with me,
> if I have got a friend or somebody with me then nine out of ten times
> they will ask that person.
> G: So, they will defer to that person?

Maggie: Yes.

G: Okay.

Maggie: And they will not answer because you know, that is what they find that annoying, well no not annoying, I find it annoying, and so they won't answer, or they will say, well ask Maggie you know, she can tell you that. If I am on my own then I think, I think they speak to me as a person rather than a disabled person, but obviously I am disabled, and I have got Sunny because I am disabled, so the two I think kind of go hand in hand, you know

Maggie (358-366)

Helen encounters this situation on a regular basis when she is out and about with her able-bodied partner:

If I am out with Mike and it (has) happened an awful lot, he has got quite used to it now, so he does sidestep it a lot, but people speak to him not me. That happens regular, you know, and it happened, it happened the other day in a, in this coffee bar in, where was I, Edinburgh, it doesn't matter, it was somewhere else. Someone asked him if they could stroke the dog.

Helen (600-604)

Other participants recalled incidents whereby they had paid for an item in a shop or restaurant and the person at the register would hand the change back to the able-bodied companion even though it was the participant's money. At first, I found this finding rather puzzling. Why is it that when a participant was out in public alone apart from their assistance dog, they would experience being approached and interacted with in the ways described above; however, when they are with an able-bodied person, in addition to their assistance dog, they experienced almost fading into the background? It is possible that in our society the 'othering' of those with visible differences is so ingrained that for some individuals their default position is to

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privilege the able-bodied person in such interactions, when that option is available to them.

4.4　　　　VISIBLE SELVES

Without an assistance dog, the participants experienced feeling INVISIBLE but when together they perceived they became VISIBLE. Their meaning-making implies that in those moments of interaction, of connection with other people, the participants' impairment is rendered INVISIBLE. The differences between able-bodied and dis-abled are replaced with sameness, centring upon the assistance dog who becomes a nexus connecting them all. Through the dog, the hyper/in-visible person becomes VISIBLE but not it would seem as an individual; as Maggie states, 'people got to know us and talk to us' (93). Here, participants' use of language alters, signalling a shift in their understanding of how they come to be seen in public situations.

Participants were rarely seen in public without their assistance dogs, and this coupled with the fact they are still a relatively unusual sight in many parts of the country, It is unsurprising that participants would start to refer to themselves and their assistance dog as 'we' rather than 'me and my dog' or 'I'. In addition to which, they reported experiencing feedback from others identifying them in terms of their visible presence in the community as a joint entity. Data relating to the sub-theme of VISIBLE SELVES manifested in diverse ways. For some, it was expressed in relation to how the participants' meaning making of their local community's response to the presence or absence of their assistance dog.

As referred to earlier, assistance dogs are permitted to accompany their handler into

restricted areas such as shops and supermarkets. It is in supermarkets that the

following participants' extracts illustrating this finding are situated. Supermarkets are

a public space where the presence of an assistance dog (or any animal) would be

hard to miss. They are also spaces where patrons may shop on the same day around

the same time each week. Several participants reported that they became a familiar

sight in their local area over time and as a result could form social relationships with

local people. The following extract involves Nicky (Roy's wife) recounting how she

perceives a positive benefit of being HYPER-VISIBLE when in public with Roy's first

assistance dog Millie:

> we can't go to [ ] to our local shopping area, everybody knows Millie in
> fact someone said to me 'oh I haven't seen your dog for a while…and
> when Millie died half of Tesco's were distraught weren't they, and when
> we first had Cassie and Roy used to go out with Cassie and not Millie
> they would all say, 'oh has something happened to Millie', don't they
> and they all worry you know.
>
> Nicky (123-8)

By the time of interview, Sunny was eight years old and Maggie reflects on how

community relationships have developed over time:

> Maggie: I used to go to erm, Sainsbury's we used to refer to as the
> Tuesday Club because people came, and it was coming to see
> Sunny… Well and Ella you know..: And then Sunny and it was lovely, I
> got to know so many people that almost became friends you know, that
> really were totally strangers you know, but we chatted and so in that
> sense you were treated differently, but to me in a much, much nicer
> way [inaudible] it's just lovely because people are there waiting and this
> morning, because I went up, and it is usually Tuesday when I go to the
> (supermarket)… And I said, oh we are going to be going up to the
> centre (assistance dog training centre where the interview took place)

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and so I am not going tomorrow as well, and I wanted to pop in, so
treated differently in that, in that way, but to me a nice way…

<div align="right">Maggie (318-335)</div>

This extract exemplifies participants' sense-making of how their VISIBILITY in society becomes contingent on them being with their assistance dog. What may appear initially to be an ice breaker to initiate conversation, over time serves to foster more meaningful social relationships within a participant's lifeworld. This account is not without further insights as Maggie is aware that people are 'coming to see Sunny' (and before that, Ella) but that is acceptable, because she will be the beneficiary of the positive atmosphere and interaction her assistance dog generates. She acknowledges that she '…got to know so many people that *almost became friends'* (my emphasis), distinguishing between genuine friendships she enjoys and these social, friendly, regular interactions. However, they are of sufficient importance to her that she makes sure to 'pop in' to let people know that they will be absent from the following day's 'Tuesday club' in Sainsbury's. Signifying, perhaps that she recognises her and her assistance dog's presence as a visible unit in that community and, if they were absent, they would be missed.

Other participants expressed how they perceived they were seen by others when out in diverse shared spaces. June is considered in her meaning-making of the experience of being out always seen with her assistance dog around her local area:

I do know I am often called the lady with the wheelchair and Max you know… I used to be known as Alan's wife and now you know, Max, they talk about Max's owner and things like that.

<div align="right">June (328-334)</div>

Additionally, Jo relates that she is:

> the only one with an assistance dog in the immediate area. So, people
> don't seem to, they are not able to forget the lady on the scooter with
> the dog and the jacket. So, a lot of people you know, smile and say oh
> hello, how are you? And I am going, where do I know you from… it is
> because they have seen me go past their house several times and I am
> easily recognisable, so we have to behave when we are out [both
> laugh]… I am known as Honey's mum.
>
> Jo (281-294)

Both June and Jo appear perfectly content to be described in terms of their
relationship to their assistance dog as either preferable to being known as someone's
wife or characterised as being akin to a mother and child, with all the bonding and
closeness that image suggests. This speaks to an acceptance of the perceptions of
others that there is a strong link between themselves and their assistance dog. They
are becoming an indivisible unit, each contingent on the presence of the other for
their IDENTITY.

It is not unusual to discover a certain amount of overlap of themes in super-ordinate
themes in an IPA study. Consideration of this dimension of living with MS and the use
of an assistance dog is explored in much greater depth in Chapter 6 of the thesis,
where I examine findings relating to the third super-ordinate theme identified, that of
IDENTITY.

4.5   INVISIBILITY - Regained

This section concludes with a consideration of findings wherein participants spoke about the future, when their assistance dog would no longer be with them, specifically in the context of the meaning they ascribed to their VISIBILITY. The focus of this brief section of the chapter is on a selection of those participants who expressed fears and anxieties about the future. For some, the thought of being without an assistance dog, through the retirement, illness, rehoming, or death of their assistance dog, would mean they would once again become INVISIBLE. They anticipated that they would stop going out or that they may remain alone and unseen in their homes.

When interviewed, Steve was partnered with his third assistance dog Bill, who was 9 years old. Bill's estimated retirement age was 12 years of age, assuming his health status remained good and Steve can meet his needs (with some input from Julie, Steve's human paid carer). Steve lived alone, apart from his assistance dog, and his MS has progressed over the last 27 years to a stage where he can now only move his head. He uses a 'suck and blow' computer to operate items such as his wheelchair and door locks. The extract below followed my observation that perhaps Bill might be Steve's last assistance dog, it also introduces the intertwined thread of UNCERTAINTY related to aging with MS and retirement of an assistance dog which is explored the following subsection (5.2):

> Steve: Seems it, seems it at times, at the moment can't say the answer, but we will see.
>
> G: It must be quite worrying?
>
> Steve: Yeah because I have had assistance dogs since 2000, so 16 years I have had one of them, and you get kind of used to them.

Julie: They said (assistance dog charity) oh, it's your companionship, it is a big thing having him here isn't it?

Steve: Same time, empty house just me, that would be hard. [pause to drink] see what happens, lot of water to flow under the bridge.

Steve (370-378)

This exchange appeared to be exceedingly difficult emotionally for Steve and highlights the potential reality for those participants who live alone except for their assistance dog. In the extract Steve vacillates between acknowledging the high probability that Bill will be his last assistance dog- 'seems it' - and hanging onto the hope that perhaps he is not, 'we'll see,' maybe something else will happen to intervene. He briefly expresses his sense-making of what that may mean in reality, 'same time, empty house, just me, that would be hard'. After pausing for a drink, Steve shuts down the direction the conversation is going. It seems to be too unbearable to think about at that time.

In contrast to Steve, Amanda appears to have a vivid sense of what a future without her assistance dog Izzy might mean to her VISIBILITY in society. In the following abstract, she envisages a return to the INVISIBLE/HYPER-VISIBLE state she experienced prior to using an assistance dog:

so with her there is your confidence or when you go out, nobody would talk to you, nobody […], not to me personally, nobody will talk to you, but when you have got [an assistance dog], they go instantly to her and that is all you want. You don't care if they talk to you or not. They have stopped, and they have given her some attention, so you have got some interaction that you would never have any other time

Amanda (489-496)

Finally, we return to Helen's interview for the concluding words on a future without

her assistance dog in this findings chapter on the first super-ordinate theme of

VISIBILITY*:*

> I know I wouldn't, I wouldn't. So, that is the bottom line really when it
> comes down to it, emotionally I wouldn't manage and that leads on to
> the physical things like I wouldn't go out. I wouldn't do it at all. I might
> go to the doctors occasionally myself and I might go to the hospital in a
> taxi myself, but other than that, that would be it… No, it would be a very
> small world, very small…
>
> <div align="right">Helen (800-804)</div>

4.6   Summary

In this chapter I have presented findings using a blend of description and

interpretation of those key emergent themes across cases which contributed to the

first super-ordinate theme identified in this study, that of VISIBILITY. It focussed on

what could be considered an outer layer of the experience of living with MS and the

use of an assistance dog, both those things seen and unseen. In the next chapter the

IPA narrative extends deeper into the experiences of participants in relation to the

knowns and unknowns of living and aging with MS and the lived experience of

partnership with an assistance dog/s, with a focus on (UN)CERTAINTIES.

Chapter 5 (UN)CERTAINTY

Participants' sensemaking of both the (UN)CERTAINTY inherent in living and aging

with Multiple Sclerosis (MS) as well as the (UN)CERTAINTY unique to the use of an

assistance dog form the focus of the second findings chapter. Through the process of

exploration and interpretation of participants' understanding of their experiences, a

picture emerges illuminating a complex tapestry of converging and diverging threads.

Some of these experiences are intrinsic to each individual participant living with MS,

others reflect experiences which are related to individual assistance dogs; others are

more extrinsic, reflecting organisational (assistance dog charity) and societal realities

outside the control of participants but all impacting profoundly on their individual lived

experiences.

The chapter explores the collective sense-making of experiences spanning over two

decades of living with MS and using an assistance dog/s across the 11 participants.

In total this involved the use of 19 assistance dogs. An infographic (Figure 1, below)

provides an overview of each of the 19 assistance dog partnerships experienced.

This high-level view of participants' journeys helps to contextualise their accounts

and reveals patterns within and between cases. It reveals that the lived experience

for many of those partnerships was by no means a linear or certain one. The chapter

continues with a narrowing of the focus on the individual interwoven threads of

participants' experiences providing a fine-grained interpretation of the data. There

was a range of experiences revealed in the findings related to four main sub-themes

nested within the super-ordinate theme of UNCERTAINTIES in participants' use of

assistance dogs. They were: the unexpected death of an assistance dog prematurely for a medical reason; the unexpected early retirement of an assistance dog for medical or behavioural reasons; issues around an assistance dog's expected retirement or death and UNCERTAINTIES surrounding its successor; as well as the complex experiences and UNCERTAINTIES of aging with MS. Some participants had experienced more than one aspect of UNCERTAINTY at the time of their interview and the extracts from their transcripts on occasion contain a mix of subthemes. For example, in Maggie's account, the sub-themes of the expected retirement of both of her assistance dogs over 22 years also highlight UNCERTAINTIES around Maggie's own aging with MS and UNCERTAINTIES around experiences of getting a successor dog. Each sub-theme is different but overlaps or exists in parallel to another. The first sub-theme (section 5.1) explores the unknowns around getting an assistance dog qualified initially, and then the unexpected events that can end a partnership for medical or behavioural reasons. The known or expected dimensions of participants' experiences are examined in section 5.2. Contrasting experiences which on one level appear straightforward and clear cut – planned retirement of an assistance dog and the arrival of a successor – are revealed to have blurred and overlapping edges. These are made more complicated by the relentless and uncertain progress of participants' MS. At times the human partner's needs are foregrounded but they influence and shape the assistance dog partner and vice versa.
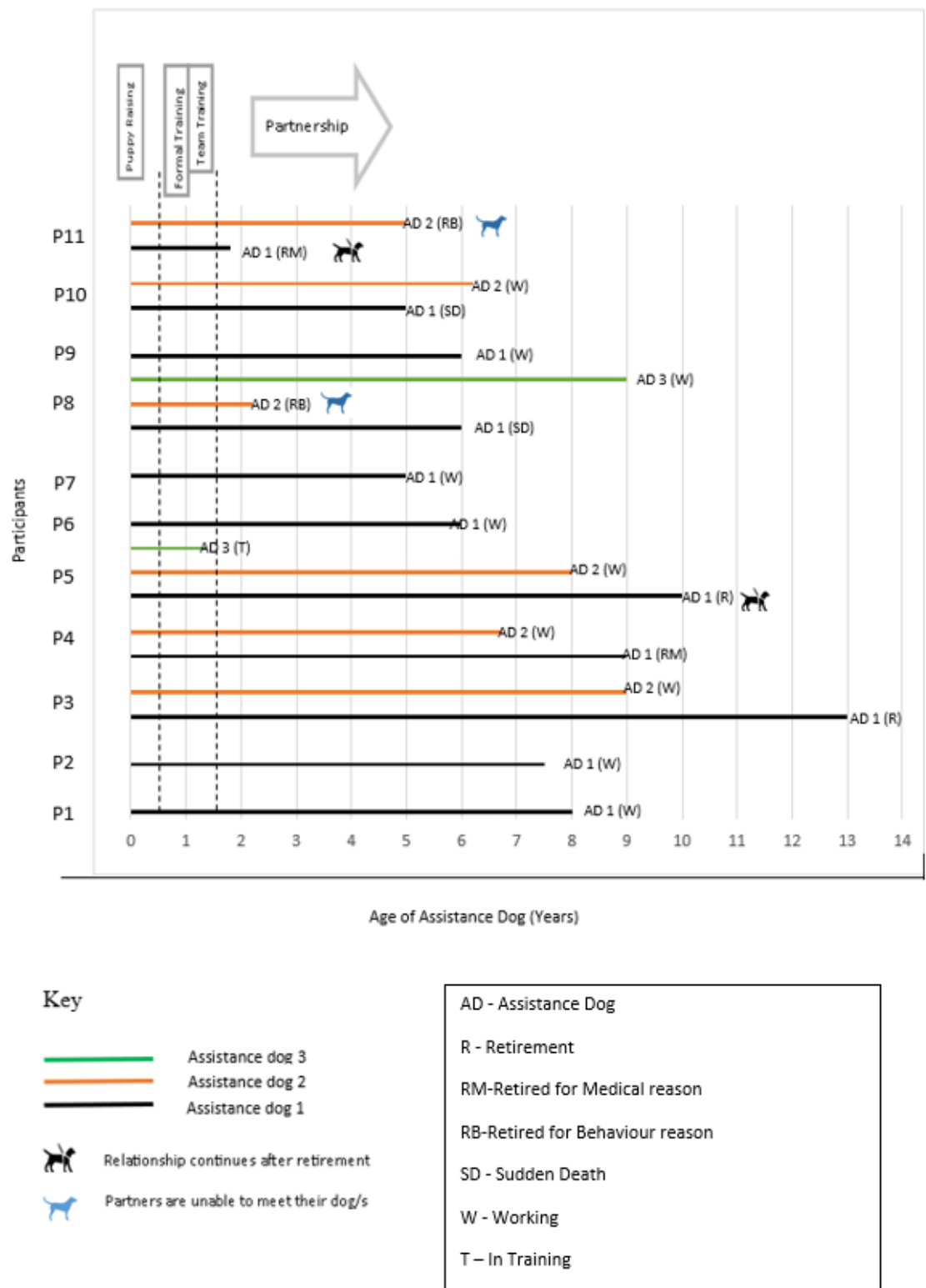
Figure 1 Outcomes for participants' working assistance dog partnerships with causes for retirement

Source: Data from O'Connor, 2020, adapted from Yamamoto & Hart, 2018

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5.1   Beginnings and endings – 'Hot air balloons and tortoises'

In the following extracts, participants describe experiencing UNCERTAINTY at different times, in relation to the matching process, health, training and lifespan of their assistance dog/s, as well as the many UNCERTAINTIES surrounding the availability or appropriateness of its successor.

Sean's own pet dog, Ben, a yellow Labrador Retriever, was accepted onto assistance dog training at two years of age, after assessments of his behaviour, temperament and health showed he was a suitable candidate for training as a disability assistance dog. Anticipation and expectation soon turned to disappointment when halfway through his training

> …they identified a problem in his elbow, took him to the vets, did a X-ray noticed a problem, an inflammation on the elbow and it was deemed that the training was too intense for him, for his elbow, so that was it. So we came home.
>
> <div align="right">Sean (197-204)</div>

A short-time later Sean was contacted by the assistance dog charity to see if he would be open to having a dog that was already trained. When Sean agreed, a dog was sourced – a change of career dog, Louis – originally a police search dog who, though good at searching, was not consistent in his work ethic.

> I had to spend that couple of weeks having a bond with Louis, who wasn't originally my dog. Ben had to take a bit of a back seat, (for a) period of time through that and he coped admirably… but, so he coped very well. I was, I don't know, I don't know almost euphoria, I had this job to do… Yeah, to, it was like going to work, but it was something that like a job I had never had before that was wonderful.
>
> <div align="right">Sean (257-266)</div>

After successfully completing the assistance dog training, Sean and Louis settled into their working partnership. Louis's physical health was good, and all was well until out of the blue Louis was attacked on two separate occasions. These were unprovoked incidents by two different pet dogs who escaped from the garden of the house across the road from Sean. Whilst physically unharmed the incidents deeply affected Louis' behaviour.

> Yeah, he was still the same dog, still did the same things, but when another dog was about, he would be… unpredictable...I had a dog trainer come and was doing some work with us, it was authenticated through the assistance dog charity, and we did some stuff, this guy was a dog trainer for his business, he had dogs in the back of his van, we would bring different dogs each time and we would do walk past… some things, erm, and it got to a stage where Louis was getting really, really good at it… then you would think, oh we are getting somewhere with this and then all of a sudden he would have a go at another dog.
>
> Sean (636-649)

Throughout this period of retraining Louis was not allowed to work in restricted areas in public as an assistance dog but continued to assist Sean at home. Louis' unpredictable behaviour persisted and Sean had no option but to inform the assistance dog charity who took steps to intensify Louis' retraining, initially with and then without Sean.

> We told [the assistance dog charity] about it, they arranged for us to go up there. I think we were there for a couple of days, oh yes, we went to a walk, for a walk on a common up there with Niamh (Trainer) and she saw something, he was quite good that day, but she saw something that she didn't like there. So the idea was that Louis would stay up there and to get this trained out of him and we come home and we would go back up later on and, in the hope that they had trained it out of him. They weren't able to. So decision was made that he could come back here, but not as an assistance dog. I made the difficult decision that we probably wanted another assistance dog at another time and not worry

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him, but it was a mutual agreement between me and assistance dog charity, that when we are here, more to the point, while those dogs are there, there is not going to be an assistance dog living here.

<div align="right">Sean (682-690)</div>

Sean initially conveyed the information about both Ben and Louis's life with him in a very pragmatic, unemotional manner. He reports what he sees as the facts. It was a sensible decision to not have Louis back, even as a pet dog, because he envisaged that he would continue to need an assistance dog and he already had Ben. However, when asked about where Louis is now, a different softer side to Sean revealed itself:

> Yeah, he has erm, been rehomed, he went to a foster family while [the assistance dog charity staff] worked with him. When we took him up there, next door neighbour showed an interest in him and said that if he didn't come back, they would be interested in having him. So that is where he has gone. They asked if I wanted to you know, have regular...updates on how he is getting on and I said, you know, I would prefer not to because I was very, very emotionally upset to the point where Niamh (Trainer) would be on the phone to me and I couldn't say a word, so I had to end the call and try to phone Sue (his wife) to take over and so, Sue had to take over and we decided that he wasn't going to come back and I, erm, for whatever reason it is, that erm, it would be like, if you had your child fostered; I would imagine that would be the same, you are not allowed to have contact with the child if you fostered your child or whatever, but I elected to not be in regular contact with Louis because, not that it's, might not be, well he wouldn't know anyway, but I would know

<div align="right">Sean (803-821)</div>

Sean's account of the experience of giving up Louis is likened to that of a parent giving up their child for fostering. It was so emotionally painful for him he was rendered speechless, unable to articulate his distress to the assistance dog trainer. At the time of interview, Sean was reflecting on both of his experiences of using assistance dogs, experiences that were shaped by events outside himself and his

MS. Ben was withdrawn from training because of a physical problem with his elbow, a defect specific to him; whereas Louis' career as an assistance dog was cut short by events that happened to him. External random encounters with aggressive, unsupervised dogs affected Louis's behaviour permanently and ended a successful working partnership in an instant. Though he expresses how devastating the loss of Louis was, Sean has made sense of the ramifications of the attacks.

> So we are looking at moving and we are looking at moving up north, because Sue's parents are from there…where we are more likely to get help. Whenever we move from here the assistance dog charity will look at getting me back with a dog…I might decide to move on my own just so that I can get a dog.
>
> Sean (786-794)

In the interim, with an uncertain future in terms of when they may move and where he and his wife will be living, Sean continues to acknowledge Louis's presence in his daily life,

> it seems that it was only five minutes he was here, there is a picture of him up there in the hallway…Yeah, and when I go to go upstairs at the end of the day I position this chair so that my chairlift is beside me and I will always say good night to him, because he is there looking at me.
>
> Sean (596-603)

Elaine's understanding of her own motivation for applying to get an assistance dog was clarified and communicated by means of a story she shared, of when she first travelled to the assistance dog charity training centre for an information day:

> I always remember sitting having our lunch and there was a man in a wheelchair there and he was waiting to find his match to the right dog, and he said it might not be today, it might take a while to find the right dog, but you know, just take, take your time or whatever and he looked really old and tired and really, and he said my carer puts me to bed at

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half past nine at night. He said, I don't want to go to bed at half past nine and he said, I sit just watching videos and DVDs, I don't want to go to bed at that time. Then he looked down and he, he's, for a minute and he looked up and smiled and he said, when I get my dog, the dog will put me to bed when I want to go to bed, and I thought, you can't buy independence like that

<div align="right">Elaine (312-324)</div>

Elaine's sensemaking of the experiences shared with her have resonated with her own experience of living by herself with MS and the daily struggle to remain independent. Her assertion that 'independence like that' cannot be bought is, ironically, quickly followed by an account of exactly how much that kind of independence can indeed be bought for. However, she is self-deprecating about whether she should be given an assistance dog at all. Elaine is puzzling over her 'worth' and the thousands of pounds it costs the assistance dog charity to provide an assistance dog to give what, for her, is the priceless gift of independence.

and at the end of the day [the assistance dog charity] said, do you think we will be right for you and I am thinking, do you think I am right for you when you, I mean they are hugely expensive these dogs. I know it costs £10,000 to train her to the point where I got her and it is going to be another £10,000 for her life and you just can't hand these dogs [out], I mean there must be a huge waiting list.

<div align="right">Elaine (325-331)</div>

Once the decision to apply for an assistance dog was made Elaine describes the lengthy process of checks that followed. However, unlike the HYPER-VISIBILITY discussed previously (Chapter 4), it is scrutiny with a purpose; its steps mirroring the links of a chain being forged and interconnected – a satisfactory home check, a recognised medical diagnosis, a report from GP/Consultant – any of which could halt the process at any given point, the outcome by no means certain.

I applied and it took a long time to go through the 'can we check your house, can we check your medical records, can we write to your doctors' and all the stuff you go through and then they invited me down two or three more times, and I always remember you just went through all the loops and stuff that need going through and I got a letter from them one day saying, our panel has met and we have decided that we are going to start searching for a dog; and I hadn't realised how much it meant and do you know I got that letter coz I had just been struggling for so long and I just sat and cried and they started to search and then they sent me a letter saying, we have got five dogs we think might, because they knew me from that point. They knew my medical, they knew what I was struggling with, they knew I lived alone, they knew I needed someone to hit a panic button in an emergency

Elaine (331-350)

Elaine's trust that the assistance dog charity knows her in great detail and have taken time, effort and resources to find her first assistance dog contrasts with her previous experiences with mainstream NHS health professionals over many years (outlined in Chapter 4), which resulted in Elaine feeling both unseen and unheard. Matched with Leo, a two-year-old black Labrador retriever, whom she describes as 'a sensitive little soul.' Although frightened of vacuum cleaners, Leo proved to be good at his job, until:

my sister she came around for cuddles every now and then, but he, she found he got a lump on his neck when he was, I mean he was five when he died. He got cancer and died, he was only five…so I had only had him three years and it was a really [a]shock, this tiny little lump and the vet went and said, oh can we you know, can we take a blood test or whatever and then I got a phone call saying, 'oh he has got lymphoma, he has got four to six weeks to live if you do nothing'. I thought, what… I was so, such a shock and I am like, to the assistance dog charity, do, do some[thing], because they still owned him legally, I was just his guardian and they said, I was really shocked, they said no chemotherapy allowed, but with hindsight it is probably the best thing because they couldn't save him. He had got four to six weeks, they had me issued all his vet reports and they have a panel. Like I didn't realise the assistance dog charity had a panel of vets themselves. So it is a case of my people will speak to your people… And I spoke to my vet at the end and they said, the assistance dog charity said no chemotherapy, and I said, he is their dog, it is up to them. He said, but we [always] give chemotherapy. I think you do know it is terminal, but we always give chemo

Elaine (431 – 458)

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The shock of the terminal cancer diagnosis, at such an early age of her assistance dog, is further compounded by the shock of the assistance dog charity not approving treatment for Leo. Suddenly the strength of Elaine and Leo's bond, the empowerment engendered by their partnership and the independence so highly prized, is revealed for the fragile thing it is. Elaine is rendered powerless, no longer an independent, highly skilled assistance dog handler but 'just his guardian'. When it comes down to it 'he is their dog, it is up to them'. Elaine is suddenly out of the loop, 'my people will speak to your people'. The conflicting veterinary advice adds to Elaine's shock and confusion at the time; however, with the passage of time her sensemaking leads her to a more balanced understanding of her experience 'but with hindsight it is probably the best thing because they couldn't save him'.

At the time of Leo's death, Elaine was living with her partner and his 14-year-old pet dog. Sadly, two months later that dog also died. Grieving for the loss of both dogs, Elaine describes her experience:

> it was almost like my friends gone, so that Christmas we had lost both dogs, it was an awful time really, it was a real shock, and a couple of months after that, the assistance dog charity phoned up, it is the assistance dog trainer… but she is lovely and she very, she came round, she looked at my pictures, had a cup of tea. She very gently suggested starting the search for a successor dog, what a great title, it sounds like we should be wearing Superman pants doesn't it, but she was saying, this new dog when we find it, it won't be anything like Leo you know, little sensitive Leo. I will say she is not, I think she is bombproof, nothing phases her, nothing, [except] hot air balloons and tortoises, she doesn't like them, but anything else, nothing phases her.
>
> Elaine (534-547)

Elaine's musings on the term 'successor dog' evokes an image of a superhero, elevating the status of not just the successor assistance dog to Leo (whose identity is uncertain, and yet to be revealed) but also Elaine herself. In addition, her use of the plural, 'we should be wearing Superman pants,' alludes to the notion of a shared identity between assistance dog and human partner. Both the concept of status and shared identity will be explored in the next findings chapter (Chapter 6). Initially, Elaine's (human) partner was unsure whether he was ready to have a new dog in the house feeling that for him, his pet dog was to him, irreplaceable. Elaine, however, having experienced living with MS both with and without an assistance dog, was adamant that she was not ready to surrender her independence, despite her partner's reservations and her own acute feelings of grief:

> Martin was grief stricken over losing his dog Bonnie and he said, I can never replace her, she is just, he was just and I said, well I have to replace Leo because you don't realise how much he does until he was gone. It was like, who is going to get my washing to the washing machine and all the stuff that he did, despite the fact that the walking and the companionship and the lift that they give you. He does (Leo), helps me around the house and I can't do it and the MS is making my world smaller and it was such, such a struggle. So, to get another dog. suddenly, I had to replace h(im) and she (current assistance dog, Meg) barrelled into our lives completely oblivious that Martin was grieving over his dog and he's struggling with his own health issues anyway and she has helped him as well.
>
> Elaine (602-614)

There were four months between the death of Elaine's assistance dog Leo and matching her to a successor dog, Meg. Elaine's assertion that Meg was 'completely oblivious' to the fact that her partner was still grieving for the loss of his pet dog appears to mirror her own disregard of his feelings about the issue. Ultimately, she views the partnership with Meg as successful not only on its own terms but within the

context of her ongoing relationship with her human partner. The assistance dog is not solely existing within the context of the assistance dog/human partner dyad, it must operate within the dynamics of that human partner's world. In Elaine's case, Meg has enriched her experience of living with MS, but the benefits have spilled over into helping her partner Martin in his struggles with his own health.

Steve's assistance dog, Jenny, was both a physical and emotional support throughout the period in which his relationship with his wife deteriorated and ultimately broke down. Jenny's death aged six from cancer was as unexpected as it was untimely.

> my first [assistance] dog, Jenny, she was, you're bound to say, the best dog because she was my first, but really she was good, she was as good as Bill [Third assistance dog] is now… Jet black in colour, smaller than Bill but nevertheless, she was brilliant. So it was me and Jenny as a team and we were a good partnership… March time, just before the ex (wife) left [with his two children], Jenny died of cancer, so I was devastated. So I immediately applied for my second and that was a black Labrador
>
> Steve (70-96)

Steve here talks about Jenny as if she is family – his first love. It is unclear exactly which he is more devastated by, the loss of his marriage or the loss of Jenny. There is a blurring of the boundaries between his human family and his relationship with Jenny. Also revealed is a stark contrast between the language Steve uses when referring to Jenny – she is 'brilliant'; together they are a team, a 'good partnership'. All terms that seem more suited to a romantic partner's description of their human partner. His actual wife and the mother of his children assumes the role of 'the ex'

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who left. The theme of assistance dogs as being in a kinship-like relationship with their human partner is explored in depth in the following chapter (Chapter 6).

Steve's next assistance dog entered his life only weeks after Jenny's death. Extending the metaphor 'like family' to his next relationship, this new relationship 'on the rebound' does not last. Matched initially with Sam, Steve describes why the pairing did not prove to be a good fit. Steve felt Sam's boundless energy and high play drive matched with poor behaviour on the lead which meant he could not continue with the partnership, despite all attempts by the assistance dog charity to strengthen Sam's training. As with Elaine, the individual characteristics of the assistance dog and how they mesh with the social and personal context of their human partner appears crucial to the partnership's success. At the time of interview Steve further reflected on what has been a long and successful partnership with his third assistance dog, Bill. His lived experiences of using assistance dogs over many years illuminates a temporal dimension to the phenomenon of assistance dog use and the UNCERTAINTIES the passing of time might bring.

Diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) when aged twenty-six in 1990, Steve went to a disability roadshow and saw an assistance dog in action. By 2000 he was a permanent manual wheelchair user and had his first assistance dog Jenny. At the time of interview (2016), Steve's MS had progressed to being categorised as Secondary Progressive MS (SPMS) and the previous year his condition had further progressed, resulting in him losing the use of both arms. Confined to his electric wheelchair by day, Steve lived alone, apart from his third

assistance dog Bill, who was nine years old. As Steve's MS has progressed, he has

relied more on technology and the input of a paid carer, Julie; at the time of interview

he was only able to move his head. The progression of Steve's MS over time unfolds

in parallel with the normal aging of his assistance dog. They both coalesce in the

following account:

> I use a computer that operates using suck/blow, I blow into it, it
> transmits a signal. It opens and closes the back door, which is an
> electric door and it answers the phone. It does the intercom, so I can
> talk to people outside. So, Bill's main job is companionship. When Julie
> is gone he looks after me purely by the fact that he is there, that is it.
> Sits and looks at me at night when I am waiting for Julie to come back, I
> look at the clock and think an hour left, so Bill looks at me, unless I tell
> him how many minutes he won't stop looking at me, so I have to say
> sixty minutes. So then ten minutes later he will look at me, ten minutes,
> but if I didn't tell him how long he just pesters me, so, so now I have got
> a lot of gadgets in the house to help me, but so Bill, […] Bill's main job
> is companionship. When Julie is gone, he looks after me purely by the
> fact that he is there, that is it.
>
> Steve (141-158)

As his MS progressed, his human carer Julie was assuming more of the

responsibility to not only provide physical care to Steve but also assuming the role of

meeting Bill's needs. This required negotiation with the assistance dog charity that

supplied and trained Bill to ensure the trio were accredited as a working team which

they subsequently were. Over time, Roy's understanding of his current assistance

dog's role has altered just like Steve's, perhaps as the physical effects of their MS

have been equally severe with both. He observes that,

> because the condition has gone, now gone on and on, I think for the, I
> think physically what I need a dog to do is not so much because,
> because you can't do most there is less for the dog to do… but mentally
> see, it, it's obviously got more because as I say it is yeah, I mean
> obviously you go everywhere, she certainly will go everywhere and you
> do literally feel she is a part of you

Roy's wife, Nicky, goes on to reveal Roy's deep and enduring connection to Millie on

an emotional level and, ultimately, physical level: 'Millie is going to buried with Roy

and Cassie, depends how long he lasts [laughs]…' It is Nicky who verbalises her

experiences from the point of view of a family member observing the inevitable

passing of time from a unique perspective:

> She picks anything and everything up, like this is stupid but, I sleep
> upstairs but I hear, ah he has dropped the television changer, you
> know, she will pick all that up for him, that is basically, Cassie is
> basically, other than company, is just picking up stuff now

<div align="right">Nicky (367-370)</div>

No longer sleeping in the same room as his wife, because of limited space in the

house for all the equipment he needs, Roy and Cassie see out the nights together

like Steve and Bill waiting for their human carers to come.

It is Nicky who speaks about her fears for the future for Roy, she highlights the wider

effects of the use of assistance dogs:

> My fear is that when anything happens to Cassie, that Roy doesn't have
> another assistance dog. That is a fear. Well I suppose he is nearly 70,
> 67… Well three years, I have mentioned it to [assistance dog trainer], I
> have said, oh god I just... it gives me complete and utter and total
> peace of mind really… I know he is not on his own, I know it is a dog,
> but he is not on his own

<div align="right">Nicky (636-643)</div>

Steve, Sean and Elaine's experiences encompasses many of the UNCERTAINTIES

assistance dog users can face, including that of the death or withdrawal of their

assistance dogs unexpectedly through illness, or whose nature, temperament or physiological makeup is unsuitable for their human partner's requirements. Arguably, though tragic or deeply upsetting, these could befall any dog owner. However, as the following section highlights, UNCERTAINTIES around a different aspect of living with and using an assistance dog became the object of significant concern for some participants. Facing the retirement and death of an assistance dog in parallel with their own aging and progression of their MS can, for some, be too much to contemplate.

5.2 UNCERTAINTIES – The known unknowns

Maggie was one of the participants who had used an assistance dog for the longest period. Her sensemaking not only provides a unique insight into her lived experiences over twenty-two years of using assistance dogs but also illuminates changes in the field of assistance dog training generally over time. Beginning with her first assistance dog, a golden retriever named Ella, who eventually retired aged thirteen and died aged fifteen:

> there wasn't a definite cut off point (for assistance dog retirement), so she was still having assessments and in my mind she was still - okay to work with her and she was, but as I say, they said she couldn't go on forever, the best thing to do was – they didn't want me to have a spell without… an assistance dog that was qualified and ready to take over. The reason it was me that at all points was in opposition because, I suppose the problem is when you are on your own you haven't got somebody to take over that responsibility if the dog is retiring and I… I don't know, it is, you know it is putting a human erm, aspect to some extent, on the dog, which I know they are not but I thought, is she going to be hurt, you know, I am suddenly going to have this, this dog that is taking over and everything that she did, and she was still very happy to work at home you know, she was still, and it was just, if there had been. I think it would have been easier if I had somebody else that could have you know, sort of taken over her, kept her entertained if you like if you

know what I mean, whilst the other dog gradually took over, but with not having that erm, I just couldn't see how it was going to be and of course, I left it too late because I introduced a puppy to Ella when she wasn't really erm… at her best to take on a lively you know, young dog. So in the end I made it more difficult for her because I was dividing my time between… I mean after this very lively puppy that needed my attention and very old dog that was going downhill and also needing my attention, so it was very, very stressful time and one I wouldn't want to go through again.

<div align="right">Maggie (179-210)</div>

Maggie delayed the introduction of a successor assistance dog because she believed Ella's feelings would be 'hurt', offended by a young pretender taking over her job. There is a tension between the part of Maggie who understands that Ella is a dog whilst also ascribing human emotions like hurt feelings to her. Believing Ella would not understand why a younger dog has taken over ultimately leaves her in a position whereby Ella was too old to work as an assistance dog and Sunny, her second assistance dog, was still in training and not ready to assume the responsibilities of a qualified assistance dog. Maggie's understanding of that whole experience in those final years was one that was ultimately detrimental to her wellbeing and potentially to both dogs. Her sensemaking of that experience unveils a further aspect of assistance dog use echoed by other participants – the care of the retired assistance dog for the human partner who lives alone. The very thing that facilitates the ability of single participants to live successfully with MS and maintain their independence when living alone, becomes problematic when their assistance dog nears retirement.

Maggie's lived experiences foreground UNCERTAINTIES surrounding aging with a degenerative condition. It raises issues around living alone or facing the prospect of formal care and how long the ability to continue meeting the retired assistance dog's needs will be maintained. Even those with another person who could assume responsibility for the care of that retiring assistance dog, the retirement of the much loved and trusted partner, and the transition to a new assistance dog can be fraught with emotion.

Roy and Nicky had been married for over 45 years at the time of interview. It was Nicky who wrote to an assistance dog charity on Roy's behalf after she had read an article about the charity's founder. Roy and Nicky's pet dog, Millie, was accepted for assistance dog training in the year after Roy was diagnosed with Primary Progressive Multiple Sclerosis. So important was it to the couple that Millie succeed in her training, on the night before Roy and Millie's qualification assessment, Nicky slept on the floor of their hotel room so that Millie could sleep on the bed with Roy and get a good night's sleep. As Nicky worked full-time and their son was grown up and had left home, Roy and Millie formed a strong and successful partnership. Always together they undertook many fundraising activities and events for the charity that trained Millie, as well as contributing to the NHS' Expert Patient Programme and visiting various community groups.

When interviewed, Roy's MS had progressed to the point where he could just move his left hand. His voice was affected by his MS in that it was very quiet, and it proved to be labour intensive and exhausting to speak for any length of time. Nicky stayed

close by, often assisting Roy to have a drink and to fill in gaps in Roy's answers when

he struggled to speak audibly. The transition from his first dog Millie came earlier

than expected when, aged nine, Millie developed bladder problems; although

managed with medication they had to start planning towards her retirement. The

assistance dog charity supplied a successor dog, Cassie, but neither Roy nor Millie it

seems were quite ready to let go of their interdependent relationship. What appears

to be a planned, expected retirement of Millie and the CERTAINTY of her

replacement by Cassie was a more gradual, emotion led process than practical. It is

not the swapping of an old wheelchair for a newer model, it is the disentangling of a

shared IDENTITY (see Chapter 6) between interdependent beings.

> yeah it was handy having Cassie (already trained). Because obviously,
> the only time we felt uncomfortable was when we had to take the jacket
> off of one and put it on the other you know, I mean obviously we can
> understand, but I don't think Millie could ever understand why we did
> that.
>
> Roy (200-203)

Both dogs lived together for a further three years,

> We had Cassie for three years, which was a bit unfair on Cassie in lots
> of ways because Millie was always Millie and so much a big part of well
> nearly 15 years of our lives. I mean I am not saying that, Cassie wasn't
> lovely but it was always Millie... Millie never lost her loyalty to Roy, even
> though she wasn't on the lead, she was happy if she was walking
> behind him if Roy did …dropped something Millie would still, you know,
> but Millie had to retire because she starts to wee as she was walking,
> so we knew really.
>
> Nicky (148-155)

June's experiences of the retirement and death of her assistance dogs over time are

discussed below. Her account illuminates the (UN)CERTAINTIES across the life-

course of the phenomenon of using an assistance dog and living with MS. June's

experiences span the life and work of three assistance dogs, one (Oscar) that retired as expected then died a few years later, his successor (Max) who June expects to retire as planned but needed unexpected additional training, and one who has just started to train (Sam) so he is ready to takeover but whether he will succeed is UNCERTAIN.

June's first assistance dog Oscar's role was mostly focussed around picking up dropped items, opening and closing doors and acting as a social icebreaker. The latter being especially important for June socially, coming as it did off the back of her divorce some eighteen months earlier; whereby she found herself in the position that her ex-husband and herself had the same circle of friends. This prompted June to widen her circle of friends and acquaintances. Oscar facilitated the transition to her new life as a single person:

> And then I had this dog and I met loads of people with him and they were all asking questions about what he did and all that, and have made many friends since then
>
> June (8:112-113)

As she relates below, Oscar's calm, friendly nature contributed to making the transition to her second assistance dog, Max, smooth and relatively stress free:

> Well swapping over was sort of done gradually really, because Oscar continued, the older dog, continued to do some things like picking up for me. I let him carry on. Max himself, the new one, was starting to do things like opening the doors and all that and I think that erm Oscar was quite happy to just do nothing really after a while. So he was that sort of character, laid back.
>
> June (5:68-73)

Oscar's retirement when aged ten ('and a bit'), and his unexpected death two and a half years later, saw Max stepping to the role of June's second assistance dog seamlessly. His reaction to Oscar's death is recalled by June; her understanding of that experience is conveyed poignantly:

> yes, it was hard when he died, but I had actually got Max which does soften the blow a little bit and Max missed him for a short while. It was sad really watching him going in all the rooms…searching and then he wanted to go outside and have a look and, he was a bit miserable for a while but it didn't last long. He thought 'oh well, I am top dog' and again, he is very laid back
>
> June (79-88)

During the time that Oscar was June's assistance dog, her MS was slowly progressing and when it was time for Max to take on the role, his training needed enhancing from the menu of tasks that Oscar had performed. June is light-hearted about some aspects of the progression of her long-term condition, most notably her 'absolutely appalling balance':

> Yeah, I get down on the floor and balance when I am getting up, I start walking backwards, but Max is used to that, so he comes backwards with me.
>
> June (122-124)

She goes on to reflect more on how her needs have increased with each assistance dog as her MS progresses and she herself ages.

> Then over the years, when I got to Max my second assistance dog, I was a lot more disabled, but I was still managing to walk on two sticks [pause], but I needed a lot more help then and I started having problems getting my legs on the bed and things like that and erm, they came along and they trained Max to get my legs on the bed. That was really important for me. He would take my, I can't take my jacket off in a wheelchair for example, or I was really fatigued when I got in and he would pull my jacket off… because I just couldn't get them (her legs) on (the bed) and they kept, on and they would fall off, and on and fall off and I was exhausted
>
> June (150-161)

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The effects of MS, like those of normal aging process, have not remained static and June acknowledges that her needs continue to evolve; her thoughts are increasingly focused on the future. Potential assistance dog number three is already in the wings, her third chocolate Labrador, Sam. June is hopeful that Sam will succeed Max as seamlessly as Max succeeded Oscar, but hers is a cautious optimism as she knows that there is no guarantee that Sam will make it through the training. A recent experience of June's encapsulates perhaps the complexity of the phenomenon of assistance dog use:

> so the needs, my needs have got more each assistance dog I have had, so I am now stumbling and falling a bit because I try to walk around the house… and erm, about a year ago now I fell in the, on the patio and I must have knocked myself out for just a short period of time and I came to and Max was shaking beside me, really shaking. Sam was in the flower bed pulling out all the pansies totally unconcerned… anyhow, I was alright when I got up, but erm, they have been trying to teach Max to bark if I fall. So [the assistance dog charity] came to my house to try. The problem is, Max is not a barking dog, so they haven't been successful on that at the moment, but they said they will give it another try up here when he comes for his annual assessment and they have advised, well everyone is advising me to have one of those (Security alarm). So that is the next stage and hopefully when they start, if Sam is satisfactory and he goes on his training, they will be able to teach him that right at the very beginning.
>
> <div align="right">June (178-196)</div>

As an assistance dog, Max is so intuitive that he automatically walks backwards in sync with June, he was capable of upskilling to learn to lift June's legs so she can put herself to bed without needing a human carer to come in. Yet his unique personality - which means he is not very vocal - is creating a barrier to him learning to alert by barking when June falls. Not every assistance dog is equally good at every task but

that is not known until June's MS progresses over time to a point where that need

becomes apparent. In the interim, June is advised to get a security alarm that will

alert for help if she falls and requires assistance. She remains living with

UNCERTAINTY; Max may learn the alert when he and June travel to the assistance

dog charity training centre for their annual accreditation assessment. Sam may be

successful over the next 12-15 months in his assistance dog training, incorporating

the barking to alert for help, and ultimately take his place as her third assistance dog,

allowing Max to take his well-earned rest.

At the time of interview four of the participants were in their forties, a further three in

their fifties and the remaining four in their sixties. Maggie has made sense not only of

the impact her first assistance dog's death had on her, she also has reached an

understanding that, for her, the death of an assistance dog is qualitatively different

from that of a pet dog:

> When Meg died erm I was at a very low ebb... For quite a long time because losing any pet is traumatic, losing one that has absolutely done everything and been everywhere with you 24 hours a day. Somebody had said to me that erm, you know it was worse and I don't know it can't be worse I don't think, than losing your pet dog, but it is, very much so because suddenly that dog that is a pet dog, they're a companion but they are also your rock, you know, they are absolutely everything to you, and erm… she (Ella) wasn't there anymore because she (Sunny) didn't understand even though she (Ella) was old, you know grey come on...You can give me 24 hours' attention now you know, and so yeah it was, it was and I don't, I just don't know how it could have been any easier, okay I left it too late to get a puppy, but I don't think it would have made it any less traumatic for me. You know, these things hurt at any stage really, without having somebody that would have just taken that responsibility […] and I am not meaning that you need your dog any more if you are on your own, but I think you rely on them a lot more because they are your only source in a way *for everything, so it was difficult in the end, very.*

> Maggie (210-220)

Maggie's understanding of her experiences of attempting to meet the diverse needs of a retiring assistance dog, Ella, alongside an assistance dog in-training, Sunny, has strongly affected her sensemaking of Sunny's upcoming retirement. The passing of time has seen the introduction of a definite cut-off date when Sunny must retire - on her tenth birthday. When Sunny was eight, at her yearly accreditation assessment, the dog trainer broached the topic of Sunny's retirement two years hence with Maggie. This would give the assistance dog charity two years to source, train and match a successor dog to Sunny and allow for a more planned, gradual transition from Sunny to her successor. This time Maggie finds herself in what, for her, is an impossible situation; she has told the assistance dog charity that she will not be getting a successor dog for Sunny. It is essentially a 'catch 22' situation:

> I [am]still absolutely dogmatic that I won't get another dog, [but] the thing I am absolutely dogmatic about is, I need another dog, I need another assistance dog, but I can't manage two dogs unless something happens within the next twelve months, you know, I would be so cruel to, to get another dog when I haven't got somebody that could take over the responsibility of Sunny for me you know, and I could not, I have sat in interviews where people are having another and they are… really want to let this dog go to another place
>
> Maggie (713-722)

Adamant that she needs another assistance dog, but equally adamant that she will not put herself back in the position of managing two dogs, only one of which would be able to work in restricted areas, Maggie also rejects outright the possibility of rehoming Sunny which she feels is 'absolutely not' an option. At the time of interview, and with Sunny's ninth birthday in three months' time, Maggie attempts to make meaning from the experience she is living through:

Yes, and it's erm, it is almost… you know overtaking my pleasure of having her here if you know what I mean… because I keep thinking, she'll be 9 on the 3rd of July, my birthday is in July and I am thinking, that will be the last time that I will be able to go out for a birthday lunch with my friends because next birthday, my next birthday she will have retired. You know, I am starting to think like that, I can't help it you know… Yes, more so than, much more than me worrying about how I am going to you know, my physical condition because in a way it is all tied in because she is keeping me going whilst ever I am keeping going, I am keeping control

Maggie (31/32: 728-744)

When asked whether Sunny's retirement would mean she would have to employ paid carers she is certain the outcome would be wholly unacceptable, insisting it '...is something that would be absolutely the end for me…'

Jo's assistance dog, Honey, was eight when she was interviewed, her predicted retirement is going to be at twelve years of age. Although retirement is still a way off for Honey, Jo has considered what it may mean for her and her family. As Honey's retirement coincides roughly with that of her husband Tom, then he will be able to take on the role of primary carer for Honey while Jo takes on a successor assistance dog. Well that is what will happen theoretically, but as Jo goes on to relate, she is uncertain as to how things will work out when the time comes. She goes as far as to suggest that she will forgo the opportunity to have a successor assistance dog if Honey is not 'happy' with the arrangement. It is Honey's perceived needs, rather than Jo's real needs for assistance, that take precedence in her sensemaking; framing it somehow as her duty to repay Honey for the years of service she will have given Jo by the time she retires,

but I think I am half and half about another dog. I am not quite sure, but probably. As long as Honey was happy with it, you know she comes

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first. She will have been my partner for ten and a half years, it will be her turn to come first. She retires… Even if it means she becomes a pet and I hold fire on a new dog you know...Yeah, she comes first.

<div align="right">Jo (424-437)</div>

Jo speaks about the inevitable retirement of Honey, the transition to a successor assistance dog and Honey's eventual death with a mixture of dread and (UN)CERTAINTY. Her certainty that Honey will remain within the family after she retires is apparent, but the idea of a successor dog elicits a more uncertain response:

> Well, she will still be with me, she is not going anywhere… She will stay with me, so you know, I mean, the thought of her passing is just something you just don't, I don't think I would be able to cope with and they say there is a possibility I will get another one, which I think is a good thing for me, but you know, we will have to see where that goes, but yeah, for me it will be a good thing, but who knows where that will go.

<div align="right">Jo (503-511</div>

5.3 Summary

This findings chapter has focused on an under-examined dimension of living with a degenerative, long-term condition with an assistance dog over a long period of time. It illuminates the more challenging side of having an assistance dog, away from the glare of inspiring media coverage and charity images of cute puppies who grow up to transform the lives of people with impairments. It reveals the lived experiences of participants to be of both dimensions. Interwoven with the positive, transformative aspects of assistance dog use, findings reveal layers of UNCERTAINTIES regarding the health, behaviour and shorter life span of assistance dogs which are lived in

parallel with impairment effects which increase over time, and aging over the life course of participants.

Within the UNCERTAINTY however is CERTAINTY, the certainty that whatever else is happening, participants' priority is the 'happiness' and welfare of their assistance dog. The findings suggest that for most people, they had previously, or they envisaged they would in the future, position their assistance dog's perceived needs before their own. Some regarding this as being right and necessary to return the care and companionship their assistance dog has provided to them. Ultimately a vulnerability is exposed, revealing a strength implicit in this inter-species, interdependent partnership, at once empowering yet fragile. The next findings chapter continues the exploration of this complex and uniquely personal phenomenon by examining participants' experiences and understanding at the deepest of levels, that of IDENTITY.

Chapter 6 IDENTITY

Whilst Chapter 6 is related to the previous discussions on VISIBILITY (Chapter 4), it is distinguished by the emphasis on change and evolution of participants' IDENTITY. The term IDENTITY here is used in its broadest sense of both the more personal manifestation - participants sense of who they are and, the public or social meaning (roles). This third and final super-ordinate theme encompasses participants' understanding and perceptions of their identity, including the perceived shared IDENTITY which defines their partnership with their assistance dog. In as much as Chapter 4 focused on the experience of becoming disabled – the losses incurred when participants perceive they are made INVISIBLE/HYPER-VISIBLE and ascribed an identity based on how they appear; this findings chapter concerns that which is gained, becoming a partnership, re-becoming human. The findings suggest that by choosing to use an assistance dog, participants are claiming their Disabled IDENTITY on their terms and asserting their right to be in public; to be acknowledged as human rather than 'a non-person' (Helen, 590); a 'disgusting creature' (Jo, 350). This meaning making speaks to a complex process whereby participants' IDENTITY is restructured and reclaimed, shaped by a combination of elements involved in becoming an assistance dog partner over an extended period of time. For some, findings suggest, by the perceived assimilation of their assistance dog into their identity, intrinsic to the experience of living with multiple sclerosis (MS).

The superordinate theme of IDENTITY brought together three sub-themes found to re-occur most frequently and extensively amongst participants (6.1 PURPOSE, 6.2

AGENCY, 6.3 RELATIONSHIPS). These were concerned with how the use of an assistance dog reshaped participants' perceived IDENTITY that they understood to have been ascribed to them when they became visibly disabled. Within the sub-theme 6.3 RELATIONSHIPS, are the further sub subthemes of 6.3.1 WARRANT, 6.3.2 WITNESS, and 6.3.3 STATUS. These concern how participants experienced perceived changes to this ascribed IDENTITY involving an increase in the esteem or positive regard to which they were shown in public places when accompanied by their assistance dog.

6.1   PURPOSE

MS is an acquired condition which each participant had developed in adulthood, after their IDENTITY had largely been formed. Participants varied in the primacy to which they gave distinct aspects of their IDENTITY before the diagnosis of MS. For some it seemed important to foreground their job (For example: the soldier, the deputy headteacher, the health and social care professional, the graphic designer). For others, it was their physical abilities that they referenced, self-defining as being previously a very fit or active person. Only one participant, June, remained in employment (in health and social care) until she retired, aged 67 years. The others had left work at various points in their working lives as their MS progressed, making it increasingly difficult to do their job.

It may seem counter-intuitive to take on the care of a dog when living with a significant, degenerative condition like MS. Even an assistance dog, no matter how well-behaved or helpful they are, still requires a degree of input from their handler to

maintain their training. In addition to which, they must be exercised, played with, fed, groomed, picked up after and their routine health needs attended to. In fact, the opposite appeared to be the case. Findings would suggest that the work of caring for their assistance dog provided all participants with a sense of PURPOSE, a reason to get up in the morning, a reason to leave the house and to interact with others in society. The following selected extracts best illustrate how, participants navigate the competing demands of assistance dog use with the unpredictability of impairment effects and their sense-making of those experiences.

When the topic of the commitment required to look after an assistance dog was raised, Roy was quick to respond:

> I suppose really I am not, because of the situation [being disabled, no longer part of the workforce] you are not… your diary is not exactly full
>
> Roy (564-565).

Roy's tongue in cheek description of how the one thing he does have is plenty of time to focus on reciprocating the assistance dog's care of him, follows on from his earlier assertion that

> I think the erm, the biggest, biggest thing is really to try and forget what I used to and concentrate (on) what you can do
>
> Roy (35-36)

Here, Roy is attempting to make sense of his diagnosis of primary progressive multiple sclerosis (PPMS) - the most severe form of MS. He has developed his own strategy of consciously forgetting his previous IDENTITY as an able-bodied newspaper man, and everything he did and thought of himself as doing, choosing to focus on what he can do with and for his assistance dog. Not on what he cannot do,

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but on what they can do together. Though he does concede 'That is the easier said than done mind you, but it really helps' (Roy, 35-38).

As wonderful as having a sense of purpose when partnered with an assistance dog may be, it does not protect the person from experiencing impairment effects and the reality of inclement weather. Jo vividly recalls her experiences in her first year with her assistance dog Honey:

> It was the year we had very deep snow and I found it hard getting out with her, so that first winter was quite stressful because I mean, she was full of energy… I was knackered [meaning MS fatigue] and trying to keep her entertained and her mind ticking over and some exercise, but we managed, you know the family helped me and we got through that and then we started to, and we could get out and about again and get into our routine, we were a lot better, but the winter threw things a little bit.
>
> Jo (166-175)

In Jo's extract she initially refers to herself as 'I,' separate from her first assistance dog, but as the extract unfolds her use of pronoun alters from 'I' to 'we,' reflecting a change over time as the relationship changes and her bond with Honey deepens. Her extract foregrounds the concept, touched on previously, that over time many participants appear by a process of assimilation, to come to understand their assistance dog has become a part of their own personal identity. This is further explored later in the chapter.

Elaine reflects on how the need to take out her assistance dog daily, regardless of the weather, has allowed her to develop a new social circle of fellow dog walkers and enjoy the beauty of nature; both of which Elaine suggests have positively affected her

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emotional well-being and sense of self. Her meaning making of the experience of being out with Meg everyday allows her to compare two identities. Without the sense of PURPOSE that Meg gives her, she envisages herself as isolated, her world contracted and diminished. However, she eschews this IDENTITY, the one characterised by not leaving the house, cut off from both those she meets when out with Meg but also from the natural environment. Over time she has restructured her IDENTITY, assisted in part by the sense of PURPOSE which the use of an assistance dog imbues. This opens up the possibility for her to experience living with MS in a world in which her horizons are broadened, and the future is perceived as less bleak:

> Yeah. I wouldn't know any of those people, I would be sitting at home watching TV, my world would be getting smaller and smaller and I know I have had like clinical depression in the past and it would be so easy, it is part of MS I think really, but you start to struggle, I get so angry, I can't do stuff, I am thinking yeah, it is so frustrating all the time and she (Meg) just makes the world softer with it. I have to get out and sometimes it is raining, and people are saying, how are you going to walk the dog? And I am thinking, there is a beautiful nature reserve, I didn't know that was there when I moved here, but it is beautiful when you get early in the morning and the frost and the, it's, some of the, I was picking up her poo last week and there is, I noticed there is this beautiful striped snail, I think I have never seen that before… I Googled it for goodness sake, striped snail what I would never have seen that had you (addressing assistance dog Meg) not positioned your poo there where you did. [laughs] haven't seen that before, and there is a whole world I would never have known really…
>
> Elaine (898-916)

Like Roy previously, Elaine's daily lived experience of MS is no longer focused solely on the struggle, the anger, the 'stuff' she cannot do. What she experienced her life with MS to be, prior to living with her assistance dogs, is described as one of ongoing frustration lived in a harsh and rather bleak world. Elaine's use of the present tense to vent her frustrations and struggles suggests she acknowledges that her embodied,

enduring experience of impairment effects remain; they have not vanished now she has an assistance dog. However, her experiences of using both of her assistance dogs is perceived in her sense making, as the harshness of her life with MS is made 'softer' and eminently more bearable. Not only has she developed a sense of PURPOSE in her mutual care of Meg, meeting other dog walkers affords Elaine a sense of being one of them, of the dog walking community, an IDENTITY beyond that ascribed as just another disabled body.

Equally, for Sean the sense of PURPOSE engendered by looking after his assistance dog has not only provided him with a new 'wonderful job' to do, it also directly connects him with an important aspect of his previous, non-disabled IDENTITY as a soldier. His use of the expression 'man up' on more than one occasion echoes the military ethos of achieving a goal, despite personal discomfort, for the good of the unit. For his canine comrade:

> ...assistance dog makes me have to go out, whether I liked it or not, come rain or shine. The difference being from having a normal dog… you have to take an assistance dog to places… Going on a train was great with Louis because I hadn't been on a train for absolutely years, I am going to go on a train today, I am going to go to London on the train to give my dog [the experience]… So, my experience of living with an assistance dog has been an eye opener, been a whole new lease of life, got me out of the house… sometimes you feel a bit down for whatever reason, but you will give it an excuse (as) if I didn't feel very well. To have a dog you have always got to man up and think, right he needs to go out, he has done nothing wrong… and you go, okay, and then you feel so much more better tha(t) you have got to man up and go outside the door… you have achieved it… and if it is raining, skin is waterproof, I got a coat. The only bummer about it is I have got to make sure towels are ready before I go out.
>
> Sean (1104-1145)

Through the process of working in partnership with his assistance dog, Sean begins to integrate aspects of his pre-MS IDENTITY (soldier, love of the outdoors, able-bodied) with the restructure of the disabled IDENTITY he perceives society has ascribed to him ('stupid', 'blind', 'whatever') (405) and the experiences of living with MS and using an assistance dog. The moment Louis his second assistance dog was attacked, signalled the end of his career (see Chapter 5 for a full account of the incident); the IDENTITY of a disabled person living with MS with a PURPOSE, 'a job,' altered. At the time of interview Sean was without a qualified assistance dog and, as discussed in depth in Chapter 5, his perceptions of living with MS without Louis are viewed through a lens of UNCERTAINTY, with his future dependent on a possible house move and then a new application for a successor assistance dog. He admits that in the time Louis has been absent, 'I have kind of gone back to how I was…' (724). From a self-identity of en-abled back to an IDENTITY of dis-abled. He has lost the sense of PURPOSE he had re-gained with Louis.

Maggie's sense making of going out with her assistance dog is framed by the interaction between the impairment effects she is coping with at that time, and the perceived ability of her assistance dog to interpret her feelings and needs. Whether she is experiencing a 'really bad day' with her MS; or, if not, the assistance dog can 'demand' attention or care and they will go out.

> Ella was right for me because she was a very quiet dog who loved going out… I mean there are occasions where I got to the car and thought I can't do this – Ella was quietly determined… she (Sunny) is perfect for me now because I am so frightened of giving in because I know it would be easy to give in. If I am genuinely having a really bad day, she is so perceptive, she knows that, she puts no demands on me… no demands on me whatsoever, she understood perfectly, but if I

am just thinking – oh I just can't be bothered, no way she is going to let that [happen]… so she is perfect, because I always feel better for going out, you know.

<div align="right">Maggie (416-430)</div>

Similarly, Richard's understanding of his assistance dog Noah's behaviour is intrinsically linked to his perception of Noah's perception of his impairment effects:

It's, it's incredible and you can tell by how far he is from me how bad a day I am having. If I am having a really bad day, he is never more than two feet from me, even in the park and he is off lead, but you know, that bond is very important and just having someone there who knows how you're feeling, somehow supports you mentally

<div align="right">Richard (3-7)</div>

Richard's sense of PURPOSE is strengthened by his meaning making of Noah's perceived understanding of how his human partner is feeling so that even on 'a really bad day' they will still get to the park. Integral to Richard's account is his understanding that Noah knows how he is feeling and consequently adjusts his behaviour, 'choosing' to stay close by (even off lead and out of his working jacket on a free run). Such sense-making rests on an element of anthropomorphism and this attribution of human traits and emotions to Noah permeate Richard's account and indeed in that of several of the other participants. It may be argued that this perception that their assistance dog understands their feelings, their needs, and the impact of MS on daily life and vice versa, appears to underlie the process of reconstruction of IDENTITY. Elements of Richard's meaning-making are centred upon an assimilation of IDENTITY between himself and Noah, creating a distinct shared IDENTITY (which is explored further below).

Jo offers a vivid and powerful description of the day-to-day embodied experience of living with MS, with its many impairment effects combined with the strength of her sense making of her relationship with her assistance dog Honey. The sense of PURPOSE it imbues, assumes a significance far beyond the daily routine of, feeding, exercising, and playing with her assistance dog. Findings indicate the challenges of living with MS and using an assistance dog are, for Jo, embodied and acknowledged, but they must be overcome for the relationship to flourish:

> I think its days where I am so exhausted, it's usually more in the summer with the heat, and it is not, I mean you may or may not understand, it is not tired, sleep tired… It is just total exhaustion and by the time I have walked into the kitchen I can feel my legs going you know, and I [might] have just woken up and those days are, are quite hard because she needs to go out and I have literally found myself not really with it on my (mobility) scooter, because I have just been so tired and shut down, but she needs a walk and I can't say to her, well I am really very sorry, I will find you some munchies… you have a good munch of those and then dad will take you later, you know, you can't get her to she just knows 'come on I haven't had a walk yet'. So, I think then I feel guilty if she is not out by, oh another hour yet. You know, I we have got, we are partners, I have got needs, she has got needs and both of them are 50/50 you know the day is planned with both our needs incorporated into it, but if I can't keep my end of the bargain I tend to feel guilty… And I am whizzing the clock to move forward so somebody is around who can take her for me, or I go out half dead. It is only if I daren't leave the loo behind that I don't go out now, Honey needs to go out we go, you know that is what she needs
>
> Jo (572-597)

Jo articulated how her sense of PURPOSE as Honey's partner, and her commitment to meeting her welfare needs, supersedes the embodied experience of just a few of the many impairment effects that MS can bring to her daily life. Her description gives insight into the breadth of impairments (fatigue, heat sensitivity, muscle weakness, cognitive impairment ('Cog Fog') and incontinence) working in concert to make Jo feel 'half dead' but she must transcend these barriers if she is to keep her 'end of the

bargain'. Jo's assertion that her partnership with Honey is based on an understanding that both members of the dyad have needs which she perceives as equally important. Their IDENTITY, as far as Jo understands it, is SHARED, one of two halves of a whole. They are interdependent partners whose PURPOSE, their reason for being together, revolves around and is contingent on the meeting of both partner's needs.

This mutual caretaking between assistance dog and their human partner appeared to deepen over time, assuming for some participants in this study, a significance far beyond the elements of that care. For Amanda, her assistance dog serves both as a way of maintaining her independence and acts as a protective factor, keeping her in the world,

> there is many a times I have wanted to give up, oh so many times you have no idea, but I have sat there and said 'I can't because who would have her? Who would look after her?

<div align="right">Amanda (432-434)</div>

Amanda's IDENTITY as her assistance dog Izzy's primary caregiver, fuels her determination to keep going. This is explored further in the following section where findings point to the second aspect of IDENTITY to which we now turn, that of a sense of AGENCY.

6.2 AGENCY

A second sub-theme identified in the interpretative phenomenological analysis was around the AGENCY. Findings suggest that participants found using an assistance

dog when living with MS was perceived to increase AGENCY. There was an understanding that if they use an assistance dog to enable their living with MS, they remain independent, exercising AGENCY in their own lives. It is almost as if they have done whatever it is themselves. For those participants, who lived on their own, findings suggest that for some participants, dependency on other people must be resisted for as long as possible. This contrasted with the experiences when participants worked with their assistance dog thereby increasing a sense of AGENCY, the opposite appeared to be understood when participants received help and assistance from another person, their sense of AGENCY decreased.

Returning to Amanda, who lives for most of the time alone apart from Izzy, maintaining a sense of AGENCY could not have greater importance:

> ...I don't want to go into a care situation, never going to be for me, it is not for me, it is not what I want, but I think I would have gone into depression now and the down mode and the not getting out of bed mode and the I have had enough, type mode if it wasn't for her. She is the reason I will carry on and if I got another (assistance dog) she is another reason why I will carry on because you can stay in your own house, you don't have to have those carers there, she will pick up the post for me, she will get the phone to me, she will get the towel I have just dropped out the bath that I can't reach now. Do you see what I mean?

> Amanda (476-487)

Amanda's experiences of living with MS and her expressed feelings about not having 'those carers there' are situated in the context of close personal experience. She reveals she had a brother who also had MS, which she describes as the worst type you can get; he was paralysed from the neck down and he died from complications

quite quickly 'the MS just consumed him' (75). In addition, her insight into formal care

remains live and ongoing, serving to reinforce her sensemaking:

> ...I will not have a carer. I won't have somebody come brush my teeth, I won't come to have somebody comb my hair, that will never be. My son and my daughter know that. So, when that time comes… I have just spent two and a half years with my mother with dementia in a care home, watching her most [pause], watching the carers going on in there is the most horrendous thing I have ever seen. They are not cruel, they are not nasty, they are not, it is just structured, they have to get a meal out, get the food out, get their medication and it stops there, it stops there, and I thought to myself – the one thing that I, it sounds as though oh, she is on the edge. No, I am not, I'm, and my doctor agrees with me, erm that, agrees with where I am thinking I mean, but when my time comes when I can't do things for myself and function, which I can so far I don't intend to carry on, but that is not a suicide, that is not me saying, 'I have had enough, I am I am depressed and cry'…That is me taking control…
>
> <div align="right">Amanda (450-469)</div>

Amanda's repetition of 'it stops there, it stops there' (454) reiterates her assessment

of the threshold of 'those carers' level of care of her mother as being somewhat care-

less and task orientated rather than holistic and caring, it also asserts that the same

fate will not befall her. It stops with her brother and with her mother. Citing the tacit

understanding of her grown up children and the inclusion of her doctor's alleged

agreement 'with where I am thinking,' Amanda garners support for her meaning

making; when she reveals her arguably, socially undesirable intention, to end her

own life when she (with her assistance dog) can no longer care for herself. She has

considered the very real possibility of a future living with MS and aging and being

dependant, but Amanda rejects that option with the understanding that, for her, this

would be unbearable. For now, her experiences of living with MS and using an

assistance dog represents taking control, exercising AGENCY, living with MS. Their

shared endeavour is perceived as Amanda doing things for herself, caring for herself. The ultimate expression of Amanda's IDENTITY is found when her sense of PURPOSE (as Izzy's partner), the perceived strength of their relationship and an unshakeable desire for AGENCY, coalesce in her decision to continue to live.

A similar sentiment is echoed by Maggie, albeit more tentatively, for whom the prospect of relinquishing that AGENCY, that locus of control and needing to have formal paid care:

> is something that would be absolutely the end for me because…
> Because I am such an independent person… Yes, more so than, much
> more than me worrying about how I am going to you know, my physical
> condition because in a way it is all tied in because she (Sunny) is
> keeping me going. Whilst ever I am keeping going, I am keeping
> control.
>
> Maggie (742-745)

The findings provide compelling and powerful accounts of those participants' experiences living with MS without additional external human assistance. The two accounts above, in combination with June's account previously (Chapter 5), outlining how her second assistance dog Max has been upskilled to facilitate her being able to put herself to bed by lifting her weaker leg, convey the crucial importance of an assistance dog for participants living alone in the restructuring of a core dimension of the IDENTITY around their ability to do things for themselves and their perceived control over their environment. Overall, seven participants: (Maggie, June, Elaine, Helen, Amanda, Jo and Anne) did not require paid formal care, managing their MS with a mixture of family help and their assistance dog for their care when required (as discussed in Chapter 5).

Four participants identified in the findings (Richard, Roy, Steve, and Sean) received daily additional care from paid carers at the time of interview and had done so for some time. This was because of the inevitable progression of their MS over time and the specific impairment effects involved which fall outside the remit of their assistance dog (for example, bowel care or complex lifting and handling needs). Considering these four participants separately highlights the range and severity of impairment effects that can manifest in MS. It also gives an indication of the breadth of skills and abilities that those participants understood to be possessed by their assistance dogs. Finally, it demonstrates the depth of feeling engendered by the relationship between human and canine, such that the very core of participants' IDENTITIES is experienced as transformed.

In an account which blends elements of AGENCY and RELATIONSHIPS, Richard spoke of having many different (human) carers over time, in addition to his wife and Noah, his first assistance dog. His account of how the nature and strength of his bond with Noah remains consistent throughout the day-to-day challenges of living with MS is understood by him to provide a unique stability; outside of which he perceives as a human carer's threshold for care.

> So, you know, however caring a carer you have, if you dropped the
> same pencil six times in a row they get a little fed up with picking it up
> again, he (Noah) couldn't care less… yes, it is his job and he enjoys it,
> so it is, it is very stabilising…

Richard (10-12)

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This lived experience has taught Richard that his assistance dog will adapt to fluctuations and deteriorations in his condition, sustaining his sense of AGENCY as much as possible, for as long as possible, even within an overarching environment of dependency:

> I used to be able to take things in my left hand, but now I can't, I take them in my right hand, but now I can't do that, he puts them on my knee and he has taught himself that within two or three days, because if he puts it in my hand I drop it, he has got to pick it up again, so he puts it somewhere where it is safe.
>
> Richard (404-409)

Thus far, the aspects of IDENTITY explored relate to participants experiencing a new sense of PURPOSE specific to using an assistance dog and, through that use, developing and regaining/maintaining a degree of AGENCY, within the limitations of their MS. This would indicate findings which centre upon participants' understanding of both 'doing' and 'being,' as will be discussed below. It concerns care of their assistance dogs' physical and psycho-emotional needs (and vice versa), combined with a sense of exercising AGENCY over their lives and their environment.

6.3 RELATIONSHIPS: from I to We

For two participants (Roy and Steve), their experiences of living with MS and the use of an assistance dog has passed through all the stages of complete independence with their assistance dog to, at the time of interview, experiencing complete physical dependence on formal (paid) carers outside of family.

Roy, with his assistance dog Cassie, was diagnosed with PPMS and, at the time of interview, was paralysed from the neck down bar the ability to move his left hand. Steve, with his assistance dog Bill, had originally been diagnosed with RRMS but by the time of interview had progressed to SPMS, and was paralysed from the neck down leaving only the ability to turn his head. Both of their accounts serve to reinforce those sub-themes explored previously (as both had experienced using an assistance dog for task work when, they were much less physically impaired). They also extend the understanding of the role of their assistance dog over time and its effect on IDENTITY. This sense-making offers an insight into the phenomenon of assistance dog use, whereby the physical task work decreases for the dog as the accrued disability of their human partner increases beyond their assistance dogs' abilities. For both Steve and Roy, their assistance dogs' primary role as emotional and psychological supporter comes to the fore. This is a role for which these assistance dogs had not been formally trained to undertake. Instead, it appears to be understood by participants as a skill or ability that they recognise as innate in their assistance dogs. Equally, this role change does not appear to affect participants' AGENCY with regards to their assistance dog. By which is meant, the assistance dog remains obedient primarily to the participants, despite the significant change in their handlers' physical abilities and the introduction of additional humans into the dynamic of the partnership in the form of paid carers. The meaning participants make of the attachment relationship they have to each other is undiminished, if anything it is strengthened further.

Similarly, with Steve, when he is separated from his assistance dog Bill, even if only

for a couple of hours, he experiences emotional and psychological effects:

> Yeah, when he goes to the groomers it is just like being bed bound,
> there is something wrong here, it don't feel right, (even) putting him
> outside in shops, seeing him at a distance (through the shop window)…
> but when he is not there, it is only you, it is weird, it is weird.
>
> <div align="right">Steve (176-180)</div>

This attachment is perceived and understood to be mutualistic, as Steve affirms

when he calls to mind a recent bout of ill health:

> last week when I was so poorly Bill just didn't leave me, was right next
> to me all the time. He would only wake up at night when he wanted to
> pee.
>
> <div align="right">Steve (412-414)</div>

Steve and Roy's accounts speak to their understanding of their relationships with

their assistance dogs. Roy describes feeling as though a part of himself is missing

when Cassie is not with him; Steve relates how Bill senses when he was poorly and

never leaves his side; just like Noah in the park with Richard when he is having a

really bad day.

This is also the case for Sean for whom, even though his working partnership with

Louis was cut short after he was attacked by other dogs (see Chapter five for a full

account). The intensity of his attachment and feeling for his assistance dog is writ

large in his sense-making of his experiences. Re-homing him after he could no longer

work as an assistance dog was described as akin to:

> it would be like, if you had your child fostered; I would imagine that
> would be the same, you are not allowed to have contact with the child if

you fostered your child or whatever, but I elected to not be in regular contact with Louis because, not that it's, might not be, well he wouldn't know anyway, but I would know and… I find it too upsetting, yeah, too painful yeah. So that is why I chose not to.

<div align="right">Sean (816-825)</div>

The perceived quality of their relationship with their assistance dog and the understanding of their assistance dogs' ability to pick up on their feelings and interpret their needs were foremost in the findings. this speaks to an interspecies relationship which is understood by many of the participants on one level in terms of kinship, their assistance dog becoming like family, or considered to be part of the family (even closer than family by some). On another level, ultimately their assistance dog is understood and experienced as being a part of themselves and their IDENTITY, becoming in this sense-making an inextricably bonded extension of themselves.

Turning away now from the very personal inner dimension of the self for participants in relationship with their assistance dog; the emphasis returns to a close interpretation of how elements of that shared IDENTITY impact on the interactions with society perceived as 'out there' are considered. Once they are part of an assistance dog/person with impairments team in social situations their IDENTITY is understood to alter again. In the following section, aspects of participants' IDENTITY in the public realm, uniquely shaped by assistance dog use, are explored.

6.3.1 WARRANT

As discussed earlier, a notable difference was perceived by participants between how they were understood to become INVISIBLE without their assistance dog. Participants in their meaning making also understood that their new VISIBILITY (see Chapter 4) - their positive experiences of social encounters were in part because of their assistance dog acting as a kind of WARRANT for them. Assistance dogs served as a highly visible, living signal to others that their human partner is a legitimate disabled person. Thus, avoiding the need for awkward misunderstandings, hostility, avoidance or running the risk of engendering a feeling of responsibility in the onlooker for the disabled person. In addition, their assistance dog was perceived by some to facilitate the categorisation of participants by the type of impairment they may exhibit, establishing what may be interpreted as a hierarchy of impairments. This meaning making perhaps reflects the participant's own previously held feelings and assumptions about those with physical and intellectual impairments and their relative worth. Nonetheless, this is perceived by some participants as contributing to the process of restructuring their IDENTITY, as the following linked extracts demonstrate:

> Yes, it certainly bridges the gap, especially if you are having a bad speech day, they don't know how to treat you because they don't know whether you are mentally disabled or physically disabled, they don't know, but if there is [an assistance] dog there they will often talk about the dogs, assess you by your response change their behaviour in line with that response… Yeah, instead of becoming a problem, you become well it is the opposite, you become attraction, which has its own problems, but they are not the same as if they thought you were drunk. So, it is a different you know, you have got this official dog with you, it is it changes the dynamics of the whole relationship… or when you are slurring your speech, the cognition slows down with MS sometimes, if you have got a dog there it softens the whole situation. It is amazing.

> Richard (245-260)

> They talk to the dog and you can see their brain working as they start to
> follow the leader and there is a person on the other end of the lead.
> They go, erm, do I talk to him or not, is he stupid, is he blind or
> whatever.

<div align="right">Sean (402-404)</div>

> You know, they obviously they still talked to the dog. And they realised
> that you know because you are in the chair you are not, not as lonely or
> something…

<div align="right">Roy (112-117)</div>

Whether or not participants viewed themselves as being stigmatised by society, as 'lonely', or 'stupid', 'mentally disabled or whatever', they did subscribe to the notion that

> They regard you as a unit and as a unit you are independent of them,
> you are less likely to need help from them…

<div align="right">Richard (367-369)</div>

This understanding by participants of a SHARED IDENTITY as an assistance dog and person with MS becoming a discrete, self-contained unit was touched upon consistently by the participants throughout the three findings chapters.

As discussed previously, findings suggest one half of the dyad (canine) is perceived as providing a WARRANT for the humanness of their partner. Now, however, it is apposite to consider how the human half of the dyad is supported through much of the process of restructuring and reclaiming their IDENTITY. In the following section participants share their experiences of the process of transformation in their IDENTITY over time.

6.3.2 WITNESS

The process of re-structuring, and hence claiming a shared 'we' IDENTITY and 'Disability' (capital 'D') IDENTITY, revealed in the findings, contains a unifying thread around the socialisation of participants into their role as assistance dog users. It is common practice for both assistance dog charities, from whom participants were recruited, to encourage them once qualified, to assist in fundraising and awareness raising at public events like county shows, in schools, scout/guide troops, the Women's Institute (WI), Rotary clubs and a myriad of other community groups; as well as to participate in local and national media interviews. Participants' confidence as assistance dog users and their perception of the change to their IDENTITY was developed and consolidated by telling their story repeatedly in many different contexts; about how having an assistance dog had enhanced or transformed the quality of their lives. Telling and re-telling their story about who they perceive they were, who they became because of their lived experience of MS, and now with their assistance dog who they, as a team, identify as.

This service user perspective corroborates the charities claims around the impact of assistance dogs on people's lives. Participants' authenticity and lived experience made them ambassadors for the charities that had trained/supplied their assistance dogs and they were instrumental in raising funds for those organisations.

Demonstrating their skills and abilities as an assistance dog team in a carefully

managed setting that is guaranteed to evoke an overwhelmingly positive and/or

sympathetic reaction, helps to reinforce this new IDENTITY. These public occasions

serve to scaffold the restructuring of IDENTITY, aiding the assimilation of their

assistance dog IDENTITY into their own. This constitutes a public claiming of a

Disabled IDENTITY which invites, rather than avoids, public gaze. It is an experience

as far removed as possible from the telling and retelling of their illness narrative when

they were being investigated and originally diagnosed with MS, as discussed in the

first findings chapter (Chapter 4).

There follow some selected extracts which illustrate the import of participants telling

their story publicly and how this is interwoven into participants' experiences of

assistance dog use. It is argued that such behaviours, though clearly part of the

assistance dog charities' fundraising strategy, form an important part of the

restructuring process of the IDENTITY of participants.

Jo offers an abridged version of such a talk below. Although it could be argued it

appears as somewhat well-rehearsed, its emotional power and her sincerity are

evident:

> I coined a phrase when I started giving talks for assistance dog charity
> and it's… 'before Honey I suffered from MS and since I have had
> Honey I now live with MS', and I have got my life back, different and I
> suppose before you get MS, you think your life is always going to be the
> same, but maybe a bit crankier as you get older but when you get
> something like this and it changes rather dramatically, and you, you
> know, coming to terms with the loss of things and you can no longer do
> and finding things that you can do, it is probably similar to going through

a bereavement and going out the other side after being diagnosed and so, you know, although it can rankle me at times that if I can't do anything particular, on the whole now with Honey it is as good as it gets, as it going to be you know, with her I am now living again, which I didn't for a long time. [pause>5] [without Honey] … I don't think I would have been here… yeah. Think she saved my life.

Jo (686-705)

For one participant the strength of emotion evoked by this public telling and retelling of his and his assistance dogs' journey proved too intense and affecting to continue in this particularly public role:

Part of it, having these dogs, I used to give talks about (assistance) dogs for the first six months, but I couldn't do it because it got too emotional thought I ain't doing this.

Steve (403-405

Steve's reluctance to continue giving talks about the difference Jenny (his first assistance dog) made to his life since being diagnosed with PPMS is unsurprising. His meaning making of his experiences living with MS with Jenny through some challenging times became overwhelming. As outlined earlier in this thesis, he credits Jenny with supporting him physically and emotionally through the breakdown of his marriage and Jenny's sudden, unexpected death from cancer was devastating for him.

Maggie contextualises how it is a combination of experiences, interests and opportunities related to her use of an assistance dog that helps frame the process of restructuring her IDENTITY:

(it's) not just in the confidence, in all the other interests, I mean coming here (assistance dog training centre) you know and the fund-raising things, the talks we have been on, you know, all those sort of spin offs

from the actual assistance dog work, you know sort of thing, because everybody here is so lovely you know.

<div align="right">Maggie (697-701)</div>

Having had assistance dogs for over 20 years it has and continues to be, a significant factor in the shaping and restructuring of Maggie's IDENTITY. It is within this context that Maggie's anticipatory grief and deep distress at the upcoming mandatory retirement of her second assistance dog Sunny (see Chapter 5 (UN)CERTAINTY) is located. As stated previously, adamant that she will be unable to care for two dogs (both retired and successor assistance dogs), it is clear that living with MS without an assistance dog, without Sunny, could impact Maggie's IDENTITY in all aspects quite profoundly.

6.3.3 STATUS

Finally, conceptualised within the super-ordinate theme of IDENTITY is the subtheme of STATUS. Earlier, this was interpreted in its most fundamental meaning as that of being human, existing as a person, and was articulated initially in Chapter 4 where it was introduced as the experience of becoming IN/ HYPER-VISIBLE. This was interpreted through a lens of loss when participants become disabled, where they described the loss or diminishment of their STATUS in society. Echoing the finding becoming VISIBLE, discussed in Chapter 4 (section 4.4), the aspect of STATUS I will now discuss is synonymous with prestige or the regard with which participants perceived the assistance dog was held in, and by association their re-becoming human, but this time considered as a human-assistance dog shared IDENTITY. This included foregrounding experiences of when accompanied by their assistance dog, in which participants predominantly experienced positive social encounters.

Helen recalls that when in public with Alfie, that not only is she no longer 'a non-

person' - INVISIBLE but:

> I feel that I have got a more social presence when he is with me, which
> I definitely have because people find him attractive and want to say
> hello...they have asked questions, they have said hello and then, what
> is nice is that lots of ladies with children say, you know, you will hear
> them say 'don't touch the doggy, we have to ask permission because
> he is working', you know, and you know, 'he is not here to play, he is
> doing something special for this lady', so, which is nice..

<div align="right">Helen (61-65)</div>

And at her regular hospital appointments:

> people say hello, it's…I don't know, perhaps it is not so...people say
> hello and smile at you and this, that and the other, it is not such a …oh,
> it's not such a sad affair, you know

<div align="right">Helen (514-516)</div>

Steve and his carer Julie recall in the past when his voice was stronger:

> Julie: But before your voice you had problems with your voice, quite
> often I would find if I went into a shop you would wait outside, you know
> if it was like in XXXX or somewhere wasn't it, quite often you could, you
> could say that when you walked out there would be a group of women
> around you, talking to you, wouldn't there? [all laugh] About, you know,
> about the dogs?
>
> Steve: Yeah. Yeah, nowt to do with me [all laugh], but everything to do
> with the dog. So they make a big difference, just having them you feel
> part of society...

<div align="right">Steve and Julie (217-226)</div>

Finally, Elaine brings this sub subsection concerning STATUS, and the chapter on

IDENTITY as a whole, to a close in her characteristic 'from the sublime to the

ridiculous' fashion:

end of the day they said, do you think we will be right for you and I am thinking, do you think I am right for you when you, I mean they are hugely expensive these dogs. I know it costs £10,000 to train her to the point where I got her and it is going to be another £10,000 for her life and you just can hand these dog(s) [out] I mean there must be a huge waiting list. So I applied and it took a long time...

Elaine (325-331)

Assistance dogs are highly regarded, in short supply and in high demand which, as outlined in Chapter 1, has influenced the creation of their prestigious status even after they retire and require rehoming, like Sean's second assistance dog Louis. Elaine sums up her sense-making of being out accompanied by her second assistance dog Meg:

I find with a dog it is like walking with a celebrity everywhere because they want to stroke [her] and say, what is your dog and where did you get her from, what does she do around the house and all this, so I just feel like her PA really…

Elaine (736-739)

6.4 Chapter summary

In this chapter I have presented the third and final super-ordinate theme from the analysis of the data, that of IDENTITY and its sub-themes 6.1 PURPOSE, 6.2 AGENCY and 6.3 RELATIONSHIPS. The first two sub-themes centre around those aspects of participants sense of self; in that they have a job – to care for their assistance dog. The relationship is bi-directional, the assistance dog must be trained, exercised, and their welfare ensured. Even once they qualify as a working partnership their skills must be maintained. The 'We' must be cared for or there can be no 'I'. This mutually caring relationship is experienced all day every day and is interpreted as the foundation of the strength of the bond between participants and their assistance dogs. The chapter then examined the nature of their unique RELATIONSHIP developed overtime through this process of prolonged and

mutualistic care-giving more closely. Participants understood this to be reciprocal in that their assistance dog was considered as a WARRANT, authenticating the legitimacy of participants claims to be disabled and access state support and services. In return they were motivated, when possible, to bear WITNESS to the power and impact of the relationship on them, enacted through speaking at public events and in the media. Lastly, I have offered an interpretation of final facet within the development and maintenance of the RELATIONSHIP between each participant and each of their assistance dogs, that of STATUS. Assistance dogs were considered as prestigious to use and were described in terms of their ability to influence others.

Before moving on to Chapter 7, and a discussion of the findings' Chapters (4-6) in relationship to the literature, Table 8 (below), provides an overview of the recurrence of each of the three super ordinate themes across cases.

Table 8 Recurrence of themes across cases

	INVISIBLE/HYPER-VISIBLE	IDENTITY	UNCERTAINTY
Helen	YES	YES	YES
Amanda	YES	YES	YES
Maggie	YES – ALL	YES - ALL	NO (AD 1)
			YES (AD 2)
Roy	YES – ALL	YES - ALL	YES (AD 1)
June	YES – ALL	YES – ALL	YES (AD2)
			YES (AD3
Richard	YES	YES	YES
Jo	YES	YES	YES
Steve	YES	YES (AD1 & 3) NO (AD 2)	YES (AD 1 & 2)
Anne	YES	YES	YES
Elaine	YES – ALL	YES (AD 1)	YES (AD 1)
Sean	YES – ALL	YES/NO	YES (AD1 & 2)

The next chapter discusses the findings chapters in relation to the literature in the

fields of disability studies, human-animal interaction,and multiple sclerosis. These

disparate bodies of knowledge are synthesised with the data from the interpretative

phenomenological analysis to provide a coherent and plausible account which

answers the research question originally posed at the start of the thesis:

What are the experiences of people with MS who use an assistance dog?

Chapter 7 Discussion

7.1   Overview

The overall aims of this study were to explore the experiences and perceptions of

people with multiple sclerosis (MS) who use an assistance dog and, in doing so,

understand what impact, if any, they have on living with this long-term condition. To

achieve its aims, the present study addressed the primary research question:

- What are the experiences of people living with multiple sclerosis who have

  used an assistance dog for two years or more?

And the following underpinning questions were posed to examine and determine:

- To what extent do pre-existing theories in both disabilities and human-animal

  interaction studies explicate and contextualise these accounts?

- What are the perceived benefits and challenges of assistance dog use for

  participants living with this long-term disabling condition?

This study had as its focus eleven people in the UK with MS who have used an

assistance dog for at least two years. Single,

in-depth semi-structured interviews were undertaken which generated rich data

regarding their experiences. Interpretative phenomenological analysis was applied to

the data which resulted in three super-ordinate themes (and their related sub-

themes); each forming one of the three findings Chapters 4-6. As is consistent with

IPA studies, these findings were initially reported without reference to the literature

(Smith et al., 2009). In this chapter, these findings are now discussed in relation to

the literature (outlined in Chapter 2) and relevant additional bodies of literature explored because of those findings: grounded in participants' descriptions and sense-making of their experiences and my interpretations of those understandings. The purpose of this discussion chapter is to both describe and interpret the significance of the findings in relation to the literature. This highlights the place of IPA as an experiential method, illuminating 'a chain of connection' between participants' subjective experiences of living with MS with and without an assistance dog, their account of those experiences along with their emotional response and meaning making of them (Smith, 2011 p. 10). This examination of the findings informs the conclusions identified in the final chapter of the thesis (Chapter 8), which then follows.

The main body of the chapter is divided into sections with both the first and third super-ordinate themes VISIBILITY and IDENTITY being considered together as connected but distinct entities; the third superordinate theme (UN)CERTAINTY is considered in the second section. Where appropriate, vignettes are presented as a reminder of key aspects of the findings' chapters interwoven with findings from extant literature. I begin with a restatement of the key findings of this study.

The current study found that acquiring the degenerative condition multiple sclerosis resulted in a fundamental shift in the participants' sense of who they are and their role in society. Firstly, this transition was perceived as one of becoming disabled. Understood as an identity ascribed to them by society, manifest in everyday interactions and enacted in distinct but connected, and at times overlapping ways.

Secondly, understandings of society's response to their visible physical impairment were described initially as the experience of becoming invisible, being ignored, or avoided, acquiring a diminished status as a non-person. This was not experienced as a stable state of being but alternated or co-existed with the experience of being hyper-visible, leading to heightened scrutiny. For some this meant being subjected to denigrating or disparaging comments and awkward or threatening social encounters. Thirdly, the participants' meaning making of these experiences in relation to others 'out there', of being diagnosed with and then living with MS, describes a lack of control over one's (In)visibility which was problematic and for some distressing. The common reaction to these experiences was to withdraw from social situations, and participants where possible, stopped going out. This strategic (In)visibility reinforced the non-identity participants expressed they had acquired. It contrasted with the pre-MS aspects of their identity they chose to share, such as career/job roles or physical abilities. It was understood and foregrounded by participants in this study not as being lived within structural confines but affectively and along psychological and emotional lines (Thomas, 1999, 2007).

Fourthly, and conversely, findings suggest the choice to use an assistance dog influenced how participants perceived they were identified as different thereafter, yet again, by society. Becoming once more human, and as a person-assistance dog unit 'an attraction' or 'worth talking to'. Finally, the meanings participants ascribed to living with MS and using an assistance dog while, overwhelmingly positive, and for some considered lifesaving, were also suffused with uncertainties. Identified as

uncertainties originating from discrete domains connected to personal, individual assistance dog and/or external factors.

The first main section of the chapter begins with a vignette which encapsulates one participant's experiences of living with MS and two assistance dogs over a period of twenty-two years. Her journey touches on all the key findings in this study and opens the discussion of the integration of lived experiences and diverse literatures. Together they provide a compelling and thought-provoking account.

7.2 Becoming

> As the deputy head of a large secondary school for children with severe learning difficulties, behavioural issues and physical impairments, Maggie had every expectation her own experience of Becoming disabled would be one of support or at least accommodation. This proved untrue and an unsympathetic manager and a consultant who advised her to conceal her MS led to early retirement and social isolation.

When living with the visible impairment effects caused by MS, Maggie experienced disablism in her social interactions with others. This manifested explicitly with hostile encounters where her unsteady gait was interpreted as public drunkenness, and implicitly enacted in awkward and anxious social encounters characterised by feeling ignored or avoided. These experiences were internalised by Maggie and influenced both what she did and who she perceived she was: Invisible and hyper-visible, vulnerable, and isolated. When her physiotherapist suggested a new initiative where people with disabilities could have their own pet dogs trained to assist them with practical tasks, a keen animal lover Maggie had her dog Ella trained '..if I can take my dog with me I will go out again' (1:49).

Over the next 11 years Maggie and Ella developed a strong and synergistic relationship and partnership identity supported by the assistance dog charity who trained them and their allies: [it's] not just in the confidence, [it's] in all the other interests, I mean coming here you know and the fund raising things, the talks we have been on, you know, all those sort of spin offs from the actual assistance dog work..' (478-470).

On one occasion in over 20 years of having assistance dogs, Maggie, and her second assistance dog Sunny were explicitly refused access to a café as they said no dogs were allowed. Undaunted, Maggie stood her ground and reported them, advocating for their rights of access as an assistance dog partnership under the Equality Act 2010.

Afraid that Ella's feelings would be hurt by the introduction of a new
assistance dog, Maggie delayed the training of her second assistance
dog. Until she faced the reality of an elderly retired Ella and a young
Sunny neither able to assist her which caused Maggie significant
distress. Time past and Maggie and Sunny became a successful
partnership. Now a year from retiring Sunny, Maggie was anguished by
the thought of impending retirement for her second assistance dog.
Emotionally and psychologically unable to rehome her, unwilling and
unable to manage an old dog and a young assistance dog in training
again, an era seems to be ending. At the time of interview, at the age of
60 and living with MS which was now considered secondary
progressive (SPMS), Maggie and Sunny's future is incredibly uncertain:
'It has played on my mind in every conceivable way....much more than
me worrying about how I am going to you know, my physical condition
because in a way it is all tied in because she is keeping me going whilst
ever I am keeping going, I am keeping control' (Maggie, 512-514).

A full anonymised transcript of Maggie's semi-structured interview is provided in
(Appendix E) of this thesis.

7.2.1 Becoming Other

This study found that participants perceived that they were viewed differently, both by

others and themselves when they became visibly disabled because of MS. This

manifested itself in several ways, from the friends who spoke to them differently or

stopped visiting, to experiencing hostile encounters in public places when strangers

thought their atypical bodily movements or slurred speech signified that they were

drunk. As a homogenous group, participants, by virtue of having an acquired

condition had already formed a sense of themselves as an able-bodied 'normal' adult

before their diagnosis. Participants consistently described experiences where they perceived they had become or were made to feel invisible, less than human, Other. These experiences influenced the process of becoming disabled by impacting participants' sense of who they are – 'normal' to one of 'less than human'. They also impacted what they perceived they could do, as evidenced by their descriptions of behaviour changes in their day-to-day, taken for granted lives overtime whereby, they withdrew from social interactions where they could.

> Because you can no longer do the things that you once done and people tend to, either don't like to handle your illness or they can't cope with it, or you know, they don't want the burden of somebody coming around and you know, with a stick and what have you, with a wheelchair….That is how I felt, and I suppose in a sense I became a little bit reclusive in so much as I wouldn't go out to the shops on my own or go into a shop, because you lose a bit of confidence as well, and when I was on the sticks you stagger a bit and people look at you as if you are drunk.
>
> Jo (134-144)

The finding that each participant in this study experienced what they perceived as the stigma of becoming disabled and had lived experiences of disablism is consistent with what is found in the disabilities studies literature globally (Goffman, 1963, 1986; Charmaz, 1983; Thomas, 1999, 2007; WHO, 2011; Leary, 2018; Wang and Ashburn-Nardo, 2019; Dovidio et al., 2019; Goodley, 2020) and 'trans historically' (Hughes, 2020, p. 92).

To understand this finding in comparison to the further finding that participants' perceptions, when accompanied by their assistance dog, of their experiences were almost the opposite; requires firstly, a consideration of identities. The following sections address this, beginning with the concept that the age a person acquires a disability/chronic illness can affect their experiences of living with disability and their sense of self. This is followed by an exploration of the identity people with visible disability may be ascribed in social interactions with non-disabled people. With the aim of understanding what may be happening within these encounters, these explorations are framed within the relevant literature. Lastly, perceived changes to identity and lived experiences of disability when accompanied by a dog/assistance dog are examined. For reasons of both clarity and consistency the term identity in this study is used in its commonplace understanding, situated culturally in the UK, as meaning both a person's sense of self - 'who they are' and in the public sense of identity – a person's roles or how they are identified in relation to others for example (dis)abled (Lawler, 2014).

7.2.2 Acquired disability and IDENTITY

MS is a long-term condition with an average age of diagnosis being thirty years of age. There is limited evidence which examines differences in the experiences of people with congenital impairments and those who develop them over the course of their life (Dunn, 2019; Kriofske Mainella and Miller, 2018; Hutchinson, 2018; Bogart, 2014). There is broad agreement amongst researchers which suggest a relationship between whether a person's impairment is congenital or acquired may influence a person's 'disability self-concept'. This is defined as a positive disability identity and

one's disability self-efficacy combined. Bogart (2014) ackn owledges that age of onset of disability is invariably a factor associated with a positive disability identity, with those born with disabilities more likely to develop a positive disability identity. Barnes and Mercer (2010) concur, contending that people who:

> acquire a stigmatised condition in adulthood are usually more resistant to identifying as a disabled person because of their prior assimilation of a personal tragedy perspective on impairment and disability

> (2010, p. 49).

Charmaz (1983, 2010) draws on a symbolic interactionist perspective in her analysis of the lives of those who have a chronic illness which assumes the self is basically social, that is,

> developed and maintained through social relations…illness as an experience, shapes situations in which the person learns new definitions of self and often relinquishes old ones

> (Charmaz, 1983, p. 171).

The findings of this study are consistent with the literature surrounding the impact of chronic conditions. The severity and relative speed of progression in their MS experienced by some participants, such as Roy, can fundamentally affect social interactions.

Roy was diagnosed with primary progressive MS and within a year he was a full-time wheelchair user. At the time of interview, he was only able to move his left hand. Roy's previous occupation was working for a newspaper.

> 'But I think the erm, the biggest, the biggest thing is really to try and forget what I used to and concentrate and what you can do…that's easier said than done mind.'
> Roy (2:38-40)

Charmaz (1983), develops this further, contending that meaning making of a current chronic condition is achieved through the lens of previous social experiences, knowledge and cultural situatedness. She states that ultimately the nature of suffering in people with chronic illnesses is fundamentally that of loss of self as they 'observe their former self-images crumbling away without the simultaneous development of equally valued new ones' (Charmaz, 1983, p. 168). It is argued here however, that Roy's (and the other participants') MS is not his only defining characteristic, it is not perceived or expressed by Roy as a permanent loss of self; rather it becomes a unique and shared identity with Millie, his first assistance dog, and subsequently Cassie. This shared identity is explored in greater detail later in the chapter.

Overall, in this study, participants understood this first transition from a 'normal' identity to an identity as 'a disabled person' was ascribed to them by society and experienced and enacted through interactions. Thomas (2007, 2010) considers these interactions, which may include hurtful comments, stares (HYPER-VISIBILITY) and avoidance (INVISIBILITY) as another form of disablism. Their impacts on disabled people along emotional and psychological lines (psycho-emotional disablism) can be just as powerful as a structural barrier to participating in society. It is of interest to note that while the findings of the present study agree with the authors cited above, it

was further identified in some participants' data that the ableist discourse may, in part, have originated within themselves. This finding implies that, potentially, some participant's may harbour a pre-existing hierarchy of impairments (Deal, 2003), where their previous able- self, ranks most highly, followed by their disabled self with an assistance dog, followed by their physically disabled self without their assistance dog and, lastly, the least preferable social identity of being perceived as 'mentally disabled' (see vignette below). It further suggests that the use of assistance dog may become a means of impression management or self-presentation (Leary, 2018; Jones, 1990, Goffman, 1959, 1963) amongst participants who can no longer 'pass' or 'cover' their impairment effects (Goffman, 1963, pp. 73-102).

Roy, Richard, and Sean for example, explicitly refer to one of the benefits of having an assistance dog as being it signalled to others that they were competent.

'if they see me with a dog, they always talk to the dog not me. They talk to the dog and you can see their brain working as they start to follow the leader and there is a person on the other end of the lead. They go, erm, do I talk to him or not, is he stupid, is he blind or whatever'.

Sean (18: 401- 405)

'they don't know how to treat you because they don't know whether you are mentally disabled or physically disabled, they don't know, but if there is a dog there they will often talk about the dogs, assess you by your response and then change their behaviour in line with that response'

Richard (13: 283 -288)

This aspect of the use of their assistance dog as an integral part of how participants make sense of their experiences in social interactions, with and without their assistance dog is further explored, later in the chapter.

7.2.3   Stigma: Explicit and Implicit attitudes to people with physical impairments

The lived experiences of the participants in this study are complex and multidimensional in their nature. Their experiences are culturally situated in a country (UK, Global North) and in a society where their rights as a person with a disability (MS) to be protected from discrimination in areas including but not limited to work, education and in dealings with the police, are enshrined in law. The Equality Act, 2010 (excluding Northern Ireland) and the United Nations (UN) Convention on disability rights (2006) promote, protect, and assist in the enforcement of those rights. Yet, the most recent statistics on disabilities hate crime (2018/19) reveal it is rising while both the numbers of successful charges and prosecutions fall (United Response, 2020; Office for National Statistics (ONS), 2019). Hughes (2020) suggests that disability hate crime 'might be explained – in socio-emotional terms – as a manifestation of fear of impairment, resentment, and hatred actualised as virtual or visceral violence against disabled people' (2020, p. 93). Acknowledging the place of Thomas'(1999) work in influencing the field of disabilities studies to explore the

impact of psycho-emotional disablism, Hughes describes how the impact of

discrimination and exclusion of disabled people amounts to an:

> attack on their existential security…augmented by a disablist interaction
> order in which people with impairments are patronised, ignored,
> abused, and subjected to subcutaneous violence of the intrusive,
> demeaning, and disturbing non-disabled gaze.
>
> (Hughes, 2020, p. 90)

However, as Rohmer and Louvet (2016) explain, the pressure from society against

the discrimination of disabled people (and other marginalised groups) means that

people may be reluctant to explicitly express negative attitudes towards people with

disabilities. This has resulted in researchers developing ways in which stereotyping

and prejudicial attitudes can be captured (Greenwald and Banaji, 1995; Greenwald et

al., 1998). Studies over recent decades have employed measurement techniques

(mostly focusing on racism) which reveal these explicit and implicit negative attitudes.

Explicit biases are attitudes that are consciously held and expressed whereas implicit

biases are those held (often unconsciously) by people. In addition, assessments of

explicit and implicit attitudes towards people with disabilities yield similar results to

those concerning race (Dovidio et al., 2019). Research indicates significant bias

against disabled people when implicit attitudes are measured, yet assessment of

explicit attitudes may reveal little evidence of prejudice (Rohmer and Louvet, 2012,

2018).

Conversely, there are also studies which consistently describe people with disabilities

positively. The bodies of literature concerning prejudice and discrimination are broad

and complex however, I will focus now on recent work by Dovidio et al., (2019) which acknowledges that both bodies of literature may be correct. Examples of which include research that explores the origins of bias against people with disabilities, concluding that non-disabled people will invariably stigmatise them (Schaller and Neuberg, 201 2; Seo and Chen, 2009; Goffman, 1963). This is juxtaposed with the literature that demonstrates an improvement in expressed attitudes to disabled people which have become more positive in recent years (Norton et al., 2012; Rohmer and Louvet, 2012; Dovidio et al., 2019).

Dovidio et al. (2019) argue that 'a substantial proportion of people have both positive and negative attitudes toward people with disabilities, which manifest behaviourally in complex but systematic ways' (Dovidio et al. 2019, p. 242). Below is listed a number of nonverbal responses which are thought to reflect negative implicit attitudes to people with physical disabilities. Presented alongside these are verbal responses that have been connected to explicit positive attitudes to people with disabilities arising from Dovidio et al.'s (2019) review of the area. These verbal/nonverbal mismatches are thought to profoundly influence the form and nature of the interactions between the (Dis)abled.

Nonverbal behaviours by non-disabled people include:

- Attempts to avoid interactions
- Reduced gesturing and standing further away
- Cutting short interactions sooner

Verbal and nonverbal behaviours and expressions mismatch include:

- Non-disabled people may try to appear supportive or sympathetic to people with disabilities but simultaneously exhibit signs which indicate anxiety such as gaze avoidance, increased interpersonal distancing and a closed posture.
- Disabled people in the presence of these nonverbal behaviours may perceive them as indications of anxiety, dislike, or rejection. They may respond in confirmatory ways which exacerbate the tension and increase anxiety further, leading to awkward, uncomfortable interactions on both sides.

Before moving on from the human half of this dyad, two vignettes focusing on experiences of participants in this study are shared which demonstrate very different responses by able-bodied people to two different participants. The first returns briefly to Maggie. This experience concerns an occasion when Maggie was inadvertently standing by a main road, when she had her first dog assistance dog Ella, it provides quite a contrast from her equal access stance outlined at the beginning of the chapter.

> Maggie: I mean people still don't know about assistance dogs in many ways, but at that point it really was guide dogs with as much as people knew, and also I am light sensitive so my glasses very quickly go dark, so that didn't help and – oh I was taken across zebra crossing that I didn't want to cross at.
>
> INT: Oh no.

> Maggie: But it, that was necessary.
>
> INT: Did you just go with it?
>
> Maggie: Yes, I though, you know well they were being helpful and I didn't want to stop that.
>
> Maggie (73- 80)

As suggested by Dovidio et al. (2019, p. 247), because people are generally explicitly sympathetic toward and supportive of people with disabilities, people may express their bias in ostensibly prosocial but ultimately still harmful ways. Given their child-like associations (e.g., weak and dependent) with people with disabilities, people may tend to behave in patronising ways toward individuals with disabilities. When they offer assistance to people with disabilities, it will tend to promote dependency rather than to empower them, which can also generate resentment among people with disabilities, or perhaps compliance or infantilisation in Maggie (Thomas, 2007, Reeve, 2004)

Helen is pragmatic in her estimation of her perceived value in society as a visibly disabled person without her assistance dog Alfie:

> Oh yeah, I am very much a non-person when I don't have the dog, or I feel that I am not. I feel that I have got a more social presence when he is with me, which I definitely have because people find him attractive and want to say hello or are a bit curious about what is happening.
>
> Helen (590 – 593

However, the work of Dovidio and colleagues only applies to one half of a dyad. In the present study, participants unanimously perceived a difference in their experiences of living with MS when accompanied by their assistance dog. Therefore, firmly embedded in the experiences of participants and in acknowledgement of recent advances in the field of human-animal interaction studies, literature concerning this phenomenon is also addressed. The following section explores the process that may explain the findings which are identified, described, and interpreted here. They are salient in and of themselves because they further support, explicate, and conceptualise the findings. In addition to which they also link to current literature, outlined in the next section, that relates to explicit/implicit attitudes to people with dogs/assistance dogs (Coleman et al., 2015).

7.2.4 Re-Becoming Human: VISIBILITY reclaimed and IDENTITY remade

This section draws together the lived experiences of participants in this study with their assistance dogs, insights from HAI research and from the wider field of the study of disability literature. The present study's finding, that the use of an assistance dog by participants influences their experience of living with impairments, is potentially of value in increasing our understanding of human and non-human ways of being in the world and what this might mean. Experiences of living with MS were understood by participants to alter depending on whether they had their assistance dog with them. Participants' sense making of this experience moved along a continuum. Extracts from participants such as those presented throughout Chapters 4 and 6, illustrate this dynamic transition from a discredited, stigmatised identity of 'disabled', or state of non-existence when they are without their assistance dog to

one where they perceive they become a person 'worth talking to' (Roy), 'a celebrity (Elaine), 'an attraction' (Richard). The HYPER-VISIBILITY evoking heightened scrutiny becomes a HYPER-VISIBILITY which for most part is welcomed. These external, positive interactions are interpreted as both feeding and being fed by the dyadic relationship of participant and their assistance dog mirroring the hermeneutic circle integral to the use of IPA itself. The dynamic relationship between the participant and their assistance dog makes possible the undertaking of social interactions with others. Equally the positive interaction of others to both the assistance dog and the participants impacts the relationship between the assistance dog and their human partner. This feedback loop is understood by participants to arise from spontaneous positive encounters when out in public with their assistance dog, and not when they are alone. Ultimately over time, this resulted in a perceived move from being present in a community as person with disabilities (with the potential for negative experiences and interactions) to becoming one of participation in society as a working partnership with their assistance dog. This finding mirrors those from other studies more generally where the presence of a dog is associated with being perceived as friendlier, more trustworthy, happier, more relaxed, and even more attractive (Rossbach and Wilson, 1992; Geries-Johnson and Kennedy, 1995). Also, more specifically, the finding is consistent with those studies concerning the impact on disabled people with an assistance dog and their lived experiences during some social interactions (Whitney, 2020; Hall, 2017; Crowe; 2014; Coleman, 2013; Eddy et al., 1988; Hart and Bergin, 1987). Findings are further supported and underpinned by current understanding of the unique relationship that has existed between humans and dogs over millennia and the human-animal bond 'rooted in evolutionary, psychological and physiological processes' (Beck, 2014, as discussed in Chapter 2).

Coleman et al. (2015) provide a promising beginning to the development of a deeper, empirical basis for this 'assistance dog effect', helping to integrate the diverse bodies of literature included in explorations of human-animal interactions in disability (HAI-D). Following on from Greenwald et al. (1998), Coleman et al. (2015) developed a Disability and Assistance Dog Implicit Association Test (IAT-D) which determined whether people's implicit attitudes to people with a visible disability (wheelchair user) would differ depending on whether or not they were accompanied by an assistance dog. Results revealed:

- Participants had more positive implicit attitudes toward an individual with a disability when paired with an assistance dog instead of pictured alone.

- Participants who were assessed as holding more positive attitudes toward dogs generally also revealed a stronger positive implicit bias toward individuals with disability with an assistance dog over that individual alone.

- Support for previous research findings that social interactions are different for people with disabilities who are with assistance dogs compared to those people with disabilities alone.

- Significant differences in implicit attitudes toward individuals with disabilities paired with assistance dogs based on the race of the perceiver, with white participants more likely to demonstrate a positive implicit attitude toward an individual with a disability paired with a dog, than those from the Black ethnic group as a whole

The study led the authors to reflect on the dearth of research that has examined ethnic or racial differences in attitudes to dogs and to pet keeping practices generally. Despite dogs having been found to be the most common pet across cultures globally (Gray & Young, 2011), this does not mean that all cultures or racial groups hold the same attitudes about dogs.

- Differences in implicit measures of social attitudes toward an individual with a disability paired with an assistance dog in the study may, help to explain the differences in social behaviours found in previous research involving non-disabled people, people with physical disability who use an assistance dog.

- The authors suggest the study provides further evidence in support of the biophilia theory (Wilson, 1984) that humans have a positive implicit bias toward animals.

- The need for further research to better understand how and why social interactions differ when an animal is present, be it for individuals with disabilities or individuals in general.

The findings above are congruent with this study's in its interpretation of the sub theme of the assistance dog as a WARRANT. Extending and enhancing the work of others that suggests the presence of a dog makes people appear more approachable, more trustworthy, more attractive and so on (Greenwald et al., 1998; Rossbach and Wilson, 1992) and more recently that of Coleman et.al (2015) whereby a visibly disabled person with an assistance dog evokes more positive

implicit social attitudes than when without an assistance dog. This foregrounds the concept that even the sight of a visibly impaired person with an assistance dog becomes a heuristic for positive associations and many influence subsequent interactions. However, as discussed previously this is a culturally situated experience understood to encompass a skein of entanglements both metaphorically (following from Haraway, 2008) and literally ('a person at the other end of the lead' Sean, 402) which serve to endorse the human-ness of participants. To the author's knowledge the finding that participants understood their assistance dog to highlight their status as a person rather than an invisible Other has not been recorded elsewhere in the literature.

Many participants in this study shared the experience of feeling they were seen again as being human when they were in public. Below is a reminder of some of the experiences they had in relation to others. Each participant in the study emphasised this was experienced only when they were with their assistance dog and perceived not to occur when they were alone. This finding was demonstrated primarily in Chapter 4 (section 4.4 VISIBLE SELVES) where participants June, Jo, Maggie, and Roy's wife/carer Nicky share how their experiences of social acknowledgement and friendship building which contrasts with their earlier accounts of becoming INVISIBLE. Chapter 4 (Section 4.5) suggests another state of TRANSLUCENCE where some participants when with their assistance dog and an able-bodied companion, encounter experiences of being overlooked when a stranger will defer to the able bodied human companion regarding the assistance dog, despite the participants being visibly the assistance dog's handlers. The participants' descriptions of such experiences in which they perceived they were neither fully seen nor feeling

totally INVISIBLE revealed a tension expressed as annoyance of being excluded from interaction but equally being present (at the end of the lead) and desiring equal inclusion; it was preferable to being perceived as Invisible without their assistance dog. To the authors knowledge this finding has not been recorded previously in the literature in this context and speaks to the strength of IPA as an inductive, idiographic approach whereby individual differences in participants experiences may be revealed which may not have been apparent in studies with large sample sizes.

Thus far, the first part of the chapter has sought to both describe and interpret the significance of the findings concerning those experiential claims of participants, in relation to social interactions and then to selected literature. Four findings based around the two super ordinate themes of VISIBILITY and IDENTITY, and their related sub themes (section 7.1), were foregrounded and will inform the conclusions set out in the following chapter. A thread of 'Becoming' runs through the narrative journey of participants' experiences. Their journey to becoming disabled after growing to adulthood as able bodied, and the perceived loss of self in the process of becoming Other. This was subsumed in time by a profound becoming 'we', understood to be more than a partnership for some, to an experience where identity was perceived as shared. Participants in their meaning making understood that their assistance dog became a part of themselves and their identity implicitly; it was also perceived to influence and shape perceptions and reactions of others to them explicitly.

The discussion of the findings around VISIBIITY and IDENTITY grounded as they are in the phenomenological accounts of participants in this study urge a reconsideration of what is it is to be human and illuminates a dimension of other ways of being in the world. The extent to which existing theories in both human-animal interaction studies and disabilities studies may explicate and contextualise these accounts, coalesce within the bounds of critical disabilities studies literature.   Acknowledged as a key concern in critical disability studies, the concept that 'disability necessarily demands and affirms interdependent connections with other humans, technologies, non-human entities, communication streams and people and non-peopled networks' (Goodley et al., 2014, p.10) is foregrounded. Here I consider how critical disability studies may inform our thinking about the human and non-human inter-relationships and alliances revealed in this study's findings,

Firstly, I return to eco-feminist scholar Donna Haraway, first introduced in Chapter 2 (Section 2.4), and her questions concerning the entanglement of human-canine relationships. Haraway suggests that when a human and an animal form a connection it may occasion a self-questioning about the nature of our identity and that of the animals in our lives. Haraway's notion of 'making kin' – by which she means 'those enduring mutual, obligatory, non-optional, you-can't-just-cast-that-away-when-it-gets-inconvenient, enduring relatedness that carries consequences……I have a dog, a dog has me' (Haraway, 2019, p.5), is apparent in the findings. This view of dogs as kin echoes participants' accounts whereby they talked about feeling unable to proceed with obtaining a subsequent assistance dog for fear of hurting their current one's feelings or were unable to consider rehoming

them once their assistance dog retired or could be regarded as 'inconvenient'. The

obligation to meet the needs of their assistance dog despite experiencing multiple

impairment effects because an assistance dog must be exercised and toileted

demonstrating a prioritisation of another's needs over their own. In this thesis the

participants without exception made sense of their experiences of living in

relationship with their assistance dog as more than that of a person with impairments

and an 'auxiliary aid' (Equality Act, 2010). For some their assistance dog became kin,

for those living alone especially, they were perceived to be even closer than family

prompting a reconsideration of understandings of identity. Critical disability studies

provides the conceptual language which can accommodate concepts such as

Haraway's redefinition of kinship (2019) or indeed the complex blending of human

and non-human entities such as the cyborg or the transhuman (Haraway, 2003,

2008; Braidotti, 2015). Goodley et al, (2014) acknowledge that some critical disability

studies scholars within the field have aligned themselves with the concept of post-

human ways of being (Braidotti, 2006, 2013, 2019) contending that critical disabilities

studies 'are perfectly at ease with the posthuman because disability has always

contravened the traditional classical humanist conception of what it means to be

human' (Goodley et al., 2014, p.3). However, the influence of culture on individuals

interpretations of their experiences and their identity remains.(Goodley, 2017). This

helps inform our thinking about the cultural situatedness of assistance dog use as a

predominantly global north-centric phenomenon. As discussed previously, assistance

dogs are regarded as a form of assistive technology or an auxiliary aid providing

practical and psycho-emotional support to those participants living with MS however,

this occurs within the materialist limitations of the charities' ability to provide those

assistance dogs. Although not revealed as an object of concern for the participants in

this study, there are financial costs associated with having an assistance dog which may render it outside the reach of people living with impairments living in what Flynn (2017, p.1) describes as the 'often-harsh material reality of disability.'

Reeve (2012), writing on Haraway's contribution to disability studies around the cyborg , reminds us of the persistent inequalities around access to and availability of assistance technologies to people living with impairments. The findings in this thesis are situated in a cultural landscape where assistance dogs are understood to be a scarce and highly sought-after resource, only available to the few.

I conclude this first part of the Discussion Chapter contending that a consideration of the findings of this study participants' perceptions of IDENTITY in relation to the literature reveals a multifaceted and fluid state of being in the world as a human living with MS in an 'obligatory, constitutive and protean' interspecies alliance with their assistance dog (Haraway, 2003). This follows Goodley et al.'s assertion (2014, p.18) 'that reinvigorating discussion around human/animal relations around disability might provide the necessary conditions and impetus for revaluing animals and humans as sharing a posthuman space of becoming'. The findings in this thesis offer insights into new understandings of a human-assistance dog identity which resonates with Reeves (2012) notion of 'the impaired cyborg'. Foregrounding the potential for human/technology or human/assistance animal hybrids not as a means of 'fixing' impaired bodies but as means of minimising impairment effects and expanding opportunities to be in the world. However, as the discussion moves on to the second part of the chapter, I argue that following Reeve's (2012) further assertion that the benefits of this fusion of the impaired human body with an assistance dog remains contingent upon many aspects of lived experience out-with participants' control.

The second part of the discussion chapter moves away from participants'

understanding of experiences 'out there' (Thomas, 1999) concerning daily

encounters with able bodied individuals in social interactions. It focuses instead on

the third super ordinate theme, that of UNCERTAINTY. Whilst perceived by

participants as overwhelmingly positive, and for some considered lifesaving, living

with MS and using an assistance dog was also found to be suffused with

uncertainties. These were identified as uncertainties originating from discrete

domains connected to individual assistance dogs, and/or factors external to the

working partnership but profoundly involved in shaping it. In addition, the discussion

will address the UNCERTAINTIES concerning some participants' own aging with a

degenerative condition, which revealed unvoiced but implied concerns. This includes

a consideration about the point at which the next assistance dog (such as was

explored at the beginning of the chapter in Maggie's vignette) becomes the final

assistance dog and what this might mean for participants.

7.3   (UN)CERTAINTY

As discussed throughout this thesis, living with MS means living with a degenerative

condition that 'by its nature, carries uncertainty as a hallmark characteristic (Alschuler

and Beier, 2015). Jenkins et al. (2005) acknowledge the inevitability of uncertainty

when illness exposes the fragility of human life. Citing the long history of studies

which explore the question of how people manage life's uncertainties, Jenkins et al.

(2005) contend 'In the face of indeterminacy, people everywhere struggle to

influence, even if they cannot completely control, their present and future situations'

(2005, p. 11). This perspective resonates with both the research paradigm and the findings of this study. The participants' choice to use an assistance dog suggests a turn away from the biomedical model focused on a cure or rehabilitation instead turning towards a position whereby 'for particular humans in particular situations reasons for being and for behaviour may differ slightly from the reasons of science' (Jenkins et al., 2005, p. 13). However, in this particular situation, given the shorter lifespan of a dog in comparison to their human partner, the experience of the death of an assistance dog or its retirement is inevitable and often repeated several times over a lifetime. Even if all goes well, the profound and unique relationship, and perceived shared identity, comes under threat every eight/ten years.

The decision to include participants who had used an assistance dog for two years or more was, as discussed in Chapter 3, to capture the experiences of mature assistance dog partnerships. This aimed to explore and examine the continuum of experiences across the life-course of participants and their assistance dog/s, thereby increasing insight and understanding into this phenomenon. This serves to both extend and complement research findings in both human-animal interaction studies where participants had their assistance dog's for a shorter period of time as outlined in works by O'Haire et al.(2019),

There are many studies that have focused on the impact on people who have experienced the loss of their companion animal (pet). These have identified features of grief which are commonly experienced, and identified some difficulties which are thought to indicate a more complicated reaction to grief.

Studies broadly agree that the grief over the loss of a pet can best be understood within the context of attachment theory (Sable, 2013; Zilcha-Mano et al., 2011). Field et al. (2009) found that the strongest predictor of grief severity is related to how close the owner was to them. This was also found in a more recent study by Eckerd et al., (2016). Many bereaved pet owners can experience what is known as disenfranchised grief, defined by Doka (1989) as:

> the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported

> (1989, p. 4)

This may occur because of social factors such as minimisation or shaming which invalidate the grief of others (Clements et al., 2003; Doka, 2002; Miller, 2017). Further types of disenfranchised grief and loss are proposed by Doka (2002) including, if the relationship is not recognised, if the loss is not acknowledged, because of the ways that the individual grieves and when the person who is bereaved is excluded.

7.3.1 Loss, grief, and transition: The three goodbyes.

Whilst literature concerning the impact and meaning of pet loss cited above is useful, it is not sufficient to capture the depth and breadth of the assistance dog/partner dyads specifically, including those experienced by the participants in this study. Kwong and Bartholomew (2011) suggest that it is the high level of interdependence between a human partner, and the strong attachment bonds with their assistance dog partnerships that make them unique. Below, the literature relating to the loss of

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an assistance dog is explored. As discussed earlier there are more research studies concerning loss and bereavement of guide dog partners generally than other types of assistance dog partners. This is most likely due to the higher numbers of guide dogs that have been trained over the last eighty-nine years or so. Where the aspect of grief or loss identified in the literature, such as it is, proves consistent with the findings from this study, a brief vignette is presented alongside as a reminder of the finding that participants experienced (described in detail in Chapter 5). Where relevant, the readers' attention is drawn to additional literature - a small proportion of which was explored after the original interview schedule was created. This grew out of the idiographic unique concerns of participants and had not influenced data collection and analysis. It further recognises recent developments within the area which previously did not exist.

> Milly never lost her loyalty to Neil, even though she wasn't on the lead, she was happy if she was walking behind him, if Neil did something, dropped something Milly would still, you know, but Milly had to retire because she starts to wee as she was walking, so we knew really.

Schneider (2005) suggests' three significant farewells transpire in the process of concluding one's partnership with an assistance dog: (1) the "decision-making goodbye," (2) the "working relationship goodbye," and (3) "the goodbye of death". Miller (2020) goes on to describe this initial "decision-making goodbye" as:

> the bittersweet process of coming to recognise the nearing time for a dog's retirement, as evidenced by increasing changes in the dog's ability and/or motivation to work, frequently offset by compensatory adjustments on the part of the human partner for as long as is possible.

Such a process may be uniquely marked by anticipatory grief as well as remembrances of the partnership in times past.

Miller (2020, p. 214)

In this study, six of the participants were told their assistance dog would retire aged ten years old and five were told this would happen when their dog was twelve years old. In an ideal situation, an assistance dog's retirement is typically planned up to two years in advance. Once the retirement age is reached this is followed by a transitional period during which the first assistance dog's retirement overlaps with or is followed smoothly by the successor dog partnership.

> June's first assistance dog Oscar died peacefully after retiring and staying with her until his death from old age. June was comforted somewhat in her grief by having Oscar's successor dog Max already in place.

However, some assistance dog partners who keep their retired dogs as pets may experience unique difficulties. With a retired dog at home, partners worry about welcoming in a new assistance dog. There is evidence that on occasion people will refuse to have a successor dog and thereby lose their independence because of this. When this happens, the retirement of assistance dogs can affect their partners' daily life considerably. Partners are often in this situation when their first assistance dog retires – a phase sometimes called the "second dog syndrome" (Allen, 2006; Schneider, 2005). As a result of the intense, emotional, attachment to their previous dog it may be extremely difficult for partners to build a relationship with a successor dog, this can be problematic for both the dogs and the person.

Maggie's first assistance dog Ella died aged 15 after retiring aged 13 and before strict cut off dates for retirement were implemented. Maggie found the whole process traumatic trying to care for Ella in her last months as she was simultaneously trying to train her successor dog Sunny. Maggie recounted that she delayed getting Sunny trained fearing Ella's feelings would be hurt by having another dog taking over her role. When interviewed Maggie spoke about her feelings that the impact of Ella's death was experienced as being far more devastating emotionally than previous pet's she had lost, emphasising because she lived alone her assistance dogs became her 'rock' and 'her everything'. Maggie admitted being extremely low for a long time after Ella's death.

Some people's experiences of an assistance dog's sudden or unexpected death are very often traumatic, disorienting, and furthermore functionally disabling. Among guide dog partners, distress is consistently attributed to abrupt endings; partners often compare the sudden loss of the guide dog to the initial loss of one's sight (Nicholson, Kemp-Wheeler, & Griffith, 1995).

Findings from this study included the accounts of two participants, Steve and Elaine, both had experienced the unexpected death of their assistance dogs. Steve's first assistance dog - Jenny from cancer at six years of age, and Elaine's first assistance dog - Leo aged five from lymphoma six weeks after diagnosis. The circumstances for both participants surrounding the deaths were difficult with Steve going through a breakdown of his marriage and Elaine instructed by the assistance dog charity who supplied Leo that treatment would not be of use for Leo and was not approved. Both participants expressed shock, grief, and sadness at the death of their assistance dog which indicated they had had a strong attachment to their dogs. Steve immediately applied for a successor dog which he got a few weeks later but the partnership was unsuccessful so that dog was rehomed. Elaine delayed getting her second assistance dog for three months and although still grieving for Leo went on to form a successful second partnership with Meg. Before applying for Meg, the assistance dog charity visited and spent time chatting with Elaine about Leo, looking at photos, and preparing her for the fact that Meg would be a totally different character to Leo.

Nicholson, Kemp-Wheeler, and Griffiths (1995) found in their research on the loss of an assistance dog that more than two thirds of those who had lost contact with their dog through death or retirement spoke about their experiences as being similar to the loss of a relative or even a close friend. Weiss (2001) suggests human relationships between human partners provides a context in which both attachment and caregiving are present, however typically the concern of the bereaved spouse could be focused on either themselves or their partner. Similarly, the human-assistance dog relationship may involve both the attachment and caregiving systems. However, it is suggested that it is hard to predict exactly how these systems may operate when

owners are faced with the loss of their dog (Fraley & Shaver, 1999). Thus, the experience of grief engendered by the loss of an assistance dog may reflect the activation of either the attachment or caregiving systems.

The super ordinate theme UNCERTAINTY was assigned to the overarching interpretation of participants experiences, because, while individual participants may have experienced a singular event, it has a range of effects which can affect people with disabilities differently. Whelan (2017) suggests that early retirements of a guide dog may cause "ambiguous loss" and "disenfranchised grief." Early retirement happens suddenly, and assistance dog partners do not have enough time to understand the situation well before separating from their dogs. Also, it can be hard for them to receive the kind of understanding that they need from people. The "ambiguous loss" and "disenfranchised grief" complicate partners' psychological distress. Although their relationships with their assistance dogs were short, such unique separations may cause great distress and difficulties. Grief becomes even more severe when people are already experiencing challenges in their lives besides the loss of their assistance dog (Nicholson et al., 1995), such as living alone with a degenerative condition.

Kwong and Bartholomew, (2011) and Whelan, (2017) suggest even if this relationship was short, assistance dog partners, by virtue of the fact that they are together all the time, typically form an extremely strong attachment to their dogs and often feel guilt, shock, and even anger for their dogs' early retirements and death. In addition, Whelan (2017) found in a study of guide dog users that some partners

choose to keep living with their retired dogs. In this case, it is not a true separation

from their dogs (Schneider, 2005). However, retiring an assistance dog does mean

that the relationship between the assistance dogs and their partners fundamentally

changes. Retired assistance dogs no longer perform the same tasks as before in

public because they no longer accompany their partners as assistance dogs do.

Losing the assistance provided by these dogs may require their partners to re-

acknowledge their disabilities. Social participation and independence that had been

facilitated by assistance dogs can deteriorate following the retirement of a dog.

In interviews conducted by Whelan (2017), guide dog partners experienced strain

and suffering from their dogs' behaviour problems, going through significant

difficulties when making the decision to return their dogs and thereby also losing their

partners. Additionally, people have to wait until their next guide dog is trained and

worry that they might experience an early retirement again with the upcoming dog.

Nicholson and her colleagues (1995) found that when partners knew their dogs are

given good care once rehomed, they reported being relieved, but if they did not have

any information, people developed considerable worry. Assistance dog partners

usually make the decision for early retirement, and they tend to blame themselves,

and feel guilt, doubt, and confusion for this decision. Assistance dogs are designed to

provide assisting tasks, and at the same time they are important companions – two

different roles. Assistance dog partners face a dilemma when deciding to return their

dogs, while at the same time having a good relationship with their dogs as

companions. Partners often question the decision they have made, and worry about

the future after their dogs have been returned to a school or training facility.

Conversely, the same things which make grieving for the assistance dog who has died so intense may potentially protect partners against disenfranchised grief experiences. For example, when other people in the community recognise the absence and loss of the assistance dog, by inquiring after the well-being of the bereaved partner, their grief reactions and processes may be recognised and validated in ways not always experienced by companion animal owners following the death of their pet dogs. However, bereaved assistance dog partners are very likely to encounter reminders of their loss while out and about, in part due to such inquiries from people accustomed to seeing person and dog together in restricted areas.

Roy's first assistance dog Millie died three years after retirement and his wife Nicky was keen to emphasise Roy and Ella's relationship was so strong, he had expressed the desire for her ashes to be buried alongside him when he dies. Nicky recalls that Ella was so well known and loved in the local community:

'we can't go to [ ] to our local shopping area, everybody knows Millie in fact someone said to me 'oh I haven't seen your dog for a while…and when Millie died half of Tesco's were distraught weren't they, and when we first had Cassie and Roy used to go out with Cassie and not Millie they would all say, 'oh has something happened to Millie', don't they and they all worry you know.

Roy, (7:123-8)

The interwoven threads of uncertainty experienced by participants, concerning the certain-uncertainties of living with MS, coupled with the shorter lifespan, potential unknowns around health, behaviour or safety of assistance dogs coalesce in this study with a consideration of the passage of time. None of the research participants knew when they would be too old to have an assistance dog, but more than one did express concern as to whether they would be 'allowed' to have another or could manage another (Helen, Steve, Nicky/Roy, and Maggie). Others expressed deep concern over the possibility that their current assistance dog would be their last (Amanda, Maggie, and Anne). This would appear to be a grey area among assistance dog charities with no published information on the human age cut off in force unlike the retirement age for the assistance dog which is clear (ADI, ADUK, 2020).

7.4 Chapter summary

The integration and interpretation of findings from this research study with those of existing literature have been explored in relation to key findings from human-animal interaction research. These combine to increase understanding of the participants' sense making of the phenomenon of assistance dog use whilst living with MS. This has been a process of understanding, what Gadamer termed a 'fusion of horizons' in which one learns 'to look beyond what is close at hand – not in order to look away from it but to see it better' (Gadamer (1972/1989). Integral to Gadamer's contention, coming from a hermeneutic phenomenological perspective, is that our 'horizon' of understanding (everything we know about something):

can move with us rather than being something into which we move. Gadamer determined a fusion of horizons occurs when 'our own horizon is understood to understand that of another.

<div align="right">(Turner, 2003, p. 7)</div>

Exploring the experiences of participants over the whole of the assistance dog partnership over many years together allows for a holistic interpretation of their experiences and the meaning they give them. As discussed in detail in the literature review (Chapter 2) the diagnosis of MS will mean a life lived with unpredictability in terms of which systems of the body will be affected, the severity of those effects and the impact that has on each individual with the condition, their families, carers and loved ones. Whilst the underlying trend will point to a gradual accumulation of the burden of disability (Coles & Compston, 2008) each person with MS will travel that journey in different amounts of time and in unique ways and it is within this (UN)CERTAIN lived experience that participants exist.

The following chapter is the final chapter of the thesis. It concludes the thesis and addresses further issues including a discussion on the study's contribution to knowledge, and strengths and limitations of the study. Also, in the concluding chapter the choice of IPA as a methodological approach and an evaluation of the methods is presented. Suggestions for future research are also offered before the thesis is brought to a close with a summary of the final chapter.

Chapter 8 Conclusions and evaluation

The previous chapter considered the key features of participants' sense making of

their experiences of living with MS both with and without an assistance dog. The

application of interpretative phenomenological analysis to the data (Chapter 3)

allowed for an interpretation of that sense making which, when examined in the

context of extant literature, inform the conclusions presented in this final chapter. The

main conclusions drawn from the discussion, which I discuss below, are considered

alongside thoughts concerning their contribution to existing knowledge. The chapter

also provides an appraisal of the methodology employed and evaluates the methods

used in relation to the research questions posed at the beginning of the study. Also

discussed are perceived strengths and limitations of this study, alongside

suggestions for future research.

For the eleven individuals in this study, the choice to incorporate an assistance dog

into their lives may have begun as a pragmatic endeavour, to obtain assistance with

mundane tasks that were proving increasingly difficult to do, as well as giving them

companionship or a reason to get out of the house. Their sense making of the lived

experiences with their assistance dog/s revealed a complex interspecies

collaboration which fundamentally altered their perceptions of themselves and the

society they live in, their lifeworld. This study set out to answer the question: what are

the experiences of people with MS who use an assistance dog? The conclusions

outlined below, drawn from the previous discussion of the findings in relation to the

literature, contextualise those everyday experiences and elevate their importance to

and impact on participants. This is evident in the meanings they ascribe to those experiences.

The acquisition of a visible physical impairment affected participants in many ways which were perceived as negative, challenging, and contributed to a loss of self. Participants interpreted these subjective experiences as a transition from a 'normal' identity to one of Other. This was initially described as a process whereby many participants attempted to cope or manage how they were perceived in public; for example, eschewing aids which signified their disability. Others attempted to manage when they revealed their medical condition or minimised their social interactions. As they became more visibly disabled and this was no longer possible, participants experienced some difficult and negative experiences when involved in-day-to day interactions with able bodied people in society. In their sense making, participants consolidated and internalised their acquired identity as a disabled person. This was a common perception amongst participants irrespective of their gender, age, type of MS, previous job role or previous levels of physical ability.

A further transition was understood to occur once participants began to use an assistance dog in public situations. The transition was made sense of by participants as the development of a shared identity with their assistance dog which afforded positive synergistic effects, was culturally validated and legally protected. Participants presented their visibly disabled selves to what had been experienced by many as an explicitly ableist society with their assistance dog; who, by virtue of many thousands

of years of intentional human selection was perceived to shape the interaction positively. As such, their human-ness was amplified and differences minimised.

Secondary research questions were also addressed. These concerned how existing theories in both disability studies and human-animal interaction studies might contribute to an understanding of those experiences. Consistent with the research paradigm generally, and IPA specifically, contextualising the phenomenon of assistance dog use by participants in this study culturally and in time was important. Understanding biophilia theory (Wilson, 1985) (imperfect as it is), and the place of the domesticated dog in human evolution, deepens the resonance somehow of those experiences of strong and enduring bonds and synergistic effects generated by those partnerships. Returning to Haraway's (2008) questions posed earlier in this thesis - Whom and what do I touch when I touch my dog? Initially, I considered assistance dog use may be a uniquely modern phenomenon, a twenty-first century human/non-human animal endeavour exploring alternative new ways of being in an ableist society living and with impairment and ableism. During the process of doing this PhD, I developed an appreciation for the lived experiences of participant's in this study to touch, to connect with and to 'become with' their assistance dog; concluding that on some level it constitutes merely the continuation of a conversation between humans and dogs which began more than 16,000 years ago. It is intriguing to note that the long history and large body of disability literature (Chapter 2), concerning explicit and implicit biases against people with visible disabilities, dovetails with the nascent beginnings of human-animal interactions empirical research, which is beginning to

suggest an explicit and implicit positive bias towards visibly impaired people when they are with animals (particularly dogs/assistance dogs (Coleman et al., 2015)).

Leaving considerations of the meanings that participants ascribe to their assistance dog use aside, I conclude this overview with a reintroduction of an overarching feature of assistance dog use by participants in this study concerning living with multiple sclerosis. That this was lived within a landscape of uncertainty and change. Finally, this thesis has explored the lived experiences of participants over the life course. Deeply emotional and uniquely challenging accounts of recurring loss, interwoven with the experience of increasing age and disability were, as much a part of living with MS and using an assistance dog as the media friendly snapshots of 'amazing' canine helpers. The phenomenon of living with MS and using an assistance dog is shown in this thesis as ultimately becoming for participants a culturally situated, human response to disablism and to impairment.

8.1 Contribution to knowledge

This study contributes to the fields of human-animal interactions, critical disability studies and rehabilitation studies by providing insights into the experiences of disabled participants and their connections to, and use of, assistance dogs in living with a disability/chronic condition. It provides new insights into the challenges, benefits and lived experiences of using an assistance dog when also living with MS and its self-management. In addition, it provides in-depth insights into the experiences of a subset of the population of assistance dog users with MS. These findings may be of utility to assistance dog training organisations in targeting limited

resources for support of clients with MS, and to potentially assist them to make an informed/evidence-based decision about possible benefits and challenges of assistance dog use.

This thesis also contributes to the body of knowledge of IPA more widely, adding to and deepening the pool of IPA studies examining the accounts of people living with MS in relation to an aspect of those lived experiences – the use of an assistance dog. Smith (2011a, p. 25) presents four targets for the future development of IPA, the first of which supports the undertaking of new IPA studies in areas which now have extant IPA research in that area. IPA studies of illness experiences in neurological conditions such as MS, for example Borkoles et al. (2008), now exist. As such my research may contribute to 'the emergence of more integrative IPA research findings for particular topic areas' (Smith, 2011a, p. 25).

8.2 Strengths and limitations

Firstly, both a strength and limitation of this study is my status as an insider researcher, as outlined in Chapter 1 (Section 1.3-1.3.3). Being an assistance dog user and a person living with MS gave me the knowledge and experience to build credibility and trusting relationships with participants quickly and effectively. Allied to this was the assurance that participants were given of anonymity. The assistance dog community is fairly small, and it was important to make participants feel that they could share any of their anxieties and experiences, positive or negative; without the concern that a full report, in which they may be easily identifiable, would be going back to the charity that supplied their assistance dog (and remained the legal owner

of their assistance dog). In addition, many of the participants' previous experiences of interviews were 'feel good', triumph over tragedy pieces in media interviews or public appearances managed by assistance dog charities. The interviews undertaken in this study were such that the participants were relieved of the expectation that any negative comments may adversely affect the reputation or financial standing of the assistance dog charity. It allowed for an interviewee/interviewer relationship to develop beyond the more superficial, media friendly version of assistance dog use typically seen. This meant that interviews were in line with IPA's commitment to explore 'objects of concern' for participants and facilitated a participant-led interview. My experience as an assistance dog user afforded a degree of immunity from the novelty effects of the assistance dog-human partnership opening the possibility of a more balanced and authentic exploration of the phenomenon. This is demonstrable in the depth of experiences shared by participants and their willingness to share sensitive and difficult experiences of assistance dog use, and living with MS, with me.

An acknowledged limitation of the study is the ethnic makeup of the sample. Although IPA advocates the use of a broadly homogeneous sample, I am alert to the absence of any perspectives from a non-white participant with MS who uses an assistance dog, or indeed evidence of divergent experiences of participants in social interactions with more diverse members of the community. Equally the sample was exclusively made up of English people and the findings must be considered in the light of this cultural bias. Again, this is balanced by the acknowledgment that IPA places an emphasis on theoretical transferability rather than empirical generalisability

(King et al., 2014; Pringle et al., 2011). Meaning participants were recruited because they represented 'a perspective rather than a population' (Smith et al., 2009, p. 49).

Smith (2011a) describes the criteria for a good IPA study, and these include having a clear focus; demonstrating rigour; moving beyond a purely descriptive account of the data and offering a more interpretative analysis. Smith further advocates identification of areas of both convergence and divergence within the analysis. Criteria for a good IPA study also include those generating strong data (Smith, 2011a, p. 24). This study contains these elements which would, in accordance with Smith's criteria, be considered as key strengths.

8.2.1 IPA as an approach.

The clear theoretical underpinnings and established procedures in IPA made it possible to systematically examine the experiences of participants in this study whilst retaining a degree of flexibility in the presentation of results. This was both supportive to me as a researcher new to IPA and reassuring, knowing that the methodology and methods were appropriate to answer the research questions. IPA as an approach is clear that its commitment to idiographic engagement with the data is crucial to the understanding of the experiences of participants as individuals. For me this was an extremely rewarding, if at times overwhelming, experience. The amount of in-depth data generated by the semi-structured interviews was great and, the challenge of producing a plausible and coherent interpretation of participants' sense making of their experiences of living with MS and using an assistance dog was substantial. Being able to immerse myself in the minute idiographic details of participants' lived

experiences allowed me to develop a deep and personal understanding of their lives and was a great privilege. Equally, as an insider researcher the choice of IPA as an approach was highly appropriate in that it acknowledges upfront the challenging nature of bracketing one's previous experiences and fore-conceptions while providing a clear expectation that these must be openly acknowledged and shared. Unexpectedly, the process allowed me to put my own experiences into perspective and perhaps prepare for the retirement of my own assistance dog, in both practical and emotional ways, when that time comes.

8.3   Suggestions for future research

As discussed earlier in the 'strengths and limitations' section, this study represents the perspectives of a small sample that is exclusively white and English. As noted in the discussion chapter there is a dearth of research which explores the experiences and attitudes of non-white people around disability and the use of an assistance dog. The body of literature would be enriched by further research which is more representative of the UK today.

Similarly, the research identified more widely in a review of the literature and in the findings of the freedom of information request, a significant mismatch between the use of assistance dogs by disabled people on many levels and the evidence available. The need for further quantitative and qualitative research to establish in what circumstances, and for which populations, assistance dogs are likely to be appropriate or beneficial in living with their disability, is indicated. In particular, research is required to assess the scale and complexity of assistance dog use in the

UK by people with disabilities, other than physical impairments, which is unknown. Participants in this study initially applied for and obtained their assistance dog/s in mitigation of their physical impairments but, as has been established, emotional and psychological dimensions of living with MS were uppermost on many participants' minds.

In line with Fine and Ng (2020), and consistent with findings in this study, additional research on how to better support and prepare people with disabilities, their families, and allies; concerning the realities of (repeated) retirement/s and loss/es of an assistance dog/s over the life-course is needed. This should be explored with due consideration to the multiple uncertainties that may exist around living with particular disabilities and in particular situations. This may include issues around the continuing care and maintenance of the welfare of an assistance dog and the burden on their human partner/family/allies of caring for that assistance dog should circumstances change.

8.5 Chapter summary

This final chapter of the thesis has presented the conclusions of a study concerning the experiences of participants who live with multiple sclerosis and have chosen to use an assistance dog. An evaluation of the methodology and methods confirmed their appropriateness for exploring and systematically examining the perceptions and understandings of participants' experiences. This chapter has identified the strengths of the study, as well as acknowledging areas of weakness alongside recommendations for future research.

The phenomenon of assistance dog use is uniquely culturally situated. It is also under researched and rapidly expanding. This study has added to the body of knowledge on this phenomenon This may be useful in enhancing and adding to existing knowledge within the field of qualitative research, insights into human-animal interactions in disability and experiences of living with multiple sclerosis with an assistance dog.

APPENDICES

A   The Open University's Human Research Committee 'favourable opinion' –

Memorandum

B   Participant Information sheet

C   Consent Form

D   Interview Schedule

E   Interview Transcript Original – anonymised (P3 Maggie)

Appendix A: HREC approval

From Dr Louise Westmarland Chair, The Open University Human
Research Ethics Committee Email louise.westmarland@open.ac.uk Extension 01908
652462

To Grainne O'Connor, HSC

Project title Making the unbearable bearable: An interpretative
phenomenological analysis of people living with multiple sclerosis and the
experiential use of assistance dogs.

HREC Ref HREC/2015/2170 AMS ref Submitted 26/11/15 Decision date 01/02/16

Memorandum

This memorandum is to confirm that the research protocol for the above-named
research project, as submitted for ethics review, has been given a favourable opinion
by the Open University Human Research Ethics Committee (HREC).

Please note the following:

1. You are responsible for notifying the HREC immediately of any information
received by you, or of which you become aware which would cast doubt on, or alter,
any information contained in the original application, or a later amendment which
would raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the
HREC for review, so they can be recorded and a favourable opinion given prior to the
any changes being implemented (except only in cases of emergency when the
welfare of the participant or researcher is may be effected).

3. You are authorised to present this memorandum to outside bodies such as NHS
Research Ethics Committees in support of any application for future research
clearance. Also, where there is an external ethics review, a copy of the application
and outcome should be sent to the HREC.

4. OU research ethics review procedures are fully compliant with the majority of
grant awarding bodies and their frameworks for research ethics.

5. At the conclusion of your project, by the date stated in your application, you are required to provide the Committee with a final report to reflect how the project has progressed, and importantly whether any ethics issues arose and how they were dealt with. A copy of the final report template can be found on the research ethics website - http://www.open.ac.uk/research/ethics/human-research/human-researchethics-full-review-process-and-proforma#final report.

Kind regards,

Dr Louise Westmarland Chair OU HREC http://www.open.ac.uk/research/ethics/

Participant Information

Living with Multiple Sclerosis and the use of an Assistance Dog research project

Grainne O'Connor, PhD student, The Open University, Walton Hall, Milton Keynes, MK7 6AA email: grainne.oconnor@open.ac.uk Tel: xxxx xxxxxxx

Who am I?

My name is Grainne O'Connor and I am a PhD student doing a three-year research project with The Open University.

What is my research about?

I am researching the experiences of people with multiple sclerosis (MS), and their carers who have an assistance dog. I am particularly interested in people's experience of living with multiple sclerosis before and after they had their assistance dog. In the interview I would like to talk to you about a range of your experiences, whether positive or more challenging. You will only be asked to share what you are comfortable talking about.

How will I undertake the research?

I will be interviewing people with MS who have had their assistance dog **for at least two years,** about their experiences. The interviews will take a maximum of an hour. This should give you the opportunity to talk in depth about your experiences of living with MS before and after you were partnered with your assistance dog. If you wish to stop and rest at any time during the interview you are welcome to do so.

The interview will take place either at the centre where you and your dog were trained or if that's not possible in your own home, or if preferred by Skype.

I will be recording the interview so that I can make sure that I correctly remember what you say.

Will the information I collect remain confidential?

Yes. Your real name will not be used in any write-up of this research. The information you give will be treated in confidence and only shared with my supervisors Dr. Liz Tilley and Dr. Lindsay O'Dell (contact details below). My notes will be stored securely at all times and will be destroyed after the research is finished. I have to comply with the Data Protection Act (1998) and the Freedom of Information Act (2000). All the information you give me will be treated as confidential within the research team.

However, if you tell me something which may be considered a risk of significant harm to you or others, I am obliged to pass that on to the appropriate authorities.

Appendix B (continued)

If you would like any more information about any aspect of the research, please ask me. The original data from this project is destroyed five years after the date I started the project.

Can you leave the research?

Yes. You can leave the research project **at any time** without giving a reason. If you choose to leave the research before, I begin analysing the information and actively writing (approximately 6 months after I interviewed you), I will destroy all the information you have given me, unless you give me consent for it to be used in this study.

How will the research be used?

I will be writing up the results of the research for my PhD degree. It may be published in academic journals and for educational purposes. Extracts from the interviews will appear in the publications. No individual taking part in the research will be identifiable.

Are there any risks associated with you taking part in the research?

I do not anticipate that there are any risks associated with you taking part in the research. I am very happy to discuss anything with you during the research, and you can contact me using the details at the top of this information sheet.

Will I be paid?

Money will be paid to cover any out of pocket expenses like travel. Participation in the study is voluntary and it is important to show that the people who take part were not paid to do so.

If you would like to take part:

Please contact me if you would like any further information about the research or would like a consent form. I may be contacted by email or by phone using the details which are at the top of the sheet.

If you would like to talk to someone else about any aspect of this research from The Open University, you can contact the Director of Postgraduate Studies: **Dr Lindsay O'Dell at the Faculty of Health and Social Care, the Open University, Walton Hall, Milton Keynes, MK7 6AA**

Thank you for taking the time to read about my research project. I look forward to hearing from you.

Grainne O'Connor

Research supervisors: Dr. Liz Tilley email: elizabeth.tilley@open.ac.uk

Dr. Lindsay O'Dell email: Lindsay.odell@open.ac.uk

Appendix C: Consent form for persons participating in the research project:

Living with MS and the use of an assistance dog

Name*:*

Name of Project researcher: Grainne O'Connor

I would be grateful if you would please read the following and then sign at the bottom.

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have these answered to my satisfaction.

I understand my participation is voluntary and that I can withdraw at any time without giving any reason, and to withdraw any unprocessed data I have provided up to the point of analysing the data.

I understand that my participation involves being interviewed and have agreed that the information I provide can be used for educational and research purposes, including publication of interview extracts.

I have been informed that a summary copy of the research findings will be forwarded to me, should I request this.

I have been informed that the confidentiality of the information I provide will be protected as specified in the information sheet.

I consent to this interview being audio taped.

Participant Signature: _____   Date: _____

Appendix D: Interview Schedule

Introduction – Interviewer to read to all prior to starting

Thank you for coming to talk to me today about your experiences of living with ms and having your assistance dog.

If you need to take a break or stop at any point just let me know.

As you can see (only interviews with INT assistance dog present) my assistance dog is with me today. However, if you can, I would like you to answer the questions as though you are talking to someone who knows nothing about assistance dog's or MS.

Any questions before we begin?

ICE BREAKER

Can you tell me about when you were first diagnosed with MS?

How does your MS affect you day to day?

BACKGROUND

Is x your first assistance dog? **

What made you decide to apply for an assistance dog?

Prompt: family/carer reaction

TOPIC Living with MS/Long term condition

What does your dog do for you?

Prompt: physical/practical tasks, psychologically, emotionally, socially (may skip to Q about reactions from society).

What would you say the main differences are between living with MS before and after you had an assistance dog?

Prompt: physically, emotionally/psychologically, socially

How do you think your life would be if you didn't have an assistance dog?

TOPIC SOCIETY

How have you found people react to you with and without your dog?

Prompt: cultural differences, hostility, talk to the dog not you

How does that make you feel?

TOPIC CHALLENGES

Do you find any aspects of having an assistance dog challenging?

IF PARTICIPANT HAS EXPERIENCED RETIREMENT OR DEATH OF A DOG

Can you tell me about your experiences of losing your assistance dog?

P5 June Oscar Max Sam

Emergent themes in chronological order

Theme Key words	Page/Line	
Professional identities nurse was a nurse	1:6	am a
HP as unhelpful/peripheral the judge of that	1:11-14	I'll be
Managing self, managing ms own, always worked,	2: 21, 25-26, 9:114	I managed on my
Temporality AD's as markers of time more disability each AD	10:148-150, 150-162, 12: 144	
AD's are not machines Sam pulling out pansies	13/14: 184-192	Max was shaking,
Upskilling say yes, AD can't do it all	15:208 -210	contact them, they
AD as maintaining independence myself, tick off the list	16: 217-22	Pigheaded, worse for

Closer than family   17:236-243 good neighbours, family

miles away, won't move

Misdirection, visibility, validity   23: 317   not drunk something she's

got, attention on AD

AD assisting in adaptation in progression   23:326   in a wheelchair now

June,… back to Max

Reflections on identities - past, post diagnosis, throughout I used to be….. a nurse,

midwife, manager, social worker, athlete, Alan's wife, 'drunk', Not socialising,

nightmare, not wanting to be seen/not being seen Max's owner, social, healthy

person,

Appendix F: Thematic Framework

1.1.1.1.1.1.1 Recurrent Themes	1.1.1.1.1.1.2 Thematic Clusters	1.1.1.1.1.1.3 Super-ordinate 1.1.1.1.1.1.4 Theme
1.1.1.1.1.1.5 Illness account dismissed by health professional		
1.1.1.1.1.1.6 'Invisible' – self referred as	1.1.1.1.1.1.7 INVISIBLE	
1.1.1.1.1.1.9 Compares to previous ID no longer visible		1.1.1.1.1.1.8 VISIBILITY
1.1.1.1.1.1.10 Ignored by others		
1.1.1.1.1.1.11 'Non-person'		
1.1.1.1.1.1.12 Only ignored		

1.1.1.1.1.1.1.13	when with able bodied – Translucent self *Translucent self calculated as non-recurrent but partially related to aspects of recurrent theme so included	
Verbal hostility when perceived as drunk Slurred speech	1.1.1.1.1.1.1.14 HYPERVISIBLE	
Unsteady gait - physical Walking aids refused/accepted		

Needing extra space/time		
Leaky body in public sphere		
Use of 'we' or 'us' for partnership		
AD described as 'part of' self		
Participant as Parent		
	1.1.1.1.1.1.15 VISIBLE as 'We'	
Separation felt physically 'naked'/part of oneself missing/wish to be buried with		
AD-Human as 'Team' or 'Unit' Unable to 'see' future without AD		
Socially recognised as a pair Absence of AD noticed and questioned		

Appendix G: Super-ordinate Theme I – VISIBILTY: Calculating recurrence across the data set

Recurrent Themes across the group	HELEN	AMANDA	MAGGIE	ROY	JUNE	RICHARD	JO	STEVE	ANNE	ELAINE	SEAN	Present in over half the sample?
Invisible Self	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Hyper-visible self	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Translucent Self	YES	NO	YES	NO	NO	NO	NO	NO	NO	YES	NO	NO
Misdirection	YES	YES	YES	YES	YES	YES	NO	YES	NO	YES	NO	YES
Warrant 1.1.1.1.1.1	YES	YES	YES	YES	YES	YES	NO	YES	YES	YES	NO	YES

Appendix H Interview transcript

Participant: P3 'Maggie'

Interview date: 9 June 2016

1 INT: Thank you for coming to talk to us today. The first thing I am going to ask you about when you

2 were diagnosed first with MS?

3 P3: You mean what I was actually doing at that time. I was deputy head of a very large split site

4 secondary school for students with severe learning difficulties was their main, you know, they

5 didn't fit in anywhere. Along with that, of course, they had behavioural problems and physical

6 disabilities and epilepsy, autism, blind and deaf unit. 42 members of staff and, and daily there

7 was other therapies coming in; speech therapists, psychiatrists, the lot. So it was a very.

8 INT: Busy, high pressure.

9 P3: Busy. It was one that I enjoyed because you never quite knew what my day was going to bring. I

10 mean obviously I had certain set things. There was always a crisis or something. You know it

11 perhaps sounds silly to say, but I did you know and then gradually of course, I started to get ill

12 you know, all kinds of different things that I didn't quite know what was going on you know. I

13 did nothing about it for ages, I am very good at putting up with things and I did that, but I did

14 that for quite a long time and gradually got referred to a neurologist and that and the diagnosis

15 was given. I was told by a neurologist

16 not to mention it, so I had to absolutely had to because in his experience I would probably find

17 that I would lose my job or you know, how things sort of go. So, it was you know locally, the

18 place I work in is designed for people with physical disabilities, it should have been the perfect

19 sort of work set up, but unfortunately at that time the head that I had worked with had retired

20 and a new one came along, but obviously I was in no position to, which as everybody thought I

21 would take over and erm, {pause <5] well to put it mildly, she had no sympathy whatsoever with

22 anybody and things got pretty bad. In the end she did actually bring the school into special

23 measures, she lost her job and she ended up in a psychiatric unit and she died before she was,

24 she was only about 50 I think. So you know I don't think it was just me, it was you know the

25 circumstances. I was told if I didn't retire and take early retirement then I would be you know, I

26 would {pause <5] go really downhill very quickly. So I made the decision to take early

27 retirement and erm, but I was still very determined that, to get the better of it, but I erm, very

28 self-conscious, I always tried not to draw attention and suddenly finding myself going out, very

29 wobbly you know, sort of all the things I am sure you are very familiar with – I found people's

30 comments and people asking me things and people, not quite knowing how to react, 'oh it is a

31 bit early to have been hitting the bottle' or 'you should put more water with it', oh they were

32 meaning it in good fun, but you know it got to the point where I was getting – one more person

33 makes a

Appendix E: (continued)

34 comment like that to me, you know I am going to, I am frightened I might just be a little bit cross

35 and I just you know, felt so vulnerable that in the end of going out. At that time, I had to go out

36 shopping, I mean the idea of shopping on the internet or something was totally unfamiliar to me

37 at that time.

INT: It wasn't 38 really the norm.

39 P3: No, and so I didn't, that was really it. I didn't go out. I had got neighbours who, a very young girl

40 that helped me and I had a community physio who dealt just with motor neurone and she used

41 to come to the house and visit me every week, and she also visited the very first support dog

42 that was ever trained, erm [Name}, and she told me about this and got the leaflet and

43 mentioned. If I am rambling on let me know.

44 INT: No, no.

45 P3: And she got me the leaflet about it and it still took me ages, but the main thing that really struck

46 me with it. Well there was two main things that struck me. One was that they would not take a

47 dog off you once it didn't (qualify) at that point, at no point and the second thing was, that if the

48 dog was successful and qualified, they could go everywhere with you. That was what they did

49 want, and that was what did it for me. I thought If I can take my dog with me I will go out again,

50 and obviously got on to training process. I must say, by this time I

51

Appendix E: (continued)

didn't realise just how much I had lost confidence you know, I was very apprehensive 52 at going

53 out, wasn't doing things and so was Ella, because I live in a village and obviously, she was used

54 to going in the fields all the time, but not really busy areas.

55 INT: Of course, yeah.

56 P3: So, in a way both of us together learnt again to go out and meet people, and I just, I mean [AD

57 Trainer]says she still uses, she trained Ella, she was you know the first person that I had contact

58 in for that, [AD Trainer] and she says that you know, she used to phone me and I was always at

59 home and then suddenly when I had this dog, when she qualified, she used to phone and I was

60 never in, she started leaving messages for me and so, you know, that just made, just made such

61 a tremendous difference and it takes a while, as you will know, to actually, adjust to having this

62 dog and suddenly when she was qualified and I could go out on my own. I know I have heard

63 people say it and it is a bit like it really, that erm, it is just like suddenly getting your driving

64 license. You start learning in a way, but you are on your own and you are going out and I was,

65 she hadn't got this training jacket on. She can't make mistakes, you know, I can't say well she is

66 just in training because she is not, but it was just the beginning and people got to know us and

67 talk to us and you know.

68 INT: It must have been quite an unusual sight at that point?

69 P3: That's right, well I was considered blind.

70 INT: Right.

71 P3: By most people because she was a golden retriever for one thing.

72 INT: Okay, you can understand that yeah, yeah.

73 P3: I mean people still don't know about assistance dogs in many ways, but at

that point it really

74 was guide dogs with as much as people knew, and also I am light sensitive so my

glasses very

75 quickly go dark, so that didn't help and – oh I was taken across zebra crossing

that I didn't want

76 to cross at.

77 INT: Oh no.

78 P3: But it, that was necessary.

79 INT: Did you just go with it?

80 P3: Yes, I though, you know well they were being helpful and I didn't want to stop

that.

81 INT: It was coming from a good place.

P3: That is right, but erm, I think the funniest thing really was when somebody 82 stopped and

83 watched me park my car next to them and got out of it and then they guided me into the place I

84 was going in, it was my driving instructor. Did they think Ella was so clever that she was telling

85 me what to do you know [both laugh [, but no, I mean I just, it just absolutely, absolutely 100%

86 changed

87 my life, you know, having Ella so. I don't know if that is the sort of thing you wanted to hear.

88 INT: Obviously Ella was your first assistance dog and Sunny, who is here today?

89 P3: Second.

90 INT: Second. What, so what, how long did you have Ella for?

91 P3: She worked tile she was 13 because at that point they didn't have the cut off at 10. I got, I

92 didn't get Sunny until Ella had actually retired and I still need, although they had tried to get me

93 to get another dog and soon realised that I was almost back to square one because I couldn't go

94 out again. So then, so I had still got Ella and I wanted a dog that was totally

different. I [pause

95 <5] also wanted a dog that, you know, would have a good life span and I know

anything is you

96 know, the luck of the draw whatever you do, but that I felt would have a good life

span and I

97 knew about [AD breed] and so I got all the information I could and basically,

everything I read

98 was just perfect about them. They love to be with you, they like joining you with

everything and

99 they go on forever. So, I applied to the [AD Breed] club and spoke to them. I didn't

realise at

100 that time that you did actually have to apply for a dog, they were very, very strict

about who

101 they let their dogs go to, which is to their credit isn't it, but AD Trainer again, she

always,

102 eventually I was told about this little dog. In the meantime, AD Trainer had gone

to a place to

103 see beagles because they

104 didn't know about them and, which is something that they insist you do and

Sunny was chosen

105 from the litter at six weeks old and then I went and picked her up at [inaudible] and she more or

106 less started her training from the time she was fully vaccinated because they allowed me to

107 puppy walk her. You know, she was assessed with, she was fine with them and the places that

108 knew me with Ella allowed me to take her in. I mean I wanted a different dog and oh what a

109 difference. I know the first time I went to Sainsbury's with her, I mean, I didn't go shopping.

110 She whipped me around the trolley so quickly I couldn't do it. [both laugh], so I went down and

111 popped her in the car and went back in [both laugh].

112 INT: And did your shopping.

113 P3: So, but and then erm, Ella went downhill fairly quickly. She was nearly 15, but she died, but

114 Sunny wasn't qualified at that point, but I was using her and then, which was initially quite good

115 because at the end of the day with Ella you had to say to her, {inaudible} you know at the end,

116 but then [pause <5] you know, sadly Ella died.

117 INT: Yeah and yet.

P3: It is not easy to talk about 118 those things.

119 INT: But you mentioned that the charity had obviously introduced to you that Ella

was going to need

120 a successful dog if you wanted to continue with assistance

121 dog and you say they tried to, to, to broach that and bring that up with you. Yeah,

what, how

122 was that brought across?

123 P3: Well I mean it was done very similar to how they do it now really, except

there wasn't a definite

124 cut off point, so she was still having assessment and in my mind she was still -

okay to work with

125 her and she was, but as I say, they said she couldn't go on forever, the best

thing to do was –

126 they didn't want me to have a spell without.

127 INT: A dog.

128 P3: An assistance dog that was qualified and ready to take over. The reason it

was me that at all

129 points was in opposition because, I suppose the problem is when you are on

your own you

130 haven't got somebody to take over that responsibility if the dog is retiring and I,
]pause <5], I

131 don't know, it is, you know it is putting a human erm, aspect to some extent, on
the dog, which I

132 know they are not but I thought, is she going to be hurt, you know, I am suddenly
going to have

133 this, this dog that is taking over and everything that she did, and she was still
very happy to work

134 at home you know, she was still, and it was just, fi there had been. I think it
would have been

135 easier if I had somebody else that could have you know, sort of taken over her,
kept her

136 entertained if you like if you know what I mean, whilst the other dog gradually
took over, but

137 with not having that erm, I just couldn't see how it was going to be and of course,
I left it too

138 late because I introduced a puppy to Ella when

139 she wasn't really erm [pause <5] at her best to take on a lively you know, young
dog. So in the

140 end I made it more difficult for her because I was dividing my time between.

141 INT: You were conflicted.

142 P3: I mean after this very lively puppy that needed my attention and very old dog that was going

143 downhill and also needing my attention, so it was very, very stressful time and one I wouldn't

144 want to go through again. When Ella died erm I was at a very low ebb.

145 INT: Of course.

146 P3: For quite a long time because losing any pet is traumatic, losing one that has absolutely done

147 everything and been everywhere with you 24 hours a day. Somebody had said to me that erm,

148 you know it was worse and I don't know it can't be worse I don't think, than losing your pet dog,

149 but it is, very much so because suddenly that dog that is a pet dog, a companion, but they are

150 also your rock, you know, they are absolutely everything to you, because she wouldn't

151 understand even though she was old, you know grey come on.

152 INT: Let's play.

P3: You can give me 24 hours' attention now you know, and so yeah it was, it was and 153 I don't, I just

154 don't know how it could have been any easier, okay I left it too late to get a puppy, but I don't

155 think it would have made it any less

156 traumatic for me. You know, these things hurt at any stage really, without having somebody

157 that would have just taken that responsibility.

158 INT: And been there and been there for Ella if she had retired.

159 P3: [inaudible] and I am not meaning that you need any more if you are on your own, but I think you

160 rely on them a lot more because they are your only source in life, for everything, so it was

161 difficult in the end, very.

162 INT: And it is interesting you say about how you, you don't think you could have made it any easier.

163 We have talked a little bit about Sunny who is nine in June is it?

164 P3: July.

165 INT: July, and that must be playing on your mind a little bit?

166 P3: It has played on my mind in every conceivable way, I think I have spoken to you because I have

167 to say I don't understand there is this same cut off, every dog is different. I think there are some

168 dogs definitely that are ready to retire, so, but I think there are some dogs that, I can think, I

169 have already had the last assessment she had or interview and I have had to say that no, I can't

170 have another dog because..

171 INT: Oh really.

172 P3: For several reasons. I can't see that I can manage two dogs, two active dogs. I can only go on

173 how Sunny is now, I mean in a years' time something could have happened, but I can't, I can

174 only go on how she is now. How Sunny is now being that she absolutely loves going out, I live in

175 this very quiet village where, unless people come to visit me, I don't see anybody because there

176 has never been a shop or anything like that and she just loves people. We can go out every day

177 even if it is just a short visit somewhere, we go out and meet people, she loves it. I mean, post,

178 the washing machine, all these things, I mean she just, I mean I still don't know she doesn't

179 knock herself out when she hears the postman because I have this long passageway, which leads

180 down to the front doorway, the post box there and she goes charging down and I think, please

181 stop [both laugh] before you get to the door.

182 INT: Crash.

183 P3: And she charges back in the same way with the post. The washing machine, I mean she can be,

184 and I have a very large one, she can be right down the garden and she still hears that click.

185 INT: Really.

P3: The washing machine has finished and she charges back up as if it's like the best
186 thing that could

187 ever happen to her, you know, she is going to empty the washing machine and that, I wouldn't

188 be surprised if the whole village doesn't

189 hear her emptying because she is so excited, and the idea of just stopping all that, just because

190 she has reached ten. You know.

191 INT: That feels unfair?

192 P3: I can't understand it, and to then leave her at home and take another dog out, I can't see it and I

193 am very frightened because I think I will just stop going out again you know, and of course now I

194 don't have to go out I can go – apart from places where I can actually take a pet dog, you know,

195 that will be it really. I mean you know going out for coffee, meeting friends for lunch, all those

196 things where I can take her with me, just, I just can't see.

197 INT: That wouldn't happen?

198 P3: I can't see how I could erm, and as I say I can't see how I can physically now manage two dogs

199 you know, even though I only have to literally walk a little way to the fields, I still have to go that

200 little way along the road and when it is icy or you know, in winter, I still struggle.

201 INT: That feels treacherous?

202 P3: Yeah. So

203 INT: Talking a little bit about when you are out with Sunny, do you feel people treat you differently

204 when you have Sunny? Obviously you are not very, very often ever without her, but maybe

205 thinking back to before, the way people treat you with the dog and the way they treat you

206 without a dog?

207 P3: Yes, without a dog I think people were unsure of what was wrong with you, they didn't know

208 how to approach you. They certainly, some, I won't say, well to some extent they weren't as

209 willing to give you time to do things you know, because obviously I am a lot slower at doing

210 things. It takes me a lot longer to do things and you know, that little bit extra space as well I

211 think to you know, if I am crowded then I feel not used to it, I feel very vulnerable and worried

212 because I am capable of falling over very quickly, and with a dog first of all for me, the very good

213 thing is people notice the dog and not me, which suits me down to the ground. That is what I

214 want, the fact that people will say 'hello Ella' 'hello Sunny' and not even know who I am, to

215 some people they would find that offensive, for me, that was absolutely ideal. I could work

216 through my dog sort of thing you know. People give you space and they might not have any

217 idea what is the matter, they might not even know you, but they know that if you have got an

218 assistance dog you have got it for a reason, so there is something wrong and, erm I mean just

219 look at me, people I mean, I used to go to erm, Sainsbury's we used to refer to as the Thursday

220 Club because people came and it was coming to see Sunny.

221 INT: Oh really.

P3: Well 222 and Ella you know.

223 INT: Yeah, yeah, yeah.

224 P3: And then Sunny and it was lovely, I got to know so many people that almost became friends you

225 know, that really were totally strangers you know, but we chatted and so in that sense you were

226 treated differently, but to me in a much, much nicer way [inaudible] it's just lovely because

227 people are there waiting and this morning, because I went up, and it is usually Thursday when I

228 go to the.

229 INT: Oh my you have been today.

230 P3: And I said, oh we are going to be going up to the centre and so I am not going tomorrow as well,

231 and I wanted to pop in, so treated differently in that, in that way, but to me a nice way, and

232 people will spend, of course I get stopped for two reasons by total strangers. One, people don't

233 know [AD Breed], so first of all it is.

234 INT: It is an unusual dog breed.

235 P3: Or they come up with their own ideas ranging from Afghan Hounds to erm, Labradoodles to, you

236 name it, but just occasionally somebody will turn up who knows [inaudible] and of course they

237 want to know what she does, so it is a wonderful opportunity to promote the breed and the

238 charity really, and the work that they do and that there are dogs other than guide dogs you

239 know so.

240 INT: When you say you think people treat you differently, when they are asking you questions about

241 Sunny, what she does for you, do you feel they are talking to you as you rather than a disabled

242 person that they would have ignored?

243 P3: I think they are genuinely interested in what, it is a difficult one to answer because if I have

244 somebody with me, if I have got a friend or somebody with me then nine out of ten times they

245 will ask that person.

246 INT: So they will defer to that person?

247 P3: Yes.

248 INT: Okay.

249 P3: And they will not answer because you know, that is what they find that annoying, well no not

250 annoying, I find it annoying, and so they won't answer or they will say, well ask Maggie you

251 know, she can tell you that. If I am on my own then I think, I think they speak to me as a person

252 rather than a disabled person, but obviously I am disabled and I have got Sunny because I am

253 disabled, so the two I think kind of go hand in hand, you know, the, the questions they are

254 asking me are related to what she does for me.

255 INT: Do you think they find it easier to talk to you because you have the dog?

P3: Much, definitely, yes definitely and the question I get are sensible questions 256 as opposed to

257 people not quite knowing what to say to me, like I even once got 'oh dear, couldn't you keep on

258 the skis?' and you know it is just, I understand that it is people's kind of embarrassment at not

259 knowing what to say.

260 INT: They feel awkward?

261 P3: That's right, so I think when you have got a dog with you they feel much more comfortable, and

262 erm [pause <5] and they are the, they break the ice, they you know, they can talk about the dog

263 initially. You know, 'what a lovely dog she is'

264 'what kind of dog is she?' and then they can, if they want to, they can broach 'what does she do

265 for you?', but if they don't want to, they don't have to you know, they have just spoken about

266 Sunny as a dog. So, I think there is lots, I think it depends very much on the person that you are

267 talking to, but definitely if I am with somebody then they would ignore me in front of that

268 person, not always.

269 INT: Yeah, you have talked a little bit about obviously, Sunny, Sunny's

retirement, obviously one of

270 the big challenges about having an assistance dog they don't go on forever as

you say, but as

271 well as the brilliantly positive things that you re saying that she does, can you

think of any other

272 challenges about having an assistance dog, apart from obviously that they?

273 P3: Quite honestly I can't think of a single thing, no I can't think of a single thing

that I find difficult

274 of having an assistance dog, nothing. She is still my pet dog, she is my

companion, but she just

275 makes me laugh every day, at some point every day she is just so bizarre.

276 INT: [laughs]

277 P3: And we need it if it is just coming in from outside, actually covered in dried

leaves and tree

278 stuck, because I have got a massive Christmas tree in the

279 garden, all that kind of stuff and you know, thing that she does if I am not looking

at her, she

280 comes with her little paw you know, and taps me on the leg and I mean, this

particular day

281 when she started that you know, and there was one time and I turned round and she was just

282 absolutely covered, honestly,

283 she must have been rolling and I just burst out laughing at her, and so she started to do what

284 you know [inaudible] do, which is twirl round and round you know.

285 INT: Yeah, yeah, yeah.

286 P3: And of course stuff was going absolutely everywhere, in the kitchen I had got things flying here,

287 there and everywhere, but you know it is those sort of things she does every day, she just, and

288 she can make the most mundane task enjoyable, you know she really can and – Ella was right for

289 me because she was a very quiet dog who loved going out or finding it difficult to go out, I mean

290 there are occasions where I got to the car and thought I can't do this – Ella was quietly

determined, come on, definitely not, she is perfect for me now because I am 291 so frightened of

292 giving in because I know it would be easy to give in. If I am genuinely having a really bad day,

293 she is so perceptive, she knows that, she puts no demands on me, like she is,

when you know

294 the [inaudible] no demands on me whatsoever, she understood perfectly, but if I

am just

295 thinking – oh I just can't be bothered, no way she is going to let that.

296 INT: She is not going to accept that?

297 P3: So she is perfect, because I always feel better for going out, you know. So,

erm, I genuinely can't

298 think of one single thing that I would say was, worried me about having and

assistance dog or

299 made me uncomfortable about having it, I just love going out with her, I am 100%

confident

300 with her when I am out in whatever situation I am in, whether it is shopping or

restaurant or

301 anywhere you know, she is, no I think take her jacket off and she is.

302 INT: She is an angel.

303 P3: She is an angel; she is a dog in two halves.

304 INT: Obviously with your MS you must have a lot of interactions with the NHS

and Sunny can be with

305 you?

306 P3: Yes.

307 INT: Is that something where you, do you have quite a few hospital appointments or?

308 P3: She goes to hospital with me, there has been occasions I have had weekly visits for quite a long

309 time to a hospital in XXX for physio, which is quite recently actually and they were more than

310 happy for her to go, but we didn't do anything because everybody was so [laugh], she was the

311 life and soul of everything, you know, and it was, it was [pause <5] what do you call it,

312 rehabilitation or something neurologic rehabilitation I think it was or, so it was a big open room

313 and there were other propel and nobody did anything because everybody wanted to talk to her,

314 even all the physios wanted to come and talk

315 to her. So, I just think perhaps you know, it would be a good idea if I leave her in the car, which

316 is actually, Sunny has never been left at all, but she is happy

317 to stay in the car for short spells you know, I don't think very often, so that is, but that is the

318 physio therapy sessions I have been to, anything like that she always comes with me. I am kind

319 of on my own accord, stay away from endless visits to neurologists. It is just

depressing that you

320 are not getting anywhere, so, but she has always been allowed to go. I have

taken her to visit

321 people who are in hospital.

322 INT: Oh I bet that has been fun?

323 P3: Oh yes, yes, yes, I visited somebody fairly recently and it was in the XXX

Hospital in XXX and they

324 were thrilled to bits to see Sunny, except we, I don't think I really spoke to her at

all because

there was these constant stream of nurses and doctors going, we have been 325 told

to come and

326 have a look at this wonderful dog. [laughs] and so, by the time we had finished

all that the

327 visiting hours were finished you know [laughs], anyway, the person I had gone to

see had

328 enjoyed it and she said later, she said, 'well actually' she said 'everybody just

kept coming to talk

329 to me about her', so she got spoken to through her. So I have never had, the

only time I have

330 been you know, that there are any problems is there is any sort of treatment, if

you are going

331 into a treatment room, it is you know, but otherwise they have been really welcoming, we have

332 never had any problems whatsoever.

333 INT: It sounds like the experience of going to hospital more?

334 P3: Enjoyable.

335 INT: More enjoyable.

336 P3: And for everybody actually because I have walked into waiting rooms where there has been

337 people all sitting looking glum, I have walked in with Sunny and immediately you can see this

338 kind of, people are smiling, people start to talk about her, ask questions, and so.

339 INT: It lifts the mood.

340 P3: That is right, yeah, yeah, very much so. So I am sorry I am not finding any negatives for you.

341 INT: That is not a bad thing at all. I am going to have a look at me, I think if there is anything I

342 haven't.

343 P3: It is because I keep rambling on don't I?

344 INT: It is all good stuff; it is not rambling at all. It is lovely.

345 INT: Do you have family or relatives in this local area, or how did those people react when you said

346 you were going to get an assistance dog? Can you remember back?

347 P3: Yes, my family are in Canada and I don't have any family, well I have a cousin who is nearly 90

348 who lives in Scotland, but other than that, they were all very,

349 very supportive and pleased because dogs have always been in a very big part of our life anyway

350 so the idea of something like that. When they, my brother and sister in law come over to

351 England they are always really, you know, want to go out with them and do things so they are

352 very, very supportive and understanding. Friends; erm, you know extremely so, in fact they are

353 all worried sick as to what is going to happen over time and stuff, so no negatives on that score

354 either. [inaudible] No, no negatives at all no and also very willing and they are all well trained

355 now, but when Ella was being trained initially I had to get everybody, that they all have to react

356 exactly in the right ways and they were all very good about it, even to the point of when Ella was

357 very frightened of anybody with a helmet on. So they lent me, some squeaky toy, they lent me

358 this helmet and asked that anybody coming to visit me would perhaps put this

helmet on, so

[laughs] I had this helmet at the door [both laugh]. You can come in if you 359 put

this helmet on

360 [both laugh], which they did willingly I have to say, so that has all been good and

it is getting you

361 know, [inaudible], so they have been good.

362 INT: Have you ever had negative reactions to her when you have been out?

363 P3: Yes, quite recently at a place that I have been going to for years. It was very,

very distressing

364 and I do intend to go back there some day, I did report it to AD Charity it is erm,

a little, it

365 started out as a herb centre, just a herb centre and it just did herbs and things, I

am very

366 interested in herbs and things and I went with Ella and that was fine, they were

very welcoming,

367 then this place over the

368 years this place has developed and developed until it is a lovely, it was just a

coffee place and

369 this herb centre, then it was a shop and coffee place and then it was a place

where you could

370 have lunch. It has got bigger and bigger and I have gone on a regular basis and taken people,

371 you

372 know friends and things and introduced them to, and one day [inaudible] and I took her in and

373 we were going somewhere else. I was not feeling very good, so the friend I was with said 'look, I

374 don't think you should go there you are not really fit to go, let's go to the herb centre and have a

375 coffee'. So we were slightly early – they don't open until ten, but the shop part does, so we were

376 in the shop just looking around and the assistant, the one came and stood next to me and didn't

377 say anything and I didn't say anything you know, but thought it rather strange you know

378 because they were all so friendly, and I didn't actually recognise this assistance, but the people

379 in the coffee place because it is like all one place really, just go through an archway into it, were

380 all chatting to us because they knew us, you know and when we walked through the archway

381 this person that had been standing next to me in the shop, came through and said 'we don't

382 allow dogs in here', so, but before I had a chance to answer, looked down and said 'oh but she is

383 an hearing dog', so I started to say 'no she is not a hearing dog', when you said 'I think you have

384 been extremely impolite with us, and you should have asked if you could come in', so I said 'well

385 I am very sorry it didn't occur to me to because I have been coming here for years'. So he said,

386 'well I have never seen you before', so I said, 'well other people have', you know, I said 'I have

387 been coming here', but

388 he was so offensive and went on. So, in the end, I said, 'well look', he said, he just kept saying

389 'you know all I am saying is should have asked' and 'you should have asked', so I said 'look', I

390 said 'I got my little yellow what [inaudible]' and he started to say 'no, no' the person I was with

391 actually was

392 really getting quite upset as well, so I just said, 'look', I said, 'I am not sure whether you are

393 aware, but you have actually broken the law by saying that I can't come in here'.
Went through

394 various places, but she is allowed and you know, should have been and I said, 'I
am sorry but I

395 will report you'. So he said, 'fair enough, go ahead, report me'. So, I did, I rang
AD Charity and

396 told them, but erm.

INT: Oh that must have been 397 very upsetting.

398 P3: It was upsetting, and also there was, we were the first people there, there
was nobody else in.

399 When AD Trainer rang them, erm, they said, 'oh we had just had a lot of dogs in
that morning'.

400 Dogs, they had already told me they didn't allow dogs and there was absolutely
nobody there

401 anyway and nobody even came whilst we were there, you know, and so they just
lied and said

402 that they were really, you know very supportive and they always welcome
disabled people in

403 there. They had had a group in in wheelchairs, well for one thing you couldn't get
a wheelchair

404 in there you know, it is not good in that sense.

405 INT: Access wise.

406 P3: No, so I have not yet found anybody who is prepared to go back with me because you know,

407 everybody that I told was so upset about it, well I have every intention of going back because if I

408 don't he has won.

409 INT: Yes, yes.

410 P3: And I shall go back and I shan't ask if I can go in, I shall just go in. That is the only negative in 20

411 years or something of having a support dog.

412 INT: That is not bad is it?

413 P3: No, it isn't, but it was extremely distressing. Went, seeing as we couldn't have coffee there,

414 went to XXX where I mean they were just, I know 'oh a wonderful dog, come on', talking.

415 INT: Come in, come in.

416 P3: Yeah, so couldn't have been more different you know at that time. Yeah, so there are still

417 people out there, few and far between, yeah and I mean, obviously it wouldn't have occurred to

418 me to ask there, even if I hadn't been before I wouldn't have asked first, because I know they

419 are allowed in places like that. If, if I think there is any doubt then I don't would always say, 'you

420 don't mind if I bring my dog in do you?', you know, even though I know she can go in, I would

421 still question, just to be polite really. So to be called impolite, I was [laughs].

422 INT: If anybody was being impolite it probably was him.

423 P3: Well it was yes.

424 INT: So because you are really one of the original people having assistance dogs in XXX, you must

425 have seen a huge growth in the whole assistance dog world in the time that you have been

426 around?

427 P3: Oh yes definitely and they are certainly much more accepted now I think generally and I think

428 people more and more, certainly major shops are very aware of all these types of assistance

429 dogs, and I think one thing that you still rarely see, but is gradually has got less is, I mean for a

430 long time what you saw was guide dogs and you are now, it is very, very rare to see them, you

usually seeing assistance, dogs allowed in, so in that there has been a great 431 improvement. I

432 think just generally there is more facilities available, like when I go, a lot of places I go to now

433 are very quick to say 'would your dog like a bowl of water?', you know which you would never

434 have gotten at one point, not because they were against it, but because it would, they didn't

435 have that kind of facility to offer you. Theatres, you know, all those kind of places, I mean, they

436 just ask you let them know if you are going with an assistance dog, but that is so that they can

437 make sure that you have suitable seat, a bowl of water, it is generally to make things easier for

438 you. So, yeah and I think the general public are getting more aware. I think, unfortunately, it is

439 still for some reason the two that are best known are guide dogs and hearing dogs, you know,

440 probably hearing dogs was the next to guide dogs probably, in getting established I don't know,

441 but I am not sure about that. I think also in names [inaudible] in this.

442 INT: With, with support dog or with assistance dogs?

443 P3: With a support dog, the name support dog. I have had I am afraid, people say, 'oh I do support

444 dogs' you know PDSA or the RSPCA. So that, that is a shame, so I am not sure if you have, be told

445 the idea of what they do for you

446 as an assistance dog, but obviously it is support dogs that you have got and see first, but again

447 that is not often you know.

448 INT: The, one of the first things people seem to ask you certainly, what does the dog do for you?

449 So that, and it is lovely to say, well she will do the washing, she will do the post, she will, and all of those

450 tasks, and a lot of what has come across today is actually the emotional impact of an assistance dog.

451 P3: It is the first thing I say almost, when people say to me, 'what does she do for you?', I always say

452 'first of all she has given me the confidence to come out', I said, I always say that every time I am

453 asked, and then I will say the different tasks that she does, occasionally people will say to me

454 [inaudible] 'is she one of the dogs that does the washing for you' you know, so if they approach

455 that first then I will obviously say yes, and you know, but I definitely always say because it was,

456 that was why when I had my initial interview and it was [inaudible] obviously in the days of AD

457 Charity founder and you know 'what are you hoping to get from having an assistance dog?' and I

458 said 'confidence, confidence to make me go out again without the embarrassment' and that is,

459 they have given me confidence in, in summary. I mean in the early days I remember one of them

460 saying, 'you know, I have never heard you talk so much to total strangers, you have never been

461 that sort of person, you have always been you know, quiet and', I wasn't exactly withdrawn, my

462 job didn't allow me to be withdrawn, you know, sort of always taking a back seat and now you

463 are quite ready to chat and talk so.

464 INT: You are out there

465 P3: And, so erm, and I would still say [inaudible] are very good and still say to

me, as you say, the

466 emotional, the confidence and that kind of support has been a major thing for

me. Anything

467 else?

INT: You can say anything you want, it has been absolutely lovely, I have had a look

468 at my list and I

469 think we have, I am going to see if there is anything I can think of.

470 I suppose on balance really, what do you feel the main difference is in having an

assistance dog

471 and not having one? If you were going to kind of summarise?

472 P3: Pretty well everything, I dread to think had I not got, had that physio not

introduced me to AD

473 Charity I dread to think how I would be now.

474 INT: Really?

475 P3: Yes. I am not a person that given in easily at all, I am [pause >5] very, I don't

really like talking

476 about disability nor anything else, but I really think that I would have given in in

the sense that I

477 probably would have become a hermit I think and unfortunately, with technology

now allows

478 you to be and I think that is how I would have been, it wouldn't be just, not just in the

479 confidence, in all the other interests, I mean coming here you know and the fund raising things,

480 the talks we have been on, you know, all those sort of spin offs from the actual

481 assistance dog work, you know sort of thing, because everybody here is so lovely you know.

482 INT: Absolutely.

483 P3: So, and even though it is not part of what you know you are doing, but that is what worries me

484 terribly in a years' time, because I am just over a year and I know, I mean my friends said if we

485 write a letter you know, they are more worried than me really you know, so, but I don't think

486 there is anyway. I mean I don't want special privileges or anything when I scored from that, I

487 would just like another couple of years if she was still happy to work with me, would make a

488 massive difference, and yeah, that is by the by.

489 INT: Is that something that is an ongoing conversation between you and the charity?

490 P3: Well I think it's, I think that is it now I mean I have, it is [pause<5] am I still

absolutely dogmatic

491 that I won't get another dog, well that is not so attractive when you think, the

thing I am

492 absolutely dogmatic about is I need another dog, I need another assistance dog,

but I can't

493 manage two dogs unless something happens within the next twelve months, you

know, to, to

494 get another dog when I haven't got somebody that could take over the

responsibility of Sunny

495 for me you know, and I could not, I have sat in interviews where people are

having another and

496 they are [pause <5] really want to let this dog go to another place.

497 INT: So to have them rehomed?

498 P3: Yeah, No I it is absolutely.

499 INT: Not an option?

500 P3: No absolutely not, so.

INT: So that is facing quite an 501 uncertain future?

502 P3: Yes, and it's erm, it is almost [pause <5] you know overtaking my pleasure of

having her here if

503 you know what I mean.

504 INT: It is spoiling the working time?

505 P3: Yeah because I keep thinking, she wills 9 on the 3rd of July, my birthday is in July and I am

506 thinking, that will be the last time that I will be able to go out for a birthday lunch with my

507 friends [laughs] because next birthday, my next birthday she won't have time. You know, I am

508 starting to think like that, I can't help it you know.

509 INT: Do you feel like the clock is counting down?

510 P3: Hm.

511 INT: Very much?

512 P3: Yes, more so than, much more than me worrying about how I am going to you know, my

513 physical condition because in a way it is all tied in because she is keeping me going whilst ever I

514 am keeping going, I am keeping control.

515 INT: You are managing?

516 P3: The condition.

517 INT: Your condition?

518 P3: Yeah.

519 INT: Do you feel that if, if when Sunny retires that you will need to take on care,

paid carers or is that

520 something you would not be keen to do?

521 P3: It is something that would be absolutely the end for me because.

522 INT: Really?

523 P3: Because I am such an independent person that you know the only kind of

paid help I have now is

524 the window cleaner [laughs] because I can't manage that. The garden is going

to, but it is a

525 wonderful wild garden you know, wonderful for her and me, got a very good

friend who come

526 and cuts the grass for me and you know, does a bit of gardening when things,

just kind of walk

527 around the garden anymore you know, so but in the house I am still, it takes me

massively

528 longer than and nothing is as immaculate as it used to be you know, it is.

529 INT: But you are managing?

P3: I manage, yeah and she will still be able to help me because in the home she

530 is retired. I am

531 sorry that has got nothing to do with you. Well in a way it has because.

532 INT: Well it is your experience of living with MS with an assistance dog and it is very pertinent

533 because that is something that all assistance dog owners will face, yeah.

534 P3: And in a way it is similar to how you were before, how the assistance dog, because it is going

535 back to not having an assistance dog, but in a way worse because you have had the experience,

536 so.

537 INT: You have had the help and now it has been taken away?

538 P3: That's right, it is going to be slightly harder, a medication that is really helping you and suddenly

539 somebody saying, 'look I am sorry we have suddenly decided and for no good reason, but we

540 have decided we are not letting you have it anymore', that is how I see it at the moment

541 because erm, and then somebody will [pause <] hates every morning when I am counting out

542 almost outside, being so against that kind of thing all my life and suddenly to find I am

543 dependent on is one thing, but the only side effects that belonged to an assistance dog are

544 wonderful, it is going to be taken away you know it's, it's difficult, very difficult, especially if she

545 is still.

546 INT: Fit and well?

547 P3: Fit and well, erm you know, so [pause <5], but there we go, rules are rules.

548 INT: Obviously it feels very difficult?

549 P3: I can see there is good about it from their point of view, from an administrative point of view, a

550 cut off you know, but I mean everything is a cost, so why.

551 INT: To train the dogs?

552 P3: So why train another dog if you have got one that is you know.

553 INT: Still able to work?

554 P3: But that is [pause <5]. I am sorry.

555 INT: No need to apologise for that

556 P3: [inaudible] [laughs]

557 INT: Well thank you for today, I think we are coming to a natural end point.

558 P3: If there is anything that you can, you know, you can help us in, I don't mean help, but anything

559 else you want to talk to me on.

INT: It has been lovely, it has been a privilege talking to you today and 560 I just want to.

561 P3: It's been lovely to meet you.

562 INT: It is lovely to talk, all the experience that you have had has been you know, it has been lovely to

563 hear about it. Food for thought for me obviously as well.

564 P3: Yeah.

565 INT: But it has been lovely so thank you for sharing your story.

566 P3: Thank you.

567 INT: And thank you Sunny for being brilliant and beautifully behaved.

568 P3: We are both happy and I do apologise for messing you about.

569 INT: That wasn't messing me about, that was…

END OF RECORDING.

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