Exploring the experiences of physiotherapy in North Wales for people with Multiple Sclerosis: informing service development and practice

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Professional Doctorate

2019

Submitted in partial fulfilment for the award of a Professional Doctorate in Health through the University of Wales, May 2019.

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Research was undertaken under the auspices of the University of Wales and Betsi Cadwaladr University Health Board and was submitted in partial fulfilment for the award of a Professional doctorate in Health through the University of Wales

May 2019

Acknowledgements

A huge thank you to my supervisory team Dr Edna Astbury-Ward, Dr Joanne Pike and Prof. Debbie Roberts. Your expertise, advice, time and patience have been invaluable to me.

Contents

Title

Exploring the experiences of physiotherapy in North Wales for people with Multiple Sclerosis: informing service development and practice.

Abstract

Background: Multiple Sclerosis (MS) is one of the most prevalent neurological conditions affecting adults and physiotherapy is recommended for people with MS (PwMS) (National Institute of Clinical Excellence (NICE), 2018). The high prevalence and complex needs of this group of people often require significant physiotherapy, yet there is a paucity of research exploring experiences of physiotherapy for PwMS.

Aim: To explore the experiences of physiotherapy for PwMS in North Wales to inform physiotherapy service development and practice. This will make an original contribution to research by exploring this under-researched area, providing insight and understanding for physiotherapists and other people involved in the care of PwMS which can lead to better informed, more empathetic practice (Cassidy et al., 2011) and service development.

Design: Six PwMS were interviewed. Interview transcripts were analysed and interpreted using interpretive phenomenological analysis (IPA) methodology. Themes were developed, explored and considered alongside relevant research to situate and contextualise this research.

Findings: Three main themes emerged. There was an over-arching theme of *sense of self* in relation to experience of physiotherapy; sense of self was affected by most aspects of physiotherapy, from practical aspects of service delivery, to more nuanced aspects such as the context in which exercise was situated. *Embodied experience of physiotherapy* explored the lived experience of physiotherapy, including what physiotherapy meant to these PwMS regarding self-management, person centred care and communication as examples. *Embodied experience of living with MS* was intrinsic to each participant's experience of physiotherapy and included aspects such as the emotional and physical effects of living with MS.

Recommendations: Increased awareness regarding highlighted aspects of the lived experience of physiotherapy and the significant impact physiotherapy can have on sense of self for PwMS, would help improve, enrich and individualise experience of physiotherapy in its' broadest sense. This research increases insight and awareness regarding the lived experience, thoughts, feelings and perceptions of PwMS regarding physiotherapy which can lead to more sensitive, informed, empathetic and contextualised physiotherapy for this population. This research has found the experiences of physiotherapy for PwMS are inextricably linked and inter-dependent with sense of self, a concept further explored within this research.

Glossary

Adherence: Attachment or commitment to a person, cause, or belief; the fact of someone behaving exactly according to rules, beliefs, etc. (Oxford On-line English Dictionary, 2016)

Ataxia: Ataxia is a term for disorders that affects movement control, co-ordination, balance and speech. Any part of the body can be affected, but people with ataxia often have difficulties with: balance and walking, speaking, swallowing, tasks that require a high degree of control, such as writing and eating, vision. The exact symptoms and their severity vary depending on the type of ataxia a person has (National Health Service (NHS), 2016). Ataxia UK (United Kingdom) is a charitable organization that offers support to its members and funds research into progressive cerebellar ataxia.

Dropped foot/foot drop: Foot drop is a muscular weakness or nerve dysfunction that makes it difficult to lift the front part of the foot and toes. It can cause dragging of the foot on the ground when walking (NHS, 2016).

Hope: Feeling of expectation and desire for a particular thing to happen (Oxford On-line English Dictionary, 2016). Hope looks to balance the present with an expectation of a better future (Soundy et al., 2010).

Spasticity and spasms: Spasticity refers to feelings of stiffness and a wide range of involuntary muscle spasms (sustained muscle contractions or sudden movements). It is one of the more common symptoms of MS. Spasticity may be as mild as the feeling of tightness of muscles or may be so severe as to produce painful, uncontrollable spasms of extremities, usually of the legs. Spasticity may also produce feelings of pain or tightness in and around joints, and can cause low back pain (National MS Society, 2016; Oreja-Guevara, González-Segura and Vila, 2013).

1.0 Chapter One: Introduction

1.1. Notes for reading this thesis

[ ] indicates text omitted

( ) added text to assist clarification of text

'x' indicates direct quotation. Direct quotation/verbatim extracts are also presented using indented text without the use of quotation marks

"X" quotation to indicate *known as* ("in inverted commas"), or to indicate use of a common phrase (not a direct quotation)

FIGURE 1: NOTES FOR READING THESIS

Terminology:

People who access health care are referred to as recipients, service users, customers, partners, clients or patients- the descriptors are prolific. The majority of the research that I have examined as part of this thesis refers to patients. Rather than continue to use a range of terms depending on the document or discussion, I will use the term patient for the remainder of this text, with the understanding that various descriptions are often used interchangeably. Selecting the description of "patient" is not with any intention to medicalise or disempower people, but rather is used as an inclusive term for an individual who is in partnership with health care services. It is my experience that most PwMS accessing physiotherapy services refer to themselves as patients, including those within this study.

1.2 Introduction to Chapter One

Chapter one provides the background to the development of this research question before outlining the context for this research to include information about the condition of MS, MS healthcare and MS physiotherapy services in North Wales. This chapter will also overview physiotherapy as a profession and its relationship with evidence based practice and research methodology.

1.3 Development of the research question

Part of my role as advanced physiotherapy practitioner for neurology was to review and improve service provision. To help with this, I met regularly with patient user groups to include the MS patient forum, to listen to their experiences, feedback and concerns about physiotherapy services. This was useful and insightful, however, I encountered limitations to the meeting format that comprised only minimal representation from the population using the services. Some of these limitations meant that in practice: only certain aspects of service delivery were focused upon, there was a lack of adequate context and understanding, or the meeting could become focused on one individual's concerns as examples. It was difficult to understand a person's experience without further in-depth discussion, which the meeting forum did not facilitate. However, it was wholly apparent there were issues regarding the delivery and experience of physiotherapy for PwMS which warranted further understanding and consideration. I stepped back from the local situation, looking to the literature to see what was already known about the experiences of physiotherapy for this population and how other areas and services might have explored this, and was surprised to find no published qualitative research that specifically aimed to explore the experiences of physiotherapy for PwMS. Some specific aspects of physiotherapy care or method of delivery have been explored and this research will be further discussed in chapter two. The starting point for this research arose at this stage, at which point I examined and explored relevant issues regarding the local population and situation to provide cultural, geographic and political context for this research, which will now be discussed.

1.4 Multiple Sclerosis physiotherapy services in North Wales: the geographical and political (health) contexts

There is a prevalence of 138-144 PwMS per 100,000 people in Wales (nearer 144 specifically in North Wales) with a calculated 3006 PwMS in Wales in 2010, now estimated to be around 4300 (Balbuena et al., 2016; MacKenzie et al., 2014). A further six people per 100,000 are diagnosed each year and the number of people with MS in the UK is growing by around 2.4% per year, due to PwMS living longer (MacKenzie et al., 2014; North Wales Neuroscience Network, 2012; Wales

Neurological Alliance (WNA), 2013). North Wales has a population in the region of 690,000, hence there are at least 950 PwMS in North Wales, with around 40 people being diagnosed annually. However, the most recent figures available have estimated there are as many as 1,111 PwMS in North Wales (Public Health Wales, 2012). Population density varies significantly across the 6,172 square kilometre area comprising six counties, all of which have their healthcare needs delivered by one large health board. This health board has three main hospitals, 16 other general and community hospitals and numerous community services (NHS Wales, 2017). Gwynedd is the least densely populated county with 49 people per square kilometre, while Flintshire the most densely populated with 350 people per square kilometre. This disparity presents a variation of healthcare needs, provision and access across the region covered by this health board, with people often having to travel significant distances to their nearest hospital, health and leisure services in the less densely populated areas. This can be even more challenging when trying to access more specialist services (such as MS services).

There is currently no specialist neurological inpatient rehabilitation despite recommendations for this having been made (NHS Wales, 2008; NHS Wales, 2009; NHS Wales and North Wales Neurosciences Network, 2015), and this being advised in the relevant clinical standards (British Society of Rehabilitation Medicine, 2009). There is currently a service level agreement in place that a health board in England provides neurology services to the North Wales health board (through Welsh Health Specialised Services). This service in England provides specifically identified aspects of specialised medical care for PwMS. In practice, this means that PwMS may need to travel to England for certain diagnostic tests or specialist interventions- this can be a journey of over 100 miles and as much as three hours' travel. However, in order to deliver more accessible healthcare for PwMS, most of their consultant and MS nurse care is delivered through satellite clinics in the three main hospitals by medical staff employed by the health board in England. In addition, there is a MS advice helpline available during the working week, multi-disciplinary MS clinics held monthly at each of these sites, which provide a 'one stop shop' assessment and advice service for PwMS from numerous health care professionals and voluntary services and bi-annual information days for people diagnosed with MS. The MS clinic and information days are attended by specialist neurological physiotherapists who provide patients with education and advice and refer on to local services for further physiotherapy intervention as required.

Physiotherapy services for PwMS follow a different model of care, with all physiotherapy services (apart from those delivered during inpatient episodes at the health board in England) being delivered locally by the North Wales health board. Physiotherapy is delivered in the hospitals through in and out-patient services, or in the community through domiciliary and leisure services (Welsh Physiotherapy Leaders Advisory Group (WPLAG), 2013). Some areas offer MS exercise classes in collaboration with leisure services and the MS Society, whereas other areas are not currently able to provide these within available resources. It is an ongoing challenge to provide accessible equitable physiotherapy care despite the wide variation in population density and the large distances that people may live from health care services. There remains considerable variation in access to specialist neurological physiotherapy, waiting times and access to self-referral (WNA, 2013). This is despite the knowledge that physiotherapy is important to PwMS in North Wales for maintaining their function and quality of life (WNA, 2013) and despite recommendations that PwMS should be seen by a specialist physiotherapist in a timely manner and have the ability to self-refer to physiotherapy services (NICE, 2014; WPLAG, 2013).

One of the most apparent frustrations for both staff and patients is this variability across a large geographical area. There are specialised neurological physiotherapists who are well placed to treat patients with MS in each of the district hospitals and they do provide services across a wide geographical area. However, due to the significant distances between places, restricted staff time and resources, specialist physiotherapy is limited. To help improve this situation, physiotherapy staff working in different settings and specialisms (out-with neurology) receive training so that they are better placed to meet the therapy needs of PwMS. However, the situation remains that some patients who would likely benefit from being seen by a therapist who specialises in MS will struggle to access one in a timely way without having to travel significant distances. Anecdotally, it is suggested that travelling long distances can have a negative impact on symptoms such as fatigue for PwMS, and reduce the effectiveness of the therapeutic intervention they have travelled for (MS Society, 2016). Fatigue is a common symptom of MS. MS fatigue differs from tiredness experienced in the absence of MS in both severity and impact, often limiting or preventing participation in everyday activities, work, leisure and social pursuits, and reducing psychological well-being (Thomas et al., 2013). The variability and issues highlighted above all form improvement targets for the health board as set out by the government in the Together for Health Neurological Conditions Delivery Plan 2017 (Welsh Government, 2014).

Nearly 30% of people in Wales speak Welsh, but this amount is higher in many areas of North Wales, with over 60% Welsh speakers in Anglesey and Gwynedd and over 35% in Conwy and Denbighshire (for further details, see Appendix II). The North Wales health board is regulated by national Welsh language standards and has in practice adopted the principle that Welsh and English languages should be treated on the basis of equality when providing services to the public. This can be of particular importance and relevance for people whose first language is Welsh and who are experiencing difficulties with cognition, memory, language and fatigue- all symptoms that PwMS can experience. A considerable number of the physiotherapists speak Welsh, but not all physiotherapists specialising in neurology are bilingual, and so this element of service delivery presents another area of variability. PwMS would be able to see a physiotherapist who speaks Welsh, but may have limited access to a neurological specialist physiotherapist who can speak Welsh.

1.5 Physiotherapy

Physiotherapy is described by the UK professional body for physiotherapy- the Chartered Society of Physiotherapy (CSP) as:

> Using physical methods to optimise individuals' functional ability, health, well-being and quality of life [ ] in partnership with individuals to optimise their functional ability and quality of life (CSP, 2010, p.6)
>
> Physiotherapists help people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. The profession helps to encourage development and facilitate recovery, enabling people [ ], while

> helping them to remain independent for as long as possible. Physiotherapy [ ] takes a ‘whole person’ approach to health and wellbeing [ ] (CSP, 2013)

Although physiotherapists often use physical methods of intervention, these definitions acknowledge and embrace the focus on working with patients to help them achieve their goals and improve their quality of life, rather than solely on improving physical capability. Although there is not consensus on the definition of quality of life within healthcare literature (Post, 2014), it is generally understood to encapsulate fulfilment within a range of dimensions to include a person’s physical and mental health and well-being, their role within education, recreation and leisure, and their social belonging (family and friends). The general definition is ‘the standard of health, comfort, and happiness experienced by an individual or group’ (Oxford On-line Dictionary, 2016). In essence, the above descriptors by the CSP make implicit that it is fundamental to physiotherapy clinical practice to treat patients in a holistic way rather than focusing on treating only their condition. This necessitates trying to understand each patient as an individual, for example, discussing previous experiences of physiotherapy and how their condition affects their lives, their fears, hopes, beliefs and current understandings as examples. Best practice indicates that exploring these factors forms part of every physiotherapy assessment and intervention (Higgs et al., 2008), with a health condition or problem being assessed and understood in terms of the individual and their quality of life. The World Health Organisation international classification of function framework (illustrated in Figure 2 below) is recommended for use in physiotherapy assessment and goal setting (Higgs et al., 2008) to help guide clinicians with this process by demonstrating that a person’s functioning and disability is affected by interactions between their health condition and contextual factors (both personal and environmental). This figure represents that a person’s health condition is interdependent with their body function, their ability to carry out tasks and activities, and participation in their social, work and recreational lives.

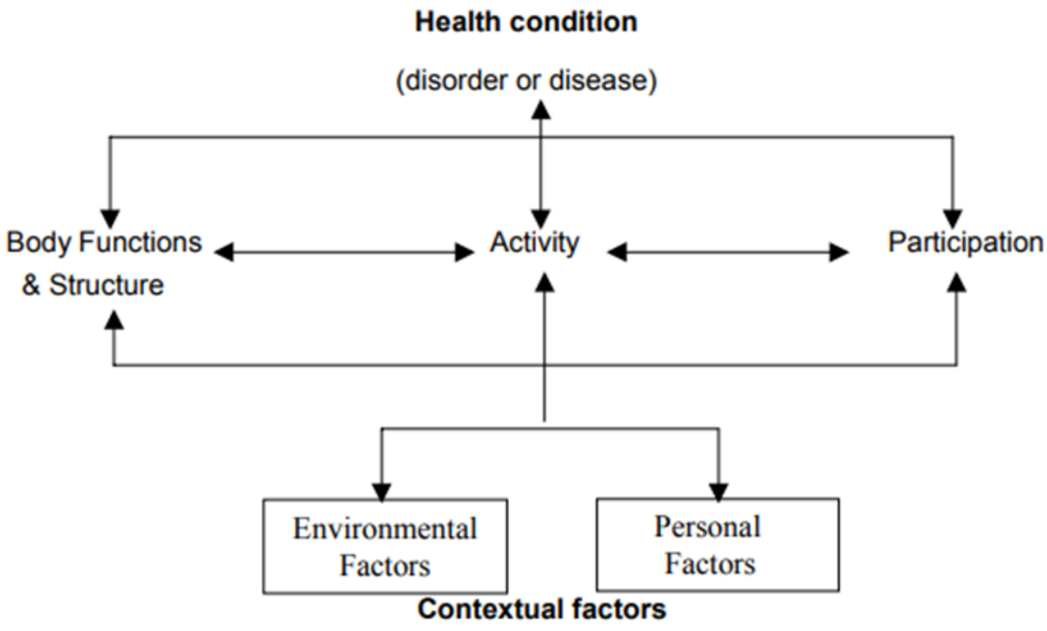


FIGURE 2: FRAMEWORK OF FUNCTIONING, DISABILITY AND HEALTH (P.18, HIGGS ET AL., 2008).

Physiotherapy places emphasis not only on understanding patient's needs, but also upon asking their views, exploring their experiences, and involving them effectively in decision-making as integral elements to clinical practice, service development, and physiotherapy research (CSP, 2010; WPLAG, 2013). Indeed, the CSP state that 'recipients of physiotherapy services are the best advocates of the profession's value in meeting their needs' (p.8), suggesting that physiotherapists actively engage with patients to inform service development and re-design to best meet local population and patient needs. This is in accordance with national policies such as 'Guidance in Involving Adult NHS Users and Carers', (Welsh Government, 2010)', which advises it is 'crucial that services are planned, delivered and reviewed with the perspective of the service user or patient at their centre' (p.4). The position of the CSP makes clear that physiotherapists need to be resourceful and innovative to ensure that we involve patients in a meaningful and valuable way, with this partnership remaining at the heart of physiotherapy practise and research.

The value of qualitative research methods that seek to explore patient experience, perceptions and feelings is increasingly acknowledged within physiotherapy. However, research that involves exploration of patients' experiences and perceptions, particularly research of this nature that seeks to inform service development and influence service change remains in the minority (Petty et al., 2012; Potter, Gordon and Hamer, 2003). Although it is beyond the scope of this thesis to explore physiotherapy research principles, physiotherapy research involving patients will be overviewed later in this chapter to contextualise my research.

1.6 Multiple Sclerosis and Physiotherapy

MS is one of the most common neurological conditions affecting adults, with over 100,000 adults in the UK having MS and around 100 people being diagnosed with MS every week. Figures as high as 126, 669 people living with MS in the UK in 2010 have been reported (203.4 people per 100, 000 population), with 6003 new cases being diagnosed that year (9.64 per 100, 000 population), suggesting a trend of an increasing population living longer with MS when compared with previous data, as previously discussed (MacKenzie et al., 2014). Understanding the experiences of physiotherapy for PwMS is therefore of increasing importance; as the population of people living with MS increases, so too will the demand for physiotherapy as PwMS often require physiotherapy throughout their lives (Freeman and Gunn, 2018).

MS is a condition that results from auto-immune attack on the insulating protective sheath around nerves (myelin), as well as on the nerve fibres themselves. The damaged myelin forms scar tissue (sclerosis), which gives the disease its name. When any part of the myelin sheath or nerve fibre is damaged or destroyed, nerve impulses travelling to and from the brain and spinal cord are distorted or interrupted, producing a wide variety of symptoms (Lublin et al., 2014). MS is two to three times more common in women than men, suggesting that hormones, amongst other affecting factors, may play a significant role in determining susceptibility to MS. Despite the identification of some affecting factors, the cause of MS remains unknown. MS is typically diagnosed between the ages of 20 and 50 years and affects people throughout their lives with a range of variable physical symptoms to include altered sensation, pain, weakness, spasticity, stiffness, and impaired balance (Compston and Coles, 2008; Lublin et al., 2014; Freeman and Gunn, 2018) which can be improved through physiotherapy intervention (Heesen et al., 2006; Khan et al., 2007; Wiles et al., 2001). PwMS can also experience a range of other symptoms such as changes in sexual function, continence, cognition, mood and memory. Sadly, MS is a long term, degenerative condition for which there is currently no cure. Symptoms can however be reduced or managed with a range of treatments and interventions, such as physiotherapy (Compston and Coles, 2008; Ng et al., 2008).

It has been shown that physiotherapy and rehabilitation is associated with improved mobility, activity, wellbeing, and improved mood for PwMS (Wiles et al., 2001). Furthermore, physiotherapy can help improve patients' experience of living with MS and their ability to manage their condition (Khan et al., 2007), for example through reducing disability (Patti et al., 2003) and improving functional ability and long term symptoms (Campbell et al., 2016; Compston and Coles, 2008; Heesen et al., 2006). In an effort to help maintain independence, slow physical deterioration, and prevent social exclusion, physiotherapists play a significant part in the process of treatment delivery to patients (Department of Health (DOH), 2005b), assisting in the ongoing practice of physical management and care for patients with the aspiration of helping them to achieve their full physical potential (Health and Care Professions Council, 2007; Soundy et al., 2010). Within the context of neurological rehabilitation, with particular reference to PwMS, physiotherapy is most likely to include: exercise therapy (to include general advice on exercise and activity, prescribed exercises, stretches and respiratory muscle training), multidisciplinary and functional, task-based rehabilitation, functional electrical stimulation, spasticity management (possibly in conjunction with medication), therapeutic standing, acupuncture, and body weight supported treadmill training (Campbell et al., 2016). PwMS require different approaches and types of physiotherapy depending on the type, stage and presentation of their condition (Freeman and Gunn, 2018) and perceive a need for physiotherapy from early stages of their condition (Ytterberg et al., 2008). WPLAG (2013) report that the nature of chronic and degenerative conditions such as MS, requires partnership working between physiotherapist and PwMS to help individuals continually readapt and manage their life-long condition over time. Due to the complex nature of the condition, PwMS commonly access physiotherapy throughout their lives, their needs and goals of therapy changing dependant on their condition and situation (Freeman and Gunn, 2018).

The relapsing remitting form of MS consists of acute episodes of increased symptoms and reduced function due to inflammation within the nervous system resulting in a relapse, followed by reduced inflammation and recovery of the nervous system resulting in remission (Compston and Coles, 2008; Coles, 2009). Physiotherapy aims to help people with this form of MS return as near to their previous functional ability prior to the relapse of their condition, though this is limited by the extent to which the nervous system can recover and repair. Following a relapse, physiotherapy will likely include strengthening, stretching, balance, body control and functional task practice that aim towards restoration of function and mobility, alongside advice about their condition, fatigue management and health promotion (Campbell et al., 2016; Freeman and Gunn, 2018).

The secondary progressive type of MS typically follows the relapsing remitting type due to the nervous system sustaining long term damage that results in progressive deterioration with variable presentation depending on the extent and where the damage is within the nervous system. There are two other types of MS: a benign form, where people experience an isolated episode of nervous system inflammation, and a primary progressive form (constituting 10-15 % of those diagnosed with MS), where the condition continues to progress with no remission (Compston and Coles, 2008; Freeman and Gunn, 2018). Physiotherapy for the progressive forms of MS often focuses on maintenance rehabilitation (maintaining strength, range of movement, balance and functional ability), prevention of secondary complications such as falls, contracture and pressure areas, and latterly on palliative care due to the more rapidly deteriorating nature of this form of the condition. As the level of disability increases, the focus of physiotherapy shifts towards 24 hour management and supportive care of the condition involving all of the relevant people that help care for the person with MS through promoting autonomy and quality of life to include the provision of equipment and environmental adaptations as required (Freeman and Gunn, 2018).

Both the UK and Wales national guidelines advise that people who have mobility problems due to MS have access to rehabilitation specialists and physiotherapists with expertise in MS, provided at home or on an outpatient basis, depending on the preference of the person with MS and local resources. Rehabilitation should be provided at an appropriately early stage to reduce the risk of developing preventable secondary complications and prolonging hospital stay and readmission (DOH, 2005b; NICE, 2014; Welsh Government, 2014). As previously discussed, the high prevalence and long term needs of PwMS result in this group of people often requiring a significant amount of physiotherapy delivered across many areas of service delivery. In keeping with other populations (Ytterberg et al., 2008), PwMS in North Wales have highlighted that physiotherapy is important to them for maintaining their function and quality of life (WNA, 2013). PwMS regularly and continuously use physiotherapy services throughout their lives, and have also highlighted the importance of physiotherapy, therefore it is particularly relevant to explore physiotherapy experience for PwMS.

1.7 Research involving patients and exploring experiences of physiotherapy

Research suggests that the general public are able and keen to contribute to healthcare decision making (Litva et al., 2002; McKie et al., 2008). Focus group research that gauged the opinions of patients and professionals regarding who should be involved in healthcare decision-making (and how this might occur in practice), found that qualitative methods of investigation have the potential to contribute to better understanding of public values (McKie et al., 2008). The NHS has made a commitment to engage patients about how best to configure and provide healthcare services (DOH, 2005a; DOH, 2006; Welsh Government and National leadership and innovation agency for healthcare, 2010). Patient participation has also been promoted at an international level through the World Health Organisation (WHO, 2008).

As previously discussed, the CSP (2010) advocates the involvement of patients in research, advising that research involving the people that actually use physiotherapy services should form part of the evidence base upon which practice is shaped. Therefore, patient perception and experience about the treatment they receive is important within both the NHS (DOH, 2012), and physiotherapy; ‘increasing value is placed on a patient’s perception of his or her own outcome and experience (rather than the clinician’s perception of “recovery”)’ (Tolan, 2012, p.34). Professional training, and the subsequent increased knowledge and expertise this provides, enables therapists to inform patients about the physiology of their condition and symptoms, and provide optimal interventions to treat or manage these. This demands the integrative use of the appropriate research and evidence base which, by the nature of research objectives to improve physical function, is often quantitative data within physiotherapy (Gibson and Martin, 2003; Greenfield, Greene and Johnson, 2007). But this body of research is only part of the jigsaw of what constitutes evidence based, patient-centred (also known as person-centred) physiotherapy.

Traditionally, physiotherapy research has been predominantly quantitative in approach, focusing on objective research about impairment or intervention, rather than on obtaining patients’ contribution to service construction and delivery through exploring their thoughts and experiences (Gibson and Martin, 2003; Greenfield et al., 2007). Many aspects of care are arguably best discovered by listening to people; for example, exploring the effect of aspects of their condition on their lives, their experience of certain interventions, or what makes an intervention successful for them (Potter et al., 2003). Qualitative health research aims to provide a deep, multi-faceted understanding of a person’s experience of either a health condition, or a health service experience, that can lead to better informed, more empathetic practice (Cassidy et al., 2011). In this way, information from qualitative research of this nature can be used to influence and direct health care decision making and contribute to evidence based practice. Greenhalgh, Howick and Maskrey (2014) promote that in order to deliver “real” evidence based practice, ‘the research agenda must become broader and more interdisciplinary, embracing the experience (of illness)’ (p.4), to include anecdotal patient experience research (Greenhalgh et al., 2015).

The rich, descriptive, insightful data that a qualitative approach to research can yield is beginning to be viewed as an essential foundation upon which to construct and contextualise other knowledge and research (Bithell, 2000; Cassidy et al., 2011; Gibson and Martin, 2003; Greenfield et al., 2007; Greenfield and Jensen, 2010; Johnson and Waterfield, 2004; Petty et al., 2012; Rauscher and Greenfield 2009; Richardson and Lindquist, 2010). Although qualitative research methods that focus on the lived experience of people with health conditions remain relatively underutilised in physiotherapy research (Cassidy et al., 2011), there is a significant and growing body of qualitative research in physiotherapy that explores specific conditions, aspects or models of intervention. However, research employing qualitative methodology with the aim of broadly exploring patient experiences of physiotherapy remains surprisingly limited (Underwood, Harding and Klaber Moffett, 2006) and 'few projects have focused entirely on exploring the patient's perspective in physiotherapy' (Potter et al., 2003, p.196). Research that explores the experience of physiotherapy as a phenomenon will be reviewed within chapter two.

A recent study carried out by Janssen et al., (2016) interviewed physiotherapists in New Zealand about their perceptions of research and found that 'randomised controlled trials and systematic reviews were mentioned as being the main source of information (p.213)' with the majority of physiotherapists interviewed perceiving these research approaches as 'good research' whereas 'qualitative research was not mentioned' (p.213). Janssen et al. (2016) explain that the implication from this is that 'physiotherapists' views were largely influenced by positivist views of knowledge through the evidence-based medicine paradigm, which ranks the evidence of a scientific publication [more highly]' (p.214). This recent research, alongside the lack of physiotherapy research focused on patients' experience of physiotherapy, brings into question the extent to which the paradigmatic shift in physiotherapy research (which has now been discussed for over twenty-five years (Bithell, 2000)) from a positivist quantitative stance, to include a more interpretivist qualitative one has actually occurred.

1.8 Physiotherapy and Evidence based practice

Evidence based practice (EBP) has been defined as ‘the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients’ (Sackett et al., 1996, p.71). EBP plays an important role in the current physiotherapy profession (Janssen et al., 2016), yet continues to have many definitions (Higgs et al., 2008), and its’ contribution to delivering effective healthcare remains undetermined (Greenhalgh et al., 2014). Greenhalgh et al. (2014) suggest that emphasis on experimental evidence in EBP risks undervaluing knowledge generated through clinical experience and that findings from average results in clinical studies might not best reflect real patient situations. However, they also highlight the more positive and relevant impact that well-informed and considered EBP can make if it ‘accommodates basic scientific principles, the subtleties of clinical judgement, and the patient’s clinical and personal idiosyncrasies’ (Greenhalgh et al., 2014, p.1). Thereby, at its’ best, working within EBP integrates the preferences and needs of the patient alongside current and applicable evidence using the clinicians’ expertise and training, whilst also taking into account the clinical setting and available resources (Condon et al., 2016). Bithell (2000) explains that the evidence based medical model used for EBP based its ranking of evidence in medical literature on research methodologies most suited to clinical testing drug efficacy, explaining that ‘there is no intrinsic reason why [this] should be the best way to demonstrate effectiveness of therapies which depend so much on human interaction (p59). Over a decade later, authors continue to highlight concerns that qualitative research (particularly that involving patients) remains in the minority in research, with the medical evidence based hierarchy (of evidence) affording low priority and value to the patient experience (Dannapfel, Peolsson and Nilsen, 2013; Greenhalgh et al., 2014; Greenhalgh et al., 2015). This study will provide further research and insight into the experiences, preferences and needs of patients that will contribute towards qualitative research forming part of the evidence base for clinical decision making.

Greenhalgh et al. (2014) highlight another problem with clinicians engaging with EBP is that ‘the volume of evidence, especially in clinical guidelines, has become unmanageable' (p.2). The issues that these authors raise are reflected in a scoping review recently carried out by Condon et al. (2016) into physiotherapists performing the steps of EBP. They found there was limited evidence that physiotherapists undertake 'the full EBP process' (relating to sourcing evidence through literature), preferring instead to use discussion with colleagues and patients. The authors found this was due to divergence of the literature and time constraints amongst other factors. It is hoped this research will deliver accessible research that is meaningful, resonant, applicable and credible through being conducted with the patients themselves, therefore addressing some of the difficulties that physiotherapists report (Condon et al., 2016).

1.9 Physiotherapy and Interpretive Phenomenological Analysis (IPA)

To date, there are fifteen known examples where IPA has been used as the methodology in published physiotherapy research (See appendix III for a table of these papers). Additionally, there is physiotherapy research that employs the principles of phenomenology. Cassidy et al. (2011) advocate IPA as a qualitative approach to research that is both accessible and relevant to physiotherapists, suggesting this method can be used in a clinical setting to contextualise quantitative research and inform physiotherapy practice and service development founded on the perspective of people with health conditions. Cassidy et al. (2011) reviewed the literature on IPA and state that although this approach 'is firmly embedded in psychology,' the method is also increasingly used in health care by those without formal training in the method, such as health care professionals. This review also confirms there is a 'growing interest in exploring service users' and health care practitioners' experiences of services and health care processes' (p.264) as previously discussed.

1.10 Aims of this research

This research will explore the experiences and perceptions of physiotherapy for people in North Wales who have MS, using IPA as the research method. This research will inform and improve physiotherapy practice through increased understanding and empathy as well as through increased knowledge and insight, helping to guide and improve physiotherapy service development in North Wales for PwMS. This research may also provide some relevant insight for physiotherapists working in other geographical areas with PwMS and in other specialities, particularly those involving long term neurological conditions. This research makes an original contribution to knowledge, as there is no other known research that explores the experience of physiotherapy for PwMS using IPA. This study will also contribute to the growing body of qualitative research within physiotherapy that involves patients and will continue to explore and progress the use of IPA within physiotherapy research.

No qualitative research was found that explores the perceptions and experiences of PwMS regarding physiotherapy. Jones et al. (2009) analysed the qualitative data in the free comments section of questionnaires that were completed as part of a national audit of the implementation of the 2003 NICE guidelines for the management of MS. They found a poor correlation between global expressions of satisfaction and quantitative outcomes and the ‘at times heart wrenching’ free text comments, concluding that ‘simple, single questions on satisfaction with services do not offer a valid measure of patient experience, [showing that] there is a place for qualitative research’ (p.2071). It is arguably important for such research to be carried out in order to better understand the context and needs of PwMS, enabling more informed, empathetic person-centred care, physiotherapy clinical practice and service development.

1.11 Summary of Chapter One

This chapter has provided the context and background for this research by explaining the complexity of MS and the role of physiotherapy for PwMS with particular reference to MS related physiotherapy services in North Wales. Physiotherapy as a profession is introduced followed by some insight into where physiotherapy is situated in terms of clinical reasoning, evidence based practice and research, before physiotherapy research involving patients and IPA is overviewed. Finally, the aims of this research are summarised at the end of chapter one.

2.0 Chapter Two: Literature review

2.1 Introduction to Chapter Two

Chapter two will initially explore the lived experience of MS and the perspectives of people living with MS about their healthcare to provide background and context and to inform this research. The subsequent section of this literature review will focus on the experience of physiotherapy, particularly for people with long term neurological conditions, and specifically for PwMS. This body of literature will directly inform this study, identifying its importance and relevance within the context of the current literature.

2.2 The lived experience of MS

Due to the focus of this research being situated in the UK and the large volume of literature regarding the subject, only contemporary literature carried out in the past five years within the UK exploring the lived experience of MS has been included within this section of the review. Researching lived experience involves exploring and understanding issues from the perspectives of individuals, therefore, as expected (Davies et al., 2015; Silverman, 2011), the studies identified for inclusion in this section of the literature review identified were qualitative in design. Therefore these identified papers were reviewed using the consolidated criteria for reporting research (COREQ) as this criteria can help researchers to comprehensively report important aspects of qualitative research (Tong, Sainsbury and Craig, 2007). It involves a detailed 32 item checklist and provides suggestions for good research practice for each item (see Appendix IV for details). Later within this chapter, appropriate critical appraisal skills programme (CASP) tools have been used to appraise the relevant literature (CASP, 2018). These tools have been used to ensure that literature has been reviewed in a robust and comparable way and items of relevance will be focused on within this literature review, rather, each item within these tools are not reported in full.

Following a literature search (see Appendix V), nine studies that explored the lived experience of MS were initially included that met the criteria above. Two of these papers were thematic synthesis in which the reviewed studies fell out-with the inclusion criteria of this section of the literature review and therefore they have not been included (see table A in Appendix V for details of these studies). Four studies used thematic analysis. These will each be reviewed sequentially to enable comparisons regarding methodology, before reviewing the remaining three studies, two that used IPA and one that used Paul Ricoeur's model of interpretation. There are some commonalities between these studies. All seven studies collected data using in-depth and semi-structured interviews that were recorded and transcribed verbatim. Semi-structured interviews enable exploration of participant experiences and are therefore often used to help understand experience and meaning of disease (Tong et al., 2007). Another commonality included purposive sampling to recruit English speaking PwMS over 18 years of age who consented to taking part in the proposed research. Purposive sampling is appropriate when exploring a particular experience as participants are recruited because of their expertise and experience of the phenomenon being researched (Reid, Flowers and Larkin, 2005). The four thematic analysis studies used 'NVivo' software to help manage their data. These methodological aspects will not be discussed for each study to reduce repetition, unless an aspect has specific relevance.

Browne, Salmon and Kehoe (2015) carried out a robust and sensitive thematic analysis that aimed to deepen understanding regarding the effect of bladder dysfunction, a symptom which affects up to 75 % of PwMS, on quality of life for PwMS. Purposive sampling recruited a broadly representative sample of participants in terms of stage and type of MS, gender and age and all participants had at least one bladder dysfunction symptom. However, participants were recruited from one branch of the MS Society of Ireland, with officials of this branch acting 'as gatekeepers', restricting the sample to PwMS who are in contact with this society. Transparency would be increased if the 'gatekeeper' role had been clarified, as this role could introduce bias to the selection process. Researchers should fully report how participants were selected (Tong et al., 2017). Cassidy, Naylor and Reynolds (2018) report that recruitment of research volunteers through membership organisations can lead to including people who are better connected to resources, can be more knowledgeable about their condition and may also be more assertive in sharing their views. Cassidy et al. (2018) also highlight that ethnic and social minority groups and people from low-income backgrounds are less likely to be members of these organisations. These factors could result in sample bias and reduce the relevance of data findings to people who are not associated with member organisations such as the MS Society, people from ethnic and social minority groups and those from low-income backgrounds.

The interview structure was informed by previous studies to focus on experiences of living with bladder dysfunction. Topics arising from earlier interviews were introduced into subsequent interviews ‘to allow for refinement of ongoing thematic analysis’ (Browne et al., 2015, p2351). This may have resulted in interviews becoming increasingly specific, with participants being guided towards certain topics. Quality would have been further increased if the interview guide was reported as this enhances the readers understanding of the researcher’s focus and provides insight into whether participants were encouraged to discuss their own views. Interviews were carried out by three physiotherapy student researchers. There is further lack of transparency and clarity as the study does not state where the interviews were carried out and does not expand on the training or experience of these students in terms of carrying out interviews, though both aspects could affect data generated. This was not acknowledged in the study limitations. Credibility and transparency in qualitative research is increased when personal characteristics and background context of researchers are provided as this enables the reader to assess influence of these factors (Mays and Pope, 2000). Trustworthiness and rigour were increased by repeated listening to recordings, use of field notes, detailed documented thought processes and subsequent member checking using summary of interview key points. Reflexivity and rigour was apparent throughout the study, in terms of the researcher’s presence, their experience and their individual and collaborative thought processes, particularly throughout the detailed analysis process. Themes were well supported with illustrative extracts from a wide range of participants used throughout the reporting of the themes which added trustworthiness and transparency to this research (Tong et al., 2007).

One of two main themes generated was ‘Disruption and Loss’. Participants reported that bladder dysfunction due to MS disrupted most daily activities and routines including sleep, travel and sexual relationships and often resulted in loss of pleasure whilst carrying out daily tasks, or the loss of the ability to carry them out altogether. The second theme, ‘Ways of knowing,’ incorporated participants embodied knowledge about their bodies and symptoms and how participants learned through experience then used this knowledge to help self-manage bladder dysfunction. In some cases, this was due to perception that as there is no cure for this symptom, there is no benefit to seeking help or even talking about it. In other cases, self-management became enforced as healthcare professionals did not ask questions regarding this symptom and advice given was reported to be limited, unhelpful and based on lack of knowledge.

Davies et al. (2015) conducted a thematic analysis exploring participant and carers understanding, experiences and perspectives on transitioning from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS). Inclusion criteria were having MS, excluding the primary progressive form as this does not precede SPMS and so would not allow for exploration of transitioning to SPMS, and having an Expanded Disability Status Scale (EDSS) of between four and eight. These criteria were appropriately selected to increase the likelihood of participants being in or near the transition stage to SPMS. Seventy-four potential participants were identified through a database of PwMS in South Wales by one of the researchers (also an MS specialist nurse) and sent postal information. A final 20 participants and 13 carer participants agreed to take part in the study, none of whom were known to the researchers. The recruitment process, including method of approach and non-participation were clear, all factors included in the COREQ criteria for considering the quality of research (Tong et al., 2007).

Interview questions were described as being based on past research but not explained or further referenced. Questions were specific and could be considered as relatively closed and leading. For example; 'What do you find most bothersome?’ could have been rephrased as ‘Do these symptoms affect you?' to enable the participants to explain their experiences in their own words rather than potentially leading them to match their experience to one that is assumed 'bothersome.' Numerous questions focused on the secondary research aim of identifying ways to improve provision of information, such as 'How would you like to receive support and information about MS?' This could have resulted in less in-depth and experiential data than would be desirable for research that aims to understand the experiences of participants. It is worth noting that the interviews took place in different places at the participant's request. This could have affected the extent to which participants were able to speak openly, or felt empowered to speak (Tong et al., 2007).

Validity of this research was increased by carrying out three additional interviews after data saturation was thought to have occurred with no new themes being identified (Ando, Cousins and Young, 2014), and also through respondent validation which can also increase trustworthiness of data (Birt et al., 2016). However, respondent validation was carried out using focus groups which could present difficulty for individuals who have discussed personal issues within interviews but may feel less comfortable discussing, and in particular challenging these within a group. Additionally, only eight of the 20 participants with MS actually attended these groups though all were invited, therefore less than half of participants are represented. Reflexivity seeks to recognise and value the researchers' participation in shaping data and their analysis (Johnson and Waterfield, 2004) and should be apparent within qualitative research (Seale, 2004; Silverman, 2011), perhaps particularly research such as this that is reported as being based on social constructionism. Reflexivity was not mentioned or apparent within this study, therefore the reader is not able to contextualise the findings as fully as they might if this had been included.

Four themes were identified to include: 'realisation (that they had SPMS)', 'reaction (response to this realisation)', 'realities (of living with SPMS)' and 'recognising future challenges'. Themes were well illustrated and supported using a range of extracts. However these were presented in a table rather than being woven into the description of the themes which reduced the richness and impact of the themes generated for the reader and meant the reader had to refer to the table to understand how the themes were generated. Within ‘realisation’, participants discussed finding out by chance or through gradual realisation they had SPMS, rather than being informed by their healthcare team, and the process of diagnosis was unclear and varied. ‘Reaction’ to this diagnosis reflected participant perception about what having SPMS meant to them, with some participants expressing concern that moving to this phase of MS meant limited treatment options, whereas others were not interested in the label applied to their MS. ‘Reality’ of living with SPMS included loss of independence, limitation to social life, change in identity (often associated with loss of role or function) and the need for support from family and from others with MS to help deal with the reality of disease progression. ‘Reality’ also included healthcare experiences around transition, with many participants reporting infrequent healthcare contact despite the significant impact of MS on their lives. ‘Recognising future challenges’ included some participants reporting fear and uncertainty about the future, with others reporting avoiding thinking about the future due to the unpredictability of MS.

Frost, Grose and Britten (2017) interviewed 14 participants with progressive MS (PMS) to explore how they gave meaning to their experiences of MS diagnosis and self-management. Sampling was broadened as seven participants were recruited from MS Society branches in two cities in South West England and seven participants were recruited through MS specialist nurses. A topic guide for the interviews was developed by an extended expert panel to include a person with MS and included ‘demographic information, the broader context of the illness experience, sources of support and lay perspectives of living with MS’ (p320). This guide was piloted with two PwMS and it was decided that data collection would be carried out over two interviews to prevent participants becoming fatigued and to enable researchers to ‘tailor the questions in the repeat interview’ (p320). These aspects of the interview process increase rigour and credibility. However, transparency and trustworthiness could have been improved if any detail regarding the questions, in particular the way they were tailored at the second interview were apparent. The only detail is found in the results section, where it is mentioned that ‘respondents were asked about formal self-management programmes’ (p326). All interviews were carried out at participant homes by the same researcher which means the interview experience was likely to have been largely consistent. However, it was not mentioned in the study methods or discussion that any participants were interviewed with a spouse, however one extract included in the results reported discussion with the wife of one of the participants. As the presence of a spouse can influence an interview and the data collected (Norlyk, Haahr and Hall, 2015), this detail should have been made apparent and any influence to data collection or change in data analysis explained for improved transparency, credibility and contextualisation of the data. Data analysis was rigorous with initial analysis being carried out by two researchers, with resultant generated themes and narratives being subsequently analysed by a third researcher.

Four themes were reported and richly supported by illustrative extracts. In summary, 'The diagnostic process and certainty' found gender differences in the experience of diagnosis. Male participants broadly reported diagnosis being hard to come to terms with, invoking shock and fear, whereas female participants reported welcoming diagnosis as it validated their symptoms after years of 'being fobbed off' and disbelieved. Gender differences were again found in 'Sense making and uncertainty,' with female participants employing a range of strategies to help carry on with important aspects of their lives and male participants contextualising MS 'in relation to the loss of valued roles and functions' (p324). 'Self-management and management of self' included discussion around participants individualised responses and strategies to their unique symptoms and included pacing of activities, optimising function, focusing on others, exercise and social networks. 'Fears for the future and death as the only certainty' was the final theme, conveying fear of further and ongoing deterioration leading to emotional distress, isolation, loss of sense of self and suicidal ideation.

As in the study carried out by Davies et al. (2015), O'Loughlin et al. (2017) explored the experience of transitioning from relapsing remitting to secondary progressive MS from the perspective of seven MS specialist health professionals (HPs) and nine PwMS using thematic analysis. HPs were included to potentially generate a wider range of themes and contribute to identifying 'unmet needs of

PwMS during this transition, and the barriers to meeting such needs' (p1822). These factors formed two additional research aims. Participants were recruited from a neurological hospital in London, having been classified as transitioning from RRMS to SPMS within 24 months. People were excluded if they experienced onset of another co-morbidity during this time. This was to avoid the experience of transitioning to SPMS being affected by another experience of a health condition, but this may have led to numerous people being excluded depending on the definition of a co-morbidity. This factor and the number of people this excluded were not further explained. Interviews were carried out at participant homes. However, it was not clear who carried out the interviews, a factor which should be made apparent to help the reader contextualise and trust the interview process and the data generated (Tong et al., 2007). A detailed sample of the interview schedule was included and this increased transparency and added context to the data. Initial questions were open to enable exploration of the participants experience but later questions were increasingly closed and less exploratory to answer secondary research questions. The analysis is clearly detailed. Coding was carried out by the primary researcher but some sections were analysed by co-researchers to increase validation of theme identification. It was reported that significant overlap was found between the data, therefore both sets of data were coded together and the findings must be considered within this context- the combined experiences and views of PwMS and health care professionals perception of this experience for PwMS. The paper states its epistemological position as being from a critical realist approach and that interpretation of the data within the context of one's understandings and influences is important, yet the researchers do not mention their own background and context.

Four themes were identified. 'Is this really happening?' encapsulated the period where changes in disease pattern were noted by participants but this was associated lack of certainty about why this was happening, attempting to deny changes and recognising what it might mean. Participants described confirmation they had SPMS in the theme, 'Becoming a reality.' Reflective of the findings of Frost et al. (2017), some participants explained this brought relief, providing new understanding of their symptoms, while others described it as 'a psychological blow' (p1825). 'A life of struggle' described the grief, anxiety, dread, fear and loss of hope associated with facing a future of decline but participants also described their resilience and the need to ‘battle on.’ This theme was expanded further in the final theme ‘Brushing oneself off and moving on,’ where participants described coping mechanisms, physical and psychological adjustments to help cope with reclassification of MS.

Whilst themes are supported and illustrated by extracts, twice as many extracts were used from HP participants than PwMS and seven extracts were used from HP2 (the most extracts used by any participant with MS is four extracts). This suggests there could be some bias in the reporting of data. Despite the data being described as having significant overlap (leading to the decision to code the data together), the extracts suggested there were significant differences in how PwMS described their experiences compared with descriptions from HPs. The reader must interpret the results and analysis within the context of the experience being from both perspectives. However, findings could be written up in a way to identify differences rather than bringing them together in a theme, to make this more transparent and to ensure findings are explained in the appropriate context. An example of this is illustrated in an extract from the theme ‘Is this really happening’;

> ‘HPs described a reluctance to reclassify patients due to the psychological impact this could have. This sense of delay was viewed by many participants as hindering the process of adjustment to SPMS:
>
> ….you’re waiting all that time knowing in your head that I’m not getting better, but not being able to have that label….it makes the acceptance process a lot longer….HP2 (p1824).

Although the labelling and the description does specify otherwise, on first reading, it reads as if this extract is from a PwMS. Another example of this lack of clarity and distinction can be seen in the theme ‘A life of struggles’:

> Some described giving up hope, and assuming a passive stance in their relation to MS: ‘some give up hope…they don’t see that there’s much that they can do…’ HP2 (p1825)

This could be made clearer by explaining that some HPs perceived PwMS as giving up hope. The authors do acknowledge this limitation, ‘the degree to which HPs accounts accurately reflected the experiences of PwMS may be contested’ (p1827).

This section of the literature review will review three interpretive papers before summarising findings from this section. Hardwick (2017) used two narratives of PwMS to demonstrate and explain Paul Ricoeur's theory of interpretation as a method for narrative analysis, alongside aiming to provide insight into meaning-making and lived experience of MS. Ten PwMS from the North of England were recruited to tell their story about the onset of, and the adjustment to MS. This study is referred to as being the subject of further publication but this has not yet been published to my knowledge. Due to the focus of this paper being on the method of interpretation, it does lack some methodological detail which the researcher refers to as being described in the study awaiting publication, making it difficult to fully understand and contextualise the findings. The only methodological details provided were: the two participants in this paper were recruited through a regional therapy centre, ethical approval was gained, a narrative interview was carried out (at an unknown location) and, in keeping with the methodology, participants were asked to tell their story related to onset and adjustment to MS. Two narratives were selected for this study as they 'offer very different ways of making sense of life' (p654) within the context of living with MS. This research therefore presents the experiences of two individuals with MS explained through three stages of interpretation: naïve, (four or five) structural interpretations 'which provide the basis for the imaginative leap' (p655), finally contributing to the development of a critical interpretation. The interpreted data from these two narrative case studies is clear and detailed through being explicitly explained as a methodology.

Edwin's story was of two halves- life before MS was fast-paced, frenetic and defined as successful. This was abruptly ended with diagnosis of MS which led to powerlessness, particularly with regard to medical treatment, struggling to come to terms with MS, finding some acceptance and eventually trying to make the best of the present through focusing on what is good in his life, though he described himself as a different person after MS. Emma's story is described as telling half the story as she predominantly discusses early adulthood until diagnosis. Her Mother had MS and Emma describes seeing her Mother's death 'as a release from suffering' (p657) but her childhood was unhappy and lonely following her Mother's death. She describes living with MS as 'suffering in silence,' experiencing loss in many aspects of her life and lacking hope for the future. These interpretations offer insight into the experiences of living with MS for these individuals rather than representing themes.

Preston, Ballinger and Gallagher (2014) aimed to explore the experiences of participants living with MS with associated impairment of executive function (a complex cognitive impairment that affects a person’s occupation and ability to carry out their daily lives). The sampling method refers to this study being developed from previous research into executive dysfunctions most commonly associated with MS, and their impact on occupational performance (Preston, Hammersley and Gallagher, 2013). Ten of these PwMS were identified as having executive dysfunction through being categorised as ‘impaired’ using the Behavioural Assessment of Dysexecutive Syndrome and were therefore invited to take part in this research, with all of those invited agreeing to participate. Participants from the previous study were recruited through a hospital-based MS service in Scotland and were included if they had clinically definite or probable MS but excluded if; they were having a relapse, receiving corticosteroid injections (treatment for relapses), were taking medication known to affect cognition or had any history of drug or alcohol abuse, psychiatric or nervous system disorder. This criteria was adopted to enable the effect of executive function to be determined (Preston et al., 2013). The sample included a range across gender, age, duration of condition and EDSS, suggesting a representative sample. Interviews were all carried out by one researcher at the rehabilitation centre (at the participants’ request). It is not clear if the participants were known to the researcher through the previous study. This should be apparent to explain the interview context, as having a previous relationship with researchers can affect the interview experience and the data generated (Silverman, 2011). The interview question was, ‘tell me about your experience of MS,’ and then the interview continued through conversation about daily life to help understand how these participants constructed meaning around their life experiences in keeping with IPA methodology used. This enabled participants to shape the interview which could potentially increase the ability of the participant to explore their experiences as they perceived them without guidance from the interviewer. The IPA process was detailed clearly with reflexivity present. Rigour was increased through research supervision provided by the second author that incorporated further questioning, explanation of interpretations and facilitation of reflexivity.

Three emergent constructs were found: ‘gaining mastery of the disease’, ‘the reality of living with MS’ and ‘the implications of MS for personal identity’. The authors explained this paper focused on the third emergent construct as the predominant theme associated with Dysexecutive syndrome and reported the other themes would be discussed within future publications, which have not yet been published to my knowledge. Discussion in this paper was further focused on three of six recurrent themes that constructed the third emergent theme. These were ‘altered self’, ‘changing life roles’ and ‘loss of self-worth.’ Loss of self was evident for some participants as they described losing; their confidence, things they enjoyed, physical abilities, life roles, who they were and how others saw them. Participants described their current selves with shame, referring to themselves as stupid or boring. Other participants described holding onto their sense of self, for example, through maintaining friendships and trying to adapt and continue with pleasurable activities. These themes were illustrated with interview extracts from a range of participants alongside interpreted meanings, enabling the reader to contextualise and understand the research findings.

The aim of this research was to explore the experiences of PwMS with dysexecutive syndrome and the third theme was reported as this was described as being the predominant theme associated with dysexecutive syndrome. The reasoning given for this was that the participants in this study ‘struggled to find new ways of doing things that allowed them to create meaningful and satisfying lives’ (p489). However, examples used in the theme results appeared to demonstrate some participants trying successfully to make sense of their new lives through friendships or spending time with others with MS. The authors discussed a previous phenomenological study examining how debilitating diseases or accidents influenced occupation and identity for ten women with a range of disabilities which found that creating a satisfying life relies on skills such as planning and problem solving (Magnus, 2001). The authors suggest these skills are affected by dysexecutive syndrome and that participants in this study were less able to view their experience of MS as an opportunity for meaningful change in relationships and occupations, gain mastery over their illness and restore self-esteem than participants from other studies (Magnus, 2001; Paterson, 2001). However, results of phenomenological studies provide insight into phenomena rather than generalisation (Tong et al., 2007), particularly when comparisons are being made between differing populations such as in this case. Preston et al. (2014) suggested that ‘dysexecutive syndrome affects the ability to cognitively process the different stages of psychosocial adjustment, subsequently preventing the PwMS moving through the continuum’ (p489). However, the authors note that no participants mentioned dysexecutive syndrome and its consequences as having an impact on their daily lives. These suggestions are not clearly reflected within the extracts used and the interpreted theme and it seems out of keeping with IPA methodology which is ideographic and contextualised in nature. To compare the participants and make assumptions and generalisations in this way could be understood as introducing some bias in reporting the data. The remaining themes are presented in the table below as they will be considered as part of the summary of this section of the literature review but they were not discussed within this paper.

Mastering MS	**The reality of living with MS**	**Implications for personal identity**
Diagnostic journey	Unpredictability	Altered self
Diagnostic experience	Fear of progression	Living with unwanted self
Fear, anxiety, uncertainty	Fear of dependence	Loss of former self
Understanding diagnosis	Disease course	Loss of self-worth
Lack of information	Changing abilities	Reactions from others
Expectations of the disease	Meaningful occupations	Changing roles
Future hopes and aspirations	Relationships	
	Socialisation	

TABLE 1: ADAPTED FROM SUMMARY COMPONENTS OF EMERGENT THEMES TABLE (PRESTON ET AL., 2014, P486)

The final study in this section of the literature review was another IPA study, which explored the lived experience of being diagnosed with MS, in particular any effect on individual's sense of self (Strickland, Worth and Kennedy, 2016). Ten PwMS who had been diagnosed within the previous six months were recruited from a neurological clinic in Scotland. This study was part of a larger one which also explored the views of support persons regarding diagnosis with MS, and this led to participants being offered to be interviewed with their support person though the process was not fully explained. Five participants chose this option and five chose to be interviewed on their own. All participants were interviewed twice at home by one interviewer (the second interview following the first in six-twelve months' time). It was not explained if data from the second interview was analysed alongside the initial interview data or at a later point, or the significance of carrying out the interview for a second time. In keeping with IPA, a flexible interview guide was used to allow the flow of conversation to be participant guided, with examples of open questions about the journey to diagnosis or how being diagnosed felt being included. Reflexivity is not mentioned within this study though the importance and process of interpretation is apparent. Four transcripts were independently analysed by two other authors. However, IPA has a central focus on the individuals lived experience and sense making which is interpreted by the researcher to try and understand what this experience is like from the individual's perspectives in a process known as double hermeneutics (Pietkiewicz and Smith, 2012). This acknowledges that the researcher's interpretation is a key element of IPA and does not require validation through other researchers' interpretations. To maintain this element, the primary researcher could have explained their interpretation to the other authors to increase quality of this research in keeping with the methodology rather than using independent analysis.

Three themes emerged from the data; 'Road to diagnosis', 'The liminal self' and 'Learning to live with MS: an uncertain future'. All were reported to have a crosscutting theme of the 'impact on self'. 'Road to diagnosis' explores the period before participants were diagnosed where they described experiencing symptoms they did not understand but did recognise required further investigation and might have serious implications. The defining moment of being diagnosed and the transition from not knowing to knowing brought a range of feelings- relief, legitimisation (of symptoms) and devastation. Within ‘the liminal self,’ all participants reported a disrupted sense of self and a transition phase where they tried to adjust to the effects of MS upon their sense of self. MS affected every participant’s life, reported to varying levels within the final theme with uncertainty and variability being a recurring thread. Participants experienced loss, including social isolation, loss of participation in activities previously enjoyed and loss of independence. A conceptual framework was developed from the findings. Development of a theory from the data is perhaps more in keeping with a qualitative methodology such as grounded theory in comparison to IPA which primarily seeks to reveal something of the experience of each participant and may reveal any similarities and differences between participants when discussed in terms of the group of participants as a whole (Smith, Larkin and Flowers, 2009).

Despite there being differences in the focus and methodology of these seven studies, there were some overlapping and shared elements of the phenomenon of living with MS for this range of participants, providing insight into the lived experience of MS for PwMS in the UK (with data collection occurring within the past 5 years). Participants described a period prior to diagnosis in which they experienced uncertainty and disbelief, and a range of symptoms they were starting to piece together. The diagnostic process brought relief for some through affirming a reason for their symptoms, but brought disbelief and fear for others. There followed a period of realisation and sense making as participants grappled to gain mastery and some kind of acceptance about having MS to allow them to carry on, manage their condition and optimise their lives, facing future challenges as best they could. The reality of living with MS was varied but themes and threads of loss, fear, struggle, disruption and uncertainty were present in all the studies. Findings from most studies highlighted the implications of MS for personal identity, with participants having a sense of self that is different before and after MS, often associated with a transitory period (the liminal self) where participants struggled to find their new sense of self.

It is acknowledged this is a limited section of literature. A wider view of the literature, including research on the lived experience of PwMS over a longer time period and outside of the UK introduces further themes, such as the importance and role of hope, support and knowledge but also includes the themes discussed above (see tables B and C in Appendix V), suggesting some commonality across the wider range of literature.

2.3 Experience of healthcare for PwMS

In keeping with the previous section, literature reviewed regarding the experiences of healthcare for PwMS has been limited to research carried out within the UK in the past five years. Two studies met this criteria, one of which was a systematic narrative review of UK health-care service experiences for PwMS (Methley et al., 2014), thereby providing information on a wider range of research. The other study was carried out by the same researchers and explored patient and professional perspectives of healthcare services for MS (Methley et al., 2017). These will be considered in turn.

The review by Methley et al. (2014) included studies that used qualitative methods of data collection and analysis to investigate experiences, views, attitudes to and perceptions of health-care services for (adult) PwMS in the UK. The search strategy was thorough, detailed and robust. The five included studies were critically reviewed independently by one researcher using the relevant CASP tool, then jointly analysed with co-researchers through a detailed and transparent process. Using a quality assessment tool such as the CASP tool can help reviewers look at relevant individual components to evaluate and describe quality of a study's methods and guide study reporting, therefore increasing the rigour and trustworthiness of the review (Harrison et al., 2017). Studies were not excluded if they were of poor quality- rather, the quality of evidence available was part of the review and discussion findings. Overall, the included studies were reported to be mainly focused on diagnosis or palliative care and were of poor quality (with a maximum of 59.5% of CASP criteria met and an average of 51.9% across the studies). Due to the paucity of papers found and the breadth of areas researched, a narrative summary approach was taken rather than an in-depth qualitative synthesis method.

Themes were identified where there were similarities between areas of care and stage of MS and included ‘the emotional experience of health care’, ‘continuity of care’ and ‘access to services and support from HPs’. Negative descriptions of a mismanaged, drawn out and fragmented process of diagnosis at a time of great uncertainly, fear and anxiety were common. As found in the studies included in section 2.2, diagnosis brought devastation and shock for some and relief for others. There was a lack of timely information received despite this being reported as being of importance to PwMS in all of the included studies. Another finding was a variability and lack of knowledge about MS, particularly reported during encounters with general practitioners (GPs). In the post-diagnostic phase, access to treatments for MS was difficult, especially for psychosocial support. Poor communication and lack of continuity of care were experienced, leaving participants feeling isolated and abandoned. Again, these factors were also highlighted as key components of beneficial health-care. In addition, this research highlighted there is very little research that explores the health-care experiences of PwMS in the UK and further research regarding this is required, particularly research that includes people from ethnic minority backgrounds and people under the age of 35, as these groups are not represented in the current literature.

Following the above research that highlighted a paucity of knowledge and research in this area, Methley et al. (2017) sought to explore patient and professional perspectives of healthcare services for PwMS. Semi-structured interviews were carried out with 24 PwMS and 34 HPs (practice and specialist nurses and GPs) purposively sampled from within four primary care trusts to represent a variety of practice sizes and settings (urban and rural) and five foundation trusts. Ten out of 265 invited GPs and 13 out of 154 invited practice nurses agreed to participate- it could be that participants represented practitioners who had interest in MS which could bias results. Nine out of 18 invited specialist nurses participated, suggesting that staff with more specialist knowledge and interest in MS may have an increased likelihood of engaging with this research. Patients were recruited through community methods including the MS Society, except for one participant who was recruited through their GP. Recruitment was closed once category saturation was achieved, demonstrating part of the rigorous process of coding and analysis described in this study. As reflected from the previous literature review, there was a lack of representation from people from ethnic backgrounds, younger people and people with more severe disability in this study, leading to the suggestion that more innovative recruitment methods should be considered.

Interviews were carried out at the participants preferred location (mainly at work for HPs and at home for PwMS) and followed topic guides which were developed from the literature and detailed in the study, increasing context and transparency in this process. Dissemination of findings through oral presentation to an MS Society group further increased trustworthiness of this research. Three themes were reported and mapped on to the 2014 NICE guidelines for MS to make links and comparisons with national guideline recommendations. These comprised ‘access to care’, ‘interpersonal interactions’ and ‘continuity of care’. It is of note that these factors are included in recommendations in NICE guidelines for MS but lack explicit detail and nuance (NICE, 2014; NICE, 2018).

In summary, health care experiences were more positive when PwMS had access to meaningful and timely intervention and follow up, delivered with effective communication. Trust was developed and anxiety and poor experiences reduced when continuity of care with HPs providing knowledge-based and person-centred care was delivered.

2.4 The experience of physiotherapy

There is a significant body of research that explores the views and experiences of patients about a range of specific issues, services, interventions and conditions relating to physiotherapy (see Table A in Appendix VI). The aim of this section is to broadly explore patient perceptions, experiences and meaning-making of physiotherapy for a variety of populations, prior to focusing on experiences of physiotherapy for PwMS. To meet this aim, research focused on a specific aspect of physiotherapy intervention has mainly been excluded as this does not facilitate broad exploration of the experience of physiotherapy from the perspective of the patient. The exception to this is that research exploring experiences of physiotherapy from the perspectives of people with long term neurological conditions was included even if this focused on a particular aspect of physiotherapy. This is because physiotherapy shares common principles within the management and rehabilitation of long term neurological conditions, therefore it was anticipated that exploring experiences of physiotherapy for people with any neurological condition, particularly those that are long term and progressive, will provide relevant insight into experiences of physiotherapy for PwMS. This is more pertinent due to the scant research exploring experiences of physiotherapy for PwMS. In addition, a research paper by Payton and Nelson (1996) has been included in this review despite its specific focus on goal setting as this is used in all areas and specialities of physiotherapy (CSP, 2010). Two of the studies included (Bassett and Tango, 2002; Potter et al., 2003) are carried out with private practice patients' rather than with patients' accessing physiotherapy through the NHS or another public healthcare system; they therefore provide a different context to this current research but have been included as they meet the aim of exploring the experience of physiotherapy. The selected research is presented in table B in Appendix VI. One research report was found that focused on perceptions of physiotherapy for PwMS (Buckley, McLaughlin and Kennedy, 2008), this will be explored separately in section 2.6 and so has been omitted from this section.

2.4.1 The experience of physiotherapy for people with progressive neurological conditions

It is argued that research carried out in the UK, within the field of neurology, will provide the most relevant insight to inform this research, therefore these papers will be considered first. Two of these selected studies focus on people with progressive ataxia (Cassidy et al., 2018; Daker-White, Greenfield and Ealing, 2013). Both papers highlight the paucity of research undertaken to understand the patient experience for people with this condition, highlighting the importance of research in this area. This form of ataxia has similarities with MS, in that it is a long term degenerative neurological condition that cannot be cured, but may be helped with symptom management which includes physiotherapy (Miyai et al., 2012; Revuelta and Wilmot, 2010).

Daker-White et al. (2013) explored specialist neurological physiotherapy provision and utilisation for people with progressive ataxia. Thirty-eight people with ataxia living in the northwest of England were selected in a robust and purposive manner through wide sampling to include the membership list of Ataxia UK (a UK based charity for ataxia), a department of clinical genetics and a neurology department. Interviews were carried out in the participant's homes by the primary researcher, noted as being an experienced health researcher. Interviews were recorded except two due to participant refusal. In these cases, notes regarding the interviews were made. This could have led to data being missed or forgotten (Tong et al., 2007). This study was part of a wider one which was primarily concerned with the costs, provision and utilisation of health services for people with ataxia. For this reason, interviews focused on the experiences and perceptions of ataxic symptoms and health services received rather than experiences of physiotherapy. Only two thirds of participants had experienced physiotherapy but these participants were not excluded from the sample which might be expected considering the aims of this research. In addition to the 38 participants with ataxia, eight specialist physiotherapists working with people with ataxia were interviewed at their place of work, with their interviews being focused on their knowledge and experience of working with this population.

Interviews with participants with ataxia were coded using the words 'Physiotherapy/physiotherapists' as one code family, alongside several other word phrases seen to relate to physiotherapy (e.g. exercise sheets). Codes were identified by one author and managed using 'Atlas.ti' data management software. Coding of the interviews with physiotherapists took place following analysis of the patient interviews but code descriptions are not provided for these interviews. Thematic analysis generated three themes; 'Provision of (specialist neurological physiotherapy) services', 'Engagement with services' and 'Making a difference?'. Themes were brief and reported without illustrative extracts. Themes one and two were presented with no participant extracts. The main finding regarding 'provision of services' was that provision was restricted, patchy or even absent across the region, with services being difficult to access and some being stopped due to withdrawal of funding or exclusion of this condition. Of the 25 participants who had received physiotherapy, 6 were mostly dissatisfied, 9 were neutral and the remaining 10 were largely satisfied with their experiences of physiotherapy. Dissatisfaction was reported as being predominantly due lack of service. This theme did not provide further exploration or detail about these issues and did not explore patient experiences of physiotherapy.

The next theme of 'engagement with services' arose more often in physiotherapist interviews. It was identified that while many participants felt physiotherapy was their only hope, some considered it a waste of time- others reported this was suggested to them by their therapist:

> The physiotherapist . . . said there was nothing they could do. PWPA#10
>
> I took it that was what you've got, go and get on with it. PWPA#29 (Table S2, additional supplement)

Daker-White et al. (2013) highlighted a mismatch for these participants between what physiotherapists could offer and what patients expected. Some physiotherapists interviewed reported they did not feel physiotherapy could help people with progressive ataxia, perhaps in part due to concerns around how to measure improvement when the condition is progressive. It is worth noting that recruitment of physiotherapists for this research proved difficult, suggesting that neurological physiotherapists may not feel confident in managing people with progressive ataxia. However, participants reported value in physiotherapy even if it did not result in improvement. Participants reported longer term approaches to physiotherapy were beneficial, resulting in more positive experiences of physiotherapy whilst short term approaches were at best inadequate, and at worst a further source of frustration. Within this theme, there was an expectation of 'hands on' therapy mentioned but what this might consist of or mean to participants was not explored. The final theme was 'making a difference?.' A longer- term, person to person interaction with a physiotherapist was valued by these participants, rather than any focus on outcome or improvement. Exercise was recognised by some participants as being helpful but adherence was challenging. There were several extracts in a supplementary table of themes that demonstrated other aspects of physiotherapy that ‘made a difference’, but these were not reported or mentioned in this study which raises questions about the rigour and trustworthiness of the findings. Examples are illustrated below;

> They end up giving him these blooming exercise sheets…He needs some supervision on a regular basis. They referred him…for physiotherapy and they gave up with him (carer of PWPA#21, Table S3, additional supplement).

This extract suggests the exercises this person was provided with did not meet their needs and resulted in them feeling abandoned. Provision of walking aids and education as part of physiotherapy intervention was also highlighted;

> They gave me an elbow crutch and . . . I was just amazed at how much better I walked . . . That was just the best thing for me out of everything, PWPA#20.
>
> The physiotherapy has made me more aware of, well my body I suppose, moving and balancing and things, PWPA#12 (Table S3, additional supplement).

Overall, this research did provide insight about physiotherapy experiences for people with ataxia, identifying features of an ideal physiotherapy service for this population based on the findings of their research (see Appendix VII). However, perhaps due to the large sample size and the focus of the original research not being on physiotherapy services, the research lacked exploratory detail throughout, and themes apparent in the extracts provided in the supplementary table were omitted.

Cassidy et al. (2018) explored the meanings of exercise and physiotherapy for people living with progressive cerebellar ataxia. Due to the aim of my research, this review will predominantly focus on the meanings of physiotherapy from their research. The recruitment process was detailed and clear and accounted for each person involved. Twelve participants were recruited across the UK through Ataxia UK with inclusion criteria of those over 18 years of age ‘to avoid the earliest stages of grief or shock’, (p895) with a diagnosis of ataxia who also had some experience of physiotherapy. Cassidy et al. (2018) identified that most participants in their study were able to walk and did not require significant external support to live their day to day lives. It could be that experiences of this population with more severe impairment may be different to those revealed in their research. When exploring the experiences of physiotherapy for PwMS, it is important to try to recruit participants with a range of levels of disability. Recruitment through a charitable organisation can result in a biased sample of participants, as previously discussed in section 2.3 and this should be noted when considering the relevance of the findings to wider populations. However, it is possible that this bias could be inherent when recruiting from any service for people with a specific condition as this method selects people who are already engaging with services. The authors note the sample size is larger than commonly advised in IPA, but does remain appropriate for this method, as agreed by Smith et al. (2009). Details of each participant were included which provided a context for each individual.

Semi-structured interviews were carried out with questions about living with ataxia, encounters with physiotherapists and experiences of exercise as examples, but with participants' perspectives being prioritised in keeping with IPA methodology. Interviews were all recorded and carried out by the principal researcher. Eight interviews were carried out individually in participant homes, three participants chose to be interviewed at the Ataxia UK offices, with two of those choosing to be interviewed together and the remaining participant chose to be interviewed at their workplace. This research closely and transparently followed IPA methodology for interviewing, analysis and interpretation. In brief, and to highlight particularly pertinent aspects of methodology: participants perspectives were prioritised 'over and above what might already (have been) considered known about the topic' (p895), field notes were incorporated alongside full data transcription, data analysis was immersive and consisted of several detailed stages to develop themes focused on meaningful experiences both for individuals and across the group and described with a deep level of interpretation to explore those meanings. The paired data for the participants interviewed together were analysed separately as IPA is committed to the experience of each individual. The data was then analysed to consider how the participants interacted. During the analysis, a reflexive approach was maintained throughout to take into account the context of the researcher. Analysis was carried out by the principal researcher, but interrogated and challenged by co-researchers which increased credibility of the research without losing the importance of the hermeneutic circle. Two themes were identified, those of 'Connecting with knowledgeable others through physiotherapy' and 'Physical exercise as a means of sustaining a positive sense of self.'

Within theme one, and in keeping with research findings from Daker-White et al. (2013), participants expressed the benefits of long-term partnership working with physiotherapists that were knowledgeable about their condition (ideally the same therapist) but these participants also found this was frequently not available to them. A connection with 'an informed other' (p897) was identified as something that some participants in this study looked for from physiotherapy, but often found lacking (Cassidy et al., 2018). Short term approaches, lack of practical review and continuity and a focus on improvement affected participants' experience of physiotherapy and their ability to carry out prescribed exercises in a negative way. Lack of knowledge about ataxia was highlighted as a concern amongst many participants, with physiotherapy feeling like 'trial and error' to one participant. This is reflective of the findings of Daker-White et al. (2013) where physiotherapists indicated they lacked the knowledge required to treat people with ataxia. Longer term, flexible, person-centred partnership working that was supportive and empathetic and provided knowledgeable and practical advice, education and treatment was associated with positive experience of physiotherapy that had the capacity to provide hope. Cassidy et al. (2018) explained that 'participants therefore seemed to place importance on physiotherapists who could help maintain hope and maximise day-to-day living' (p898) where continuity of person-centred care was key.

The second theme was 'physical exercise as a means of sustaining a positive sense of self.' Exercise was something that all participants took part in and was of vital importance to them in numerous ways beyond that of addressing physical impairment. These ways included fulfilling social and work roles, increasing confidence and feeling a sense of purpose, achievement, control and positivity. For these participants, exercise was often self-selected rather than physiotherapy prescribed and 'seemed to be much more about being in the world' (Cassidy et al., 2018, p901) in terms of participating in activity, being part of networks and forming a wide ranging and integral part of their lives. This research found that participants perceived physiotherapists as focusing on exercise as a way to address impairment rather than for enjoyment and improved quality of life. Prescribed exercises are commonly understood to form part of physiotherapy practice (Campbell et al., 2016) as was the case for these participants. However, experiences of exercise prescription varied considerably regarding how manageable, effective or relevant this intervention was due to some of the reasons discussed. This research with people with ataxia revealed that some participants experienced prescription of exercises focused on body impairment that did not meet their needs at best, but at worst added to their feelings ‘of burden of living with a progressive ataxia, and in turn provoke(d) feelings of disappointment, disempowerment and demotivation.’ (Cassidy et al., 2018, p902).

It is useful to compare these two studies to inform my research, not only due to their relevance in terms of speciality but also as they have similar aims of exploring experiences of physiotherapy for people with ataxia but used different methodologies. This enables the methodologies to be compared and critiqued against meeting the aim of exploring the experience of physiotherapy which will directly inform my research. Both studies used purposive sampling but in the research by Daker-White et al. (2013), only two-thirds of participants had experience of physiotherapy, whereas all participants in the research by Cassidy et al. (2018) had experience of physiotherapy. To enable rich exploration of the experience of physiotherapy, purposive sampling should include having experienced physiotherapy. Cassidy et al. (2018) note the sample size of 12 they used was fairly large but within what is considered appropriate for IPA (Baker and Edwards, 2012). This allowed for exploration of each individuals story and increased depth of analysis which best met the aim of exploring experience. In contrast, the research by Daker-White et al. (2013) included 38 participants and did not explore the experiences of individuals.

IPA research (such as the research by Cassidy et al., 2018) encourages pseudonym participant names, as opposed to the use of numbered participants in the thematic analysis by Daker-White et al. (2013). This, alongside additional situating information, brought each participant to life, giving them presence and context within the research. As a reader, I found it much easier to relate to and understand the individuals experience due to these factors. As a clinician, I find that experiences rooted in stories about individuals relate more to physiotherapy practice and enhance my insight and understanding of working with people with conditions such as cerebellar ataxia and MS. This is particularly relevant for physiotherapists looking to improve services and practice. The rich use of participant extracts, illustratively interwoven and intrinsic to the themes in the research by Cassidy et al. (2018) add impact, depth and meaning, offering unique, poignant windows into participants lives, thereby enabling personal experiences to explore this phenomenon. The experience of participants resonated and connected with me as a researcher and practitioner, but also as a human, privileged and enlightened through sharing this experience with another in this way.

The use of extracts also makes the research process more transparent and trustworthy as it allows the reader to understand the themes generated, the interpretation presented and also interpret the findings themselves. IPA methodology is closely followed by Cassidy et al. (2018) and a vital aspect of this is the interpretation of data which results in a narrative that ‘should be revealing, important and of value’ (p903). The researcher’s interpretation of the participant making sense of their experience adds insight and depth about what the words and experiences mean for these participants within their ‘constructed but uniquely situated identities’ (p903). Cassidy explains that ‘accounts were co-constructed and framed by both the researchers’ and participants’ personal, cultural, historical and social contexts’ (Cassidy et al., 2018, p903). Little is known about the experience of physiotherapy for people with cerebellar ataxia or PwMS. This co-construction of knowledge can develop and enhance knowledge in a phenomenon or experience that is under-researched (Smith et al., 2009).

Daker-White et al. (2013) identified features of an ideal neurological physiotherapy service for people with a progressive ataxia. These features have been presented alongside some of the findings from the research by Cassidy et al. (2018) and can be found in Appendix VII. These findings are specific to people with ataxia but may offer some insight into the experiences of physiotherapy for people with long term neurological conditions, important as background knowledge for the current research exploring experience of physiotherapy for PwMS. It is acknowledged that summarising these complex and multi-factorial findings for the purposes of this review loses the depth that is particularly key to IPA methodology and the research findings of Cassidy et al. (2018).

The findings of the research by Cassidy et al. (2018) and Daker-White et al. (2013) present key findings about the experiences of physiotherapy for people with ataxia. Participants found physiotherapy to be most valuable and meaningful when their physiotherapist had knowledge of their condition and also sought to understand living with ataxia and therefore what physiotherapy might mean to them. Participants had more positive experiences of physiotherapy when an accessible, long term, collaborative approach was taken which was flexible and took into account each individual's needs. It was important to people living with ataxia to have the ongoing support, empathy and at times, the counsel of a physiotherapist. This was enhanced with the same physiotherapist as a trusted relationship could be built. People with ataxia found that physiotherapy tended to have a short-term approach with focus on body impairment which was unhelpful and lacking in meaning compared with a focus on helping them to live well with (and despite) their condition. As this is a progressive condition, outcomes should be focused on measuring function and quality of life in a way that is meaningful to each individual based on their own situation and needs.

2.4.2 The experience of physiotherapy for people with neurological conditions

Dowswell et al. (2002) aimed to 'explore in-depth patients' and caregivers' understanding of the purpose, expectations and perceived value of late community physiotherapy and their own role in the treatment programme' (p362), highlighting that little is known about the experiences of physiotherapy following stroke. This qualitative study was conducted as part of a larger RCT (n =170) which examined the effect of physiotherapy intervention delivered one year post-stroke in the north-west of England (the intervention group had physiotherapy for up to three months, and the control group had no physiotherapy; both groups were followed up at three monthly observation points). An additional nine of the intervention patients (and their seven carers) were interviewed separately in their own homes using a range of structured but open-ended questions to include their expectations of the intervention, what they hoped it would achieve and what they saw as the best and worst things likely to arise from the sessions. The participants also had previous experience of physiotherapy following their stroke. Questions were asked prospectively before the intervention and then retrospectively following intervention. Although this study is not regarding a specific physiotherapy treatment mode or technique (the intervention was described as ‘physiotherapy that was designed to improve mobility’, p362), it is focused on the experience of this particular intervention, and not on the broad experience of physiotherapy for people following stroke. Although stroke is considered a long term neurological condition, people can recover from the effects of a stroke and the condition is not progressive (Veerbeek and Verheyden, 2018). In this way, stroke rehabilitation differs from rehabilitation for progressive conditions such as ataxia or MS. Physiotherapy approaches for stroke often focus on recovery rather than management of the condition (depending on the severity of the stroke), although therapeutic approaches often move towards management of the condition as recovery tends to lessen over time. This difference is important to take into account when considering the experiences of physiotherapy for people with stroke as compared to progressive neurological conditions as experiences may have less commonality and resonance between these different populations.

Interviews were carried out separately and simultaneously with carers in participant homes. It is assumed the interviews were carried out by the same researcher for all patient and carer participants but this is not clear. Interviews were transcribed, coded and analysed with the assistance of NUD*IST software to develop a coding frame ‘to reflect the main patterns of responses, consistencies and divergences across the interviews’ (Dowswell et al., 2002, p362). Physiotherapy records were also made available to the research team, however, they did not elaborate on what the records were used for, except to note the number of sessions included in the intervention. This research was to explore the patient’s’ and caregivers’ experiences rather than the physiotherapists. It would increase transparency and trustworthiness in the research process and findings if it was made clear the purpose of physiotherapy records being made available to the research team.

The nine participants had 63 sessions of physiotherapy between them. The results were presented as pre and post-physiotherapy issues with ‘verbatim accounts [ ] used to illustrate response categories’ (p362). Participants were not identifiable within this research either through sample information or pseudonyms and so there was no individual context associated with the extracts used. When asked what physiotherapy at this later stage post stroke might consist of pre-physiotherapy, responses were ‘similar and concise’ (p362), consisting of two broad categories. Firstly, participants did not know what to expect. Secondly, participants thought physiotherapy (at this stage) would consist of working on specific tasks such as walking, and they discussed this in relation to body parts or movements. The authors identified these expectations were largely based on previous experience of physiotherapy which may pose difficulty for determining expectations of the intervention that is the focus of this study but provides insight into past experiences of physiotherapy for my research. Pre-physiotherapy responses when asked about their hopes for this physiotherapy intervention were ‘more personal and diverse’ (p363) and more likely to discuss functionality (e.g. walking outside to get to the shops) whilst including other issues such as increasing confidence, memory, speech. Responses about hopes of physiotherapy had more of a holistic idea of recovery compared with their expectations (and experiences) of physiotherapy. Participants were also asked about the best thing that could come from physiotherapy sessions. Participants hoped for changes that helped them carry out daily tasks such as going out more and doing the housework. Another finding of note was that ‘while more ambitious hopes were mentioned, accounts were tempered with a sense of realism’ (p363).

Post-physiotherapy participants made distinctions between what actually occurred at sessions, what they thought had been achieved and what they valued. They described therapy sessions in terms of body parts and equipment used and being focused on physical tasks and exercises, therefore mirroring their expectations pre-physiotherapy. This research found that some participants were able to translate these movements into function and activities of daily living. Other findings were around what participants thought had been achieved in the physiotherapy sessions and the value they transcribed to this. For example, a small change in hand movement, which may not relate to a notable change in function, provided a source of hope which was highly valued. Benefits of physiotherapy were not confined to physical impairment. Participants 'enjoyed the stimulus of meeting the therapist and other stroke patients,' (p363). Continuity of care and the attention received was valued by some participants, 'psychologically it did me the world of good' (p364).

Based on their findings, Dowswell et al. (2002) conclude that 'expectations of what physiotherapy would involve were largely borne out' (p364). The main issues highlighted from this research relating to experiences of physiotherapy for people who have had a stroke included participants anticipating that physiotherapy would comprise of interventions focused on body impairment. As the authors state, such expectations were largely related to participants previous experience of physiotherapy post stroke, therefore this can also be understood in the context of experience of physiotherapy. However, participant expectations differed from their hopes of physiotherapy which were broader and more inclusive to focus on improving their ability to function and feel better in their daily lives. Following intervention, this same pattern was seen- the intervention focused on impairment and movement but participants valued the personalised interaction with the therapist and other patients and the hope (for example of returning to previous roles) that the therapy offered more highly as reported in the discussion section of this research. Hope, continuity of care and receiving therapeutic attention was also valued by participants. These factors and the significant differences between expectation and experience, and what participants hoped for and valued have resonance with the research of Cassidy et al. (2018) where participants found therapy often unhelpfully focused on impairment rather than helping participants live better with their condition in a more holistic and meaningful way.

Galvin, Cusack and Stokes (2009) 'aimed to examine the experience of inpatient physiotherapy intervention delivered after stroke in Ireland' (p238) from the perspectives of patients and physiotherapists. They interviewed ten patients and carried out focus group discussions with ten physiotherapists. The aim of the study was further focused with the aim of interviews being; 'to explore the views of people with stroke in relation to their physiotherapy intervention and the involvement of their family in their rehabilitation programme' (p240) as 'this study also informs the development of an intervention trial focusing on the involvement of families in the delivery of exercises to people after stroke' (p240). They explain that questions were centred around 'the duration and content of the person's physiotherapy programme, the role of their family in this programme, and their views on the concept of family assisted exercises as an adjunct to their routine physiotherapy' (p240). Discussion themes were similar for the focus groups with the physiotherapists. These questions restrict open discussion about experiences of physiotherapy due to the focus on family involvement.

Data was transcribed and analysed using a grounded theory approach to identify codes, patterns and themes. This process was verified by three other researchers other than the primary researcher to increase validity of findings. However, the themes were the question topics identified, making this study more about reporting the findings from these questions rather than grounded theory research where theory is generated through development of codes and themes (Silverman, 2011). Findings were reported in brief and did not provide further detail or depth than could have been generated through a questionnaire. For example:

> The majority of participants (n= 8) reported that they received physiotherapy on a daily basis for 30-45 min. However, 9 of the 10 participants reported that they could benefit from more physiotherapy, particularly walking (n=7) and leg exercises (n=5) (p241).

This extract is the only section that refers to experience of physiotherapy, apart from a further statement reporting that when participants were asked what attributes were important in a physiotherapist treating people with stroke, participants identified encouraging, caring and honest. The remainder of the results presented are about family involvement in rehabilitation, and these are explored further with the use of extracts and further analysis and are the focus of the remainder and majority of this study. In the discussion the authors reiterate that 'the aim of this study was to gain insight into both patients' and physiotherapists' experiences and expectations of physiotherapy after stroke in an Irish setting' (p242). They argue that 'the methodology was appropriate to the topic, as it allowed issues to be pursued in a greater depth than would have been possible using a more quantitative approach' (p242). To some extent the aims they identify are met as the study provides more insight than some quantitative research might within the section on involvement of family in rehabilitation. However, this study provides limited insight into patient experiences of physiotherapy (for people following stroke).

2.4.3 The experience of physiotherapy (not specific to people with neurological conditions)

Wottrich et al. (2004) 'aimed to explore, describe and compare the characteristics of between one and three physiotherapy sessions from both the patient and physiotherapist perspective' (p1198). Therapists invited one of their stroke patients to participate in the study which may introduce bias to this research. The focus of this research, carried out in Sweden, compared these two perspectives regarding physiotherapy sessions rather than exploring the experience of physiotherapy. This was carried out through the use of observed behaviour during treatment sessions, followed by interviews on what was observed and understood within these sessions. The subsequent comparative analysis methodology used reflected this. This research will not be discussed further as it does not contribute to the understanding of the experience of physiotherapy (beyond these observed sessions).

Basset and Tango (2002) carried out a phenomenological study in New Zealand that sought to 'interpret and understand Maori people's experience of being physiotherapy patients' (p30). Experiences of six fee-paying voluntary participants were explored using data obtained through recorded in-depth conversation (the authors use the term conversation rather than interview, suggesting the term interviewer infers this person 'holds a position of power over the interviews,' (p31)). The researcher guided the conversation using a topic guide based on another study that explored patients' perceptions of their relationships with health care professionals (Payton, Nelson and St Clair Hobbs, 1998). There were fourteen topics in total that covered a range of issues regarding patient and physiotherapist roles, their sense of comfort, information provided, and the extent to which the physiotherapist acknowledged cultural need. Topics were reported to be addressed within the flow of conversation. However, conversation topics were detailed and specific, containing descriptors regarding their level of participation and decision-making and the extent to which the therapist recognised their cultural needs as examples. In addition to this, these topics were provided prior to the interview, ‘enabling them to give some thought to these in advance’ (p32). A potential flaw of this may be that participants are prompted to discuss certain aspects of their experience and this might affect the telling of their experiences towards reflecting the interests of the researcher or research and introduce bias.

Transcripts were recorded verbatim but then ‘reassembled into a coherent account of each of the participant’s experiences’ with any ‘irrelevant information in the conversations not being included in the stories’ (p32), following repeated review of the data. This method is not in keeping with a phenomenological study where people’s experience is the focus therefore any experiences shared would not be considered ‘irrelevant’ or incoherent. However, it might be that only minimal content that did not form part of the person’s experience was removed. Credibility and transparency is improved as participants were sent copies of their reassembled stories alongside the original transcripts for verification, which could suggest their words were not changed significantly. However, participants may not have felt comfortable challenging their edited transcripts.

Data analysis occurred through grouping the transcript content with the topics set out by the researchers. It could be suggested this analysis followed a comparative method as the guide topics were used as a baseline for analysing the themes and the five broad themes identified were based on the original topics (some were grouped together). In contrast, phenomenological research tends to follow an inductive approach that allows themes to be developed from the words of the participants. The authors state that ‘in this form of phenomenology it is important that the researcher sets aside or brackets their own perceptions of peoples experience and only describes the participants’ experience’ (p31). This seems at odds with using a previously devised topic guide and analysing the data with reference to this guide. A potential benefit to using a more structured topic guide was that a range of issues considered relevant to the researchers are covered within the conversations; this may result in more information regarding specific aspects of service provision (e.g. comfort of the patient or if their cultural needs were met).

Five themes were identified: personal and cultural respect, patient-physiotherapist interaction, treatment techniques and participant's beliefs about them, reasons for attending physiotherapy and the influence of previous physiotherapy experience, and the expectations and outcomes of physiotherapy. Numerous extracts are used that illustrate the themes but also suggest involvement of the topic guide, for example in focusing on cultural values:

> Concerning my cultural values and how they have been addressed within my physiotherapy treatment […] (p33)

This research focuses on the experience of being Maori and how this affects experiences of physiotherapy. One of the findings was that it was more important to be respected as people than for the physiotherapist to overtly address any cultural practice; participants did not want or need to be treated any differently to other people. From this finding, it is surmised that had this topic had not been suggested and prepared for, it may not have formed such a significant part of this reported experience of physiotherapy.

This research highlighted the importance of explanation, education and use of visual aids for learning and carrying out exercises in physiotherapy. Positive experiences (and outcomes) of physiotherapy for these participants were associated with regular review and assessment, caring patient-therapist relationships with personal attention and a clean and comfortable treatment environment. These broad findings were consistent with previous research findings discussed.

In the penultimate study reviewed in this section, Payton and Nelson (1996) carried out a preliminary study of patients' perceptions of certain aspects of their physiotherapy experience in the USA with the specific aim of discovering 'how physiotherapy patients understand their role or involvement in goal-setting, treatment planning and evaluation of outcomes' (p29). This study is not set in a public health service and is over twenty years old, therefore the context of physiotherapy differs significantly to my research, meaning research findings may have less relevance. They describe their study as 'descriptive [ ] with some qualitative elements' (p31). Data was collected through 20 semi-structured interviews with participants selected by physiotherapists in local healthcare settings with the exclusion criteria of having cognitive impairment that would limit discussion. Participants had at least two weeks experience of physiotherapy and had a range of conditions (10 of which were neurological). 'The first three questions [ ] were intended to lead the patients to discuss goals, treatment and outcomes of therapy' but the 'content for the last two questions were allowed to emerge from the data without prompting from the interviewer.' The questions are presented in full below in Figure 3 below. It is assumed from the description that the first three questions were asked directly but the second two were questions asked by the researcher when analysing the transcripts, but this is not wholly clear.

1. Do patients undergoing physiotherapy believe that they have effective input in setting therapeutic goals?
2. Do these patients believe that their input is sought and accepted in planning treatment?
3. Do these patients believe that they provide useful information to the therapist relating to the assessment of therapeutic outcomes?
4. Do these patients value physiotherapy and, if they do, why or how is it important to them?
5. How do they describe their interpersonal relationships with their therapist?

Figure 3 Interview questions (adapted from Payton and Nelson 1996, p29)

Interviews were all carried out by one researcher and data coding was checked by three researchers, thereby increasing validity, after 10 of the 20 interviews carried out were randomly selected for inclusion. The authors note a limitation that participants had to interpret the interviewer's questions and then select personal experiences which seemed to them to be relevant to the question (p32). In this way, participants filtered their experiences to deliver those that best met the questions, which will affect the data. It could be that this, alongside participants being selected by participants that were known to them could result in the Hawthorne effect whereby the effect of the taking part in the research changes behaviour (McCambridge, Witton and Elbourne, 2014). The transcripts were interpreted as providing strong, moderate or weak, positive and negative data in relation to each question, depending on the level of detail of the response or the number of times it was mentioned, with the aim of increasing validity. The authors were ‘looking for content to emerge from the data which would support or refute the philosophical construct of patient participation’ (p31). Emergent data was compared against the constructed five questions and then ranked to state how strongly data correlated with these questions. The results were presented in terms of patient perceptions of their roles in physiotherapy relative to the five questions above. Descriptive statistics presented the strength of the data for each of these followed by a descriptive analysis of the findings, illustrated by some extracts. This methodology limits the exploration of the participants experience as this research is focused on the extent to which the interview data agrees or disagrees with the question framework.

The findings will now be summarised. Minimal evidence was found that participants had effective input into goal setting. Responses were varied when asked whether participants believed their input was sought and utilised in planning treatment but only one-third of participants ‘provided very clear evidence that they perceived an influential role for themselves in treatment planning’ (p33). Responses were generally positive regarding the perception that they provide useful information to the therapist relating to assessment of outcomes. The authors highlight that ‘(the) sample volunteered strong affirmation of the significance of physiotherapy in their lives and many developed a sense of personal relationship with their therapists’ (p37). Again, the meaning and importance of physiotherapy and working in partnership with physiotherapy is highlighted as being consistent in the literature and it is of note that participants were not directly about asked the value of physiotherapy in contrast with the above findings generated through specific questioning.

In the final study about experiences of physiotherapy, Potter et al. (2003) sought patient perspectives of the physiotherapy experience in private practice in Australia. These research findings also have a significantly different context to research carried out in the UK within the NHS. A nominal group technique with a purposive sample of 26 fee-paying patients was used to discuss physiotherapy experiences in small groups of five or six. Despite what the potentially broad exploratory title suggests, the main aim of this study narrowed 'to explore the patient's perspective regarding the qualities of a 'good' physiotherapist, and to gain insight into the characteristics of good and bad experiences in private practice' (p196). The group technique involved 'highly structured' meeting processes, and discussed 'i) the qualities of a 'good' physiotherapist as defined by the patients, ii) the physiotherapy experience' (p197), and followed stages of introduction and explanation, silent generation of ideas, sharing ideas, group discussion, and finally voting and ranking of ideas. This data collection technique may have limited individuals' ability to discuss personal experiences or to explore experiences in depth. The generated ideas were ranked, with only the highest ranking being reported which biases the findings towards those most often cited, rather than relating to the impact or importance to a person, or to the subject area. Data collection continued until saturation was achieved and the data was then subject to analyst triangulation by two independent researchers. The analysis procedure was not further explained.

The results were presented in two tables. Table one listed the qualities of a good physiotherapist, separated into three main categories: the physiotherapists' communication ability (skills, manners and teaching ability ranked most important), their 'other attributes' and the characteristics of the service provided by the physiotherapist. The second table of 'patient quotes of good and bad experiences of physiotherapy' had a column of 'good experiences' and one of 'bad experiences', and comprised a list of quotes that fell into one of those two categories. They cross referenced which of the quotes in table two demonstrated 'the presence or absence of qualities of a good physiotherapist' (p198). The results section reporting on 'the physiotherapy experience' has been copied verbatim for purposes of clarity:

> As illustrated in table 2, the vast majority of patients shared a mixture of good and bad experiences in physiotherapy. A small number of patients could only recall either good, or bad experiences, while a further two patients did not contribute any specific information in response to this issue.
>
> Patients most often attributed good experiences to effective communication ability, followed by the high quality service provided by the physiotherapist. Conversely, the main commonality of bad experiences related to criticism of the service

> provided and the ineffective communication skills on the part of the physiotherapist (p200).

There is extensive rich data found in both the ‘good’ and bad’ columns, with the extracts presented suggesting a broader range of themes than simply ‘good or bad experiences’ and a far more complex picture than the above summary describes. An example of a ‘good experience’ and subsequently a ‘bad experience’ are illustrated below:

> ‘My physiotherapist was friendly and open, explained what was being done and seemed to understand me as an individual’
>
> ‘[ ] my condition gradually deteriorated when I was trying to do the exercises [ ] and she insisted I keep doing them [ ] she didn’t listen [ ] ’

More themes would have likely emerged and extracts would have been contextualised and made more meaningful and relevant if this data had been analysed and interpreted rather than being presented and summarised so succinctly. Such polarisation of views could even result in inaccuracy as some of the extracts (cited below) present complex issues that are lost within the themes of ‘good or bad experiences.’ The categorisation into these two options reduced the depth and breadth of the data and also limited the credibility of the exploratory aim of the research. Subsequent to the results, the discussion situated these findings with other research about patient satisfaction, under the broad categories above, and only one other issue was highlighted from the verbatim extracts- the issue of power in the physiotherapist-patient interaction. Examples from these extracts included:

> [ ] this new guy said ‘take your shirt off’ [ ] I was taken aback. I hadn’t checked my underclothes [ ] I felt embarrassed and self-conscious.
>
> I did have a physiotherapist once who thought she knew it all and ignored what I said [ ] She focused on my injury and not on listening to me (p198).

Bad experiences were reported as ‘relating to poor communication and poor service quality’ without further account, and the issue of power in the physiotherapist-patient interaction was addressed by a brief statement ‘there were a number of quotes from patients that suggest that some physiotherapists may have exerted power in the relationship that was not welcomed by the patients’ (p201). However, the statements above are powerful, disturbing, of extreme significance and merited further discussion and analysis. The findings of this research were that ‘physiotherapists should actively seek to involve patients in their management’, and that ‘physiotherapists would benefit from more training in communication skills to ensure that they can successfully adopt a patient-centred approach’ (p200) though the words of these participants convey far more.

Considering the eight research papers reviewed in this section, certain methodological features are key to effectively exploring the under-researched phenomenon of the experience of physiotherapy. These features have been discussed throughout the review but are summarised here. Themes generated through the data and not compared or matched to frameworks or topics allow for exploratory research that does not assume what the experiences of physiotherapy are. Research that is rich in verbatim extracts where individual participants are contextualised and situated, provide context and understanding of experience, with analysis and interpretation adding further depth, insight and meaning to the words of participants.

This body of research does reveal some shared or resonant themes regarding the experience of physiotherapy. Physiotherapy seems to be of greatest value to patients when it is delivered in a person-centred, responsive, accessible and flexible way with a long term approach. This is reflective of the findings of general healthcare experiences for PwMS as discussed in section 2.3, where poor communication and lack of continuity of care were often at the heart of negative experiences and trusting, person centred care delivered through interpersonal partnerships fostered positive and meaningful experiences. Returning to physiotherapy, participants often experienced this as focusing on physical impairment whereas they valued physiotherapy focused on improving function within their daily lives in a more holistic sense. There seems to be differing perceptions between patients and physiotherapists about what is important, meaningful and valuable about physiotherapy. Physiotherapy can provide hope and promote a sense of well-being if delivered in a way that meets a person’s needs. Conducting this literature review has also highlighted the paucity of physiotherapy research that explores experiences of physiotherapy. Importantly, research that employs in-depth, interpretive research methods (recognised as being the most appropriate to explore the phenomenon of experience) are particularly absent.

2.5 Experience of physiotherapy for PwMS

No published research has been found that broadly explores the experience of physiotherapy for PwMS. Studies were found that focus on the experience or satisfaction with a specific physiotherapy method or intervention, such as web-based physiotherapy delivery for PwMS (Paul et al., 2014). As the aim of these studies were to review or explore a specific physiotherapy intervention rather than the experience of physiotherapy, they have not been included within this review. Three published studies and one research and development report were found that considered perception or satisfaction of physiotherapy for PwMS. Perception can be defined as ‘the way in which something is regarded, understood, or interpreted’ or ‘awareness of something through the senses’. Experience can be described as ‘to feel (an emotion or sensation)’ as well as ‘practical contact with and observation of facts or events,’ amongst other definitions (Oxford On-line dictionary, 2018). Satisfaction with services could include elements of perception and experience by these definitions. All of these descriptors have therefore been included as there could be significant cross-over in the meaning of these terms within this context, all of which may provide insight regarding physiotherapy services. The paucity of research on this subject necessitates that all potentially relevant research will be considered. One further paper has been included that seeks to explore the experience of physiotherapy specifically through movement as this study offers insight into the experience of physiotherapy for PwMS and movement is relevant and fundamental across physiotherapy (See Appendix VIII for details of these studies).

Three papers focused on the perceptions or satisfaction of physiotherapy services for PwMS. One study was carried out in Donegal, Ireland (Buckley et al., 2008), another across England and Wales (Markwick, Singleton and Conduit, 2014) and the final paper included occupational therapy services and was carried out in Washington, Unites States (Roush, 1995). The remaining research papers are conducted in Norway and focus on perception of change and satisfaction after one session of physiotherapy (Normann et al., 2012) and contextualised perceptions of movement as a source of expanded insight into the experiences of physiotherapy for PwMS (Normann et al., 2013). Experiences of physiotherapy may vary in different countries due to different healthcare systems, physiotherapy practice and provision. For this reason, the initial two papers cited may have most relevance to this research.

The research and development report by Buckley et al. (2008) predominantly reported findings from an anonymous survey with closed question data from 97 participants, numerically analysed to give percentage responses to each question. Questionnaires were distributed by MS community visitors. It is not clear how many questionnaires were sent out initially, therefore the response rate is unknown. Participants are considered to be representative of the population of people living with MS in County Donegal with the broad inclusion criteria of having MS and living in County Donegal. Only 67 of 97 participants had received physiotherapy (in one of ten community hospitals or at the district general hospital) so some participants were answering in principle rather than in practice which will affect the context of the findings. It may have been appropriate to add the inclusion criteria of having experienced physiotherapy for the data to be considered in the same context and have more relevance. Twenty-three of these 67 had not attended physiotherapy for over 5 years, with 11 having not attended for over 10 years. This is worth noting as services are likely to have changed over this time and so feedback received may no longer relate to more current services.

The aim of the report was to ‘assess attitudes (of PwMS) towards physiotherapy services and to some proposed models for service delivery,’ rather than to explore perception of physiotherapy in a broader sense which is reflected in the research method used. This study provided the views of participants regarding a range of selected closed questions such as: Did physiotherapy help you? Would you attend an exercise group if one were available? Would you adhere to a home based exercise programme? (All answerable with Yes or No). Satisfaction ratings were 84.8% for therapist approachability and 74.2% for therapist knowledge, with 70%

of participants reporting that physiotherapy helped their symptoms (those reporting walking difficulties were more likely to report benefit from physiotherapy). However 27% reported that physiotherapy had not helped their symptoms and the remaining 3% did not answer. These findings required further exploration to gain insight into why participants answered as they did. It could be that therapy sessions met their needs and helped their symptoms but the lack of further access to physiotherapy or inconsistency of therapist seen meant that overall the therapy did not help their symptoms. Alternatively, it could be that the therapy received had not been helpful, as examples. There is a further section of information that may inform the above satisfaction figures. Waiting times for physiotherapy appointments were reported; 6% less than a week, 34% 1-4 weeks, 30% 5-12 weeks and 12% over 12 weeks (the remainder of participants did not answer). It could be that by the time participants were seen, physiotherapy was no longer as relevant to their problem and so untimely delivery resulted in therapy being less effective or valued. Furthermore, 69% of participants had no follow up appointment arranged and the report indicates that PwMS in this area required referral from a health care professional, making appointments more difficult to initially access. This data shows that waiting times, accessibility and follow up were all sources of dissatisfaction with physiotherapy, perhaps also alongside a lack of longer term approach.

Further investigation was carried out by asking how physiotherapy sessions could better meet their needs- this information is reported in column three in table 2 below. It is useful at this stage to compare this information with the reported therapy these participants received as displayed in column one in table 2 below.

Specific aspect of treatment or physiotherapy	Percentage of participants who indicated that the specific aspect of treatment was included in their session	Percentage of participants who reported that this specific factor of physiotherapy would better meet their needs
Exercise therapy	88.1 %	
A home exercise programme	61.2 %	58 % (specifically a printed exercise programme)
Thorough assessment of their symptoms	43.3 %	
Review of their symptoms		51 %
Annual review		60 %
Advice about their symptoms/Information talks	24 %	37 %
Provision of equipment	14.9 %	
Continence advice	7.5 %	
Referrals to other health care professional	11.9 %	
Seeing the same therapist each time		73 %
Group exercise class		49 %

TABLE 2: RESULTS FROM BUCKLEY ET AL., 2008 REGARDING SPECIFIC ASPECT OF TREATMENT

Some of these aspects will be considered in turn. Exercise therapy formed part of the majority of therapy sessions but around 40% of the participants did not receive an exercise programme and 58% participants reported that having a printed programme would better meet their needs. PwMS can have difficulties with memory therefore having a printed exercise programme can be key to enabling PwMS to carry out prescribed exercises. 86% of participants reported they would adhere to exercise if they were provided with a structured, individually designed home exercise programme. It could be that prescribed exercise programmes lacked structure, or perhaps, and in keeping with research by Cassidy et al. (2018), they lacked individualisation. These results do not enable further insight. Almost half of respondents reported that group exercise sessions would better meet their needs and there was a direct question asking whether group classes would be beneficial if offered- those who were walking and not using a wheelchair responded particularly positively with 88% reporting they would attend.

Less than half of participants reported having a thorough physiotherapy assessment of their symptoms despite this being a crucial element of neurological physiotherapy (Lennon and Bassile, 2018). Again, more detail would be required to understand this. For example, were participants assessed, but did not feel it was thorough? Alternatively, was dissatisfaction around assessment related to the request for regular and annual reviews? Another surprising statistic is the low percentage of participants receiving advice about their symptoms (24%) which is reflected by the request for further advice or information talks (37%) to improve the service. Again, this is a key element of physiotherapy, particularly for people with a long term condition, and has been identified as something people identify as beneficial from healthcare services and physiotherapy as presented in sections 2.3 and 2.4. There was an overwhelming response with the single biggest factor for improving overall experience of physiotherapy for participants being to see the same therapist at every appointment, also reflective of the findings in sections 2.3 and 2.4, where continuity of care was commonly cited as improving healthcare and physiotherapy experiences. This is a challenge in many areas and services where staff are covering across different areas and disciplines of physiotherapy, but perhaps particularly so in a rural area such as County Donegal where community hospital physiotherapists will often have to treat all conditions and may not specialise in MS.

This research was considered useful for reviewing and improving physiotherapy services offered to PwMS in County Donegal. The report identified that improvements should be made to: accessing physiotherapy (including consideration of self-referral), increasing reviews, more thorough assessment, improved written exercise programmes, consideration of group classes and finally considering whether one physiotherapist in each primary care network could be dedicated to meeting the needs of PwMS to increase consistency of therapist. However, this information does lack personalisation, detail, depth, nuance and insight due to the methodology and there is ambiguity regarding some responses due to the lack of detail. There was a free comments section at the end of the questionnaire, and whilst a representation of this data was given as illustrative examples, this data was not further analysed or interpreted. The free text section results included 11 excerpts, however, the report does not state how many participants used this section in their response.

The second of the five identified studies will now be discussed. In 2008, the Royal College of Physicians (RCP), in collaboration with the MS Trust, conducted an audit of NHS services for PwMS in England and Wales (RCP, 2008). Markwick et al., (2014) used the free text comments from this audit to perform content analysis on data regarding perceptions of PwMS about NHS physiotherapy provision. Information about the audit was widely displayed through newspapers and relevant websites, forums and newsletters, MS therapy centres and by healthcare professionals which resulted in wide geographical distribution to 1631 PwMS. The final analysis of the audit included 1300 PwMS when exclusions and incomplete responses were removed. Of these, 757 individuals added free text comments about MS services and this is the data used in the study, reported as correlating to 1.5% of the population with MS in England and Wales at that time. Of these 757, 41 individuals (5%) added a free text comment about physiotherapy services for PwMS in their area regarding services delivered across a range of settings and areas. The data was categorised and coded into positive, negative and neutral themes. Of the 1262 total comments about MS services, 38% were positive (mainly focused on healthcare professionals), 55% negative (mainly focused on standard of service and lack of support) and the remaining 7% were neutral (comments made about symptoms rather than services for example). The authors highlight that the original audit report found that only 10% of PwMS were ‘not at all satisfied’ and 7% were ‘very dissatisfied’ (RCP, 2008) which seems lower than the 55% negative responses found in the free text comments section.

It could be that PwMS were just ‘not satisfied,’ rather than expressing stronger dissatisfaction or it could be that quantitative assessment does not accurately reflect levels of satisfaction, as supported by other research (Jones et al., 2009; Gibson and Martin, 2003; Johnson and Waterfield, 2004). The research carried out by Jones et al. (2009) was based on a previous audit of MS services carried out in 2006 (RCP 2006) which analysed the disparity between global expressions of dissatisfaction and the negative free text comments made. Apart from the finding that dissatisfaction in free text comments were more likely to relate to provision of the service, rather than relating to service quality, they concluded that ‘simple, single questions on satisfaction with services do not offer a valid measure of patient experience,’ and suggested the need for more qualitative research in this area. This should be kept in mind when considering both the results of the previous study by Buckley et al. (2008), and the subsequent research being reviewed. Markwick et al. (2014) could not compare quantitative responses with free text comments which may have enabled further description of the data, as the data received was already anonymised.

Returning to the research findings of Markwick et al. (2014), physiotherapy services received the highest dissatisfaction rating when compared with neurology, occupational therapy, pain clinic, eye clinic, fatigue clinic and urology with 38 % negative comment (5 % was the next nearest for occupational therapy and neurology). The main problem highlighted was limited availability and long waiting lists rather than physiotherapists or physiotherapy treatment. All four of the verbatim comments included in this paper highlighted lack of physiotherapy availability, including that some PwMS had been on waiting lists for 6 months and some had their service restricted. Participants in the study commented on the importance of physiotherapy, frustration at the lack of availability and their sense of abandonment.

This study had several limitations such as minimal data specifically about physiotherapy services, this not being the focus of the original study from which the data was sourced, and the ambiguity around how participants interpreted and responded to the free text section (‘if you want to add any information or comments about the services you have received in relation to your MS over the last 12 months, please write it here’ (Marwick et al., 2014, p134). Participants tended to write in this section if they had an extreme of opinion and so this data might only reflect extremes, therefore biasing the data. The authors also identify the questionnaire was designed and piloted by specialist clinical staff and one person with MS rather than being developed by PwMS to better reflect what is important to them. Bias was reduced and reliability increased by using a secondary researcher to identify the codes. However, the themes were broad and lacked detail or depth with only four verbatim comments referring to physiotherapy used to illustrate themes. These results highlight that physiotherapy services did not meet the needs of a significant proportion of these participants, particularly with regards to access, availability and continuity of care, in keeping with previous findings. Recommendations from this research were that physiotherapy services for PwMS need to be reviewed.

The research paper by Roush (1995) is based on data from 1990 in the United States. Therapy services are highly likely to have changed considerably in almost thirty years and do not necessarily compare with healthcare services in the UK or Europe as they are largely based on healthcare insurance provision. This research used a Therapist Evaluation form with 14 items graded on a Likert scale and reported general satisfaction with physical and occupational therapy for participants with MS with participants citing therapists' interpersonal attributes as the most positive aspects of patient/professional relationships (in keeping with previous research findings) and perceptions regarding therapists' technical abilities as less positive findings. Further exploration and critique of this study will not be carried out due to the lack of relevance to this research due to the difference in healthcare provision systems as previously discussed.

Normann et al. (2012) explored perceptions of PwMS regarding physiotherapy in a hospital outpatient service by investigating the satisfaction of PwMS with a single physiotherapy consultation, all of which were carried out by the same physiotherapist. The consultation emphasised assessment, support and information provision, integrated with guidance in self-assisted exercises and exploration of treatment strategies to improve function. The service comprised of specialist MS healthcare professionals including a physiotherapist where PwMS attended for assessment and provision of onwards advice to the PwMS and their local therapists. This research is based on the experience of one specialist therapy session and so findings are specific to this. However, the aims are about exploring the experiences of physiotherapy for PwMS and the model of provision is similar to that operating in North Wales in MS MDT clinics as discussed in chapter one, therefore this study has relevance to my research.

Seventy-two PwMS were consecutively recruited into this research by the clinic administrators (bias testing showed no differences in age and gender compared to other patients at the clinic and to other populations of PwMS). Participants completed the Outpatient Experience Questionnaire (OPEQ) in the absence of a standardised, validated, and reliable questionnaire available in Norwegian that specifically addressed patient satisfaction with physiotherapy for PwMS. The OPEQ contains 52 items using 10 point scales covering aspects of patient satisfaction with descriptors at the end, and was adapted to ask about patients' opinions of physiotherapy. A final open-ended question requested the subjects' own words regarding their experience at the clinic to provide additional qualitative data but this was not reported on, apart from to state this section 'contained mainly positive statements regarding the physiotherapist's detailed assessment, information, guidance in self-assisted exercises, and that participants had learned "something new, " one wanted more focus on treatment, and some expressed a wish to continue treatment at the outpatient clinic' (Normann et al., 2012, p114). Items were scored; prior to the consultation, about the consultation and following the consultation. Items focusing on experience after the consultation asked if participants had any unanswered questions, if they felt they had been incorrectly treated, and if the consultation had any impact on their disease and health problem as examples. In summary, subjects were reported to be very satisfied with all elements of the OPEQ for the physiotherapy consultation, including aspects of interpersonal elements, professional skills, information, and guidance regardless of age, gender, ambulatory status. However, this data again does not allow for development of ideas or experiences or provide personal insight that would enable exploration of experience and some questions- such as asking if they had been incorrectly treated, do not necessarily allow for emergent, nuanced participant responses.

The authors explain they also examined patient satisfaction regarding outcome of care by focusing on perception of change in function following the consultation, though it seems unlikely change in function would be expected from one therapy session, questioning the validity of this assumption. This data was collected using a self-reported measure, Patient Global Impression of Change (PGIC), to describe the patients' perception of change in their ability to stand up, sit down and walk after the consultation using a seven-point scale depicting rate of overall change. This was used alongside the BORG perceived exertion scale which grades level of perceived physical exertion on a standardised scale commonly used in clinical practice (Borg, 1970). The results from the PGIC showed 23 participants stated a minimal improvement had taken place, 10 claimed to be much better, 2 very much better and 26 reported no change in walking and standing up/sitting down. There was a statistically significant change from more to less reported exertion during standing up/sitting down and the walking test at the end of the session suggesting that perception of improvement with regard to these activities may occur after single consultation based on these principles. Overall, functional tasks were reported to feel easier for some participants following this one session.

Limitations of this research include that scales used were not specific to MS and therefore may not have included some issues relevant to MS, participants may have felt obliged to give positive ratings as there was only one therapist and they may want to please the therapist. In addition, hope for further help through this clinic might result in more positive responses. The researchers also highlight a potential lack of variance in the data due to limitations of the scales used. The results do not tell anything about the wider experience of physiotherapy as this research was following one session at a specialist clinic. This research does not reveal the nature or duration of the subjectively experienced improvements or the meaning or importance of these perceptions.

Some of the same researchers subsequently carried out further research to deepen knowledge about how PwMS experience physiotherapy to further develop health care for this population. Their research question focused on how PwMS perceive movement during a single session of physiotherapy in a hospital outpatient clinic and what do these experiences mean, specifically regarding insight into their movement disturbance (Normann et al., 2013). This research took place in the same clinic discussed in the previous study with a purposive sample of 12 PwMS (selected as a representative sample with regards to age, sex and years since being diagnosed with MS) who had recently completed a single session of physiotherapy. Seven participants had their session video recorded (this number was thought to be adequate to ‘gain the necessary information about what happened to the patients during the sessions’ (p.22)) and all participants were interviewed either on that day or within four days.

Recorded interviews were based on a theme-oriented interview guide that included the following: 1) the main impression from the consultation; 2) the most and least important aspects of the consultation; 3) any reflections regarding the perceptions of movement; and 4) opinions regarding guidance in the self-assisted training (p23). The interviews also included follow-up questions on topics brought forward by participants and information, and were validated by re-phrasing the participant’s answer and asking if this was a correct interpretation of what they had said. The interview concluded with asking for additional comments. Field notes and observation from the video recorded data added further detail and depth to the transcribed interviews. A phenomenological hermeneutic content analysis was carried out to identify and develop codes, categories and themes (see Table 3 below).

Contextualised perceptions of movement as a source for expanded insight	
Categories	Themes
Expression through movement	Knowledge of body part interactions and consequences for activities of daily living
Perceptions of body parts' interplay	
Perceptions of change	Insight into possibilities and limitations
Tailored practical guidance	

Table 3: Adapted from table 5, p24 Normann et al., 2013

Although focused on perceptions of movement, these themes offer further insight into the broader experience of physiotherapy for PwMS within the context of this intervention in this clinic. Each theme was illustrated with verbatim comments. Theme one focused on how perception of movement and performing movement increased participant knowledge of how and which body parts work together during an activity. This enriched their experience of the physiotherapy session and improved understanding of their own movement disturbances. Theme two focused on perception of change in movement, expanding participant insight into their limitations and possibilities, providing increased applicability of physiotherapy exercises and advice given. One of the features of theme two, consistent with the findings of Normann et al., (2012), was of perceived change immediately after the therapy session. Participants reported improvement not only in body part movement but also in activity following the physiotherapist's treatment which included handling and mobilisation of their body along with exercises. Participants described how they used this recognition and learning in day to day life to take more control of their condition and try and improve their symptoms with participants also highlighting the importance of receiving self-assisted exercise advice early in the progression of the disease. This description informs the findings of the previous study, helping to explain changes in function after only one session. However, this was not the case for all participants, particularly the more disabled people who found the advice given difficult to apply to their lives.

This research appears to contrast with other research findings, particularly those of Cassidy et al. (2018) with people with ataxia and Dowswell et al. (2012) with people following stroke which suggested that focus on body impairment and movements was not as valued or meaningful for patients as a focus on function and activity in daily life. However, it could be that emphasis was on understanding movement to promote function. This research by Normann et al. (2013) is based on the experience of one session of physiotherapy in a specialist clinic in Norway and results may not be applicable or relevant to the broader experience of physiotherapy, particularly within the UK. The research does not follow up on whether the assessment and subsequent advice given in this specialist clinic affected experience of physiotherapy back within their localities or had any ongoing effect.

Reviewing the research from these five studies suggests some tentative findings about the experiences of physiotherapy for PwMS that cannot be readily generalised across the population or to my research due to the context, specificity and methodology of these studies. These include: interpersonal skills and attributes of the physiotherapist are important and result in increased satisfaction with physiotherapy, reduced accessibility (including high waiting times) and availability and restricted number of treatment sessions result in dissatisfaction with physiotherapy and are likely to reduce effectiveness, thorough assessment may be lacking in some physiotherapy services and receiving a thorough assessment (within a specialist clinic) may result in perceived improvement, group exercise is perceived as potentially helpful, exercise programmes would be more effective if they were structured, printed and individualised. These implications of these findings should be considered with caution, as all of these studies lack adequate depth and detail to explore possible reasons, context and meaning about these issues, leaving much of the experiences of physiotherapy assumed, suggested or unknown. Further research into the experience of physiotherapy for PwMS should be carried out in order to help inform physiotherapists and physiotherapy services.

There are no known studies that explore experiences of physiotherapy for PwMS in Wales or that explore experiences of physiotherapy for PwMS in the UK using phenomenological research that seeks to explore this phenomenon in an in-depth way to reveal nuanced insight into these experiences. The only study found to research patient experiences of physiotherapy for PwMS in the UK was the predominantly quantitative report that did not explore experiences (Buckley et al., 2008).

2.6 Healthcare policy affecting physiotherapy services for PwMS

Before concluding chapter two, healthcare policy guiding physiotherapy services for PwMS will be considered to optimally inform this study about the experiences of physiotherapy for PwMS and any policies that may affect these experiences. National clinical guidelines for MS (NICE, 2014; NICE, 2016: NICE, 2018) and the National Service Framework for Long Term Conditions such as MS (DOH, 2005b) both comprise broad guidelines for best practice throughout the UK based on current research. The CSP has also published ‘Physiotherapy Works-MS (CSP, 2011). The combined summary from these guidelines are:

- Care for PwMS using a co-ordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS including: consultant neurologists, MS nurses, physiotherapists and occupational therapists
- People who have mobility problems due to MS should have access to rehabilitation specialists and physiotherapists with expertise in MS, given at home or on an outpatient basis depending on the preference of the person with MS and local resources and that access to this rehabilitation is provided at an appropriately early stage to reduce the risk of developing preventable secondary complications and prolonging hospital stay and readmission
- Ensure PwMS and mobility problems have regular access to an assessment to establish individual goals and discuss ways in which to achieve them. This would usually involve rehabilitation specialists and physiotherapists with expertise in MS
- Physical therapy should include; mobility rehabilitation programmes; balance training programmes that consider vestibular rehabilitation, falls management, balance rehabilitation, aquatic exercise; transcutaneous electrical nerve stimulation should be considered for pain management; consider supervised exercise programmes involving moderate progressive resistance training and aerobic exercise to treat PwMS who have mobility and/or fatigue

- Healthcare professionals should discuss the potential benefits of exercise with adults with MS who have problems with mobility or fatigue. Encourage PwMS to keep exercising after treatment programmes end for longer term benefits. Therapists should help with this, for example, by referring PwMS to exercise referral schemes. Programmes or courses of exercise therapy should be supported by a competent professional, such as a physiotherapist with expertise in MS, who can suggest the most suitable exercises and monitor the effects.

The WNA carried out a review in 2013 (WNA, 2013) and made ten recommendation following their review. North Wales Neurosciences Network brought out 'Together for Health-Neurological conditions delivery plan in 2015 (WNA, 2015). These guideline recommendations that are specific to Wales are included within the NICE recommendations but can be found in Appendix IX for further reference.

Whilst these guidelines potentially promote standards of care, the lack of detail and specificity limit the extent to which they can shape more specific physiotherapy service improvements. They offer no guidance regarding approaches or communication methods that physiotherapists might take as an example, when this is highlighted as being important and meaningful. The recommendation about outcome measures does mention the use of validated measures, suggesting these promote physiotherapy being provided for an appropriate length of time. However, this recommendation lacks the detail to consider the importance of outcome measures that reflect changes in quality of life for progressive conditions such as MS and ataxia, as another example. They do however recommend that physiotherapy should be accessible and suggest a longer term approach might be appropriate but do not make this explicit. Reviewing these guidelines demonstrates that whilst broad recommendations for good practice are in place, there is nothing adequately detailed and specific, ideally something learned from the experiences of PwMS that might better inform physiotherapists about the needs of this population. This highlights and supports the importance of research that explores the experiences of physiotherapy for PwMS to inform physiotherapy services and practice.

2.7 Summary of Chapter two

Experiences of living with MS are unique to the individual but reviewing the literature identified some common themes. Diagnosis was often preceded by uncertainty, disbelief and followed by a range of emotions to include relief, disbelief and fear. The following period of realisation involved sense making and trying to gain acceptance and even mastery over MS to allow life to continue despite MS. Living with MS brought loss, fear, struggle, disruption, uncertainty and a change in self-identity. The struggles of living with MS are in many ways reflected in the experiences of health care for people with MS where meaningful, timely intervention delivered with continuity of care and effective communication were of paramount importance during the turbulent and changing course of living with MS.

Physiotherapy (both for PwMS and other populations) was of greatest value when delivered in a person-centred, responsive, accessible and flexible way with a long term approach that focused on functional gain and quality of life rather than physical impairment. However, there is a gap in literature regarding experiences of physiotherapy for PwMS. There are no known studies that explore experiences of physiotherapy for PwMS in Wales or that explore experiences of physiotherapy for PwMS in the UK using phenomenological research. Broad recommendations for good practice are in place within national guidelines but these are not adequately detailed and specific to better inform physiotherapists about the needs of PwMS. This review highlights and supports the importance of this research that aims to explore the experiences of physiotherapy for PwMS in North Wales. This research will increase understanding and insight into this experience and inform and improve physiotherapy services and practice in North Wales for PwMS.

3.0 Chapter Three: Methodology and Method

3.1 Chapter Overview

The aim of this research to develop understanding of the experience of physiotherapy for PwMS in North Wales through listening, interpretation and analysis. In this chapter, methodological issues and research practices are described and discussed, alongside relevant philosophical and research theory to contextualise this study. The practical and ethical aspects of carrying out this research are also discussed within this chapter.

3.2 Purpose of this research

This research will provide insight and increase understanding of the experience of physiotherapy for PwMS in North Wales to inform service provision and physiotherapy practice. Although this research does not specifically seek to evaluate or develop physiotherapy services, it is anticipated that an improved appreciation and awareness of participants' perception and experience of physiotherapy will illuminate what this service means to participants, and how it affects them (which may include individualised perceptions of effectiveness). This research aims to provide a voice for these PwMS, enabling them to explain and explore their personal experiences of physiotherapy, and what this means to them. My aspiration is that I am able to maintain the cohesion and integrity of what participants have shared, encapsulating this for the reader so they are able to step into the shoes of the participant to some extent. This sharing will develop a knowledge and appreciation of what this experience is for this group of participants.

Increasingly restricted staff resources within the NHS can result in practitioners having limited time to listen to what patients' are experiencing, and to fully involve them in their own health care, despite this being significant for patients (being listened to in itself can even make a patient feel better) (Patients Association 2015; Patient Opinion 2016). Knowing more about each individuals' unique experiential narrative is valuable to physiotherapists, as it helps build a picture of what experience of this phenomenon might be like, providing physiotherapists with increased insight. However, there are critical points in my career when I have listened and a vivid picture was painted, or when I have observed a situation with such clarity that my insight has been heightened in a way that I know will always affect me and my practice (see reflexive section in Appendix I). Each practitioner will have their own pivotal interactions that have affected them and their practice. However, clinician time within the pressures of the NHS is limited, and does not always allow adequate time to listen beyond what comprises clinical assessment. I have been fortunate and privileged to have had enhanced time with these participants during this study. It is my hope that I communicate the findings from this research in a way that will reach out to the reader, and remain with them.

3.3 Methodology

3.3.1 Epistemology

Epistemology is the philosophical term for the theory or source of knowledge; “how do we know what we know.” Epistemologically, IPA could be described as: being rooted in social construction - knowledge has been co-produced by people through social experiences; or IPA could be described as critical reality- knowledge or ‘reality’ may be out there, but our access to this reality is mediated through people, and how people understand their own particular situation is their reality (Madill, Jordan and Shirley, 2000; Silverman, 2011; Willig, 2008). It seems the terminology can be understood and used in different ways, these terms incorporating larger epistemological families that help to situate IPA. However, epistemologically, what is apparent and consistent in the literature, is that phenomenological research such as IPA, is set within a qualitative interpretivist paradigm that explores how people experience and perceive something (a phenomenon). Before commencing this research, I did not know what the experiences of this group of people were, therefore an exploratory phenomenological approach to research was required. I also sought to find out the meanings participants attributed to these experiences. It became increasingly clear as I read more IPA theory, that experiences could be further explored, and better understood through interpretation. IPA is based on the belief that meaning lies in personal experience (phenomenology) and can be further understood through interpretation by both the participant and the researcher (interpretive or hermeneutic research).

This epistemological stance is distinctly different from the positivist paradigm that underpins most physiotherapy research that sits within a biomedical model of research (as previously discussed in chapter one) where there is an objective reality that can be measured through quantitative research that seeks to determine the answer or reality through testing a hypothesis or theory, or measuring an outcome.

3.3.2 Phenomenology

Phenomenology is a philosophical approach to the study of experience, and is situated between two epistemological stances: we perceive the world (relativist) through our engagement with it (realist). Phenomenology can be understood as how people make sense of their own experiences ('the meaning of what happens to me'). 'It (phenomenology) focuses on the structure and qualities of objects and situations as they are experienced by the subject' (Moran, 2000, p.2), and is 'concerned with how knowledge is grasped by human beings.' (Gee, 2011, p.9). There are various approaches to phenomenology, but they have commonality in questioning the scientific model that attempts to produce detached objective views of the world (Larkin, 2013; Smith et al., 2009). Phenomenology attempts to understand the thoughts, feelings and perceptions of individuals through their own language and interpretation of a particular experience; a philosophical but also a broad research approach to the study of experience (Finlay, 2009; Silverman, 2011). Smith et al. (2009) note that 'one key value of phenomenological philosophy is that it provides us with a rich source of ideas about how to examine and comprehend lived experience' (p.11).

In order to better understand this concept, the history of phenomenology will now be briefly overviewed. Although the practice of phenomenology was not necessarily new, Husserl's writing brought this concept to the forefront within literature and teaching during the first four decades of the 20th century. Husserl was a philosopher and scientist, who developed and promoted descriptive-transcendental phenomenology. This philosophy aimed to reduce the understanding of experience to its core, essential structures, through careful examination (reflection) of human experience- thereby transcending personal and contextual features of experience to illuminate a shared experience without individual assumption and context (Smith et al., 2009; Beyer, 2016). Husserl suggested that the assumed (taken for granted) world is 'bracketed' (put to one side). The aim of this 'eidetic reduction' is to allow concentration upon our perception of that world or phenomenon in order to establish the essence ('the invariant properties lying underneath the subjective perception of individual manifestations' (Smith et al., 2009, p.14) of various experiences. What is taken forwards from Husserl’s work into IPA and this research is the focus on ‘how we actually perceive things, untainted by what we think we already know about them [ ] (through) commitment to exploring the life-world of each participant’ (Gee, 2011, p.10).

3.3.3 Hermeneutics

Hermeneutics is the study of how we understand and interpret our worlds (Gee, 2011). Historically, hermeneutics was studied and used to interpret significant historical texts, such as the bible, by the theologian and philosopher Schleiermacher at the end of the 19th, and into the 20th century. He studied text or discourse, separating the grammatical (exact and objective textual meaning) and the psychological interpretation (the individuality of the author or speaker), suggesting that interpretation is shaped by both as the reader attempts to understand the writer as well as the words for “understanding in the highest sense”, suggesting this understanding was deeper than that of the writer themselves (Forster, 2015). Schleiermacher explained this being due to the interpretive analyst offering yet another layer of understanding to the text, as the author cannot distinguish what he writes about a subject from what he thinks and feels about a subject due to their individuality’ (Forster, 2015). Smith et al. (2009) discuss interpretation within the context of IPA research, highlighting that:

> [ ] from an IPA perspective [ ] it allow(s) us to see how our analyses might offer meaningful insights which exceed and subsume the explicit claims of our participants [ ] some of this added value being a product of systematic and detailed analysis [ ] some of it from connections which emerge from having an overview of the larger data set [ ] and some of it with dialogue from (psychological) theory (p. 23).

3.3.4 Hermeneutic phenomenology

Heidegger and Merleau-Ponty were philosophers who wrote and taught hermeneutic phenomenology. They disagreed with Husserl’s reductionist approach to phenomenology, instead suggesting that experiences and observations are made from individual positions and contexts (rather than transcended for all humans), therefore we can only ever understand an interpretation of another's experience (from our situated viewpoint). This brought in the concept and study of existential interpretation and hermeneutic phenomenology; knowledge being from an 'interpretive stance, whilst (being) grounded in the lived world of things, people, relationships and language' (Smith et al., 2009, p.16). Heidegger argued that we are all related to the world, and our being in the world is always perspectival, temporal and in relation to something, and, this being the case, the world is always viewed through a hermeneutic lens (Gee, 2011; Smith et al., 2009). Gee (2011) summarises this succinctly, explaining that:

> Heidegger is more concerned with being or ontology (the study of existence), and with our complete (inseparable) involvement with our world and how we make sense of it (hermeneutics). One aspect of this involvement is the concept of inter-subjectivity [ ] a method by which phenomenology suggests we are able to communicate with each other, indeed able to understand each other at all, it is clearly a crucial element in any phenomenological hermeneutic approach such as IPA (p.9).

Heidegger, Merleau-Ponty, and then Sartre progressively constructed and developed existential hermeneutic phenomenology through their work, with perspective, context and interpretation being key to their philosophical approach (Smith et al., 2009; Willig, 2008). Merleau-Ponty focused on 'the embodied nature of our relationship with the world' (Smith et al., 2009, p.18), suggesting that 'the body shapes the fundamental character of our knowing about the world' (Smith et al., 2009, p.19). Smith et al. (2009) agree, stating, 'the lived experience of being a body-in-the-world can never be entirely captured or absorbed, but equally, must not be ignored or overlooked' (Smith et al., 2009, p.19), reinforcing that our physical beings (bodies) are an intrinsic element of experience, important in IPA. This relationship between experience and the physical embodiment of the experience is particularly relevant for people experiencing various physical symptoms of MS, being treated through physiotherapy that focuses on the movement and function of the body. While Merleau-Ponty focused on physical embodiment, Sartre emphasised 'the developmental, processual aspect of human being' (Smith et al., 2009, p.19). Sartre purported that we are not pre-existing selves, but rather, we are always in the process of *becoming* as we interact and engage with our world and the people within it, through freedom to choose our actions and "meaning making". Because of this complex relationship that we have with, and within our world, interpretation (of meaning making) is essential when exploring people's experience using IPA:

> Thus, through the work of all of these writers [] a complex understanding of ‘experience’ invokes a lived process, an unfurling of perspectives and meanings, which are unique to the person’s embodied and situated relationships to the world (Smith et al., 2009, p.21).

Heidegger described the interpretation of experience as hermeneutic; the phenomenologist making sense of the phenomenon through micro analysis and synthesis, thus facilitating the emergence of something that may be latent or disguised (Smith et al., 2009). The concept of bracketing has already been introduced, but it is important to note that inherent to the analysts interpretation is ‘their prior experiences, assumptions and preconceptions’ (Smith et al., 2009, p.25) through which they will understand and view a text or phenomenon. ‘In every case, interpretation is grounded in something we see in advance- in a foresight [ ] something we grasp in advance- in a fore-conception’ (Heidegger, 1962, p.191). Heidegger encouraged initial working out the fore-structures of the text in terms of the explicit content, thereby bracketing one’s own preconceptions as far as possible:

> Complex and dynamic notion of fore-understanding helps us see a more enlivened form of bracketing as both a cyclical process and something which can only be partially achieved (Smith et al., 2009, p.25).

For example, one might not consciously know what their preconceptions about a particular subject are, but might then read literature or have a conversation concerning the subject, which could then evoke and illustrate one’s own personal preconceptions (particularly if a person is aware and responsive to this).

What seems important for me as a reflexive researcher, is my awareness of this and my ability to see the effect this has on the interpretation and understanding of what I am reading or hearing. For the purposes of this research, I need to be aware that I will project my interpretation of participant accounts shaped by my wider pre-suppositions and experiences to some extent. However, the method of carrying out IPA does channel the researcher to initially focus on the words of the participants through immersion and subsequent detailed analysis with each individual narrative. Van Manen (1996) states that:

> phenomenology merely shows us what various ranges of human experiences are possible, what worlds people inhabit, how these experiences may be described, and how language (if we give it its full value) has powers to disclose the worlds in

> which we dwell, [and that], we may enrich our own lives by the recognition that these possible experiences could be or become our own actual experiences (p.9).

Further to this, Van Manen suggests that phenomenology can not only highlight our own preconceptions, but can actually enrich us through our relating to, and recognising aspects of ourselves and our own lives, within their stories (in this research, interpreting the experiences of this particular group of participants). Reflecting on the aims of this research, it is hoped that exploring the experiences of physiotherapy for this group of people will be accessible, meaningful and enriching for the reader, contributing towards changing their own perception and experience.

Heidegger discusses interpretation as being a multi-layered, dynamic and non-linear process, a concept termed the hermeneutic circle. Smith et al. (2009) describe this as the:

> Dynamic relationship between the part and the whole, at a series of levels. To understand any given part, you look to the whole; to understand the whole, you look to the parts (p.28).

They go on to describe how this directly affects IPA method and interpretation- looking at the single word (part), then at the sentence (whole), looking at a single extract (part), then at the complete text (whole), or looking at one transcript (part) compared with other transcripts (whole) as examples. They explain this process as non-linear, with the interpreter (researcher) moving between levels, and between the part and the whole, in a flexible, responsive and evolving way.

In summary, hermeneutic phenomenological research engages with people's experience, requiring the researcher to identify and reflect upon their own experiences, preconceptions and assumptions. Within this phenomenon, experiences are understood through a process of inter-subjective meaning and negotiated understanding between the researcher and participants; a process known as double hermeneutics. This dual interpretation is an important feature of IPA and involves the participants making sense of their world, and the researcher trying to make sense of, or decoding that meaning; 'in other words, IPA researchers try to understand what an experience is like from the participant's perspective (Pietkiewicz and Smith, 2012, p.362).

3.3.5 Idiography

Idiography is the focus on the particular and is 'the third major influence upon IPA' (Gee, 2011; Smith et al., 2009, p.29). Idiography is expressed in two different ways within IPA. Firstly, the focus on the detail and depth of individual analysis, which means the analysis of each case is undertaken in complete isolation prior to comparing findings (Gee, 2011). Secondly, on the understanding of a particular phenomenon from the perspective of particular people. Smith et al. (2009) explain that whilst there is focus on the individuals' experience, expressed within its own terms, there can also be movement towards more general claims as the person's experiences are situated within and related to, the larger context of the world around them. In this way, any generalisations made are 'located in the particular' (p.29), but 'delving deeper into the particular also takes us closer to the universal' (p.31). This dynamic movement between the particular and the whole is also part of the hermeneutic circle as the researcher tries to make sense of the participant making sense of their world (Smith and Osborn, 2008).

3.4 Deciding on research method

In order to conduct exploratory investigation that allows the words of individual participants to construct and advance research without previous hypothesis or theory, a range of research methods that enable qualitative, phenomenological, inductive and ideographic exploration were considered. This research aims to explore the experiences of physiotherapy for PwMS, therefore required a research method that enabled in-depth discussion or observation (Seale, 2004), and facilitated generation of rich data. Focus groups, observational study and interviewing were considered as possible research method options.

Whilst focus groups were initially considered, I reasoned that having multiple people interacting could potentially reduce the focus and expansion on the depth and breadth of the experience of the individual that was sought. Focus group research is often used to analyse group social interaction, or the study of 'talk' and social context, rather than to explore individual participant experiences (Seale, 2004; Silverman, 2011). I had attended many service user forums, which were run as focus groups. Whilst they generated useful information, I found the voice of some people tended to dominate, and control the subjects discussed. Some individuals struggled to talk about their own personal experience, and so discussion culminated around shared experiences to which the majority of people present could relate. I therefore reasoned that if focus groups were used for this research, this might give rise to more communal and prominent themes, with the potential loss of individual experience. In addition to this methodological reason, many PwMS have difficulties with communication, attention, and fatigue (Coles, 2009) alongside the practical difficulties of having to travel to a facility where a focus group could be held, and then remain there for a significant time. Individual interviews have an advantage of being adaptable to the individual for both venue choice and timing. Pauses, speed of conversation, rests and cues can be used to facilitate improved communication - these aspects of communication are more difficult to control and optimise for individuals within group situations, making it potentially more difficult for people with communication difficulties to have their voice heard.

Ethnography is a methodology based on direct observation (Silverman, 2011) and in its broadest sense, has been described as the study of people and cultures (Knoblauch, 2005) to include fieldwork, case studies and participant observation methods. Knoblauch (2005) suggests that ethnography represents all qualitative research. As phenomenological research is a study of people, it could be considered a form of ethnography, with the focus being people's perception of meaning and experience. What does seem apparent, is the emphasis of this research method on the observation of the studied person (or persons') either within their natural environment, or in the environment that was being studied, either from a distance or through interaction with the researcher. Ethnographic methodology gives priority to observation as its primary source of information (Silverman, 2011), and the presence of researchers in the field enables them to gain better understanding of the concept being explored through observing actions and behaviours (Silverman, 2011). I considered observing people within physiotherapy sessions carried out by other therapists, but reasoned that this method would not best meet the research aims, as it would not necessarily result in exploration of peoples' experiences of physiotherapy without more directed and dedicated conversation (likely through employing further research methods such as interviewing). Rather than observing participants' actions and responses, within a setting they may not feel comfortable in, I wanted to hear their opinions, experiences and feelings within a comfortable setting. People would not be likely to discuss or display their experiences and views of their overall experience of physiotherapy within clinical interaction with a therapist (although it may provide the researcher with insight regarding that specific session, alongside further discourse).

Observing people within a 'standard' NHS physiotherapy setting would likely limit in-depth open expression due to environmental limitations (for example, people are often treated behind curtains that do not maintain privacy), and schedule (fixed and time restricted appointments). An example of an ethnographic study for this research question might be to spend time with the participants at home, in MS support groups, and within physiotherapy groups or sessions- perhaps by taking this broader approach, and seeing participants in a range of settings over time, then participants experiences of physiotherapy could be explored in detail. I would potentially have needed to observe numerous sessions and been able to observe the participants within other environments in order to gain some understanding of their behaviour to provide valuable insight into peoples' behaviour, actions and reactions within physiotherapy sessions; this would not have been practical within time limitations. If I were to employ ethnography for the aim of this research, it would be in addition to carrying out interviews.

Interviewing can be used in different ways to generate information- the interviewer can aim to remain unbiased or neutral, or can become fully interactive and immersive in the interview process. The aim of this research was to explore peoples' experience, which requires active yet open interviewing to gain the depth of information required. 'In depth interviewing is a particularly useful method for examining the social world from the points of view of the research participants' (Silverman, 2011, p.137). This approach to interviewing was therefore selected to enable the depth of insight into individuals' experience to be explored, and elicit ‘authentic accounts of subjective experience’ (Silverman, 2011, p.131), as participants would be able to tell their stories, but within the context of the research question. However, it is worth noting that interviewing does not produce a ‘reality’ as such; the interview is ‘the interaction between the interviewer and the interviewed, in which both participants create and construct narrative versions of the social world.’ (Silverman, 2011, p.132). Silverman goes on to describe that for interviewers from an interactionist tradition ‘the primary issue is to generate data which give an authentic insight into people’s experiences’ and ‘may provide access to the meanings people attribute to their experiences and social worlds’, rather than to ‘provide a mirror reflection’ (p.133). I would understand myself taking an interactionist role as a physiotherapist, and as a researcher carrying out IPA research (data will therefore be interpreted through my researcher practitioner lens). A proponent of grounded theory talks about the objectivity of this research methodology being ‘that we try to describe it (his or her subjective view) with depth and detail [ ] to represent the person’s view fairly and to portray it as consistent with his or her meanings’ (Charmaz, 1995, p.54); this is a challenging statement for a novice researcher. The concept of authenticity within this form of research seems paramount, and will be expanded upon later in this thesis.

The interview technique used is similar to that used in narrative interviewing as the interview will commence with one open question (the research question), and then allow the person to answer this in their own way, with prompts only being used when required to facilitate ongoing conversation. Narrative interviewing can be topic based, but must allow participants to tell their story in their own words, with facilitation (but not directing) from the interviewer being used as required (Bowling, 2001). Employing an open interviewing technique places the person and researcher in a transparent and pragmatic partnership that enables ground up exploratory research rather than ‘fact finding’, with the emphasis on the researcher learning, exploring, and hearing as opposed to simply listening (Langer and Ribarich, 2009). This method is particularly appropriate for exploring areas where knowledge is limited because little research has been done (Stephenson and Wiles, 2000; Parker et al., 2009), and so this is well suited to this research.

The data collected through interviews required interpretation and analysis in order to bring key themes and understanding to the reader, and so a research technique that draws upon interpretive (hermeneutic) analytical methodology was appropriate. I looked to the methodology and analytical frameworks that employ interviews to include narrative inquiry, framework analysis, thematic analysis, constructivist grounded theory and interpretive phenomenological analysis.

Riessmann (in Silverman, 2011, chapter 17) describes how narrative inquiry (specifically discussing narratives generated by interviewing) is different from other qualitative approaches. In summary, Riessmann explains that whilst the 'field of narrative inquiry has mushroomed into something that is now very broad' (p.311), narrative inquiry is case centred rather than category centred, and 'the investigator preserves and interrogates particular instances, sequences of actions, the way participants negotiate language…and other unique aspects of a case… (p.311).' She highlights this can be difficult to maintain when cases are pooled to generate general statements, but that case centred methods can also generate categories, theoretical concepts and observations. She goes on to describe this as having been the case throughout the history of medicine where pathologies were noted and studied closely to generate new disease categories. The focus of narrative inquiry, as described by Riessmann, examines how the narrator accomplishes their situated accounts, how they construct their identity and that of the other characters (alongside the relative positions of the characters, themselves and the audience), and how they use language to make their points.

Langer and Ribarich (2009) outline the benefits of using stories in healthcare communication, purporting them to be 'deeply appealing and satisfying to people, with an attraction that transcends culture, religious orientation and academic disciplines' (p.55). They go on to say 'good narratives (stories) can evoke emotions that create connections in the listeners or viewers' mind that statistics, charts, clinical diagnoses and figures cannot'. They argue this helps both the participants and the researcher make sense of the world, and engage the reader/listener to also take part in the story. Carson (2001) discusses the use of stories - narrative methods- in ethics teaching with student nurses, suggesting that these ‘could be more real for students, whilst also providing them with another way of thinking about their own professional practice (p.200)’. He purports that ‘narrative methods can encourage a more reflective and ethically conscious practice’ (p.198). The focus of IPA research is upon the interpretation and analysis of a particular experience rather than on the participant’s story, and so this research method was chosen rather than narrative enquiry to meet the aims of this research. However, participants will each have their own story within discussing their experiences of physiotherapy. Although Carson (2001) talks about case studies or scenarios and Langer and Ribarich (2009) discuss narrative enquiry, the story telling aspect of exploring participant experience with individuals is a collection of narratives, and will hopefully engage the reader in these same ways - providing a story that feels authentic, relevant and important to the reader and to clinical practice.

MS is a variable condition that presents in extremely different ways as it can affect any part of the nervous system. MS can affect any person across the population; each person, and person’s experience will be wholly unique. In order to understand the experience of individuals, the selected method sought was ideographic in nature, enabling focus and depth on each person’s story, to reveal something of the experience of each individual. It was key to the research aims, that the individuals’ experience remained intact. In this way, narrative inquiry seemed a well suited methodology, but due to the focus on the importance of each person’s story as a whole, and the way it was told, I considered this would be difficult to maintain within this study, as the exploration for the research aim is specifically focused on the persons experiences and interactions regarding physiotherapy rather than on their broader story. It was for this reason, alongside the fact that I wanted to consider the experiences of numerous participants (and was not aware of the numbers of participants that this would involve at this stage), that I pursued another research methodology.

Framework analysis (FA), thematic analysis (TA), constructivist grounded theory and interpretive phenomenological analysis (IPA) were all prominent in qualitative research guides when reviewing other potential approaches to qualitative analysis.

I found these to have a considerable number of shared concepts but also some clear differences. They all move from the level of description to exploring underlying patterns, themes, processes and structures to some extent. However, (constructivist) grounded theory, according to the writing of Charmaz (2006), involves coding, then further theoretical sampling based on the initial analysis to further develop categories, with the aim of developing concepts and theories, and with less focus on the individual than IPA. I did not anticipate that the exploratory nature of this research would generate theories or concepts; an aim of emergence of themes better reflected the aim and context of this study. For this reason, I pursued TA, FA and IPA.

Although sharing many aspects of TA, FA was explicitly developed within the context of applied policy research, and aims to meet specific information needs and provide outcomes or recommendations, often within a short timescale (Lacey and Luff, 2009). This is not in keeping with the aims or expectations of this research. Thematic Analysis (TA) is recognised as being one of the more commonly used methods of qualitative analysis (Howitt and Cramer, 2008; Silverman, 2011), and is regarded as a flexible and useful research tool that can provide a rich and detailed account of data (Howitt and Cramer, 2008). Much like IPA, TA requires the researcher to identify (then usually code) themes following interpretation of the original data. However, IPA has greater emphasis on the hermeneutic process of studying sense making of both the participant and the researcher. IPA recognises that an individual’s experiences cannot be accessed directly by researchers. Therefore, researchers try to understand a particular experience by investigating the experienced phenomenon, and what meaning was given to it by an individual; the researcher then tries to make sense of the participant trying to make sense and understand their own lived experiences. (Eatough and Smith, 2008; Smith and Osborn, 2008).

As previously discussed, I began to see the ‘double hermeneutic’ interpretation could add further value to the research as I deepened my understanding of this concept. At earlier stages of conceptualising this work, I thought that being a physiotherapist working in the field I am researching might add bias and reduce credibility and trustworthiness of the interpreted findings. However, I now consider that interpretation, within the context of the wealth of knowledge and experience I have as practitioner, potentially adds to the quality of this research, as will be further discussed subsequently within this thesis. The idiographic nature of IPA prioritises a focus on both the particular and the individual; aiming to understand particular aspects, in each case, within their context, rather than making claims at a group or population level. Although idiography emphasises the individual, IPA does also enable the researcher to consider the particular within the context of the wider world (Smith et al., 2009, pp12-30; Larkin, 2013). This aspect of IPA could help place the interpreted analysis findings within the context of physiotherapy, through my interpretation as a physiotherapist researcher practitioner. The focus of the double hermeneutic and idiography inherent to IPA drew me to selecting this research methodology. In addition, IPA was also chosen for practical reasoning, as it seemed more accessible for me as a novice researcher due to the provision of structured guidelines to conduct such analysis in a step-by-step process in Smith, et al. (2009) (whereas TA has been criticised for its analytical technique varying broadly between authors (Silverman, 2011)).

This section of the thesis has illustrated that selecting IPA as a methodology and method was generated inductively through careful consideration of the aims of this research, and also reviewing and appraising physiotherapy research that has explored patients' experiences of physiotherapy, and critiquing to what extent this was achieved within chapter two. However, reviewing physiotherapy research also revealed that while qualitative research within the profession is increasing, qualitative research involving patient experience remains limited, as is research employing IPA. In this way, this research will continue to build the bridge over a methodological gap in physiotherapy research. There is limited research regarding physiotherapy that uses IPA (see Appendix III for table of this research); this research also provides opportunity to further explore and contribute to the use of this methodology within physiotherapy.

3.5 What is required of an IPA researcher?

Smith et al. (2009) describe the underlying qualities required of the IPA researcher: 'open-mindedness, flexibility, patience, empathy, and the willingness to enter into, and respond to the participant's world (and also requires) determination, persistence and curiosity' (p.55). They highlight this is a 'demanding set of qualities for researchers new to IPA' and that it is likely to take time to learn and develop these skills. My role as a physiotherapist also requires the above skills, to enable effective communication, assessment and treatment of people with complex neurological conditions, specific to their individual needs. Every person I treat has different and unique symptoms, levels of functional ability, social situations, greatly varied lifestyles, goals and needs. Assessing each person to determine how I can best help them necessitates open, responsive, enquiring, yet sensitive discussion within the context of clinical knowledge. Assessment is person-focused and person-specific (individualised), multi-faceted and multi-layered, and is carried out across a number of conversations and sessions, in combination with synthesising knowledge and information from a wide range of sources.

The process of assessment is non-linear, it involves trying certain lines of inquiry or intervention, regularly re-assessing, discussing it with the person, coming back to the question, reviewing the effect on the person and their function- finding out what their experience of that intervention was. A significant part of physiotherapy assessment is therefore ideographic, inductive, phenomenological and hermeneutic. Throughout physiotherapy assessment, I aspire to really hear what people, carers and relatives, are trying to convey to me- this often requires an element of interpretation, although not to the depth or complexity required in IPA research. It is an advantage to carrying out IPA research that the qualities and skills listed above are required and practised on a daily basis within my role. In this way, carrying out IPA research as an experienced practitioner, brings skills and aptitude to help myself as a novice researcher.

3.6 Method

3.6.1 Sample Size

A limited sample size is suggested by experts in IPA in their guide to carrying out IPA research due to the focus of IPA on rich data that can be subject to interpretation to enable in-depth exploration of experience (Smith et al., 2009). The authors emphasise there is not a 'wrong' sample size, but advise it can be difficult to maintain the commitments of IPA research for both participants and researchers with larger sample sizes. Reflecting back to philosophy underpinning IPA- phenomenological hermeneutic interpretation is at the heart of this methodology. In order to explore the participant making sense of their experience through my interpretation (employing the double hermeneutic principle), I limited the sample size. I was aware that analysing each participant story would require a significant commitment of my time, particularly as a novice to IPA research. Smith et al. (2009) confirm that successful analysis requires time, reflection and dialogue, which can present more of a challenge with large datasets. They suggest a sample size for interviews of: 3-6 for a student (undergraduate or masters level) project, 3-8 for PhD students, 4-10 for professional doctorate students, and highlight that higher numbers are not indicative of better quality work. Numerous authors are in agreement, for example:

> Fewer participants examined at a greater depth is always preferable to a broader, shallow and simply descriptive analysis of many individuals, as commonly seen in thematic analysis, grounded theory or poor IPA (Hefferon and Gil-Rodriguez, 2011, p.756).
>
> IPA is likely to entail a much smaller sample size because of the fine grained analysis that is involved (Baker and Edwards, 2012, p.18).
>
> It is better to have a smaller number of interviews, creatively and interpretively analysed, than a larger number where the researcher runs out of time to do them justice analytically (Baker and Edwards, 2012, p.19).
>
> The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size (Patton, 2002, p.245).

Baker and Edwards compiled a review paper ‘How many qualitative interviews is enough?’ in 2012 by talking to nineteen experts in qualitative research. Although not specific to IPA, it provides a useful and stimulating resource. The consistent answer to this question following a range of theories and explanations from all of these experts was: ‘it depends.’

One could not state that a specific number of interviews is required for themes to emerge, or that after a specific number of interviews, no further themes would transpire; it could never be known if, on that next interview, an entirely new theme may emerge. However, increasing the number of participants does not necessarily yield better results, with depth and richness of data being highlighted as more indicative of quality research than number and breadth (Baker and Edwards, 2012; Smith et al., 2009). To understand the value and contribution of IPA research, the value of listening to and learning from human experience must be appreciated.

I experienced a lack of confidence and discomfort in using a small sample size (see reflection from diary extract in Appendix I), but returning to the work of Baker and Edwards (2012), it was reassuring that my concerns were familiarly reflected in the words of one expert, Jennifer Mason, ‘[ ] it is often a knee jerk response for the inexperienced researcher to want to conduct more interviews because this is somehow seen as better’ (p.5). Mason goes on to explain the challenge is actually to ‘build a convincing analytical narrative based on richness, complexity and detail rather than on statistical logic’ (p.5). Kathy Charmaz set a further challenge when asked for her opinion as part of this review, ‘a very small sample can produce a study with depth and significance depending on the initial and emergent research questions and how the researcher conducted the study, and constructed the analysis’ (p.22). Although I found these statements more of a challenge than reassurance, they also illustrated that perhaps I would not know whether I had the ‘right’ number of participants until after I had analysed and explored all of the data. Peter and Patricia Adler suggested this might the case, giving their opinion as they compared quantitative with qualitative research:

> Qualitative researchers, working in the contact of discovery, are more open-ended, and often follow emergent empirical and conceptual findings in unexpected ways. Thus, they may not know, in advance, how much data they need to gather (p.8).

Although the above discussion highlights that each IPA study is different, it seemed logical to examine other IPA research regarding sample size (particularly that within healthcare) with a view to situating my research rather with the aim of directly comparing it. From reviewing the research papers in Appendix III comprising IPA research in physiotherapy, the number of participants ranged from 5 to 22. Six of these research papers have a sample of less than 10, 3 of them have a sample size of 5. Reviewing this literature helped ensure that my research was commensurate with current research using the same approach.

3.6.2 Recruitment and selection of Participants

Recruitment for this research commenced following ethical approval by the University and health-board (see Appendix X). The participants are a purposive sample of PwMS who have accessed NHS physiotherapy services within North Wales. Participants for IPA research are purposively recruited ‘because of their expertise in the phenomenon being explored’ (Reid, Flowers and Larkin, 2005, p.20); for this research, the participants have experience of physiotherapy in North Wales, and have MS. The participants are homogenous in so far as they all have this experience and condition in common; otherwise their characteristics, demographics and situations differ widely (see Table 4 in 3.6.3). No further criteria for the sample selection was indicated, as the aim of the research is to explore the experience of physiotherapy for PwMS through the idiographic analysis of each individual’s experience. I reasoned that diversity and commonalities could provide additional richness to the analysis.

IPA requires rich data, and participants are chosen ‘because they offer researchers insights from a position of shared experience’ (Reid et al., 2005, p.22); therefore the only other aspect to selection was that participants were able to engage and share through conversation, even if this required adaptation. Some

PwMS have difficulty with their speech, cognition or concentration to an extent that would not enable them to participate in in-depth interviewing. I considered that if a person was able to initiate contact following either reading a poster, or hearing about the research, they would be able to communicate adequately to participate in this research. However, it was anticipated that participants may have a range of communication abilities due to the nature of MS. The importance and focus of IPA on the individual reassured me that even if one participant had less ability to share their experience than another, this would not reduce the importance of their contribution. I anticipated this might comprise part of my challenge as an IPA researcher; to optimally analyse and interpret each participant’s words in order to explore and share their experience.

A description of the research, alongside an invitation to register interest (see Appendix XI) was placed in 6 NHS physiotherapy departments in North Wales (in the three main district general hospitals in North Wales and in three community hospitals (Anglesey, Ruthin and Alltwen) to ensure distribution across the area). This information was also sent out to local branches of the MS Society for discussion at their monthly or bi-monthly meetings. The MS Society area development officer was also provided with this information, and agreed to distribute this information to PwMS who were less likely to access the website, newsletter or physiotherapy departments, but may be interested in participating. This information was displayed and circulated at meetings for 3 months. If less than 5 people had volunteered to become involved within 3 months, this information would have been recirculated through meetings, and the poster sites increased for greater visibility. Once 10 people had volunteered, the information posters and flyers would have been removed at the time to limit the number of participants involved in this research- the reason for this is discussed in 3.6.1. I was contacted by 8 people during the 3 month circulation of this invitation to participate. I subsequently followed up their expression of interest either by email or telephone call, depending on the person’s stated preferred method of communication.

The information sheet and consent form (see Appendix XII and XIII) were explained, detailing the aim and method of the research, the topic of the interview, and how their responses and the research as a whole would be used and written up, including that their anonymised comments would be used verbatim within the body of the research. Participants were reassured they could withdraw from the research at any stage without prejudice, and their anonymity would be maintained. I confirmed again at this stage that they wanted to take part in the research before arranging the interview for the participants chosen date, time and place. The details of the interview, alongside the information sheet and consent form were posted to the participants' home address for their information and reference. This included my contact details should the person need to rearrange or cancel the interview. Additionally, with the knowledge that MS is a variable condition that affects people differently on different days, a confirmation telephone call was made on the day of the interview.

3.6.3 Participant details

Eight participants were recruited into this study: two men and six women. One man was unable to be interviewed due to deterioration in his MS and one woman was unable to be interviewed due to unexpected ill health unrelated to MS. Six participants took part in this research to include one man and five women.

Pseudonym name	Further information	Previous involvement with myself/place of interview
Peter (and Mary) 62	Married. Unable to work due to effects of MS. Secondary progressive MS for > 10 years. Able to stand with equipment and assistance. Requires assistance with most day to day tasks.	Not known prior to interview/home
Bella 38	Single. Unable to work due to effects of MS. Secondary progressive MS for > 10 years. Unable to stand, moved with the assistance of a hoist, uses an electric wheelchair for all mobility. Requires assistance with all activities of daily living	Not known prior to interview/home
Anna 70	Divorced. Retired. Secondary progressive MS for > 5 years (previously had relapsing remitting MS > 10 years). Able to walk with a walking frame. Manages most day to day tasks with the use of assistive equipment as needed	Not known prior to interview/home
Fran 48	Married. Working (though at the time of the interview, off work due to health). Diagnosed with relapsing remitting MS within the past year. At the time of the interview, was able to walk limited distances with no walking aid, and manage all day to day tasks	Not known prior to interview/home
Clare 52	Married. Working part time (reduced hours due to MS). Diagnosed with secondary progressive MS within the past year (previously had relapsing remitting MS > 10 years). Able to walk with a stick limited distances and manage all day to day independently	Had been seen in an MS class where I advised the class regarding physiotherapy/physiotherapy department meeting room
Julie 58	Single. Unable to work due to effects of MS. Diagnosed with secondary progressive MS > 5 years ago, previously had relapsing remitting MS for > 5 years. Able to walk limited distances with a stick or frame, and manage most activities of daily living independently with the help of assistive equipment	Had been treated by myself as her physiotherapist in the past, and had been seen in an MS class where I advised the class regarding physiotherapy/physiotherapy department meeting room

TABLE 4: PARTICIPANT DETAILS

3.6.4 Interviewing process and method

Four participants asked to be interviewed in their own home (one participant was interviewed at home with their spouse present at both of their request). It is recognised that many people feel more relaxed at home, and this potentially leads to more open conversation (Stephenson and Wiles, 2000). However, two participants requested an interview in the physiotherapy department they were familiar with (rather than in an alternative setting such as a café, which was also offered). A quiet and private meeting room was used for these interviews. The lone working policy of the health board was adhered to throughout this research in order to maximise safety for participants and myself. A consent form (Appendix XIII) was completed for each participant prior to the interview commencing that included permission for interview recording. Flexible interviews were conducted with participants taking the directional lead (Smith et al., 2009) within the context of the main question: what are your experiences of physiotherapy? Conversation was facilitated to flow freely following a short introduction about the research and researcher (the information in the research information sheets was discussed as required). Prompts and questions were introduced when appropriate to further explore aspects of conversation during the interviews. Examples of these are found in table 5 below.

Exemplar questions	Exemplar prompt questions
• Tell me about your experience of Physiotherapy • Did/does physiotherapy affect you? • What are your thoughts about physiotherapy?	• How did (that) make you feel? • What did (that) mean to you? • How did (that) affect you? • Can you describe that/this? • Can you tell me some more about that/this?

TABLE 5: EXAMPLE OF QUESTIONS ASKED AND VERBAL PROMPTS THAT MAY BE USED

Interviews lasted between 21 and 55 minutes. Some participants' required regular breaks, some required more prompts than others, and one required the assistance of his spouse. As a clinician, I discuss emotional and difficult issues with people on a daily basis, so I was able to alter the interview technique to meet each participant need. Interviews were digitally audio-recorded following consent. Note taking during the interview was minimised to increase eye contact and attention. Maintaining focus on participants heightened my awareness about how they were coping with the interview, as well as enabling me to monitor expression and body language.

Ensuring that participants felt comfortable both with the impending interview, and with me, was important to facilitate improved interaction and responsiveness. Sensitivity (to cultural and ethical issues as well as emotive ones), trustworthiness and empathy must all be maintained, with the interviewer being adept at leaving the respondent positive and calm following the experience. It is imperative that an interviewer must have high levels of communication skills, and be competent in establishing a rapport with people to enable open communication. I dressed casually, used informal and non-clinical language and interviewed participants in an open and collaborative manner, situating and respecting the participant within the interview as the expert of their experiences. Working as a physiotherapist in neurology for over 17 years continually develops communication skills through everyday therapeutic interaction as it involves helping people with long term and progressive neurological conditions optimise their function. It is fundamental to therapy that a rapport is built effectively to enable person centred therapy with agreement of personalised goals and establishing how therapy can help them. Whilst these communication and awareness skills did improve my interview skills required for this research, the interviews held many challenges (see reflective section on interviews in Appendix I).

Peter and Mary chose to be interviewed together at the time I arrived for the interviewing. There was no ethical concern as they both requested and agreed this, and paired interviewing was not in the exclusion criteria. It has been acknowledged the presence of a spouse might influence the interview and the data collected, particularly that this might ‘favour expressions of shared rather than individual experiences of the phenomenon studied’ (Norlyk et al., 2015, p.936). Other recognised challenges of paired interviewing include one partner dominating the discussion and the influence or constraint of the participant’s responses due to the presence of the partner. However, benefits include helping the participants’ memory and the contributions of the partner to the interview (Norlyk et al., 2015). All of these issues are recognised in this research: the interview with Peter and Mary was a story of shared experience, Mary did influence and structure the interview at times and she was reluctant for Peter to share some aspects of their experience, such as his concern about Mary caring for him (discussed further in chapter four). It is difficult to wholly determine any difference that might have been heard in Peter’s story if he had been interviewed on his own. I have tried to listen to their story and the individual stories of Mary and Peter within this through analysis and interpretation, with the awareness of the effect that Mary’s presence may have on Peter’s words.

3.6.5 Transcription

I listened to each recording in their entirety at least twice before typing them out in full, in order to familiarise myself with the recordings and to hear the flow, tone, and expression of words. I transcribed each interview within two days of carrying out the interview, adding field notes describing non-verbal communication (for example see table 6 below) as '(this information) should be inserted into the transcript either during transcription, or immediately after transcription whilst the experience is fresh in the researcher's mind (Fade, 2004, p.648).

Transcript extract Interview 1, L 44-53	**Field notes**
Mary (talking about hydrotherapy provision)….and then it never happened again, we were told, and I remember this actually now, you were told that, that, you were *actually* told, the gym based physio would be more beneficial for you, rather than going into the pool….	-speech became increasingly quick, became more angry and agitated -emphasised 'you were actually told' loudly and with disapproval
(pause)	-long pause as they both looked at me- seemed to be challenging, waiting for my comment on this
Me: And did you find that to be the case?	-I sounded quite tentative
Peter: No. Absolutely not.	-Firmly. Reinforced. Held my gaze-felt challenging. Physically drew himself up
Me: Okay… (pause)...so, in terms of how that made you feel….?	-repeated long pause. Would not speak until I asked another question
Peter: Well, it just made life more difficult really	-sounded defeated, deflated (to do with situation, and also that answers had not been given by me?). Physically rested back, posture drooped. Energy seemed to be lost.

TABLE 6: EXAMPLE OF FIELD NOTES FROM INTERVIEW 1

Smith et al. (2009) advise that 'transcription at a level suitable for IPA generally takes around seven hours for every one hour of recorded sound' (p.54). This time is used for repeatedly listening to sections of the interview to transcribe the spoken word, but also to describe pauses, sounds and expressions. I created pseudonyms for each participant and therapist (various therapists were discussed throughout the interviews as participants had often seen numerous therapists), and added transcript notes about anything additional I had observed during the interview, or that I had heard through listening to the interview with the help of my field notes. Creating pseudonyms increased the individual's story telling element and allowed me to feel more connected to the interview material and the person's story, bringing it alive as I developed more ownership and understanding of it. I began to hear phrases from the transcripts in my head during everyday life as I encountered a range of situations, making connections in my head, and providing reference points for some of the emergent themes. I found immersion in the data was broader than reading and re-reading, as the stories and experiences of participants frequently pervaded my thoughts. Aspects of what we had talked about were often highlighted or contrasted, particularly when working with other PwMS. In this way, I found that analysis and interpretation continued between sessions dedicated specifically to this task. I made notes of potentially relevant or illuminating thoughts and reviewed them when I returned to focused sessions of analysis and interpretation.

3.6.6 Data Analysis

To provide some context and explanation regarding analysis and interpretation in IPA, Smith et al. (2009) highlight and advise the need for immersion in the material for a prolonged period of time (days and weeks rather than hours) to enable adequate analysis:

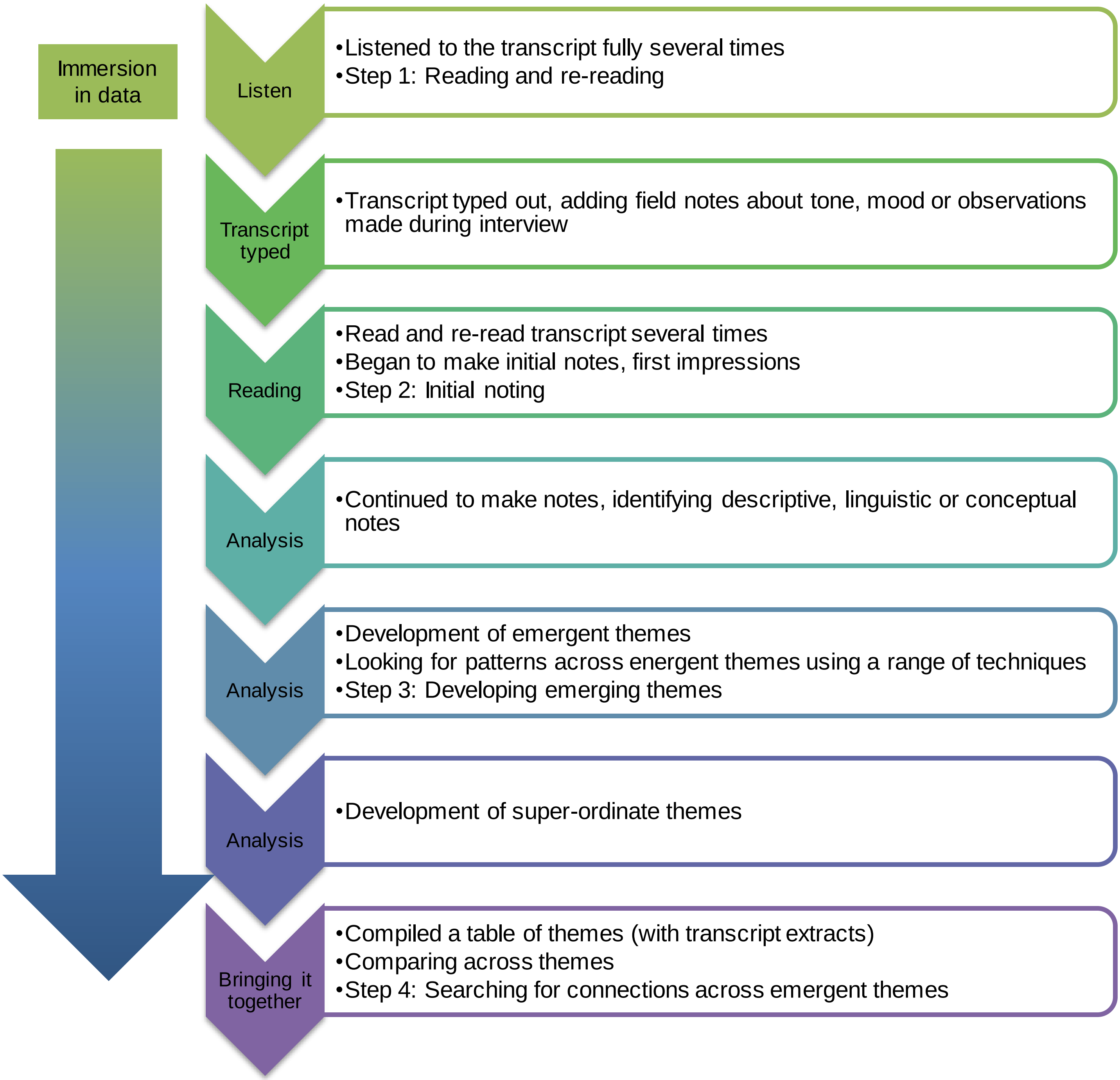
> If we are thinking about a full time student, new to IPA, in our experience a first transcript can take anything from between one week and several weeks to analyse. Subsequent transcripts may be analysed more quickly, but the task will continue to take days rather than hours for each transcript. This means that the analysis stage for an IPA study of three cases may take at least two months of full time work (p.55).

I have included this excerpt from their textbook in its entirety, as it provided a reference point for completing the analysis for myself, but also provides a context for the reader of the forthcoming complexity of the analysis and interpretation. I followed the guidelines described by Smith et al. (2009) and Pietkiewicz and Smith

(2012) to structure my analysis. I read each transcript through several times and made notes about anything that I found particularly striking at this stage (see Appendix XIV). Repeated reading and listening (sometimes I returned to the interview recording following re-reading to clarify an aspect of the interview) continually revealed more, helping me make connections within the transcript, and also optimise the idiographic dimension as I got to know each participant. I found the process of annotation more intuitive, fluid and visually apparent carrying out the analysis on paper. Each time I made (initial) notes, I used a different pen to track the layers of notes that I had made. I then altered the typed transcript layout-numbering each page line, and creating a column to one side. I used this column to then type out my notes, indicating if the notes were descriptive, linguistic or conceptual in nature and distinguishing these by using different fonts. The process of moving from written notes to typed notes helped to clarify thought process and remove repetition.

Subsequently, I changed the format again, adding another column to the left of the transcript to start to identify emergent themes (see Appendix XIV for details of the process described above), with ideas from the text being generated and extrapolated as conceptual strands themes or thoughts during immersion in the data as recommended (Fade, 2004; Smith et al., 2009). After I had completed this theme identification and extraction, extracts were printed and cut out. I was then able to visually see all the themes and cluster them together to form ‘super-ordinate’ themes through a process described by Smith et al. (2009) as abstraction, ‘a basic form of identifying emergent patterns between emergent themes….putting like with like, and developing a new name for the cluster’ (p.96). See Appendix XV for a table showing other methods of theme identification for reference. In summary, data analysis involved identifying micro-themes from the data, and then clustering these into themes, supported by extracts from the narrative material as described by Smith et al. (2009); see figure 4 below.

I created a document of each theme with examples of transcript extracts that had generated these themes. This helped me to build a clearer picture about the frequency and distinctness of themes. There were some themes that seemed strongly represented from my perspective, but when I came to bringing together transcript extracts, I was able to see that alternative themes were more heavily represented within the data. I then created a table of themes and selected exemplar extracts for each theme (see Appendix XIV for details), as represented in Figure 4 below.



Listen
- Listened to the transcript fully several times
- Step 1: Reading and re-reading

Transcript typed
- Transcript typed out, adding field notes about tone, mood or observations made during interview

Reading
- Read and re-read transcript several times
- Began to make initial notes, first impressions
- Step 2: Initial noting

Analysis
- Continued to make notes, identifying descriptive, linguistic or conceptual notes

Analysis
- Development of emergent themes
- Looking for patterns across energent themes using a range of techniques
- Step 3: Developing emerging themes

Analysis
- Development of super-ordinate themes

Bringing it together
- Compiled a table of themes (with transcript extracts)
- Comparing across themes
- Step 4: Searching for connections across emergent themes

FIGURE 4 ANALYSIS AND INTERPRETATION PROCESS

I explored and analysed each interview in turn as, 'IPA is committed to idiographic analysis, which means that the analysis of each individual is undertaken in complete isolation' (Gee, 2011, p.10). Smith et al. (2009) discuss the importance of this, explaining that the researcher should aim to '[bracket] the ideas emerging from the analysis of the first case while working on the second' (p.100). There is an acknowledgement that already your 'fore-structures' will have changed, but that maintaining the commitment to idiography is integral to IPA. I found that immersing myself in each case in turn made this possible, to the extent that I actually found it quite difficult to step back and move onto the next case, as I became familiar with that participants expression and use of language, and became more empathetic and understanding of their situation and experience.

The analysis of Peter and Mary's interview differed in some aspects. Their transcript was analysed in isolation as their own case as described above. However, there followed further layers of analysis using different lenses, trying to analyse and interpret their shared words and experiences and also the words and experiences of both Peter and Mary as individuals. I moved from analysing their words as they presented, to analysing them again within the context of the other person being present and of them being interviewed together to increase the relevance and depth of interpretation from their words.

The next stage of analysis was to look for patterns across cases, 'and then the findings [were] compared and common themes identified' (Gee, 2011, p.10). The final analysed account should offer a layered analysis of the phenomenon, a descriptive understanding of the experience, and a more probing critical analysis based on the interpretation of the researcher (Cassidy et al., 2009). I need to explain and be aware of the concepts, values and preconceptions I bring to the process of analysis in a transparent, relevant and integrative way. Larkin (2013) explains that the researcher functions as a channel/filter through which the experiences of the participants are conducted and constructed. Smith et al. (2009) advise that some account of this side of the process should be included in the analysis, writing in the active voice and the first person. Smith et al. (2009) argue the importance of the researcher being clear about their 'interpretative engagement' with participants' transcripts so they can make sense of the verbal accounts (data) being analysed. This is a 'co-constructive' approach, where the participant and the researcher are both actively involved in exploring the meaning and the understanding of this particular experience (Smith et al., 2009).

3.7 Ethical Considerations

As previously discussed, ethical approval was granted by the health-board, Glyndwr University research ethics committee (see Appendix X for details), as well as through IRAS (integrated research application system). Participants were recruited following an information flyer either being read to them in a meeting, or by them reading it from a poster on the wall. In this way, participants made the choice to participate in the research with no coercion and with reassurance there would be no associated affect or link to physiotherapy received. Hicks (2000) identifies this issue of informed consent 'which demands that the participants knowingly, willingly, rationally and freely agree to take part (p.64)', highlighting that research in healthcare often involves vulnerable people, therefore the difficulty and importance of this issue is magnified. Hicks (2000) identifies eight guidelines that should be referred to; details about how I addressed each of these ethical issues to maintain ethical and appropriate treatment of research participants in this research can be found in table 7 below.

Guidelines to ensure informed consent and appropriate treatment of participants	How these guidelines were implemented within this research
Never deceive or coerce the participants in any way	All correspondence was honest. Procedures were explained and transparent throughout. Contact details for myself and my supervisors were provided to enable any questions or concerns to be addressed
Always obtain their full and informed consent	Written consent was obtained after participants had read and discussed details of the research as set out in the participant information sheet
Never embarrass or compromise the subjects; always preserve their dignity and wellbeing	Participants were treated with care, dignity and respect at all times
Always ensure the participants' confidentiality and privacy	Data protection was maintained. Person identifiable information was removed at initial transcription and a pseudonym created. All potentially identifiable information was anonymised. Data was protected in accordance with the Data Protection Act (1998) and the NHS Research Governance Framework (DH, 2005) Personal identifiable information initially used (name, address and contact details) and copies of all personal information provided in writing (e.g. signed consent forms, contact details) kept securely within a locked filing cabinet on secure premises and will be retained for a period of ten years in accordance with the NHS Research Governance Framework (DH, 2005), after which time they will be destroyed. Participants were reassured about the above.
Always offer participants the right to withdraw from the research at any time, without jeopardising their current of future treatment	This was made clear to participants, but also documented on the information sheet and consent sheet
Always consult with and inform any relevant authority about the proposed research before embarking on it	Consultation with IRAS, Glyndwr University and the research ethics committee at Betsi Cadwaladr University Health Board was carried out
Always discuss the methodology with experienced researchers to ensure that it is appropriate and that it can be carried out without damage to the participants	Ensured through ongoing supervision provided by supervisors and following University processes
Be considerate, respectful, and as objective as possible when conducting the research; always act with integrity	Participants were treated with care, dignity and respect at all times

TABLE 7: TABLE OF ETHICAL GUIDELINES (ADAPTED FROM HICKS, 2000, P.64)

When engaging in conversation about personal experience, issues will be raised which are potentially difficult and emotive for the interviewee or interviewer to hear or discuss. This is also the case in daily clinical practice as therapeutic interaction, especially within the context of long term neurological conditions such as MS, necessitates discussion about deeply personal and emotional issues. I was aware of the numerous support mechanisms and services from health, social and voluntary sector through my clinical role that I could offer to participants if required. However, I found participants already had these support networks in place, and the interviews did not raise issues that they were not already having to deal with due to living with MS. The interview with Fran was particularly distressing as she discussed feeling suicidal. She advised that her physiotherapist had supported her through this, that she did not feel that way any longer and did not require further support or onwards referral. I was also reassured that as she worked in health care, she was also aware of available services.

I was cognisant that the context of this research may raise complaints with physiotherapy services participants had received. Participants were informed I was interviewing them as a researcher, not as a representative from the health board, though they were also aware of my role within the health board. My duty as a registered healthcare professional and an employee of the health board, meant that I would inform participants about the complaints procedure, and support them adequately to be able to follow this, if a formal complaint arose. It is worth noting these participants would likely have been aware of the complaints procedure having all received NHS treatment, thereby having the opportunity to complain previous to this research. However, I recognised that when people reflect on a situation, this can reveal further upset and distress about treatment received. Concerns were raised, most notably in the interview with Peter and Mary; the option to raise a complaint was offered, and this procedure was explained to them both, but this was not actioned as far as I was aware. There were no issues raised that required further reporting. However, this raises another potential aspect to this ethical issue. What if participants raised an issue they did not identify as a formal or reportable concern, but that I would identify as being of concern- for example, about the performance of another staff member? I thought through this prior to conducting the interviews, and considered that if issues were encountered that directly placed patient safety at risk, or compromised their care, there would be a professional duty for me to act appropriately on this, following my code of conduct as a health professional and health board employee, in line with policy and procedure.

I am aware of my moral and ethical obligation to protect participants from identification through this research, but this proved difficult to uphold. Some participants were so descriptive about their own job role, or their therapy experiences as examples, that if this research is read by therapists working in North Wales, they may be able to identify the participant. I tried to minimise this likelihood by using pseudonyms and removing the names of places discussed. However, considering Fran's interview, if I remove any reference to her job role, I would remove a significant aspect of her story, as much of her experience is narrated from the perspective of her within her job role. I decided to remove some details she disclosed about her workplace colleagues, as they could have conceivably been identified through the interview. They were not consenting participants, therefore had not given permission to be included. Fran actually stated in her interview 'and you can use this if you want,' even when she was discussing deeply personal issues. Therefore I decided not to remove any of the discussion apart from that which could identify others. I had explained to people, and it was detailed in the information sheet, that direct excerpts from the interview might be included in the research. Perhaps participants such as Fran relished the opportunity to have their full story heard, and did not want these crucial aspects removed from their story. When I considered it this way, I considered it may present more of an ethical issue to remove information that could result in misrepresentation of their story because key characters or key events had been removed. Respect, empathy and awareness of participant needs are skills required for IPA research. These provide a foundation for sensitive and ethical decision making around the use of participant words.

3.8 Considering the quality of this research

A critique of the quality of this research will be found in chapter five. However, some issues relating to quality of this research were considered prior to carrying it out- these aspects in particular are detailed here. I considered it may affect participants' expression of their experiences if I had treated them before, or they had encountered me as a physiotherapist at an education day, service user forum, or clinic. It was unavoidable that potential participants would have prior knowledge or contact with me due to my job role, therefore the inclusion criteria would need to have excluded these people from this research if this issue was considered to negatively affect this research. I considered this, but it did not seem in keeping with IPA methodology to exclude people on this basis; each individuals story would be understood and interpreted within its own context (and so therefore, this issue will be considered as part of the analysis and interpretation), providing insight into the experience of physiotherapy for PwMS- the aim of this research. Smith et al. (2009) suggest that 'IPA researchers usually try to find a fairly homogenous sample' (p.49). They go on to discuss what constitutes a homogenous sample within the context of IPA, in terms of how much any variation will affect understanding of the phenomenon. They highlight that variation can be included in the interpretation but advise this can present a more demanding analysis: 'our advice to a newcomer to IPA is to try and obtain a group which is pretty homogenous' (p.50). As I am a novice to IPA, perhaps it may have been advantageous, for a potentially simpler analysis, to avoid participants that were known to myself. However, as the focus of IPA research is seeking experiences, events and emotions significant within individual life narratives rather than comparing across a broad group, I decided that participants should not be excluded for this reason; this may form part of their experience and context.

As previously discussed, research within physiotherapy remains predominantly quantitative, despite increasing interest in qualitative research. One of my concerns of including participants that knew me as a physiotherapist, is that the potential reader audience of physiotherapists will be more familiar with assessing quality of quantitative research, where researcher and participant bias are variables that might affect results, and therefore should be minimised. However, within qualitative research, there are arguments that interviewing participants who the researcher has a rapport with, could strengthen research. Roberts (2007) suggests that having an established relationship can bring strength to research as 'personal knowledge may enable the researcher to have a greater understanding of the culture being studied because there is an established intimacy [ ]' (p.16). As previously explained, the majority of PwMS access physiotherapy regularly throughout their lives; I have established relationships with patients that I work in partnership with. Smith et al. (2009) explain that participants are selected on the basis they grant us access to a particular perspective on the phenomena under study. I potentially had more access to participant perspectives through having an established relationship with them, as well as having an increased knowledge of the phenomena that may help inform analysis and interpretation.

I have worked in the NHS as a physiotherapist for many years, which will have shaped my experiences and preconceptions. "Interviewer bias" is unavoidable, and is actually integral to this research methodology and process when used reflexively. My integrity as a researcher and interpreter will be established within and throughout the research through sharing my analysis and interpretation transparently. Inductive phenomenology involves the development of the researcher. The researcher gains further insight into their views and feelings as well as their own clinical practice and human interactions (Gee, 2011). As such my voice as the researcher will be apparent in the narrative findings and discussion of this research. Reflexivity seeks to recognise and value the researchers' participation in shaping data and their analysis (Johnson and Waterfield, 2004). This can be seen as a valuable resource and contribution to the research findings. In this way researcher 'bias' can be seen as a strength within this study. For further details and examples of my reflexive practice throughout this research, please see Appendix I.

3.9 Intended Audience and Application of Research

It has been noted that stories form part of daily human interaction. This narrative research aims to be accessible, interesting and relevant to readers, with the hope of improving person centred care. More specifically, this research will increase insight into the experiences, thoughts, feelings and perceptions of PwMS regarding physiotherapy, thereby facilitating personal and professional reflection. It is anticipated that themes emerging from this research might improve the experience of physiotherapy for PwMS in North Wales, through positively influencing and informing physiotherapy practice and service development locally. The analysis and interpretation of these findings will be directly applicable to therapists considering their own clinical practice and the services being delivered. The findings from this study will be of value in various therapeutic and healthcare settings, specifically in MS, but also particularly within the speciality of long term neurological conditions.

In addition, it would be hoped this research would also add strength to the argument for the importance and relevance of research based on the views and experiences of the people who use physiotherapy services, as well as contributing to the education of future therapists regarding this approach to research, particularly the IPA approach.

The focus on the individual in this study (and all IPA research) can provide enhanced understanding and insight and contribute to existing theories, as well as generating new themes when considered alongside what is already known about this area of research (Cassidy et al., 2011). Part of the challenge for me is to discuss findings from this research alongside existing literature to contextualise the findings, build the current evidence base and highlight new findings that have relevance for physiotherapy clinical practice.

3.10 Summary of Chapter Three

This methodology chapter has provided an overview of the relevant philosophy and theories of research underpinning IPA, and provided a methodological guideline addressing how this research was carried out to include some critique of quality. This chapter has also identified relevant ethical issues, and discussed how these were addressed to respect and protect research participants.

4.0 Chapter Four: Findings

4.1 Chapter Overview

This chapter presents the findings of this research. Emergent themes were initially identified before being categorised as sub-themes, followed by further analysis and interpretation to identify super-ordinate themes (see chapter three for further details of this process). This chapter includes verbatim extracts from participant interviews; the table below explains the annotation used in the subsequent transcript excerpts.

Annotation used in extracts	**Indication**
…	significant pause
[ ]	material omitted (where omission does not change the meaning or context of the extract)
( )	added by researcher to clarify or contextualise extract material
T	Transcript number
L	Line number within transcript
The names of participants, therapist and places have all been changed to protect anonymity	

TABLE 8: TRANSCRIPT NOTATION USED IN THESIS

Three super-ordinate themes emerged. The over-arching theme of ‘sense of self’ interweaves and at times frames the other themes of ‘embodied experience of physiotherapy’ and the ‘embodied experience of living with MS’. Participants expressed the significant affect their experience of having MS and MS-related physiotherapy has upon how they view themselves. This theme could be explored within each of the other two themes. However, due to the resounding presence of this theme throughout these narratives, sense of self is identified as a paramount theme that merits considered analysis. The embodied experience of physiotherapy explores many aspects of the lived experience of physiotherapy for these PwMS, to include practical delivery of services, what physiotherapy means to them and exploring physical self-management, person centred care and communication. The embodied experience of living with MS is intrinsically related to the experience of physiotherapy, pervading and underpinning each participant's experience and story, therefore this has been identified as the third super-ordinate theme despite this study's aim of exploring experience of physiotherapy rather than experience of having MS. Table in Appendix XIV provides an overview of the emergent and sub-ordinate themes generated from the analysis of the six interviews carried out in this study.

4.2 Theme One: Sense of self: 'this is not me'

The effect of both the experience of having MS and MS related physiotherapy on how each individual feels about themselves resonates throughout these interviews. Participants talked of feeling self-conscious, fearful, stupid and lacking in confidence but in contrast also of feeling empowered, proud and resilient as examples of how experiences of physiotherapy and living with MS affects their sense of self. I had anticipated discussions around the physical and emotional effects of MS symptoms, perhaps with a focus on how physiotherapy affected these, but I had not anticipated the extent to which these experiences are often synonymous with who these participants are and perceive themselves to be. It has been challenging to disentangle and separate this theme from the following two due to the embedded nature of sense of self within participant words. At times this theme is better illustrated and represented within other theme sections and this will be highlighted where this is the case.

4.2.1 The effect of physiotherapy on sense of self

Peter is concise yet revealing in his description of how he feels about himself at various junctures throughout the interview. It is interesting to note how Peter describes himself when discussing physiotherapy classes. These classes were set up for six weeks attendance, followed by six weeks break, and some of his sessions were cancelled due to transport issues:

> Me: So, what was the effect on your quality of life, or on your life from that physiotherapy?
>
> Peter: …It made me feel pointless really, because it wasn't helpful (T1L32/33).

Peter describes himself as pointless, not the class set up or transport which had been lacking and unhelpful for him. This provides insight into the disempowerment and negative effect on Peter's self-esteem and feeling of worth. Mary goes on to explain that Peter had to wait 'his turn:'

> Mary: [ ]...it wasn't consistent…[ ] it would sometimes be 3 months, when his turn came up again, and, and that kind of experience (T1L34/36).

I interpret this description as Mary perceiving Peter as being part of a process or "conveyor belt" of physiotherapy care over which they have little control, rather than being an individual at the centre of his care. 'When his turn came up' evokes a sense of Peter being dependent on a system that runs regardless of him, that he fits into; this may add to his diminished self-worth and increased disempowerment- all he can do is "wait his turn".

In contrast, Bella demonstrates a sense of pride when discussing an experience of physiotherapy, emphasising how important her independence is to her as she explains, 'I did it myself,' followed with 'all she had to do was explain it to me once, then I take it up from there.' Bella also makes sure I am aware she is able to think things through for herself and manage her programme independently:

> Me: And can you tell me more about that (experience of physiotherapy)?
>
> Bella: I did it myself
>
> Me: So, someone showed you what to do, and you kept doing it?
>
> Bella: Yes...
>
> Me: And did you understand what you needed to do?
>
> Bella. Yes. I am fully compos mentis (Laughs)
>
> Me: (Laughs) I more meant, was it explained fully to you?
>
> Bella: All they had to do was explain it to me once, then I take it up from there (T2L25/32).

I interpret Bella valuing and taking pride in her ability to self-manage her condition through physiotherapy and this contributes towards her sense of self as someone who can understand, motivate and structure her own rehabilitation to optimise her independence.

At some stage of their condition, 65%-90% of PwMS are affected by muscle spasms, stiffness or spasticity (Oreja-Guevara et al., 2013; MS Trust, 2016) and this is associated with reduced quality of life (Arroyo, Massana and Vila, 2013). Fran talks about physiotherapy intervention of stretching joints and muscles, explaining they felt looser and more normal following physiotherapy:

> Fran: And, so, even just getting stretches, to be able to get everything stretched, so you could actually be in a normal position (T4L113/114)

This suggests that physiotherapy helped Fran feel more her normal self. Fran goes on to talk about the hope and support physiotherapy gives her, helping her regain function and face her future more positively. Her story provides a raw account of the effect of having MS on who she is and how she values and defines her life:

> Fran: Erm, so, for me personally, it, the physios made the difference between me being able to walk and get up and down the stairs in this house, drive, work, and actually, because of how low all of that makes you feel when you have been reasonably functioning before, and you just can't, like your world has changed, and you just can't do anything…might even be why I am still here. Because (refers to her job role in health care) are usually pretty successful if they try and kill themselves…(Laughs).You know, if I had actually wanted to, and there had been points where you just thought, 'why am I bothering trying,' and actually, the physios wouldn't have known that they were making that difference as I wouldn't have said.
>
> Me: Hmmm
>
> Fran:…I wouldn't have dared tell anybody. But, but it has made that much difference- that level of difference (T4L223/234).

Reviewing this extract alongside an earlier one in Fran's interview makes clear the profound life-changing difference her physiotherapist made to her sense of self-worth and quality of life by listening to how MS affected her and helping her improve her function:

> Fran: (physiotherapy) has made the difference between being back at work, and driving, and me not being back at work and driving. And some of that almost makes the difference between being suicidal, and not being suicidal…(T4L42/44)
>
> Me: Yes?

Fran provides further insight about the value of person-centred care in physiotherapy affecting her sense of self during her interview. This is further explored in section 4.3.4.

MS is a progressive condition; as a person's function deteriorates, equipment is often needed to help people carry out day to day tasks such as washing, getting into bed or walking. Physiotherapists assess mobility and safety and prescribe and train people regarding walking aids and appropriate moving and handling equipment (NICE, 2014). The aim of this equipment is to improve quality of life through functional enablement and maintaining safety. Anna, Fran and Peter all talk about the impact of using such equipment on their sense of self.

Anna reflected she initially perceived the use of a frame (walker) as being for old people:

> 'I thought that there was no way that I was going to use this. That's what old women use' (T3L34).

She explains the walker made her feel like an old woman and she struggled to accept using one:

> Anna: And I thought 'this is not me, I am not an old woman,' going round using a walker…
>
> Me: I can understand that. So, then you continued on using the stick? (rather than using the walker which had been recommended)
>
> Anna: (Laughs) Until whenever! (Laughs) Now I am using a walker. The walker she gave me, was all big...though I used it a lot once I started using it. I have used it an awful lot in the last few years. It's been great. But it went all rickety, it was… (shakes head).
>
> So I have bought a new one myself. I call it my Jag! (laughs)
>
> Me: A souped up version then? (laughs)
>
> Anna: (laughs) It really is lovely. It's a 3 wheeled walker as well. It's got 2 little wheels at the front, and it's got a slide at the side, and I can put that down to be a seat. I can sit on it. I am really happy with it (T3L66/75)

It is not only using a walker, but the type of walker that affects Anna. Anna talks about the walker given by the physiotherapist as being 'all big' and 'rickety' before negatively comparing 'it' with the improved 'jag' she bought herself. The look and size of the walker is relevant to her sense of self and I interpret that Anna's reluctance to use the walker was not only due to it making her feel old, but also that it felt invasive and unwanted, 'all big.' Another contributing factor to this could be around how others perceive her, as she discusses how others see age within this context:

> Anna: You know, people could say that you are elderly if you are over 60! (laughs). And I am 72 now anyway. And, you know, okay, maybe I am elderly…But I still didn't feel that I wanted to (use a walker). But I now know that I am better off. I can hold myself straight… (T3L182/184)
>
> Me: And do you still think about that now?
>
> Anna: No. Not at all! I feel, I think that this is much better! I think of it as my Jag! (laughs) I am going away with my Jag...! (laughs) (T3L188/190).

Anna later extols the benefits of her new walker in terms of functionality, pleased that it enables her to sit and rest, improve her posture and walk on the pier. Anna displays personal ownership and attachment with her new walker, displaying a sense of pride in her 'Jag'

> Anna: (talking about her walker) Yes, well, shall I show it to you?
>
> Me: Yes please
>
> Anna: You see, I just use it very lightly? You see? I can stand straight. I have my balance now (T3L194/198)
>
> Anna: [ ] I still love going for walks over the pier. I love doing that. And, with this (indicates walker), I can do this (T3L212).

Although initially using the unwanted prescribed walker changed her perception of herself towards that of being 'old,' this changed over time as she embraced her new walker as it helps her do things she loves.

Fran describes the independence felt when she could use a stick provided by her physiotherapist rather than rely on using her husband's arm for support.

> Fran: [ ] and I think that a lot of people would feel like you are giving into...I mean my husband partly felt that I was giving in to being ill when I was using a stick. He would prefer that I leant on him. But, actually, it is probably better for both of us that I had a stick. But, also, a stick gives you independence, or two sticks give you independence. You know, it's harder to carry stuff (with 2 sticks), but… [ ] (T4L527/531)
>
> Because you needed something to help you do stuff, to do a bit more with things occasionally. So, somebody like a physio can at least encourage you that you are using it as a tool, not as a giving up, umm… (T4L542/543)

Fran raises concern that 'people would feel like you were giving in' by using a walking aid, further personalising this concern, as she considers her husband might think this about her. She explains that her physiotherapist helped her to see using a stick as ‘using [ ] a tool, not as giving up,’ to ultimately enable Fran increased independence. This suggests she previously thought using a stick would be ‘giving up.’ Fran did not expand on this further but it could be that her husband prefers her to lean on him as he is worried for her safety or that he wants to help her, rather than him feeling she is ‘giving in to being ill.’ However, her previous perception might influence how she thinks her husband feels.

Peter talked frankly about how using a hoist to be moved makes him feel:

> Mary: And we are able to avoid using the hoist and that…
>
> Me: (asking Peter) Which for you is significant?
>
> Peter: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it’s horrible. Horrible (T1L142/145).

Interestingly, he also reveals the outcome of using the hoist does affect this feeling to some extent:

> Peter: The only time I have been in a hoist (and doesn’t hate it) is in (name of place)…they have a pool there, they can hoist me into the pool and I can try and swim in the pool, and I enjoy that.
>
> Me: …and so it’s worth the hoist for the pool… (smiles)?
>
> Peter: (smiles) Yes, yes. I enjoy that (T1L145/149).

This is the only time in my interview with Peter that he smiles and expresses enjoyment. The only way he can access a pool is through using a hoist. The same piece of equipment that makes him feel ‘horrible’ and ‘demeaned’ also enables him to experience being in the water, which brings enjoyment. This echoes Anna’s transition from viewing the walker as something that makes her look old, to seeing it as something that helps her carry out activities she enjoys doing. These narratives illustrate the relevance of the use and context of equipment provided by physiotherapists on affecting sense of self for PwMS.

This section provides some insight into the wide ranging effect of physiotherapy on sense of self for these participants. Some felt disempowered and lacking control whilst others felt proud and empowered with increased normality, independence, quality and value of life. The effect of equipment on sense of self was dependent on acceptance, aesthetics, functional enablement and context of use.

4.2.2 The effect of having MS on sense of self

Julie exposes how MS affects her sense of self when describing why she has chosen not to exercise in her local leisure centre:

> Julie: I wouldn't go [ ], I would rather do it on my own actually [ ] you get the super-fit there. And they wouldn't understand, they just wouldn't understand. I'm not saying…they wouldn't all be like that. But, they wouldn't have the empathy with you, [ ] I feel, sort of, I don't know [ ] they have to do everyone, and, I don't know, but perhaps they wouldn't be that interested in someone with a disability. But I don't know. Perhaps I am wrong…But, I would feel so self-conscious, that I wouldn't enjoy it, and I just wouldn't go to be honest with you (T6L121/133).

Julie perceives others in the leisure centre as 'super-fit,' and not understanding, or being interested in her. Julie feels excluded from this 'super-fit' group, identifying herself as someone who is different, who is not fit, who has a disability and she is self-conscious about this. I interpret that Julie thinks everyone at the gym would be part of this 'super-fit' group and would not be interested in or understand her. This provides insight into the extent to which Julie sees herself as isolated from others due to having MS. She recognises this perception may be partly due to her own self-consciousness. She articulates trying to balance this view: 'they wouldn't all be like that,' 'perhaps I am wrong' before returning to the collective 'they wouldn't have the empathy with you,' concluding with the decision that she 'just wouldn't go.' When Julie comments 'they have to do everyone,' she refers to the staff and facilities having to meet the needs of everyone, and that 'perhaps they wouldn't be interested in someone with a disability.'

Julie expresses a combination of feelings- anxiety and negativity about the way that others may view and treat her, but also the way she views herself, separating herself from all the other leisure centre users and staff as she feels 'they have everyone else to do' with the interpreted implication they should not bother with her. Anna also identifies herself as inferior and different due to having MS when she shares hiding her MS to prospective employers; 'I thought, I wouldn't get a job if I told them that I had MS' because 'who is going to give you a job if you say you have MS?' (T3L323/324). Her acceptance within this phrase seems to indicate some agreement, which I interpret as Anna feeling inferior to others who do not have MS, particularly in relation to employability.

Anna describes how MS changes her perception of herself when discussing symptoms of her MS being particularly bad one day; ‘I was hopeless yesterday’ (T3L14). MS was causing muscle weakness, however Anna describes herself as ‘hopeless.’ She returns to this later in the interview, starting out by describing the effect of her MS, ‘Yesterday I just couldn’t lift my leg. I couldn’t. My balance was…oh…I was rubbish…’ (T3L350/350), but then transfers this back to her ‘(being) rubbish.’ Conversely, she explains how much better she feels about herself when her body does what she wants and expects of it, revealing her view of herself is inter-dependent on the physical ability of her body:

> Anna: Yesterday I just couldn’t lift my leg. I couldn’t. My balance was….oh….I was rubbish. Everything was rubbish yesterday. And so I thought, right. I am not going anywhere.
>
> And I feel much better today. I have already done my exercises today, and my balance was super today…..I do sit ups as well…I couldn’t do them yesterday…but I did 20 today. I did my 20 (T3L 350/354).

Participants also discuss the positive effects of managing their MS on their sense of self. In addition to the achievement of ‘I did my 20’, Anna emphasised that she can manage challenging activities despite her MS and that this makes her feel better about herself:

> Me: (asking about an adventure holiday that she had) And, you know, it sounds like quite a physical experience...?
>
> Anna: Yes, yes it was…
>
> Me: …When you came back did you feel any difference physically?
>
> Anna: No. No more tired. I felt better! Because I had proved to myself that I can. Yes, I can! (T3L246/248)

These statements also echo the pride that Bella expressed in being able to manage her own physiotherapy. Anna talks about being ‘a fighter’ and conveys the importance of proving this to herself, though using this phrase to define herself throughout the interview.

> Anna: I haven’t seen a physio since being here. No. I don’t want to bother…I feel there are so many people really sick, that really need help. And I feel that I am managing…
>
> Me: You seem like you are managing… (Anna interrupts and smiles)

> Anna:…very well!
>
> Me: Very well. Yes! (T3 L89/94)

The sense of Anna as a fighter is again present as she moves quickly from ‘if I can cope’ to ‘I am coping’; ‘I don’t like to trouble people if I am managing...if I can cope...I am coping…’(T3L278). However, she also reveals a more complex view that I interpret as her feeling undeserving of help in the extracts below. Anna may perceive others as needing help more her, so she does not want to ask for help when others’ needs are greater, or more deserving than hers. She intimates this thought again later in the interview, even suggesting she may deserve to experience some of her MS symptoms:

> Anna: (talking about if she thought she needed physiotherapy at the moment) …To be quite honest with you, I don’t think physio…I am exercising just as she said I should...you know?...I am balancing and stretching, and doing all of those, every morning- What else? I mean, I would be wasting her time…
>
> Me: Sounds like you are doing everything that you can do…
>
> Anna: I think so. I don’t think I could….I would be wasting their time. Wasting her time (T3L166/170).

> Anna: But, I am still stupid…because, the mind is willing, but the body isn’t…and I keep telling people, listen to your body, listen…And, am I doing it? (Laughs)...Well, I’m not you see… (T3L341/343)

Rather than praising herself for her determination to continue to keep trying to carry out activities despite her MS she defines herself as ‘stupid,’ suggesting she deserves the effects of MS fatigue, as she has not listened to her body. The way that Anna views herself within her battle with MS is complex and dynamic, often changing due to the physical manifestation of her MS impacting her sense of self. Aspects of living with MS that seem to have a positive impact on her sense of self- such as not seeing herself as sick and gaining pride through managing her condition well, are experienced alongside the more negative impacts such as Anna seeing herself as deserving aspects of her conditions and of not being worthy of help.

Participants talked of feeling inadequate, different, isolated, self-conscious, stupid and lacking confidence as examples of how having MS affects their view of themselves and at times also the choices they make. Physical symptoms of MS affect sense of self for these participants. For example, a body part failing can feel to the person like they are failing. However, participants also discussed that managing their MS and managing life despite MS can result in feeling empowered and capable.

4.2.3 The effect of shared experience on sense of self

There is a marked contrast in how Julie feels about herself when comparing the previous dialogue about attending a leisure centre to exercise and attending an exercise group specifically for PwMS. In the group discussed below, all members have MS and so share this experience:

> Julie: everyone has MS, so we all understand each other, and what we are going through. Erm, it's sort of, like a little family in a way…We all understand each other…(T6L130-133)

She talks inclusively about 'we' that she is part of rather than 'they' she is outside of and explains the hope, positivity and reassurance she derives from this group as opposed to her negative, excluded experience and perception of the leisure centre:

> Julie: I look forwards to going. Sometimes, you know if you…you know if you are…not feeling down…because that's, sort of, a different branch altogether isn't it? But, if you have sort of a pain or something somewhere. You know, we all say 'how have you been?' [ ] You might go in thinking, 'I would much rather stay in bed today' you know? But when you are with people, it sort of, jollies you up (T6L104/110).

Julie mentions 'feeling down,' though she is reluctant to define it as this, dismissing it as 'a different branch altogether.' I interpret this as Julie feeling embarrassed to discuss this, and not accepting this as part of herself, particularly as she talks about this in terms of 'you' rather than 'I,' categorising it as separate to herself. But then she talks about 'we' again as she describes the interactive discussion and support within the group, inferring a sense of belonging within this community. Clare talks about being part of the MS Society and attending local branch meetings:

> Clare: And then I got involved with the local MS branch, and that was good, because then there was a, sort of…nucleus? Although there were lots of different symptoms, a lot of themes going on, I think it was good understanding?...
>
> Me: to be with other people who have MS?

> Clare: Yes, I felt that very, very strongly. And other members of the group are saying the same things now. So that was good, and that seemed quite strong. (T5L18-20)

Clare infers identifying as being part of a strong, close community when describing this 'nucleus.' This description also indicates a central core - a source of knowledge, safety, shared experience and invokes images of a 'strong' place where, once inside, you are safe within a close cluster of people who share an understanding. In this way, as part of this group, Clare sees herself as stronger; 'and that seemed quite strong'.

While Anna and Julie describe being part of this community as being 'the best thing that could have happened,' 'the best thing that I have done,' they also convey their initial reluctance to participate:

> Anna: They tried to get me three years ago…and I would not…I would not have anything to do with MS…it's not for me…you see, even though I knew that I had MS, I did not want to belong to a group of MS…And I went last year, they had a bake sale here, just round the corner. I thought, I will go and support. And I am so pleased, it was the best thing that could have happened to me…Yes! (T3L364/371)

Anna talks about them as 'they,' separate to her, 'it's not for me [ ] I did not want to belong to a group of PwMS,' suggesting she did not want to be defined as someone with MS at that time. In fact, she wanted to place herself at a distance to MS, 'I would not have anything to do with MS.' This is further illustrated as Anna talks about the MS group in the context of 'they tried to get me,' suggesting that she was running away from the 'trap' of this group, the trap of the reality of having MS. Similarly, Julie at an earlier stage of her condition, did not want to be seen as 'not perfect,' or as being 'labelled' (as having MS) by attending an MS group. She wants to be seen as herself 'Because this is me,' rather than as someone who has MS. She reflects on another reason she might have been reluctant to join an MS group, acknowledging she was struggling to accept she had MS; 'perhaps psychologically shying away from what is wrong with me:'

> Julie: [talking about going to an MS support group] I have to admit, that first, I wouldn't sort of go to anything like that…I've not joined the MS group that long (ago). Because, this is me…I thought it would have a negative effect on me. Because I wouldn't want to be seen to be…not perfect sounds terribly arrogant, but I don't mean it that way. That there's something wrong with me, I would like…you know? But, I thought, they have done so much for me, like they have helped me with the shower*. So I thought, 'just get a grip (Julie), just give back.'

> They have helped you, just give back. So, I have joined. And, do you know, it's the best thing I have done. So, I was wrong…you know?
>
> Me: Well, sometimes you have to come to things in your own time…
>
> Julie: I think it was just me. Perhaps psychologically shying away from what is wrong with me? Perhaps I don't want to be labelled…(T6L133/142)
>
> **Julie refers to receiving a grant from the MS Society that helped fund an accessible shower for her to use*

Initially Julie and Anna both wanted to distance themselves from meeting with a group of PwMS as they feared being labelled or defined as someone with MS. However, both found that belonging to this group provided them with a sense of belonging and being understood once they were at a stage of further acceptance. Again it is sad to hear Julie describe herself as 'not perfect' and 'wrong,' and hearing her experience shame about having MS as previously discussed. Her final statement in the extract above highlights that this remains a present issue for her, providing further insight into how Julie feels about herself being labelled as a person with MS.

Being part of a group of PwMS helped participants feel stronger, better understood and part of a community. However, particularly in the early stages of MS, joining an MS group is associated with fear of being labelled and defined as a person with MS, potentially associated with a loss of their own identity.

4.2.4 Summary of theme one

Participant's provided insight regarding how their sense of self is affected not only by having MS but also by numerous aspects of physiotherapy such as provision of walking aids. Shared experience of having MS can also affect how participants perceived themselves and their MS in both positive and negative ways, depending on both the stage of their condition and acceptance of MS.

4.3 Theme Two: The embodied experience of physiotherapy: 'you need to know [ ] what functioning means to me'

The experience of physiotherapy is multi-faceted for these participants, to include service delivery, understanding and views of physiotherapy and the effect of physiotherapy on daily life.

4.3.1 Service delivery

An essential part of IPA is the interpretation of themes, generated through repeated layered analysis as previously described. There were significant sections within each interview that focused on the practical aspects of service delivery, which at first seemed to warrant less in-depth analysis and interpretation. Perhaps due to their more practical nature than the other themes. However, some service delivery issues recur frequently within individual interviews and most are present across all participants, highlighting their importance to this group of people. Important aspects of physiotherapy service delivery effecting the experience and utilisation of physiotherapy for these participants are summarised in Figure 5 below and then described in further detail within the following section. When discussing these issues, it was a challenge not to step into my role as a physiotherapist and health board employee who wanted to problem-solve, explain and even defend why some of these issues might occur. This was exacerbated in some interviews (most notably in the interview with Peter and Mary), when I felt directly challenged, or when I perceived an expectation for answers. To prioritise my application to this research and prevent myself stepping from the researcher to practitioner role, I focused on listening to participants' concerns about these issues and how they affected them, rather than on resolving these problems which felt a distinctly different role. I also made notes following each interview of issues that I might be able to help resolve more immediately within my clinical role. The knowledge that I could do this also helped me focus on the words and experiences of the individual and their meaning during both the interview and during data analysis.

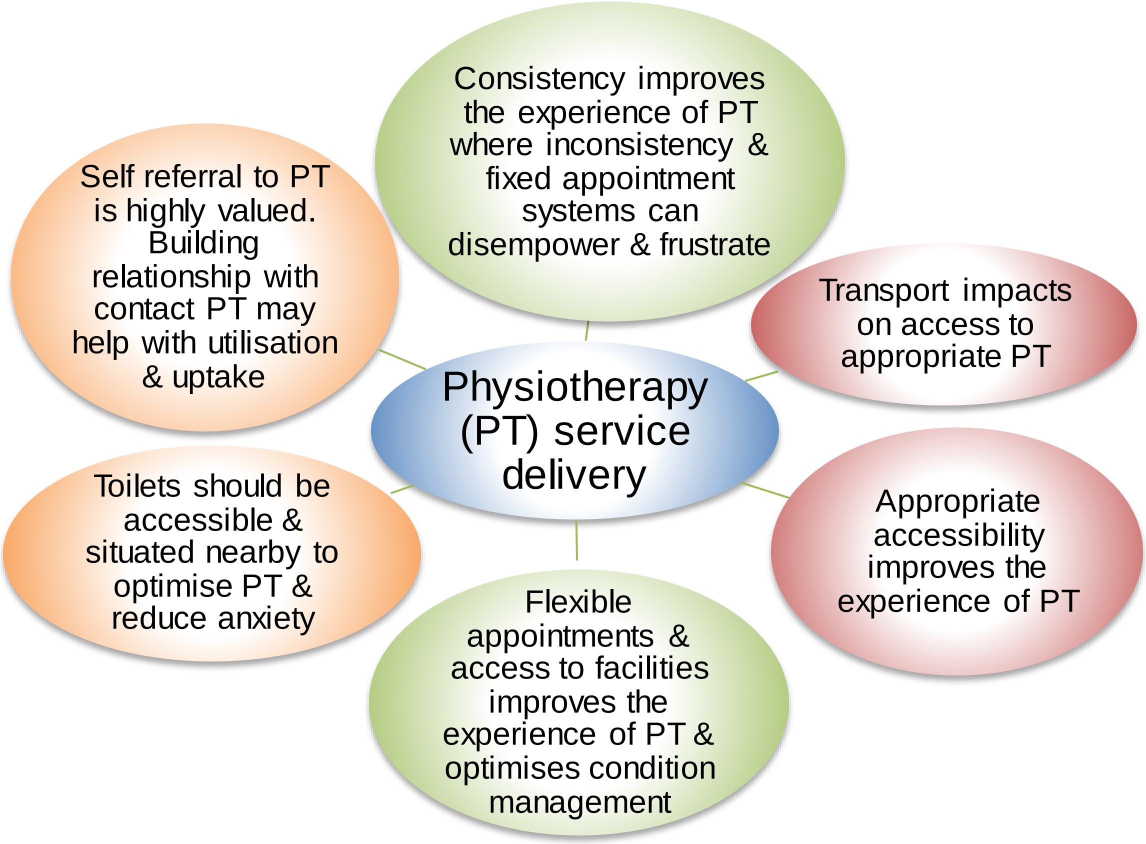


FIGURE 5 SUMMARY OF IMPORTANT ASPECTS OF PHYSIOTHERAPY SERVICE DELIVERY EFFECTING THE EXPERIENCE OF PHYSIOTHERAPY

Transport:

Three participants reported the challenge of getting to their physiotherapy sessions, highlighting the negative effects of increased fatigue, loss of dignity and ultimately a limitation to participation and attendance where facilities were not suitable. Conversely, two participants emphasised the positive impact on their energy levels and ability to carry out the impending physiotherapy session, where facilities did meet their needs. Mary reported their negative experience of hospital transport services:

> Mary: Oh, and another thing…another negative thing really, erm, it became so bad (Peter's reduced mobility due to MS), that I wasn't able to help him into the car to go for physio. So, we started depending on transport. And that was very, very, erm…
>
> Peter: Yeh…Yes.
>
> Mary…erm fragmented…so, erm, unreliable. And I can remember counting one 6 week period…that he only had physio on 3 of the 6 episodes of physio that he was supposed to have it. So… (looked to me, hands out and palms upwards, questioningly)

> Me: Due to the transport?
>
> Mary: (emphatically) Due to the transport (T1L71/78)

Following this discussion, there was a long pause, where I felt that Mary and Peter were looking to me to solve these transport problems. Although I found it difficult not to provide answers or offer apologies for their experience, I listened to their account and facilitated continuation of the interview. Peter and Mary are discussing their experience of hospital transport in the extract above, however, I interpret they associate this episode with a significant time of loss and regret- Peter is no longer able to get in and out of the car with Mary, which would have significant effect on activities they carried out together. In addition, Peter has missed out on physiotherapy sessions they view as vital to prevent further deterioration in Peter's function, as explored later in this chapter. The loss of independent transport and the shift towards relying on hospital transport meant this aspect of daily life was not only taken out of their control, but also proved to be unsatisfactory for them, reinforcing further loss, anger and regret. Fran also reinforced the negative impact on fatigue, exacerbated through travelling by hospital transport:

> Fran: [ ] and you could possibly get hospital transport, but that is always really exhausting and difficult to use [ ] and not arrive so shattered that they couldn't use it (the physiotherapy session) (T4L493/496)

Accessibility, parking and facilities:

Fran talked about the importance of suitable access to physiotherapy facilities, explaining the benefits of reduced fatigue and reduced dependency on her husband experienced when walking distances between the car park, hospital entrance and physiotherapy department were manageable. Fran preferred to receive physiotherapy in her local community hospital rather than the larger district general hospital due to the better access:

> Fran: Yes, it is easy to get in, and there is a little reception area. It's not too far to walk. I mean [ ] in the bigger hospitals [ ] my husband would have needed to find a way of leaving me with something to hold onto or lean against, then he would park the car, and then help me through to the department. And, by that time, I would have been so exhausted, that I don't think I would have been able to do anything (T4L466/472).

Fran explains the potential impact of poor access is not being able to participate in physiotherapy due to exhaustion. Clare talks about attending physiotherapy classes within an environment that meets her needs (in terms of access and facilities), improving both her mood and approach to the class:

> Yes, it is really important (talking about physiotherapy and exercise). But, I do really feel that it's the environment that works as well. Even just travelling or building up to going there can be quite stressful, when it was in (name of centre with inadequate access) [ ] But here (refers to accessible facility), you think 'oh great…', and you go into it with a more positive frame of mine. You enjoy it. It does seem to work. It's not just the exercise. I think it's being in that comfortable environment (T5L138/142).

Earlier in the interview, Clare explained the anxiety caused by having to walk from the car park to the department, and then from the toilet to the physiotherapy department where facilities were not situated close by; 'it was even getting to me,' (T5L80). I can hear the anxiety this causes Clare in the extract below, as she rehearses the mental checklist she performs prior to going anywhere, 'building up to going there can be quite stressful' (T5L140), an emotional barrier compounding the physical barrier to accessing essential areas:

> Clare: And the main thing is the parking. It's the main bug bear. I mean, even when we (PwMS) go anywhere different, its check the parking, check the loos…and, you know…yes.
>
> It really impacts on whether people go or not!
>
> I thought I was pretty good (refers to her bladder control) but it was even getting to me as I thought- I have to park near the entrance, and then walk down, and then do the exercises, and then walk back. (T5L77/81)

Clare provides insight into her fear she might not be able to manage this distance or manage without a more accessible toilet. Fran echoes both the importance of proximity and accessibility of toilets and the fear and anxiety surrounding suitable access to a toilet:

> Fran: And, as I said, just the fact that they were welcoming, there was a loo right next to where you waited, that was easy to get in and out of. And I know that I really felt that I needed to go to the loo before I did the physio. And, if I was going to be doing any movement, then I was a lot happier if I had started with an empty bladder.
>
> Avoids an accident… (T4L472/479)

Reduced continence is a common symptom of MS, with 75 % of PwMS suffering from bladder problems at some time (Browne et al., 2015; MS Trust, 2016). Neither Clare nor Fran elaborate about the effect of this on their lives, but talking about reduced continence to healthcare professionals is recognised as being difficult, embarrassing and even shameful for PwMS (Browne et al., 2015). I would suggest the fact they both addressed this difficult topic within these interviews, particularly when they were not specifically asked about it, highlights the importance and relevance of this issue.

Frequency and Flexibility of appointment and sessions:

The other participants voiced Bella's view regarding the amount and availability of physiotherapy:

> Bella**:** All I have to say is that all of my experiences have been good. I have had all the physiotherapy that I need (T2L2/3)

Only Peter and Mary reported there was not enough physiotherapy available, however, this was reported strongly:

> Mary: So, it's with determination really. We've had to…we've had to fight for physiotherapy (T1L108)

This was a key focus throughout their interview and its importance is emphasised as this subject shapes the first and last touchstone of the interview and the language used is unequivocal:

> Me: I would like you to tell me about your experiences of physiotherapy…
>
> Peter: How far do you want to go back?
>
> Me: As much as you can tell me.
>
> Peter: Well (to Mary), you had better help tell my story…I mean, there was a time when we didn't have any physio at all… (T1L1/5)

Peter returns to this as the interview culminates:

> Me: Is there anything else that you would like to add?
>
> Peter: Well, there's not enough of it… (T1L176/179)

As does Mary:

> Mary:...physiotherapy could be thought of as a treatment for MS…and yet, it's not available…(T1L188)

Mary explains their experience of physiotherapy being inconsistent and Peter having to wait 'his turn,' inferring they could not access physiotherapy when it was needed:

> Mary: [ ]...it wasn't consistent…and what we found, was that very often, um, the 6 weeks, you know, you weren't called after 6 weeks, it would sometimes be 3 months, when his turn came up again, and, and that kind of experience (T1L34/36).

Although Clare did not refer to the amount of physiotherapy she had experienced or had access to, she also echoes this lack of continuity, suggesting that more continuity of physiotherapy or exercise classes would help her follow her programme, and therefore help her to manage her condition:

> Clare: So you sort of do something, and then it stops. And you think 'oh, it's good while it lasted' but, me personally, I don't do anything without the continuity of it. (T5L126/127).

Peter and Mary experienced difficulty and frustration with inflexibility of physiotherapy services and access to exercise facilities, explaining the reality of how this restricts Peter's ability to use available resources which are 'a good thing' for him:

> Mary: So, erm. The other thing- and I think this is important to say...is that the cycle thing in the gym?
>
> Me: Yes?
>
> Mary: Which is a good thing. But, it's very inflexible, in that, you know, we were given a half hour slot on a Friday morning. And that was not flexible at all! So, you know, if it was raining on a Friday, then we wouldn't go. And we couldn't change it to any other time. We couldn't, you know! I think, especially over the summer, if you could use it any time you felt like it, erm, we would- you could use it more-you know? (T1L163/170)

Mary is referring to a motorised exercise bike that Peter was keen to access in a local leisure centre. The disempowerment and loss of ability to control their own lives is heard in the above narrative- there is a resource that could potentially help Peter but they struggle to optimise this due to the inflexibility of access offered. Conversely, Fran recalls several times during the interview how important the flexibility of her physiotherapy appointment times were for enabling her to reduce her stress:

> Fran: But it was flexiblish, I think Megan saw me at a time that she would usually have done her admin…so I wasn't having to take too much time off work, because that was…difficult. (T4L277/279)
>
> Fran: Erm, and I had cut my hours, so she managed to see me on the whole where I didn't need to take time off work to get to it [ ] Which, you know, from my point of view, that was brilliant (T4L286/288).

She also reported the importance of flexible appointments for helping her manage her fatigue and pace her activities:

> [ ] but even that amount of flexibility made a big difference, as it meant I could concentrate on that being…on my day off, I could concentrate on going to physio, and then I recovered… (laughs)…' (T4L293/295)

Self-referral

Self-referral to physiotherapy aims to enable people to optimally self-manage their condition and is recommended to promote quality patient-led services (McGahon, 2013; WPLAG, 2013) for PwMS (NICE, 2018). Participants (with the exception of Peter and Mary) enthused about physiotherapy self-referral, often extoling the benefits this results in. Bella confirms she is aware of self-referral:

> Me: And, if you got stuck with things now...?
>
> Bella: Then I know where to go to and who to contact…
>
> Me: That's good… (T2L45/47)

Julie articulates that self-referral to physiotherapy works well for her, expressing the relief it brings, 'I know that if I need to call physio then I can' (T6/L7), before going on to explain that this system has resulted in reduced waiting times for physiotherapy for her.

> Julie: I mean, in the old days, you had to wait quite a bit, but I feel that it has moved on. I really do. I have never had to wait that long for physio. So, yeah, I am quite pleased about that. Well, I am very pleased with that (T6L9/10).
>
> Julie: Now, you know, if I have a problem…and I will never phone willy-nilly, I'm not that type of person. I contact people when I need to see them, and then I see them quickly- it's fantastic, it really is (T6L164/165).

Fran explains how self-referral to physiotherapy provides reassurance, direction and guidance regarding her need for physiotherapy review:

> Fran: But, if I was to say the one bit that has made a difference in all the treatment. The one bit that actually I want - So, I have now got to the point where Megan has said that I can just phone up if there is a problem (T4L313/321).

> Fran: I know how to access it, and I think that I would have a good idea…if I thought that I had had a relapse then I would definitely want to see her. But, actually, I feel like if I thought that I might have a problem, they would be happy to see me to tell me that there wasn't... (laughs)
>
> Me: Uh huh?

> Fran: …and that is quite useful to feel like you…weren't being too much of a nuisance. You could actually say, 'I can't seem to manage to do this at the moment'… 'and I am sure that I could do it last month'…Or 'I am trying to do something different, and I hadn't realised that I can't do these bits of things…' Erm, and, she would be able to see me and say 'yes, that's fine…no, that's not…you don't need to come back…or, we need to see you again… (T4L582/600)

Fran points out that accessibility to physiotherapy not only provides reassurance and practical advice, but also makes her feel her questions are valuable and that she is being listened to '(I wasn't being) too much of a nuisance.' However, this phrasing parallels Julie's 'I will never phone willy-nilly, I'm not that type of person,' indicating that both Julie and Fran have negative perceptions of themselves and others contacting physiotherapy too often. I interpret they feel apologetic for using the service at times, despite explaining that this aspect of their experience of physiotherapy is particularly positive and beneficial to them. This perception might result in some PwMS being reluctant to contact physiotherapy even if they need it; encouragement and reassurance that PwMS should feel empowered and confident to self-refer to physiotherapy might help with this. Clare reports knowing and feeling comfortable with her physiotherapist optimises self-referral:

> Clare: Having the link in to physio is, is good…
>
> Me: Being able to contact physio when you need it?
>
> Clare: Yes, and I think that's more because we got to know Catrina through the (MS) branch and class and so I would feel more comfortable, if that's the right word. To just say, 'Oh Catrina, I have this problem'… (T5L33/37)

This suggests that knowing and feeling comfortable with the therapist who is the point of contact for physiotherapy may also help promote better communication and improved use of physiotherapy services for PwMS, as recognised in clinical guidelines (NICE, 2014; NICE 2018).

4.3.2 What does physiotherapy mean to me?

It is interesting to analyse participants' perception and understanding of what physiotherapy is and means to them alongside their experiences. It could be assumed as a physiotherapist that people have a broadly similar understanding of what the profession entails. However, despite many commonalities, these participants present differing perceptions of physiotherapy. Emergent sub-themes are illustrated in Figure 6 below. Exercise, education and functional enablement were the common elements that all participants identified as defining physiotherapy, all of which are described as part of physiotherapy by the Welsh Physiotherapy Leaders Advisory Board (2013). Most participants saw physiotherapy as something they carried out on their own following physiotherapy assessment and advice. However, Peter and Mary held a polarised view that physiotherapy should be carried out by a physiotherapist, and this significantly affects their experience of physiotherapy as will be further discussed. Although participants were not asked to describe what makes a ‘good’ physiotherapist, they all referred to either an episode or a physiotherapist as good, thereby providing description and insight into what defines good physiotherapy for these participants (see data table in Appendix XVI for further detail).

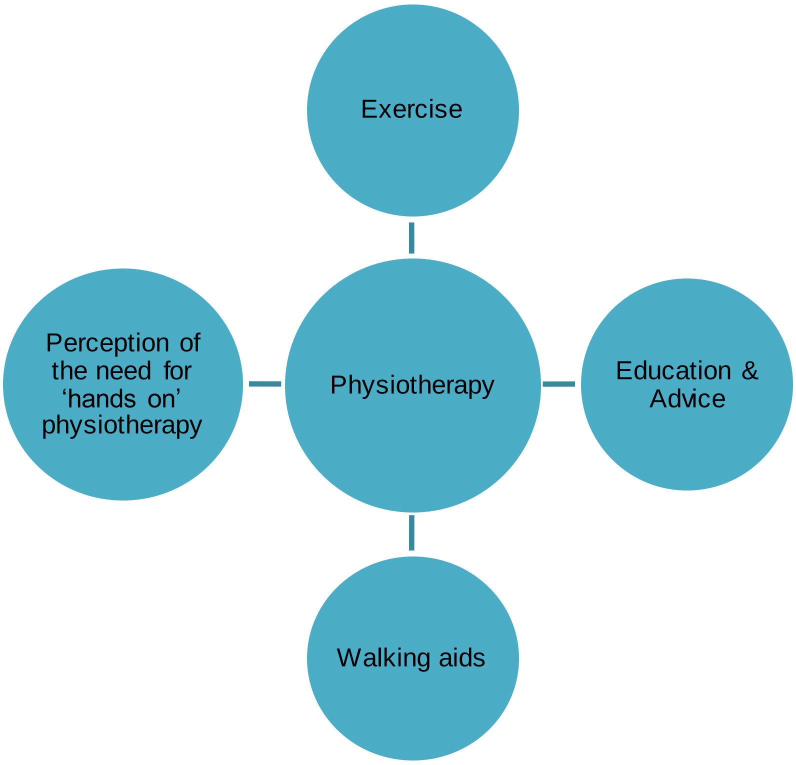


FIGURE 6 SUB-THEMES WITHIN PARTICIPANTS' UNDERSTANDING AND EXPERIENCE OF WHAT PHYSIOTHERAPY WAS TO THEM

Exercise and Physiotherapy

PwMS are prescribed exercises specific to their needs, with the aim of optimising function and comfort (through maintaining or increasing strength and range of movement in joints and soft tissue). Due to the long term nature of the condition, PwMS are advised to carry out these programmes on a regular basis as an ongoing aspect of managing their condition (Hale et al., 2012). Every participant described physiotherapy in terms of exercise. Anna and Clare's discussions about physiotherapy repeatedly report the provision of prescribed exercises for them to carry out independently, identifying this as something they consider a core element of physiotherapy:

> Anna: And she was good. She gave me all kinds of exercises that I could be doing. And I was doing it religiously (T3L40/41)
>
> Anna: I am exercising just as she said I should…you know? I am balancing and stretching, and doing all of those, every morning (T3L167/168)
>
> Clare: As far as the physio goes [ ], I think it has been really good. The exercises that I have been given are the right ones (T6L46/47)

Participants describe the effect and importance of exercise. Clare highlights the value and importance of exercise for PwMS:

> Clare: I think that exercise is really important for anyone with MS. To keep things going (T6L120)

Peter and Mary talk more specifically about exercise resulting in strengthening:

> Me: (talking about an exercise he has been given to practise) So, what effect do you think that that has on you?
>
> Peter: Well, it strengthens my legs and balance you see (T1L134/135).

Fran describes how physiotherapy felt for her following a relapse, 'waking up' her muscles and enabling her to use them:

> Fran: So, the first time I went, I more or less just got a muscle woken up … well, there isn't really a better way of describing it…When I went in, I couldn't get this particular muscle to move. And when I left, I could get that muscle to move (T4L101/104).

Julie explains her initial perception of physiotherapy as something that would be carried out on her and how this changed after working with her physiotherapist to develop 'the exercises that we have been doing:'

> Julie: Err, I used to think 'oh, *physiotherapy*' (rolls her eyes disparagingly), they just do that (prods her body)…I wasn't a great believer in it, I just thought, sort of 'what can it do?' you know? But, having experienced it…it does work. The exercises that we have been doing, yeah, they really do work- they really do work! I am very pleased… (T6L20/25)

Julie explains how she felt physically better after physiotherapy exercises, 'And, sort of, afterwards, I feel...I can feel a difference, you know? [ ] I feel looser and better (T6L57), but she also explains how the exercises help improve her function, discussed in the following section.

Physiotherapy education and advice increasing function and independence

Participants valued and understood physiotherapy as being educational, providing advice and guidance that helped improve their function and independence. Fran talks throughout her interview about the educational role of physiotherapy being of paramount importance to her, providing her with self-management strategies to improve her function; 'I mean, functionally, I would not be functioning this well without physio' and prevent disability; 'I had been more impressed by how [ ] the physio has been interested in preventing disability rather than 'making your nerves work.' (T4L63/65)

> Fran: …erm, so, for me personally, it, the physios made the difference between me being able to walk and get up and down the stairs in this house- drive, work [ ] (T4L223/224)
>
> Fran: They have taught me things to think about, for ways you could improve things [ ] it's given me strategies for doing things (T4L236/240)
>
> Fran: And, also, I might be able to use some of it if it happens again, because I have processed it, related to those sort of things (T4L272/273)
>
> Fran: Those sort of things are really useful, as I wouldn't need to ask that again. I have got that, I know how to do that (T4362/363).

Progression through what she has achieved through physiotherapy is evident in the construction of Fran's phrases. She starts by illustrating how physiotherapy has enabled her to carry out daily activities, then describes things she has learnt as being useful in the future, before arriving at the empowered stage of 'I have got that, I know how to do that.' Anna also discusses the benefit of being able to recall and use advice received from her physiotherapist to stop her foot dragging when she walks and how this defines her therapist as 'good' for her:

> Anna: …and another thing that she said…'heel, toe and up'. I say, 'right!' I say, when I can feel it dragging, I think of Laura and I say 'heel, toe and up!'…you know the things that Laura was saying. Gosh! She was good (T3L224/226).

Anna talked about how therapy affected her personally and functionally, drawing direct parallels between carrying out her physiotherapy and her personal achievements- from the day to day activity of walking down the pier for a cup of tea, to a lifetime experience of sailing on the tall ship. Anna exemplifies hope and happiness, as she sparkles through this story, expressing her doing all the things that 'normal' people can do, with such a strong sense of purpose:

> And were allowed to jump from the boat, to the sea. Awwww. So we were swimming, swimming in the sea! It was fantastic! [ ] Because I wasn't able to walk on my own…so, so, 2 fellows that were disabled [ ] went one each side (of me). We all went to the sea together. Oh, it was fantastic! Yes. It really was (T3L236/244).

Anna emphasises these things are of vital important to her as an individual, providing further insight into why she will not allow herself to 'be in a corner.'

Mary talks about physiotherapy enabling Peter to carry out tasks that he could no longer do on his own, linking the reason for describing the physiotherapist as 'fantastic' with her helping Peter to walk and stand, when he could no longer do this on his own.

> Mary: I can remember, because you weren't walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn't you?
>
> Peter: Yes. Yeah… (T1L87/92)
>
> Mary: she was fantastic really, helping him to stand here (indicating their home) (T1L102).

Julie explains that advice and education she has received through physiotherapy has increased her confidence, independence, function and safety, using the example of a practical situation to demonstrate the 'brilliant' benefit this has resulted in:

> Julie: And, you know, with the exercises that Brenda gave me, erm, sort of hints…, you know if I fall or something…and I had to get up [talks about a fall that she had, and how she managed to get up herself using a technique shown by the physiotherapist] But, before, I wouldn't have known how to get up. I would have thought 'oh no, what am I going to do…' you know? (T6L59/69)
>
> So, what I am saying is, I can get out of these situations now, because Brenda has told me what to do, you know? …so that is brilliant, brilliant. So, yeah, I am really really pleased with that 'cos I am not sort of lying there, helplessly thinking 'Ohhhhhhh' (T6L85).

This extract also provides insight into how physiotherapy can positively affect sense of self as Julie describes moving from feeling helpless to feeling enabled and in more control of that situation.

Clare highlights the value and importance of having a physiotherapist review her exercise programme to help improve her exercise technique, providing her with education and advice:

> Clare: I thought that I was doing the exercises right, 'yeah, I am doing these exercises,' and Catrina just moved me slightly like that, and I thought '…I wasn't doing those exercises right!' It's having someone there just to correct things [ ], I think that it's important. (T6L121/126)

Walking aids

Walking aids were understood as part of physiotherapy intervention resulting in improved function by most participants- this has been discussed in theme one.

Physiotherapy-Perception of the need for 'hands on' physiotherapy

During some part of their interview, all participants explained physiotherapy in terms of something they continue to carry out without a physiotherapist present, once they were shown what to do. Despite Bella requiring assistance from her carers to carry out her exercise programme, she states proudly that 'All they (the physiotherapist) had to do was explain it to me once, then I take it up from there' (T2L32), and later 'Well, as I am progressing with the use of the moto-med (an electrically assisted exercise bike), I don't find myself needing anything else.' (T2L49). Anna talks enthusiastically about doing her exercises 'every single day, every day. Half an hour every morning. The ones that Laura showed me' (T3L98).

However, Mary indicates her understanding of physiotherapy as something carried out with a physiotherapist rather than prescribed exercises carried out independently, though Peter indicates that he may not agree:

> Mary: you know you didn't have physio in London did you? (To Peter)
>
> Peter: Yes
>
> Mary: But you used to do your own exercises didn't you? (T1L10/12)

Mary talks about the need for consistent physiotherapy throughout the interview; 'our argument was, you know, that we needed consistent physiotherapy really, for him to be able to have effect' (T1L90/91). Mary struggles to find words, pausing frequently, finding the subject emotional and difficult to discuss, as she stated that Peter should not be expected to carry out exercises on his own:

> Mary: …and we were allocated a new physio…and the, the…, what shall I say…a sort of…different perspective really of what you (indicates Peter) should be doing. And, umm, a lot of it was expected that Peter should be doing stuff on his own… [ ] which was wrong really (T1L112/116).

Overall, the experiences of physiotherapy for Peter and Mary were not positive. However, they both identify one positive episode of physiotherapy with one physiotherapist, Nicki. Both Peter and Mary were emphatic in their praise of Nicki:

> Peter: Yes
>
> Mary: And that's when Nicki…
>
> Peter: Yes, yes (nods enthusiastically)
>
> Mary: (exhales in relief) …when Nicki started coming
>
> Peter: Yes. Nicki. And she was very good.
>
> Mary: Yes, she was very good (T1L81/86).

The feel of the interview changed as Peter spoke more quickly and enthusiastically. They both repeated phrases, emphasising this experience of physiotherapy as better than previous. Their description indicates that a positive aspect of this episode was Peter being seen weekly by Nicki, suggesting what they found 'good' about this physiotherapy was the regular direct contact with the physiotherapist. Mary confirms that I understood this, stopping to ask 'Okay?' before then proceeding with her story.

> Mary: Yes, she was very good. And she used to come once a week. Okay? (T1L87)

Mary explains her view that Peter required 'consistent physiotherapy really [ ],' for the physio to be effective. They describe the weekly physiotherapy delivered by Nicki in a more positive way than Peter having physiotherapy carried out for five hours a week with his carers (therefore providing significantly more consistent and regular therapy). It could be that the education and advice that Nicki provided in her physiotherapy role was valued more highly by Mary and Peter, rather than the regularity of the exercises. Perhaps professional physiotherapy contact in addition to the consistency of exercise is desirable, something that Clare suggests when she explains her need for regular physiotherapy review:

> Clare: I thought that I was doing the exercises right, 'yeah, I am doing these exercises,' and Catrina just moved me slightly like that, and I thought '…I wasn't doing those exercises right!' It's having someone there just to correct things [ ] I think that it's important (T6L121/126).

Returning to Peter and Mary's story, Nicki is introduced to Mary's chronological narration of Peter's experiences of physiotherapy at a time when Peter started to see Nicki at home because Mary had broken her foot and was struggling to help Peter with standing or walking:

> Mary: I broke my foot. And, of course, I stopped being able to help him. So, it was at that point, I think. That we started having Nicki (T1L79/81).

When reviewing this experience in context, another factor influencing this experience is that Mary indicates she was struggling to cope, 'I was not able to help him.' Nicki may have provided much needed support, help and hope to their situation. Mary goes on to identify two specific aspects of seeing Nicki that she saw as positive; that Peter was able to stand and walk with Nicki's assistance (he was not able to without this assistance), and that seeing Nicki weekly provided consistency, which provided hope ('cause I knew he could do it, you see, with the right, you know…'):

> Mary: And so what was said then, you see, 'cause I knew he could do it, you see, with the right, you know….you see, what was said then, was that the physio wanted consistency, so he needed to do that all the time for the physio to be effective. And, our argument was, you know, that we needed consistent physiotherapy really, for him to be able to have effect. Constant effect. You know it sort of went together really didn't it. Or that's what we felt.
>
> Peter: Yes…
>
> Mary: So, we went, you know with Nicki, erm, for a long time, really
>
> Peter: Yes
>
> Mary; and she was fantastic really, helping him to stand here (indicating their home). You eventually lost the ability to walk. (Peter nods yes) (T1L93/102)

Mary did seem positive about an agreement being reached whereby Peter's carers carried out his physiotherapy for five hours a week, though emphasising her disapproval about how long this took to occur:

> Mary: So, *eventually*, we got to the stage where…erm…continuing health care (Peter's funding panel) agreed that Peter could have 5 hours of physiotherapy a week.
>
> Me: uh huh?
>
> Mary: and that has been…the skill, physio skill has been transferred to the carers. So, every day now really…you have exercises every day (T1L119/122).

I interpret there are elements of physiotherapy- carrying out exercises- that she sees can be done by Peter or assisted by carers. However she also describes other elements of physiotherapy- enablement, provision of hope, continuity of care and support that she perceives should be or need to be provided by a physiotherapist and improves the experience of physiotherapy.

Participants shared their varied perceptions of what they understood physiotherapy should be. This often affected their experience of physiotherapy, their experiences perhaps being more positive when they aligned with their expectations and less so when this was not the case. Some patients explained their perceptions had changed through their experience of physiotherapy.

4.3.3 Utilising physiotherapy to help self-manage MS

Peek et al. (2016) define self-management (of a condition) as the management of the day to day impact of a condition, which is often a lifelong task. A theme arising from these interviews is that part of everyday life for these participants involves having to employ various strategies to help manage their condition, with various physical, emotional and practical factors all affecting this. Due to the nature of the interview topic, the discussion around self-management was largely focused on physical management of their condition, for example, managing MS symptoms by carrying out stretches, exercises, or using walking aids.

Factors affecting self-management using exercise therapy

All participants discuss carrying out exercise as part of their daily lives, with discussions around time pressures and organisation, fatigue management and pacing of activity all affecting their ability to follow exercise programmes. Implications for participants regarding the extent to which they carried out their programmes were also discussed. Some of these issues will be discussed in theme three.

Clare and Julie talk in detail about their struggle to follow prescribed exercises, explaining that attending an exercise group is one of the best motivational factors for them:

> Julie: Within a group for me, I find it works better. You see, the thing is, for me, I don't think too much about it, because you are chatting while you are doing it. It's not half as much effort, you know? (T6L45/47)
>
> Julie: You might go in thinking, 'I would much rather stay in bed today' you know? But when you are with people, it sort of, jollies you up. It makes the exercising a bit easier? (T6L113)

Clare talks about the class providing her with protected time to carry out exercise that she does not otherwise manage to fit in, emphasising the vital role this group plays for her:

> Clare: It's great that I have been given the exercises, and I mean to do them more, but basically it just doesn't happen…So, this exercise class that runs weekly is, is essential. And, I've asked some of the others as well, and, they say, 'we mean to' [ ], but it just doesn't happen on your own (T5L47/50).

Clare also draws on the experience of others in the above extract. I have interpreted this in two different ways. Perhaps, in part, Clare is advising me (as a physiotherapist within the health board) that this service is vital for PwMS and should be protected. I interpret that Clare is also describing a sense of shared solidarity and community, identifying and affirming it is not just her who experiences difficulty in carrying out exercises on her own- many people in this group share the same experience. Julie expresses the same difficulty, as she talks about the class enabling her to do more exercises, and identifying the risk she might 'give up' her exercise without it.

> Julie: We have got an MS physio group…and I much prefer doing it (exercise) with people. I have to say, if, you know, I do the exercises Amanda gave me. But, say if it says do them 10 times, after about 7 I think 'oh, that's enough…' I do, you know?
>
> And, I went yesterday morning. And we do something, sort of, 15-20 times. And I have consciously thought about this, 'oh, I've had enough now,' but we only have 2 or 3 more to do, and I thought 'just do it, just do it….' And I do do it!
>
> So, I feel, for me. I will continue to do the allocated amount, I'll push myself that bit [ ] But, do you know what I mean?
>
> Me: Yep

> Julie: It’s easy to give up isn’t it, basically...? (T6L30/39)

Returning to theme one, the above narratives also demonstrate that sense of self is affected by the ability to carry out an exercise programme for these participants. Julie displays a sense of pride and achievement in being able to push herself within this exercise group, exclaiming ‘And I do do it!’ However, she also shares the other side of this, ‘It’s easy to give up isn’t it,’ indicating that carrying out exercise is a continual challenge that does not always result in success. Clare also provides insight into how she feels when she is not able to complete the exercises she wants to, using language that suggests she feels weak and bad about herself (‘not very good,’ ‘not strong’).

> Clare: I am not very good at that. Not strong at that [ ] I think ‘oh I could do that while I am standing, I can do that.’ So, it does work, but I’m not very good at it… (T5L130/132)

Anna talks about carrying out physiotherapy and exercise as a means of limiting deterioration and optimising her function and quality of life:

> Anna: I have already done my exercises today, and my balance was super today [describes exercises] Well, the thing is that if I didn’t do it, I would be in a corner. And I don’t want to be in a corner.
>
> Me: ...it sounds like exercise and activity really gives you…a…
>
> Anna: (interrupts) yes, an oomph! (T3L350/354)

Anna describes activities that are important to her happiness and fulfilment, providing her with powerful motivation to carry on with her physiotherapy:

> Anna: It’s important to keep going, otherwise, I would be in a corner…I, I went on a tall ship, the Tall ship Lord Nelson…
>
> Me: Wow…
>
> Anna: …from Southampton to Rio de Janeiro, holding the para-olympic torch
>
> Me: That must have been such an experience….
>
> Anna: Absolutely fantastic!

Present in these words is fear of what the future might hold for Anna if she does not ‘keep going.’ This will be returned to in theme three.

There are several examples of participant descriptions of carrying out their exercise programme as a tool to optimising function and independence as previously discussed. Julie explains this; 'but with the tools that Brenda has given me, then I can sort myself out!' (T6L85). She uses gaming technology, using the same descriptor of 'tools', suggesting she manages her MS through a combination of factors or tools in her toolbox:

> Julie: Oh, and I have obtained a Wii. And that helps me as well. Yes, that helps me as well. Because I can, sort of, have a little game of tennis or something…at least I am standing there moving. Or, if I'm not so good, I can have a game of bowls, and I can sit down and do that, something like that. So, you know, at least I am moving. So, I find the Wii is really good.
>
> Yes, so it's all these different tools that you have...erm… (T6L182)

The above extracts describe the importance of self-management (particularly through exercise) in terms of maintaining independence, function and maintaining quality of life.

Clare reports a different side to this, 'the exercises that I have been given are the right ones,' but goes on to explain, 'that, I would like to say work…but it (MS) just seems to be moving forwards a little bit quicker than I would like…(T6L47/48), describing her condition as deteriorating despite the exercises. I interpret this contributes towards Clare finding prioritisation of exercise above her numerous other commitments so difficult- she does not experience tangible benefits, therefore carrying out exercise represents something that she should do, rather than being something essential that benefits her:

> Clare: But, by the time I have done all of that…you know, the exercises are the last thing on my mind…So, yes, that is down to me to get a bit more organised I think[ ] So (laughs), there is a lot that I intend to do-when do New Years' resolutions start? (laughs) T5L58/63.

As previously discussed, fatigue is a common symptom of MS. Fran explains how this feels for her:

> Fran: But this was completely different sort of fatigue to other fatigue I have had [ ] because sometimes you can make yourself do something with fatigue, and then collapse. But, things just didn't…you know...I am telling this leg to lift...I am telling

> this leg to lift again… (laughs). And I am telling to lift again. And it isn't lifting… (T4L243/248)

Fran repeats the phrase 'I am telling this leg to lift,' reinforcing this is something she has no control over- she wants to do it but she is unable to due to fatigue. Bella plainly states her limitation to exercise due to fatigue:

> Bella: I only do mostly on the Mondays on the moto-med…I get very physically tired…
>
> Me: …So it's quite hard to do any exercise now?
>
> Bella: Yes (T2L42/44).

Anna talks enthusiastically about the programme she wants to carry out but also describes physical limitation due to fatigue:

> Anna: So I thought, Right. Monday I will go to aqua aerobics, Tuesday I will go to, umm, yoga, Wednesday, I will go to Pilates, and…I was exhausted until the end of the week! And so I thought, aww…Ok, so the mind is willing, but the body isn't. I just couldn't do it! (T3L103/106)

She goes on to describe the effect on her body and function when she does carry out too much activity, explaining that fatigue reduces her ability to balance- thereby reducing her ability to walk. Anna articulates the daily challenge she faces, 'her mind is willing, but the body is not,' trying to achieve equilibrium between maintaining activity to optimise function and overdoing it and subsequently suffering the effects of fatigue and exhaustion which ultimately reduce her function. Through her example, she demonstrates that learning when to rest is a crucial part of her self-management- yet this is something she struggles to accept and carry out, even though she identifies she feels better having rested:

> Anna: And I am usually exhausted after it. Absolutely exhausted. You know, walking like a drunkard*, but then…It's important to keep going, otherwise, I would be in a corner… (T3L112/115)

> Anna: I keep telling people, listen to your body, listen…and, am I doing it? Laughs…well, I'm not you see. But, I did yesterday. I was supposed to go to aqua aerobics and I thought 'I am very tired' and so I stayed at home. I did rest…
>
> Me: And what about today?
>
> Anna: Better. Much better. I tried to do my exercises the other day. Yesterday I just couldn't lift my leg*. I couldn't. My balance was….oh….I was rubbish. Everything was rubbish yesterday. And so I thought, right. I am not going anywhere. And I feel much better today (T3L343/352).
>
> **MS affects Anna's balance and co-ordination. When she is fatigued, the symptoms of her MS are exacerbated, resulting in her 'walking like a drunkard'*

> *because her balance and co-ordination are worsened. She also describes physical effects of fatigue with increased muscle weakness 'I just couldn't lift my leg.'*

Julie seems to have found some acceptance of keeping this balance, 'you know, I don't do every one (referring to every exercise) every day, otherwise I would be in a heap you know?' (T6L29)

It could be considered that increased level of disability might negatively affect ability to self-manage a condition such as MS using physiotherapy. It might be assumed that Bella having the most severe physical disability of these participants, may experience more barriers to following an exercise programme. However, Bella reports having no difficulty in carrying out her exercise programme as part of her weekly routine, 'All they had to do was explain it to me once, then I take it up from there' (T2L32). Bella has a carer with her at all times as she requires assistance with all activities of daily living. Perhaps this helps increase her motivation as well as providing practical support, but perhaps this is something Bella has never struggled with. Clare was the least disabled participant interviewed, yet expressed how difficult she found fitting exercise in:

> Me: Life gets in the way doesn't it!
>
> Clare: oh, it does, it does. To start with, it was great, because I wasn't taking on so much, so I had more time. And now, I just don't feel that I have the time….which is a good excuse that everyone gives I know…but it's busy, and I have got more involved with the branch as well. So, yes, that is just down to me to organise. Erm… (T5L130/132)

Clare is more physically able then the other participants and describes a busier lifestyle during her interview. Perhaps this makes fitting in and prioritising exercise more challenging. However, it could be that Clare struggles to identify any meaningful benefit of exercise, as previously suggested.

4.3.4 Person-centred care and communication

Each individual shared different experiences of communication within physiotherapy, but consistent for all participants is that the interaction between themselves, their physiotherapist and the physiotherapy department are integral factors affecting this experience. Fran worked in healthcare, therefore perhaps she was more aware of the importance of person-centred care. However, she spoke about this in an informal way (without the phraseology often found in health care language), suggesting this simply had personal resonance and meaning for her:

> Fran: And, I think the physio department as a whole gave me a lot [ ] I think the fact they were also able to give you a bit of hope…and treat you like you were…a person… (T4L181/188)

She talks below about her physiotherapist sharing information about herself and the value that Fran placed on this, somebody was actually treating [her] like a person;'

> Fran: It feels like they are actually bothered about whoever they are seeing… (T4L194)
>
> Fran: And just things like you seeing a human being who was treating you like a human being. So, even when she was going on holiday, she said that she was going bird watching to see Condors. Actually, that's nice, 'cos that makes you feel like somebody actually, it made me feel that somebody was actually treating me like a person (T4L395/398).

I interpret this as Fran feeling she was important enough for her physiotherapist to share part of her own life and experiences which facilitated a therapeutic partnership rather than a potentially more formal professional-patient relationship. Fran also talks about the need for someone to get to know her as a person in order to understand what matters to her. She describes aspects of person-centred care and jointly developed goals;

> Fran: The personal bit helped me a lot, but, actually, if someone had been cold and efficient, but was cold and efficient about my function, then they have to be interested in me to be interested in how I function. 'Cos you need to know, like I said, you need to know what I need to be able to do…what functioning means to me…(T4L411/414)

An essential aspect of person-centred care given emphasis by participants was the value of being listened to. Fran exemplifies this:

> So, I finally got to see one of the doctors [ ], he referred me to the physio, [ ] the first time she just listened to me for about an hour, about what had been going on. And, in a sense, I know that isn't specifically physio…that was the first time that anyone had done that… [ ] And it was the first time that someone had listened to how the illness had affected me… (T4L42/62)

Fran explains she does not necessarily see the role of a physiotherapist being to listen but makes clear the profound difference her physiotherapist made by listening to her. Anna explains why Laura, her physiotherapist, was ‘very very good for [her]’, selecting this physiotherapy interaction out of many, because she identified that Laura listened to her concerns about an issue important to her at that time, and acted upon this (regardless of the outcome).

> Anna: I told her, I can feel that one leg is longer than the other. And she said ‘we’ll measure it, we’ll measure it then’- and they were both the same! (Laughs) (T3L52/54)

This experience is echoed in Fran’s words that ‘even just feeling like you weren’t going mad’ (T4L121) (stated after she described her physiotherapist explaining to her why she was finding driving so difficult) and ‘actually just someone being there, and giving you the feedback, and somebody being interested’ (T4L152/153) were vitally important to how Fran felt about herself and understanding her recovery.

In stark contrast to Anna and Fran’s experiences of communication within physiotherapy, Mary and Peter expressed anger about their experience of a particular episode of physiotherapy when Peter received hydrotherapy (exercises and movement carried out in a warm pool). Mary repeats that Peter was told what was best for him, told what was going to happen to him, emphasising that he had neither been asked nor listened to. Peter succinctly and starkly summarises the impact of not being part of the decision-making process;

> Mary: (angrily)……we were told, and I remember this actually now, you were told that….that….you were actually told, the gym based physio would be more beneficial for you, rather than going into the pool… (Both looked to me with challenging question)
>
> Me: And did you find that to be the case?
>
> Peter: (angrily) No. Absolutely not.
>
> Me: Okay… (Mary and Peter both continued to look at me)…so, in terms of how that made you feel?
>
> Peter: Well, it just made life more difficult really (T1L44/51).

As well as the value of listening being brought to the forefront, the need for communication between services was discussed by Clare, as she talks about her experience of transitioning between leisure and health services:

> Clare: I think it’s the continuity of the services and between services like the gym…it’s good, but you are, sort of doing it on your own…but because they have

> to get you to do it on your own…they are all linked, but I just don't know how well they are followed through, if that makes sense?
>
> Me: The transition between services are not easy?
>
> Clare: [ ] I think that everything is there, but the general communication between everything that is set up…just to see the full picture, or the full circle, and see the benefits that that could have [ ] but again, you go back to communication, and so it's not down to one person, or one group of people. (T5L105-119)

From this extract, I would also interpret Clare does not feel fully informed about how these services work for her, and how they might help her, indicating that communication, alongside information provision and partnership working, are vital for increasing person-centred, effective and meaningful transition between services.

Fran talks about the hope and support physiotherapy has given her, helping her regain function and face her future more positively. Throughout this theme, physiotherapy has been discussed in terms of the hope it did or did not offer to participants. This will be further explored within theme three and chapter five.

4.3.5 Summary of theme two

The experience of physiotherapy (and how this affected participation in physiotherapy) was affected by the context of physiotherapy in relation to the participant and their situation, practical elements of service provision, communication, understanding and expectation of physiotherapy.

4.4 Theme Three: The embodied experience of living with MS: 'like your world has changed'

Some participants spoke directly about how MS affected their lives, with others only alluding to it. They spoke of how MS affected their sense of self, their daily working and family lives, and their hopes, loss, regrets and fears. This thread is woven throughout all interviews and throughout the previous themes. Within this section, I have drawn together conversations where participants provide a transparent window into how MS affects them. Although the aim of this research is to explore the experiences of physiotherapy for PwMS rather than experience of living with MS, gaining further insight into the experience of living with MS will inform physiotherapy, therefore it is reported here. The effect of MS on how a person feels about themselves, and how they are situated within their own life circumstances, is directly relevant to the clinical reasoning and person-centred care essential to physiotherapy.

4.4.1 The physical effects of living with MS

Fran and Julie's words provide insight into how their bodies are affected by MS related stiffness. When this physical symptom is eased, they feel 'better', 'looser', more 'normal.'

> Fran: And, so, even just getting stretches, to be able to get everything stretched, so you could actually be in a normal position (T4L113/114)
>
> Julie: And, sort of, afterwards, I feel...I can feel a difference, you know? I can feel a difference. I feel looser and better (T6L57).

Other physical effects of MS were pointed out by all participants- I have previously examined numerous issues participants face regarding bladder control, fatigue, reduced movement, balance and limited function. Other symptoms mentioned or described, include the effects of medication and temperature:

> Fran: The steroids were magic, but they also turned you balloon faced…and made other bits not… (T4L214/215)
>
> Fran: Going into hot, or the heat, made things very difficult to function (T4L217).

Fran changed the subject and did not elaborate further on the effects of the steroids but reported that she would not take them unless she had no other option. The physical effects of having MS are apparent in every narrative of the challenges that MS presents for day to day living; these are explored within other themes.

4.4.2 Emotional effects of living with MS

Loss, Grief and Regret

All participants discuss loss and grief experienced with MS. Bella largely presents herself as positive about her situation, focusing on practical aspects of her physiotherapy experiences. However, as I went to leave, she provides a glimpse into the loss she experiences:

> Me: Nice to meet you, and see the lovely place where you live.
>
> Bella: And don't I wish I could go out and see it…thank you for coming (T2L87/88)

Similarly to Bella, Anna frames her life in a predominantly positive way, talking about the changes she has made (such as getting a trike when she was not longer able to balance on a bike, or using her frame to enable her to walk down the pier) to allow her to continue activities she enjoys. But she does express loss:

> Anna: I used to mountain climb…used to love walking in the mountains …yes… (T3L255)

Peter's whole story is narrated by Mary in terms of loss, in particular the loss of Peter's function, as his MS advances:

> Mary: And up until about 6 years ago, Peter was walking (T1L7/8)
>
> Mary: …but, what happened then… what happened then, was that. Up until this time I am talking about now, you were able to walk (T1L60/61).
>
> Mary: And Peter, although he has lost his ability to stand, err, to...to walk. He can still stand (T1L108/109)

Anna expresses regret and frustration, blaming herself here:

> Anna: [ ] I insisted on using my stick. And, because I used it so much… (showed me a lump on her wrist)…blinking nuisance, it's a nuisance, it's really a nuisance. It's my own fault (T3L34/36).

As introduced in theme one, Anna partly blames herself for this rather than considering it to be due to MS.

Mary talks here about regret that perhaps more could have been done to prevent the finality of Peter losing his ability to walk:

> Mary: You eventually lost the ability to walk. (Peter nods yes) (T1L102)
>
> Mary: I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know?

> (question directed to me)… (long pause)…That’s how I feel. Erm, But, you know, he can’t walk (T1L136/139)

The extract above illustrates how difficult this tension can be, and how many factors contribute to this issue. MS is a progressive condition, and the trajectory of the condition is different for each individual. It would be difficult to know if the course of his MS would have differed if he had continued to have weekly physiotherapy. However, living with this possibility and regret that more could have been done surely contributes to the grief that Peter and Mary feel, ‘perhaps if he had had this kind of physiotherapy when he needed it [ ] that perhaps he might still be walking. Do you know?’ Loss of hope is conveyed in Mary’s final words, ‘But, you know, he can’t walk.’

Hope and fear

As previously discussed, Fran explains the hope and support physiotherapy has provided in helping her regain function and face her future:

> Fran: [ ] the physios made the difference [ ] when you have been reasonably functioning before, and you just can’t, like your world has changed, and you just can’t do anything…might even be why I am still here. [ ] and there had been points where you just thought, ‘why am I bothering trying,’[ ] I wouldn’t have dared tell anybody. But, but it has made that much difference- that level of difference (T4L223/234).

Fran also illustrates the bewilderment resulting from an abrupt loss of function caused by an MS relapse; the shock of her whole world changing. Repeating ‘You just can’t;’ a simple statement that speaks volumes of the devastation experienced when she cannot carry out everyday tasks. She reveals the extent of just how low, helpless and lacking in hope she felt at this time leaving her to think ‘why am I bothering trying,’ contemplating suicide. Fran was not able to share these feelings ‘I wouldn’t have dared tell anybody,’ which would have led to even further isolation and fear.

Fear of what the future holds, and how MS affects their lives pervades these stories, some participants expressing this directly, and some intimating it, alluding to times ahead when life might be more difficult. I interpret tension between hope and fear when considering the driving factors behind ‘keeping going.’ Anna reinforces the importance of managing her condition as best she can through repetition of the phrase ‘if I didn’t do it, I would be in a corner. And I don’t want to be in a corner’ three times during the interview, emphasising her fear over losing further function. Peter and Mary express their fears and anxiety, and how this has shaped their lives, scared of the consequences if they did not carry out Peter’s programme. They had ‘to keep going,’ to prevent the advancement of deterioration:

> Mary: But, your walking ability was reducing pretty fast. OK? But, we kept going, didn’t we? We kept going….like I would help Peter to the sink, to the toilet, and that would be the normal wouldn’t it? (T1L61/63)

Mary provides further insight into how difficult this was for her practically, repeating the regularity with which she had to continue with the programme, and lays bare the fear that they felt.

> Mary: [ ] I gave the physiotherapy while they were coming. Didn’t I (to Peter)?
>
> Peter: Yes, yes.
>
> Mary: Every single day really. Erm, every day, every morning…Because I was so scared that he would lose what we had, what we had erm, erm…
>
> Peter: built up
>
> Mary: yes, built up you see... [ ] (T1L199/204)

Peter and Mary’s exchange below is drenched in the devastating impact that any further deterioration in Peter’s physical condition would result in, amplifying the importance of keeping up his physiotherapy to maintain his independence and ability to stand:

> Mary: And you are still able to - for a certain length of time - able to take your legs away from the support of the turn-safe
>
> (Mary refers to an exercise and task that Peter carries out with his carers, standing with the aid of equipment (turn-safe), then trying to bring his knees away from the support that the turn-safe provides)
>
> Peter: Yes. Yes [ ]
>
> Mary: He can still stand. And, having the physiotherapy keeps him going at that level. You know, you know…haven’t become unable to…to…
>
> Peter: (calmingly towards Mary)…No, no…
>
> Mary: …to move…and we are able to avoid using the hoist and that… (Looks to me despairingly and shakes her head)
>
> Me: (to Peter) Which for you is significant?

> Peter: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it's horrible. Horrible (T1L139/145)

Their fear of the possibility of Peter losing the ability to stand is palpable through the conversation. Mary struggles to say the words, Peter tries to calm and reassure her, but ultimately states the end result of using a hoist is not only horrible but also demeaning, presenting him with tangible fear. Clare's words also echo this feared advancement, the uncertainty of what the future holds, 'but it (MS) just seems to be moving forwards a little bit quicker than I would like.' (T6L48)

4.4.3 Sharing MS

The effect on loved ones

Apart from Fran mentioning how her husband perceived her using a stick, none of the participants talked about the effects of MS on their loved ones. This is not surprising as the interview topic was about their experience of MS. I have however included this emergent theme, as the effect on Mary of Peter having MS was almost tangible. Mary was vehement in her expression that Peter required more physiotherapy throughout the interview. The next extract was recorded as the interview closed:

> Mary: And, physiotherapy, is good for it (referring to MS). And, you know, erm... (long pause)...You are denied…you know…there is… (struggles to find the words)...physiotherapy could be thought of as a treatment for MS…and yet, it's not available. That's what I am trying to say I suppose… (T1L184/188)

Mary talks about being denied, 'you are denied,' rather than 'Peter was denied.' I interpret that Mary felt they had been denied the life they might have had. There is contradiction in her statement, 'and yet it is not available;' despite Mary having explained to me the physiotherapy that Peter has had and continues to have. I interpret Mary is overwhelmingly sad and frustrated with Peters' continued deterioration, and is trying to make sense of and find reason as to why this has happened.

When looking at this interview from Peter's perspective, he is continually drawn back to a difficult time in their lives where he had a change of carers and Mary had to carry out all of his therapy needs. At the opening of the interview, he tries to express his anger about this time in his initial thoughts:

> Peter: Well, (to Mary) you had better help tell my story…I mean, there was a time when we didn't have any physio at all….!
>
> Mary: (interrupts Peter) No, no, no…shall I, sort of? (indicates with hand gestures that she will help facilitate conversation between Peter and me)
>
> We moved here about 11 years ago, Yes? (T1L4/7)

Mary moves Peters' focus off this event, establishing a different starting point to their story. However, Peter returns there:

> Peter: Well, then it goes onto the dreaded council carers (referring to this episode where the council carers were unable to deliver physiotherapy)
>
> Mary: No, sweetheart, it doesn't…
>
> Peter: It goes on to Nicki?
>
> Mary: No, no, no. Well, yes, eventually… [ ] (T1L57/60)

Towards the final culmination of the interview:

> Peter: Yes. That's fine. Apart from do I want to mention the council thing? (To Mary)
>
> Mary: Well, yes, that has nothing to do with it sweetheart...
>
> Peter:…well, I didn't have any physio! (emphatically)
>
> Mary: yes, well, you see, for a while Leigh…What we have now are our own carers, yes?
>
> Me: Yes
>
> Mary:…and, for a while, we had the council carers…and, erm, they refused point blank to transfer the skills…so, you see, I gave the physiotherapy while they were coming. Didn't I (to Peter)?
>
> Peter: Yes, yes.
>
> Mary: Every single day really. Erm, every day, every morning…Because I was so scared that he would lose what we had, what we had erm, erm…
>
> Peter: built up
>
> Mary: yes, built up you see...the way, the way... Perhaps I need to explain really. That the care company that we had [before], had pulled out. And they did carry out the physio.
>
> And so the council carers were a temporary measure until we were able to, erm, employ our own. And that took 9 months right? And so, for 9 months, you would have been without physio, if it hadn't been for me…
>
> Peter: Yes, yes…
>
> Mary: that's what you are trying to say isn't it?

> Peter: Yes. Yes. Yes. (Looks to me, clearly upset)
>
> Me: and what was the impact…?
>
> Peter: (interrupts, upset)…a lot….a lot…! (the words exploded out) I mean, she's working part time… [at this point Peter became upset and Mary indicated to stop the interview] (T1L190/213)

This event pulls strands of their interview together, Peter's sadness and anger about how MS had affected Mary and their lives together interwoven throughout. The impact of care-giving in MS is beyond the scope of this study but is further explored in a meta-synthesis of qualitative research which explores themes such as change and loss, care-giving demands and burden of care (Topcu et al., 2016). On reflection perhaps Peter not being able to talk about this pressing issue sooner in the interview limited Peter being able to discuss wider issues. When reviewing the overall interview, the times that Peter interjected and volunteered information mainly referred to this episode, with Mary otherwise structuring the interview topics and Peter contributing to those.

Sharing MS with friends and support groups

The experience of MS is better for Anna, Julie and Clare when sharing their journey with others who have MS. Clare and Julie are reassured by sharing experiences with other PwMS:

> Clare: It's like with the class- we do the exercises and then we go for a coffee, so it's the social. 'I didn't know that you felt like that as well' or 'I didn't know that that happened to you too' (T6L96/97)

Clare distinguishes the social support gained through the MS exercise group, providing a sense of "being normal" and talking about everyday things: 'But we don't really talk about much. Well, we talk about loads. But not about MS.' But the group also provides a reference point and source of knowledge about MS 'then something will come up, and then someone will say 'oh, that happened to me, and what I did was…' And it's just that sharing bit (that makes a difference)' (T5L96/100). Clare and Julie talk about being part of the MS Society and attending local branch meetings:

> Clare: [ ] I think it was good understanding?...
>
> Me: to be with other people who have MS?

> Clare: Yes, I felt that very, very strongly [ ] That, basically, you don't have to deal with this on your own. And you don't have to put this front on and say 'oh yes, everything is fine.' So, it's quite good…I think, having a sense of humour is essential! (laughs). (T5L20-28)

> Julie: I look forwards to going. [ ] So, it sort of, reassures you, you're not sitting at home thinking 'oh, that's it!' And I think, in general, they are quite a positive lot. And that has an effect on you, doesn't it?
>
> Me: Yes, it does
>
> Julie: Yes, it really does! You might go in thinking, 'I would much rather stay in bed today' you know? But when you are with people, it sort of, jollies you up. It makes the exercising a bit easier?
>
> Me: uh huh
>
> Julie: …And you're thinking, 'oh well, it's not that bad is it really' (T6L104/114)

> Julie: As I say, the group that I go to is brilliant, and it motivates people. And I really look forwards to going. You know? Plus, we have a laugh as well. And, you know what they say- that's the best medicine sometimes isn't it? (T6L178)

Though reluctantly, Julie does acknowledge feeling down, and explains this class helps her with this. She perhaps indicates feeling uncomfortable talking about herself in this way by using 'you' rather than I at times, but shares that sometimes she feels like staying in bed. Having the class to go to means she gets out and talks to others, and this contextualises her own situation: 'it's not that bad really.' Julie explains this class provides a lifeline to her- helping her to exercise, improve her mood, and motivate her to leave the house and socialise. Anna does not elaborate on how the group helps her but is resolute in her conviction when discussing becoming part of the MS group:

> Anna: And I am so pleased, it was the best thing that could have happened to me…Yes! (T3L371)

4.4.4 Summary of theme three

Living with MS is a complex phenomenon as PwMS live with wide ranging and variable physical and emotional effects of a condition that affects most aspects of their lives. As participants were not questioned about this due to the aims of this study, only windows of insight are provided within these interviews. However, some of these paint such a vivid picture, providing poignant glimpses into the complexity of the embodied experience of living with MS. Fear, loss, regret and frustration are often felt alongside pride, hope and a sense of togetherness and support through spending time with others with MS. Theme one is intrinsic to this theme as altered sense of self is part of the fabric of the experience of living with MS.

4.5 Summary of chapter four

This chapter presents three super-ordinate themes generated from the generously shared, rich words offered by these participants. Themes are illustrated and supported by their extracts before further analysis and interpretation. The relevance of these findings to physiotherapy practice will be discussed in the following chapter.

5.0 Chapter Five: Discussion

5.1 Chapter Overview

This chapter will summarise and discuss the findings of this research with reference to relevant research explored in chapter two, as well as evaluating the quality and the limitations of this study. This will contextualise the findings of this research and situate subsequent recommendations and implications for physiotherapy. In some ways, it seems conflicting to the phenomenological underpinnings of IPA to disaggregate or prioritise themes, as they all interconnect to create the experience of each individual and, as such, are all of utmost importance. However, this research sought to explore the experiences of physiotherapy for PwMS therefore the findings of this research most related to this aim will be the focus of this chapter.

5.2 Sense of self

MS impacts on sense of self, in particular resulting in a changed sense of self that has the potential to impact negatively on confidence, mood, psychological and physical functioning (Irvine et al., 2009; Mozo-Dutton, Simpson and Boot, 2012). Analysis and interpretation identified that experiences of physiotherapy and living with MS affected individuals' self-identity and self-perception; experiences of physiotherapy affected sense of self. This included elements of physiotherapy such as service provision, communication and exercise advice and prescription as examples. Figure 7 below summarises the relevance and relationship of this theme with theme two.

Participants described aspects of physiotherapy that resulted in individuals feeling more informed, motivated, hopeful, in control and more confident as examples. These factors brought people closer to feeling more positively about themselves and their experience of physiotherapy (examples of which are shown nearer optimal sense of self in figure 7). However, where these factors were absent, participants felt distanced from hope, independence, feeling informed, motivated or confident (examples of which are shown further from optimal sense of self in figure 7). This over-arching theme will be further discussed within 5.3.

Service Delivery

- Transport does not meet individuals needs
- Facilities are unsuitable and inaccessible
- Access to physiotherapy is restricted

- Transport needs met and discussed with sensitivity and awareness
- Facilities are suitable
- Physiotherapy offers self-referral, regular reviews, flexible appointments, ideally with a known point of contact

Exercise, Mobility Aids and Self Management

- Lack of education & advice provided
- Mobility aids advised without context & awareness
- Generalised exercise program issued that do not relate to function or consider the individuals needs
- Self management advice does not consider fatigue, motivation or other individualised needs

- Individualised education and advice provided
- Mobility aids discussed with context, insight & sensitivity at appropriate time
- Exercise or activity program relates to function & individuals personal needs & contributes to quality of life
- Group exercise should be considered and supported
- Self management advice considers fatigue, motivation and each individuals needs

Person Centered Care

- Lack of effective personalised communication to include being listened to, joint & informed decision making
- Lack of awareness of the lived experience of MS & the potential impact of hope, regret & fear for that individual

- Feeling listened to, empowered through knowledge & informed choices
- Interaction with physiotherapy based on holistic individualised need

FIGURE 7: DIAGRAM OF RELATIONSHIP BETWEEN SENSE OF SELF AND EXPERIENCE OF PHYSIOTHERAPY

5.3 The embodied experience of Physiotherapy

Service Delivery

Where facilities did not meet participants' needs, they felt anxious, stressed, more fatigued, dependant and faced increased barriers to physiotherapy. However, where facilities were suitable, participants described feeling positive about attending sessions, comfortable and more independent within the environment. Where participants had access to regular reviews, and were able to self-refer to physiotherapy, they felt in more control and better able to manage their condition.

Transport issues had significant implications for some participants. Hospital transport (also known as patient transport services) can be required to bring patients to physiotherapy sessions. This is routinely arranged or suggested for patients who are unable to utilise alternative transport. This research identified that hospital transport can be unreliable, resulting not only in the loss of therapy sessions, but also in personal frustration and disempowerment for individuals. In Peter's case, it affected his sense of self, making him feel 'pointless' and exacerbating Peter and Mary's sense of loss due to losing the ability to manage their transport independently. Insight into these potential effects provides the opportunity for physiotherapists to consider raising the subject of using hospital transport in a sensitive way, with enhanced awareness of possibly evoking feelings of loss and being of personal significance to PwMS and their families. As PwMS are living with a condition that is varied, unpredictable and can result in feelings of disempowerment and loss of independence (Davies et al., 2015), it may help PwMS feel more informed and in control if hospital transport was suggested, discussed and explained with insight and consideration prior to using these services. Hospital transport is suggested to help a PwMS or their carers through providing a solution for transport or reducing the burden of providing transportation. However, an awareness this issue may demarcate another loss of role or function and increase emotional burden would enable healthcare staff to improve communication and discussion specific to the PwMS.

Hospital transport was also reported to increase fatigue due to unpredictable timing and long waiting and journey times. Physiotherapists should be aware of the potential physical effects of hospital transport on PwMS, particularly the effect on fatigue as a debilitating symptom of MS (Newton, Griffiths and Soundy, 2016), when considering whether physiotherapy dependant on hospital transport is the best option for an individual. Newton et al. (2016) carried out a thematic synthesis of the experience of fatigue for PwMS and suggested that physiotherapists should consider and increase their understanding of fatigue management strategies and biopsychosocial experiences of fatigue for PwMS, supporting the findings of this research. Specific to leisure facilities rather than physiotherapy, lack of suitable transport has been found to be a barrier to participation in leisure physical activity for people with neurological conditions (Hale et al., 2012; Kayes, 2011; Mulligan et al., 2012). Transport to physiotherapy appointments could be seen as an issue peripheral to physiotherapy, however, this research suggests transport affects the individual and their experience of physiotherapy physically, practically and emotionally.

Accessibility and parking affected experience of physiotherapy. Fran and Clare described increased stress, fatigue and reduced independence resulting from having to park too far from physiotherapy departments. This further increased barriers to access and also exacerbated MS symptoms. Again, findings parallel research discoveries exploring factors affecting engagement in physical activity in the community for PwMS (Hale et al., 2012; Kayes, 2011; Mulligan et al., 2012; Smith et al., 2011). These barriers oppose the common goals of physiotherapy of increasing independence and helping PwMS manage their symptoms. Access to toilets raised similar issues. This research highlighted that PwMS are more reluctant to attend physiotherapy when toilet access is an issue and lack of accessible toilets increases anxiety and stress. This has significant implications for PwMS as previously noted and is therefore of importance to the experience of physiotherapy and a person's well-being. Browne et al., (2015) identified that healthcare professionals did not often ask PwMS questions about bladder dysfunction. Therefore, it could be that physiotherapists are not always fully aware of the presence or impact of bladder dysfunction and the need for suitable toilet access due to this. If physiotherapists are better informed about the affect these barriers have for PwMS, they will be better placed to inform PwMS about suitability of facilities, inform service planning and consider appropriate physiotherapy venues for individuals with MS to optimise their experience of physiotherapy.

This research found that access to physiotherapy appointments, self-referral and regular review improved experience of physiotherapy and wider quality of life. Peter and Mary described lack of access to physiotherapy and having physiotherapy delivered in ways that did not meet Peter's needs resulted in him feeling abandoned, disempowered, 'pointless' and feeling they had to fight for physiotherapy. In contrast, flexibility of appointments and availability of self-referral meant being able to access physiotherapy in a timely and responsive way for Bella, Julie, Fran and Clare. This provided reassurance, alleviated fears of not being able to access physiotherapy when needed, therefore enabling participants to manage their MS more independently and effectively. Experience of physiotherapy was further improved when participants had a known point of contact, particularly within a relationship of trust. These issues support the importance of relevant guideline recommendations for PwMS (NICE, 2014; NICE, 2018; WPLAG, 2013).

There is minimal research regarding the experiences of physiotherapy for PwMS. However, the findings of this research are in keeping with wider healthcare experiences for PwMS and physiotherapy experiences for people with other neurological conditions (discussed in sections 2.3, 2.4 and 2.5). Good access, continuity of care and interpersonal interactions were identified as key factors of good healthcare experiences, whilst short term approaches, limited access and continuity of care were consistently found to negatively impact experiences of healthcare to include physiotherapy (Bassett and Tango, 2002; Cassidy et al., 2018; Daker-White et al., 2013, Methley et al., 2014; Methley et al., 2017). This research adds to the argument these issues are of vital importance to PwMS. This research contributes further unique insight that part of this negative experience may be due to the effect on a person's sense of self, emotional well-being and their experience of living with MS. Physiotherapists can utilise this information to optimise the experience of physiotherapy for PwMS through improving, supporting and promoting access to physiotherapy services and facilities (including regular reviews), increased continuity of care (ideally with a known point of contact) and provision of a longer term approach where possible.

Exercise and Physiotherapy

Exercise programmes carried out by PwMS result in improved muscle strength, cardiovascular fitness, aerobic thresholds and increase function, such as improved walking ability (Latimer-Cheung et al., 2013; Rietberg et al., 2004; Snook and Motl 2009; Turner, Kivlahan and Haselkorn, 2009), including for those with severe mobility disability (Edwards and Pilutti, 2017). Increased exercise levels are also likely to result in improved mood and quality of life for PwMS (Heesen et al., 2006; Latimer-Cheung et al., 2013; Motl et al., 2009). As such, physical activity and exercise are important components of comprehensive MS care and patient self-management (NICE, 2018), yet PwMS remain generally inactive (Backus, 2016; Motl, 2014; Klaren et al., 2013). Physical activity is considered any movement activity that involves using energy; examples include sport or activities of daily living such as housework or walking. Exercise is considered a form of physical activity that is intentional, structured and often recurring (Backus, 2016). Physical activity and exercise formed a core component of physiotherapy and daily life and was considered a way to self-manage MS for all participants in this research. Participants discussed exercise more explicitly during interviews, with physical activity often being mentioned more incidentally. This is likely due to the focus of this research being on physiotherapy, and the understanding of exercise as a core component of physiotherapy, as highlighted within this research.

In keeping with other research findings (Borkoles et al., 2008; Learmonth et al., 2015), participants were keen to undertake more exercise, but experienced many barriers. Borkoles et al. (2008) interviewed PwMS who actively exercised and Learmonth et al. (2015) interviewed PwMS who use wheelchairs regarding their physical activity. Both studies found that setting, accessibility, suitability of facilities and flexibility of session timings limited their ability to participate in exercise. This is reflective of the findings of this research regarding participation in physiotherapy discussed above, and also of the findings of this research regarding barriers to exercise. Mary explains Peter cannot use leisure centre exercise equipment suitable for his needs due to lack of flexible access. Julie richly articulates barriers to exercising in a leisure centre environment which she perceives (and has experienced) as being suited for 'normal' people rather than herself, where staff and users 'just wouldn't understand' MS. These issues are shared by participants in both of the studies above, with one participant explaining, 'I'm conscious that people might be looking at me because I'm different, but I put it out of my mind' (Borkoles et al., 2008, p434), and another wanting to 'pass for normal' by choosing to disguise his MS symptoms in front of the gym staff to limit social stigmatisation and negative social appraisal (Borkoles et al., 2008, p438). Borkoles et al. (2008) highlight participant concerns that leisure services have a 'one size fits all' approach (p437), highlighting a potential lack of knowledge about exercise and facility needs for PwMS, a concern Julie also expressed, 'they have to do everyone.' It is striking these issues have been identified a decade ago, yet these limitations continue to cause barriers to PwMS participating in physical activity. This raises the question whether people with a range of conditions, including MS, would feel better about themselves, more connected and better able to participate within the community if there was increased understanding of their condition. This research agrees and supports the recommendations of Borkoles et al. (2008) and Learmonth et al. (2015) regarding the need for ongoing education and awareness regarding the needs of people with PwMS in relation to promoting and facilitating positive experiences of exercise. Physiotherapists are well placed to provide this education and awareness (WPLAG, 2013) in partnership with PwMS and other providers and by doing so, could help reduce barriers to exercise for PwMS (Ploughman, 2017).

The above studies, in additional to a study carried out with women with MS exploring how fatigue influences community-based exercise participation (Smith et al., 2011), identified that carrying out physical activity and exercise are limited by MS symptoms, in particular fatigue. Fatigue also affects time availability as PwMS often have to pace themselves and prioritise tasks depending on their fatigue and energy levels (Newton et al., 2016; Smith et al., 2011; Turpin et al., 2018). Bella, Anna and Fran describe no difficulty in finding time or motivating themselves to exercise but explained they are limited and at times overwhelmed by fatigue. This finding contributes weight to the need for physiotherapists to be informed regarding factors affecting fatigue, fatigue management strategies and the effect of fatigue on PwMS, particularly to help reduce barriers to physical activity (Smith et al., 2011). When prescribing exercise programmes, physiotherapists need to consider fatigue and providing advice about pacing. A further battle with fatigue was highlighted in this research. If PwMS push themselves too hard, this can exacerbate symptoms, leading to reduced function as Anna and Fran illustrated, ‘walking like a drunkard.’ Yet, if they do not ‘keep going,’ PwMS may have fears about the effect this may have on their disease progression, ‘the thing is that if I didn’t do it, I would be in a corner- And I don’t want to be in a corner.’ This fear could add further burden to a PwMS already trying to manage this difficult symptom. Increased awareness of this will enable physiotherapists to explore these issues with PwMS and help support and educate them regarding fatigue management whilst trying to minimise fear of deterioration as a result of resting when needed.

The relationship with physiotherapy prescribed exercise and how it affected the individuals in this study regarding their sense of self and quality of life is complex, varied and adds further nuance and insight to the body of research that explores exercise and physical activity for PwMS. Participants described feelings of weakness, failure and fear experienced when they were unable to achieve exercise goals. Conversely, feelings of pride and independence were experienced when participants were able to carry out exercise independently, particularly when this resulted in recognised improvement in function. This will be explored further in the following discussion section.

Self-management through physiotherapy education, advice and exercise

Physiotherapists support and enable people to manage their own condition, maintain their independence and prevent further disability where possible, in part through helping people self-manage their condition (WPLAG, 2013). Peek et al. (2016) define ‘effective self-management’ as often being ‘dependent on the collaboration between the patient and the physiotherapist’, helping ‘patients to acquire the skills and confidence to manage their condition’ (p127). These authors emphasise the importance of adherence to self-management when people spend most of their time away from clinics or appointments. In this study, participants discussed self-management as an important component of physiotherapy, describing components of this as exercise, education and advice and highlighting the increased confidence, ability, independence and function facilitated by effective self-management through physiotherapy. Participants also described feeling reassured, better informed, more able to manage their condition and make informed choices and decisions. In contrast, when this was absent, for example, explanations were not provided to participants, they expressed feelings of frustration and worthlessness. In addition, when they did not understand the context or relevance of advice, participants were less likely to adhere to this advice (therefore less able to self-manage their condition).

Participants described the importance of being shown what to do and receiving advice regarding exercise through regular reviews for improving technique, aiding adherence and ultimately increasing function and activity. Peter, Julie and Clare described their main barriers to following prescribed exercises as lack of support and regular review, (alongside diminished motivation and time). Support and advice from healthcare professionals has been identified as being a factor in whether PwMS engaged in physical activity (Backus, 2016; Kayes, 2011). The need for regular review in physiotherapy has been discussed previously within the context of this research and other relevant research.

This research found that it is important that PwMS understand the reason behind carrying out self-management techniques, such as an exercise programme, and can translate this into functional improvement and improved quality of life. Clare offered a glimpse into one of her difficulties with prioritising exercise, despite recognising exercise as ‘really important for anyone with MS.’ She does not recognise the benefit for herself, as her disease is continuing to progress ‘I would like to say (the exercises) work…but it (MS) just seems to be moving forwards a little bit quicker than I would like.’ In addition, she does not relate carrying out exercise as having any direct benefit to her day to day life and in this way, it lacks relevance and meaning. Other participants prioritised exercise because it enabled them to carry out activities such as being able to walk down the pier, experience an adventure on the tall ship, or be able to stand up or get up from the floor. For these participants, exercise had relevance and meaning, specific to them as an individual. Aspects of these findings are in keeping with research by Cassidy et al. (2018), who highlighted that participants with ataxia placed importance on physiotherapy that maximised day to day living and physical exercise that had relevance and promoted a positive sense of self. Though not specific to physiotherapy, Mozo-Dutton et al. (2012) reported that clinicians working with PwMS can support PwMS in maintaining a positive sense of self by helping them reconnect with valued interests, roles and activities (even if these require adaptation). As examples within physiotherapy, this could be achieved through exercise and activity as discussed above, or through provision of mobility aids as discussed in the following section. Cassidy's study also identified that effective exercise for people with ataxia was often self-selected rather than physiotherapy prescribed. There is concurrence within this research, with Julie explaining she enjoys playing on the Wii console and therefore finds this easier to adhere to than prescribed exercise.

This research highlights another complex element of exercise prescription for PwMS. Clare indicates that she carries out exercise to prevent deterioration and potentially struggles to see the point in this as she continues to deteriorate regardless. Anna provides raw insight into her fear of further loss of function if she does not keep up with exercise, even to the point where she negatively impacts her function through exhaustion. Anna also talks of regret and blames herself that aspects of her condition have worsened due to what she sees as her lack of effective self- management. Peter and Mary explain their complex feelings of hope (that carrying out exercise will prevent disease progression), fear (that if they stop, Peter will get worse) and regret (that by 'missing out' on therapy, further decline has occurred) around exercise and physiotherapy. Julie and Clare criticise themselves for being weak, 'not strong at that,' for not being able to maintain exercise goals. One of the findings of this research, which is reflective of research discussed in section 2.2 of this thesis (Davies et al., 2015; Frost et al., 2017; Preston et al., 2014; Strickland et al., 2016) is that living with MS involves an altered, often diminished sense of self where people feel less resilient, less in control and experience sense of failure, shame, regret or fear to describe just some of the realities of living with MS. This research additionally suggests that although a sense of pride can be gained through 'achieving' exercise, PwMS can also feel bad about themselves if they are unable to exercise, or fear what may happen to them if they do not carry out their exercise. It is of concern that the drive to meet exercise goals could potentially add to the emotional and physical encumbrance of living with MS. It has been suggested that healthcare professionals working to promote physical activity and exercise in PwMS should promote the positive benefits of participation (Learmonth and Motl, 2016). It may be possible that through the desire to reinforce the potential benefits of exercise, the message conveyed or perceived by PwMS is that exercise is the responsibility of the PwMS (and in some cases their carer) to prevent their own deterioration. However, in contrast, the aim of providing education and advice regarding exercise and activity is to promote the contribution that exercise and activity can make as part of maintaining or improving physical function, sense of self, wellbeing and quality of life; promoting exercise and activity as being enjoyable and relevant to an individual at that particular time.

If physiotherapists better understand that exercise could add to the burden of living with MS, they could shape and promote exercise as something positive and meaningful, this may help PwMS enjoy and carry out exercise without additional burden, fear and negative affect on sense of self. An increased awareness regarding emotions of fear and regret around maintaining exercise could enable physiotherapists to contextualise exercise in a different way to address and hopefully minimise these emotions and experiences. This may include discussions around personal needs, goals and thoughts, the wider benefits of exercise and activity and what optimising quality of life means to them, all within the context of disease progression as appropriate. It could also help address these issues if they were raised within physiotherapy sessions, with the therapist asking about understanding of exercise/activity in relation to MS. Perhaps some fears could be allayed and exercise could be contextualised in a more positive way as a potential tool to help each individual with MS specific to their own needs, rather than being another factor that can negatively impact sense of self and the experience of physiotherapy and living with MS. It is also important that physiotherapists are able to explain that exercise does not wholly prevent deterioration but will help optimise function and reduce impairment, whilst still maintaining hope. This is a difficult and nuanced conversation that requires some understanding of living with MS and the effect of physiotherapy on this experience. Increased understanding about each individual and their lived experience of MS would enable physiotherapists to better shape their discussions, advice and recommendations.

Physiotherapists could focus on finding activity and exercise that people enjoy and view as positive and part of their chosen lifestyle rather than exercise as a prescriptive task which should be achieved (potentially leading to ‘failure’ if not carried out) to help increase effective, enjoyable and meaningful self-management through increased activity and exercise that is known to benefit PwMS. The findings from Cassidy et al., (2018) and this research with PwMS both suggest that physiotherapists could help people with neurological conditions, including PwMS, self-manage their condition through exercise and activity if they worked to situate these within an informed, contextualised, meaningful and functional context for each individual. A key aspect of this is that the decision to engage and the meaning of physical activity and exercise is complex, nuanced, multi-faceted, fluid and individualised, therefore physiotherapists could reduce barriers and optimise physical activity for PwMS by taking into account and listening to each individuals beliefs and perceptions regarding physical activity and exercise (Hale et al., 2012; Kayes, 2011; Mulligan et al., 2012; Ploughman, 2017; Smith et al., 2011; Stennett, De Souza and Norris, 2018).

Walking aids

Participants in this research identified provision of walking or handling aids as being part of physiotherapy, which is not surprising as PwMS commonly use aids to help increase efficiency and safety of movement (Souza et al., 2010; Stevens et al., 2013). Some participants explained these aids improved walking or standing and increased their independence and ability to participate in enjoyable and important activities. Despite this resultant increase in function, Anna and Peter both shared the effect using these aids had upon their sense of self- feeling demeaned, old or being conscious that others might view them this way.

Participants found strategies for adjusting to using aids by changing to a more visually pleasing frame and taking more ownership of it in Anna's case, and for both Anna and Peter, focusing on what using the aid allowed them to do. If they focused on functional gain or ability to take part in activity facilitated by the aid, this improved their experience and acceptance of using the aid, in keeping with research carried out with older adults (Resnik et al., 2009) and people with Stroke (Pettersson, Appelros and Ahlström 2007). It is important for physiotherapists to be aware of and sensitive to the potential impact of suggesting and providing aids and mobility equipment on a person's sense of self. This would positively impact decision-making regarding the appropriateness and timing of suggesting the use of an aid, and contextualise the aid in terms of enabling meaningful, enjoyable activities and functional gains for that individual. This may help PwMS transition towards using an aid whilst minimising the potential negative impact on sense of self.

Hope

The concept of hope has been woven into the previous sections of this discussion but will now be addressed more directly. It is demonstrated through the words of these participants that physiotherapy can offer hope or threaten feelings of hopefulness. Soundy et al. (2010) explain that some hope in recovery and maintenance is required, otherwise, treatment is considered pointless. They suggest 'physiotherapists are involved in changing the balance of worry in uncertainty to that of hope in uncertainty' (Soundy et al., 2010, p70). Their research, based on interviews with physiotherapists, found several factors contributing towards maintaining hope to include recognising the individuals' experience, while respecting the time needed for change, acceptance, and coping. These findings are in keeping with and directly relate to the findings of this research. Research into the concept of hope based on interviews with patients with MS identified three themes around hope (Soundy et al., 2012). One of these was defiance, where patients described defying their MS by 'searching for information, using medical or alternative treatments and undertaking routines diligently in order to help improve their symptoms'. This introduces yet another dynamic to the complexity around physiotherapy provision. It could be that for some PwMS, holding onto a routine of exercise, as an example, may provide

PwMS with the hope they require. Soundy et al. (2012) also identified that where improvement may not be possible, hope in the stability of symptoms was identified. These elements were both described by Anna as she battled with her MS to keep going, to stay out of ‘a corner’. Additionally, Soundy et al. (2012) found that some of their participants identified hope in their ability to cope and adapt to symptoms, retaining and maintaining independence, continuing their life and identity regardless of MS and having a sense of purpose. A participant in the study by Borkoles et al. (2008) talked about hope in this way; ‘if you were doing your exercises, you were maintaining a life, or lifestyle you’ve got’ (p433). Anna also exemplifies these aspects of hope, as she discusses sailing on the tall ship, expressing this in terms of her doing all of the things that ‘normal’ people can do, with a strong sense of purpose.

The other themes identified were of accepting the diagnosis and prognosis and accepting deterioration. Soundy et al. (2012) advised that ‘physiotherapists need to support the process of acceptance carefully because during this time patients may be the most vulnerable to experiencing hopelessness’. The importance of this is illustrated in Peter and Mary’s powerful narrative of struggling with hope and hopelessness, in Fran’s exposing revelation of contemplating suicide, Clare’s reflection that her condition is continuing to deteriorate ‘quicker than (she) would like,’ and Bella’s wistful pain, ‘and don’t I wish I could go out and see (the outside world)’, as examples. Soundy et al. (2012) made suggestions to enable physiotherapists to support and encourage the best adjustment to MS in relation to hope: listen, acknowledge, value and encourage a patient’s narrative expression of hope during rehabilitation, the different ways that patients express hope. They also highlight that poor communication can cause hopelessness, and that ‘one of the hardest aspects to accept by patients was the drastic change to their identity brought about by MS’ (p 345), returning again to the importance that physiotherapists are aware of potential impacting factors on self-identity for PwMS, including hope through physiotherapy.

Person-centred care and communication

The concept of patient centred care is fundamental to NHS healthcare delivery (DOH, 2005; Epstein et al., 2010), and is recognised as being pivotal to physiotherapy (CSP, 2010; Higgs et al., 2008). What defines patient-centred care has been the subject of research and discussion from the perspective of patients (Cooper et al., 2008; Kidd, Bond and Bell, 2011), researchers and therapists (Mead and Bower, 2000), yet its' meaning remained debateable (Cooper et al., 2008; Epstein et al., 2010). Key dimensions defining this construct are identified and shown in table 9 below.

Mead & Bower, 2000. Review of empirical literature; patient-centredness as defined by professionals and researchers	**Cooper et al., 2008. Interviews with patients**	**Kidd et al., 2011. Interviews with patients**
Six dimensions identified	**Six themes identified**	**Four core categories identified**
The biopsychosocial perspective (involves the practitioner looking wider than the biomedical aspects of illness of injury to include social and psychosocial issues)	Individual care	Understanding people & an ability to relate
The premise of the 'patient as a person' which explores the personal meaning of the illness or injury to the individual to consider their expectations, beliefs, feelings and fears	Individual care	Understanding people & an ability to relate
Patient involvement in collaborative decision making, information sharing, communication and organisation of their care with the practitioner as an integral approach	Decision-making Communication Information-sharing Organisation of care	Understanding people & an ability to relate Transparency of progress and outcome
A therapeutic alliance that acknowledges the essential element of a positive interpersonal relationship between the therapist and patient	Communication	Communication Understanding people & an ability to relate
The 'practitioner as a person' reflecting the impact of the therapist within this relationship, and therefore highlighting the importance of the therapists self-awareness in practice	The physiotherapist themselves	Confidence of the therapist, (knowledge, expertise and professionalism) Understanding people & an ability to relate

TABLE 9: RESEARCH EXPLORING PATIENT-CENTRED CARE IN PHYSIOTHERAPY

More recently, a systematic review of qualitative studies regarding patient-centeredness in physiotherapy concluded this entails characteristics to include offering individualised treatment, continuous communication, education throughout all aspects of physiotherapy and treatment developed using patient defined goals during which the patient is empowered and supported. Patient centeredness also includes the physiotherapist having social skills, confidence alongside appropriate and specific knowledge (Wijma et al., 2017). For the participants in this study, person-centred care reflected aspects of the descriptions above, including joint decision making, being listened to, provided with choices, effectively informed, and being treated in a personal way. This positively affected how participants felt about themselves and their experiences of physiotherapy. Fran described the value of feeling ‘like a person,’ because her therapist had shared simple stories about what she was doing on a holiday, therefore making a personal connection with her. Fran and Anna discussed the affirming and even vital significance of being listened to, while Clare explained the benefits of better communication in terms of experience of physiotherapy. Hale et al. (2012) have also highlighted the importance of listening to PwMS and delivering a person-centred approach in order for physiotherapy to meet individual needs for PwMS. In contrast, when Peter felt he had not been listened to or given choices, this resulted in him feeling ‘pointless’ and life being even more difficult for him. Aspects of these findings relate back to the context of physiotherapy and exercise. Perhaps if the focus on listening, joint decision-making and equal partnership between physiotherapist and the PwMS was paramount, physiotherapy would be better situated and understood as helping PwMS manage their condition rather than potentially instructing the PwMS about exercises they ‘should’ carry out. In this way, PwMS may be more likely to feel empowered in their choices regarding exercise and this in turn may improve not only adherence but also their sense of self. This study agrees with research presented in sections 2.3, 2.4 and 2.5 as well as additional research supporting the need for person-centred physiotherapy care for PwMS (Kaur et al., 2016) and highlighting the importance of establishing meaningful connections between physiotherapists and patients in a multi-faceted way (Miciak et al., 2019). PwMS have better experience of physiotherapy, and feel more positively about themselves and living with MS in the presence of effective, personalised communication with an informed and trusted professional.

Groups and sharing the experience of living with MS

Being part of a group or community of PwMS was highlighted as important to Anna, Julie and Clare. Anna focused on the benefits of the MS Society for providing friendship and social support, while Julie and Clare discussed this alongside the additional aspect of exercising with a group of PwMS. However, both Julie and Anna mentioned their reluctance to be involved with groups related to MS in earlier stages of MS due to fear of stigmatism and being defined as someone with MS, something also found in research carried out with people with early stage MS (Dennison et al., 2011). For participants in this study, being part of a group of PwMS had a positive effect on their sense of self, their experience of exercise and their experience of living with MS. They felt stronger and more positive in themselves, better understood, supported and hopeful. Being with others with MS improved participants' experience of living with their condition as they felt more 'normal' and accepted and also helped their transition towards accepting MS. They explained the practical benefits in terms of sharing information and advice and helping individuals carry out and enjoy exercise. The benefits of exercising in a group were highlighted as being key to facilitating self-management in terms of adhering with, promoting and optimising exercise. Julie and Clare explained this as the main factor affecting whether or not they were able to engage with exercise and physical activity. The support and motivation provided to PwMS through group exercise was also highlighted in research reviews identifying influencing factors and determinants of physical activity and exercise for PwMS (Christensen et al., 2016; Learmonth and Motl, 2016). Soundy et al. (2012) identified that 'being able to have a sense of purpose following MS may be fundamental to creating the most stable and unchanging expressions of hope from patients' (p349), it could be suggested from the words of Julie and Clare that the group support they experience provides them with such a sense of purpose.

This corresponds with the research findings of Clarke and Coote (2015) who found positive effects of community exercise interventions where the role of the group was a key element in reducing the impact of MS (and fatigue) and improving participation. Three themes emerged from their analysis; psychological benefits (social, motivational, empowerment, confidence, hope, sense of achievement, and pride), physical benefits (improved energy, ability and participation, reduced fatigue) and knowledge gained (a shift from thoughts that exercise might do harm, to sufficient knowledge that gave participants confidence to exercise). In addition, creating communities was found to be a way of improving sense of self, belonging and well-being for people in research carried out with people with a range of neurological conditions (Roger et al., 2014). McGahon (2013) found that increasing access to group exercise sessions reduced waiting times without having a detrimental effect on experience for patients within a musculoskeletal out-patient physiotherapy setting. These findings, alongside the findings of this research, suggest that the complex relationship between PwMS and exercise might be helped by providing physiotherapy education, information and exercise in group community settings. PwMS understand many of the challenges each other face and may be better placed to support and contextualise exercise and physiotherapy for some other PwMS within a group. Physiotherapists should consider offering group exercise sessions and signposting PwMS towards facilities for group exercise and support due to the multiple benefits that have been highlighted.

Embodiment

Participants talked of feeling inadequate, different, isolated, self-conscious, stupid and lacking confidence as examples of how having MS affects their view of themselves. Physical symptoms of MS affect sense of self for these participants. For example, a body part failing can feel to the person like they are failing, as Anna illustrated, 'Yesterday I just couldn't lift my leg. I couldn't. My balance was….oh….I was rubbish.' I feel uncomfortable in sharing some of my prior thoughts, now changed through carrying out this research, but do so with the aim of introducing complex concepts that perhaps are less familiar to many physiotherapists, myself included. I understood that the body not doing as a person needs has a deep effect on how they felt about themselves; I witnessed the devastation resulting from neurological conditions such as MS in everyday practice. However, I perceived this frustration and loss being due to living with a deteriorating body affected by the condition, the person with the condition in some way being able to delineate between their body and their selves, recognising these physical symptoms as being part of MS rather than part of themselves. What I have come to understand through this research is that the body and the person are inseparable for many PwMS, something that perhaps seems obvious on reflection now (see reflexive section in Appendix I). Research has shown that sense of self is intrinsically linked with the body, however, PwMS experienced feeling their body as becoming split from self and viewed as something separate to themselves (Mozo-Dutton et al., 2012). It is beyond the limitations of this research to fully explore this phenomenon. However, this will now be considered to situate this research within the wider consideration of the role and understanding of the body within physiotherapy.

Nicholls and Gibson wrote a theoretical article in 2010 that explained the body as being central to physiotherapy as the site and focus upon which much of physiotherapeutic work takes place. They highlight that considering physiotherapists have 'expertise in managing health problems that have as their core the function and dysfunction of the body' (p497), there is a surprising lack of theory regarding the body's theoretical complexity, suggesting 'the body is woven into the very fabric of our professional identity, but its threads are invisible to the naked eye' (p 498). In other words, the role and theory of the body is assumed rather than questioned and discussed. They critique physiotherapy as concentrating on a largely biomechanical understanding of the body, being slow and reluctant to adopt more holistic dimensions of health care; 'not taking account of all the facets of embodiment' (p501). They discussed embodiment as emphasising the whole person within the full richness of human life rather than focusing on body impairment;

> If embodiment is about understanding the reality of being embodied and not just having a body, then physiotherapists, with their unique appreciation for movement and the effect of illness and impairment on function, have a vital and enormously significant part to play in developing a new science of embodied movement (p506).

They conclude there has been little work carried out in this area within physiotherapy, and suggest there is a need for more theoretical work regarding the way physiotherapists engage with the body, and the concept of embodiment. Exploring the relevance of the theory of embodiment to physiotherapy practice could be a way to explore the effect of living with a condition such as MS, physiotherapy and exercise upon self-identity, an issue identified as being of significant importance in this research.

Connectivity is another theoretical concept that could help to explore self-identity in relation to physiotherapy practice and experience, potentially offering 'critical insights into physiotherapy practice (Nicholls et al., 2016, p159).' This theory is particularly relevant to this study as it is philosophically rooted in phenomenology and proposes that people's connections with other entities such as environment, other people and technologies define their abilities rather than medical assumptions or socially-constructed norms. Connectivity critiques people being labelled as 'other' (abnormal) both within medicine and wider society. Nicholls et al. (2016) explained that as phenomenology is prefaced on the belief that we are a product of 'being in the world' (rather than the world presenting an external reality), we come to know the world through our bodies and our senses, becoming embodied in the process. It would follow that any change in our bodies would fundamentally change the way we view the world (for example, the experience of physiotherapy) and ourselves, changing self-identity. Nicholls et al. (2016) suggested the concept of connectivity 'offers a number of interesting possibilities for physiotherapists' because it is: 'concerned with people's "doing" and engagement in the world' (focus on function), 'challenges the traditional distinction between able-bodied and disabled' and also 'resonates with [ ] person-centered care and shared care, reflecting the profession's need to adapt to the changing economy of health care (p166).' Physiotherapists work to assess patient's engagement within their world and identify their needs and desires through identifying goals. Intervention is subsequently aimed at helping individuals face challenges and break down barriers to achieve their goals. In this way, physiotherapists work in a manner that reflects connectivity theory, yet the findings of this and other research discussed suggests that the extent to which physiotherapy achieves this is variable. It could be that further knowledge and consideration of this theoretical concept could help inform physiotherapists, improve the experience of physiotherapy for PwMS and potentially even the experience of living with MS, including through optimising sense of self. Examples of this include; improving accessibility to physiotherapy services thereby increasing connectivity to this environment, improving knowledge of leisure centre staff regarding MS to help reduce PwMS feeling 'abnormal' due to facilities not meeting their needs, or physiotherapists prescribing or advising about exercise that is not contextualised or meaningful to the PwMS.

Both of these concepts interrelate and help with understanding the findings of this research- that experiences of physiotherapy (and living with MS) are intrinsically connected with a person's self-identity. Increased knowledge and insight about sense of self and the effect of physiotherapy on this could help improve the experience of physiotherapy, as well as helping physiotherapists support PwMS maintain a positive sense of self. A future step for this research could be to consider these findings in light of these theories, and how they relate to physiotherapy practice. Research exploring experiences such as this study can provide rich insight that could help develop understanding about sense of self, embodiment and connectivity in relation to physiotherapy with the aim of improving experience of physiotherapy, leading to improvements in how physiotherapy can help people maintain their self-identity and optimise their participation and being in this world. Perhaps this could enable physiotherapists to better support humans 'in being' as part of this world in a rich, meaningful context, rather than 'in doing' in the carrying out of physiotherapy that perhaps does not optimally enrich the lives and sense of self of PwMS.

5.4 Evaluating the quality and limitations of this research

As a relative novice in carrying out qualitative research, with this being my first IPA study, I attended an IPA study day prior to carrying out this research. This provided me with further information about IPA and opportunity to discuss my understanding and have this challenged by course leaders and more experienced course participants. Following on from this, I use an online forum to continue to engage with other IPA researchers internationally, including many experts in IPA. Further details can be found in Appendix XVII.

Smith (2011) reported that whilst general qualitative criteria are 'extremely useful', they lack specificity 'when confronted with the particular task of assessing the quality of [ ] IPA studies.' (p15). Smith (2011) presented tables detailing criteria for assessing the quality of IPA research. These tables can be found in Appendix XVIII, but summary criteria are displayed in figure 8 below (adapted extracts from 'IPA quality evaluation guide' (table 5, Smith 2011, p17) and 'What makes a good

IPA paper' (table 10, Smith 2011, p24)). These will be considered in turn to critique this research.

Acceptable: Overall the paper is judged sufficiently trustworthy to accept for publication and include in a systematic review

The paper meets these four criteria:

- Subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic
- Sufficiently transparent so reader can see what was done
- Coherent, plausible and interesting analysis
- Sufficient sampling to show density of evidence for each theme: (N4-8: extracts from at least three participants for each theme)

Good: Overall the paper could be recommended to a novice as a good exemplar of IPA

Paper must clearly meet all the criteria for acceptable. It then offers these three extra things:

- Well focused; offering an in-depth analysis of a specific topic
- Data and interpretation are strong
- Reader is engaged and finds it particularly enlightening

What makes a good IPA paper?

- Paper should have clear focus
- Paper will have strong data
- Paper will be rigorous
- Sufficient space must be given to the elaboration of each theme
- The analysis should be interpretive and not just descriptive
- The analysis should be pointing to both convergence and divergence
- The paper needs to be carefully written

FIGURE 8 ADAPTED EXTRACT FROM IPA QUALITY EVALUATION GUIDES

The theoretical principles of IPA have been discussed with reference to this study within chapter three, demonstrating how this research is founded upon phenomenology, hermeneutics and idiography. Generating strong IPA data requires good interviewing skills, with the ability to actively listen, ask open-ended questions and build rapport and trust with participants (Pietkiewicz and Smith 2012; Smith et al., 2009). These are skills I have developed in physiotherapy practice (see reflexive diary in Appendix I for further details). As a researcher practitioner, I was concerned that being a physiotherapist might limit how comfortable participants felt talking to me about their experiences of physiotherapy. However, my perception is that participants felt relaxed and comfortable, and trusted me sufficiently to talk honestly. Upon critiquing my interviewing technique (see also Appendix I), my initial thoughts were that I had not adequately interrogated or explored certain issues. As a physiotherapist, I question people in detail about their condition, how it affects them, and how they feel physiotherapy can help them. However, for the purposes of this research, I was focused on ensuring participants expressed their own experiences, rather than anything I imposed on them ('rather being influenced by the researcher's preconceptions' (Smith et al. 2009 p282)). Indeed, IPA interviewing can be described as 'a guide to facilitation of a natural flow of conversation' (Pietkiewicz and Smith, 2012, p365). This methodological focus resulted in me asking fewer questions and facilitating participant discussion, some of which they discussed in depth and detail. This had an ethical advantage, as participants were not drawn into discussing anything they may not have felt comfortable with- a recognised issue in ethical interviewing (Allmark et al., 2009). Interviews were wholly guided by the participants- in this way, I maintained the principles of inductive phenomenology as discussed in chapter three whilst significant, rich and insightful data was generated.

However, if I were to carry out further IPA research, I would likely question further at relevant stages of the interviews. Through immersing myself in the interview transcripts, areas where further probing would have gained further insight, depth or clarification whilst maintaining the idiographic focus essential to IPA have been revealed. Carrying out a pilot study (as suggested by Gee, 2011) may have provided me with more knowledge about this interviewing technique within the context of IPA. However, it is only following thorough analysis and immersion in the data that I gained the confidence and understanding to improve my interview technique without restriction due to concerns about over-guiding the interview. This analysis meets another criteria indicating a good study by remaining focused on the experiences of physiotherapy for these individual participants, or issues directly relevant to this phenomenon. To ensure transparency, examples of original transcript and analysis notes are available in Appendix XIV, illustrating how themes have been identified, developed and interpreted in addition to extracts analysed within chapter four. Coherence and plausibility are demonstrated in the focus on interpreted experiences of individual participants, supporting each theme with significant data, and allowing the reader to see how themes have developed. Smith et al. (2009) discuss impact and importance and highlight that, in its simplicity, IPA research should aim to tell the reader 'something interesting, important or useful.' These participant stories, experiences and reflections have enlightened and changed my practice, and challenged my own personal views, I believe the data is strong through its insightfulness and emotional connectivity. My aspiration is that I have written the analysis in a way that is both engaging and edifying, enabling the experiences of these six people to reach out to a wider audience.

Continuing to review the quality of this research, the appropriateness of the sample size for IPA has been discussed at length within chapter three and also in a reflective section in Appendix I. Nevertheless, a larger sample size would have provided the opportunity for further experiences and insight and in this way the sample size could be seen as a limitation. Rigour and sincerity are demonstrated by the thoroughness of the research, specifically in terms of the interview quality, immersive analysis, and the sample size allowing for in depth analysis and interpretation. Smith et al. (2009) advise quality IPA necessitates a good selection of extracts that indicate convergence, divergence, representativeness and variability to increase breadth and depth of analysis. Within the themes identified, I have indicated where there are shared experiences and views, but also where these are distinctly different, or even opposed, though it is acknowledged these factors are limited by word count restrictions. Each theme can be further expanded and explored in future publications. I have sought to interpret rather than describe the data, particularly as description of data was noted to limit quality when critiquing selected IPA research in the literature review of this research.

The final indicator of good IPA research from figure 8 above is that it must be carefully written, with the crucial elements of sensitivity and commitment to context and individuals (Pietkiewicz and Smith, 2012; Smith et al., 2009; Smith, 2011). This is demonstrated by the attentiveness and dedication I have shown by ensuring each participant felt comfortable and was wholly listened to and represented throughout the interview, analysis and interpretation. I have also shown care, sensitivity, sincerity and commitment to these participants, by writing this thesis with their words at its heart. I am aware of the risk of misrepresenting participants through my choice of extracts used, or interpretation of their words (Allmark et al., 2009). I have used reflective practice to continually consider, critique and appraise my thought processes alongside regular discussion with my supervisory team, to increase the credibility of this research (see Appendix I). It is acknowledged the researchers' background, clinical experience, and assumptions will contribute to the research process, adding depth and insight with reflexivity being used as a form of self-appraisal to expose biases, subjectivities and empathies (Johnson and Waterfield 2004; Greenfield et al., 2007; Smith et al., 2009). I have included reflexive extracts within Appendix I to make some of these 'biases' explicit and situate myself as part of this research process.

The aim of this IPA research is to better understand the experience of physiotherapy for these participants, providing insight into the experiences of physiotherapy for PwMS. This research does not aim to generate a generalised median theme, or make specific claims about the experiences of physiotherapy for PwMS that can be generalised; 'phenomenology is primarily about questioning, rather than drawing determinate conclusions' (Schroder Bjorbaekmo and Mengshoel 2016, p19). Good IPA research should facilitate the researcher and reader to 'make links between the findings, their personal and professional experiences and the extant literature, and 'reflect on the personal applicability of research findings as, if the studies are insightful enough, they capture 'what it is to be human at its most essential'' (Wagstaff et al., 2014, p3). Six participants were interviewed, and the importance of this research lies in the sharing, analysis and interpretation of their words. Due to the nature of this research, there is no suggestion this research provides 'the entire picture' of the experience of physiotherapy for PwMS, or that themes identified are exhaustive. The addition of any further participants would provide different insights and experiences, and so the concept of data saturation is not appropriate for this method of research (Saunders et al., 2017).

It is possible that participants either felt obliged, or eager to support their physiotherapist by talking about positive aspects of their experience (for example, to show their gratitude to their physiotherapist). Certainly, Bella, Julie, Clare and Fran all commenced the interview by talking about their good experiences, or explaining what they perceived good experiences to be. However, all of the participants shared a range of experiences, including some that were less positive. I would suggest that even if participants did feel initially they wanted to express their positive experiences, once they started talking in the interview, they were able to move beyond this to talk about their experience more broadly, as has been demonstrated in the analysis of chapter four.

5.5 Summary and Recommendations

Summarised recommendations are suggested to improve the experience of physiotherapy for PwMS based on the findings of this research, and in light of other relevant literature discussed. They have been developed inductively from the words of participants in this research, within the context of the lived experience of MS.

- Suitable transport and accessible facilities should be available, alongside an awareness of the potential impact these factors have on the experience of physiotherapy, a person’s sense of self, and their experience of living with MS.
- Regular, accessible and consistent physiotherapy reviews (including to review exercise technique as appropriate), ideally with a known point of contact, should be offered.
- Provision of flexible appointment times, in particular to maintain working life and help participants manage their fatigue is beneficial and meaningful.
- Group activities and exercise classes should be considered as they provide social and emotional support and aid adherence and progression with exercise and activity. It is suggested that physiotherapists are well placed to help construct physical activity or exercise groups that PwMS can attend, with the overview and regular advice from the physiotherapist as required. Physiotherapists are also well placed to work in collaboration with leisure

centres to help support PwMS to exercise and stay active though providing advice and education.

- Exercise and activity advice and prescription should be collaboratively considered and developed in terms of the individual's needs, functional benefit and the meaning and relevance of the exercise or activity to individuals. An awareness of the potential effects of exercise and activity on self-identity, and the emotional impact and burden of living with MS will further improve the experience of exercise, physiotherapy and living with MS.
- Discussion about mobility aids should be carried out with an awareness that using aids can negatively affect a person's sense of self. Focusing on functional gains these might offer, encouraging personal ownership over the aid, and trying to provide more aesthetically pleasing aids could help improve the experience and context of using aids.
- Personal, individualised, shared and effective communication that includes listening, shared decision-making and provision of information, whilst being aware of the impact on feelings of altered sense of self, hope, regret and fear for PwMS improves experience of physiotherapy for people with MS.
- Physiotherapists should be aware of the value of support networks, such as the MS Society and that PwMS may only find this helpful at particular stages or times of life.

This research increases insight into the experience, thoughts, feelings and perceptions of PwMS, thereby facilitating personal and professional development within the physiotherapy profession that aims to place 'the patient experience at the centre of all it does'. (WPLAG, 2013). The analysis and interpretation of these findings are directly applicable to physiotherapists considering both clinical practice and service delivery and improvement. It is anticipated that recommendations emanating from this research will improve the experience of physiotherapy for PwMS in North Wales, by positively influencing and informing local physiotherapy service development. The findings of this research can also inform physiotherapy in other geographical areas with a similar patient group (specifically in MS, but also particularly within other long term neurological conditions). Additionally, this research adds to the argument for the importance and relevance of research and service development based on the views and experiences of the people who use our physiotherapy services, including PwMS (Hale et al., 2012). If physiotherapists become increasingly aware of the lived experience of MS (and, from this research, the lived experience of physiotherapy), they will be better placed to provide sensitive, informed, empathetic and contextualised physiotherapy. This research has also demonstrated that IPA as a research method can help reveal issues that are key to physiotherapy practice, with the potential to influence physiotherapy practice and services. The WPLAG advises that ‘professional must become better at utilising the ‘patient’ story’ in order to then influence organisational structures and processes where they see changes could be made to improve patient experience. Services can still develop further and do more to empower patients’.

This thesis makes an original contribution to knowledge as no research has been carried out regarding the experiences of physiotherapy for people in North Wales or regarding the experiences of physiotherapy for PwMS in the UK using phenomenological research methods such as IPA. The lived experience of physiotherapy for PwMS has been brought to the fore through the methodology and revealed research findings, highlighting and developing numerous aspects of an embodied experience of physiotherapy for PwMS. These findings can inform physiotherapists and people working with PwMS, including those within sport and exercise facilities, to better meet the individualised needs of PwMS. Uniquely, this research has found the experiences of physiotherapy for PwMS are inextricably linked and inter-dependent with sense of self. Delivering individualised, effective and meaningful physiotherapy goes beyond clinical knowledge; if physiotherapists are more aware of the impact of physiotherapy on sense of self through the findings of this research, PwMS are likely to have better experiences of physiotherapy. As discussed in this study, maintaining sense of self is key to improved quality of life for PwMS. In this way, improving experiences of physiotherapy can also lead to helping PwMS live with and manage their condition. Physiotherapists would benefit from increased education about self-identity and the impact of physiotherapy on self-identity. Theories of embodiment and connectivity referred to in this research may offer additional insight and challenge thinking and practice within physiotherapy. These theories could provide a philosophical construct within which to enable further exploration of complex issues such as the embodied experience of physiotherapy for PwMS within a profession that is perhaps less familiar with concepts such as embodiment and sense of self. This research has highlighted that sense of self significantly affects the experiences of physiotherapy for PwMS. As patient experience is at the heart of physiotherapy, understanding this phenomenon and how physiotherapy can optimise sense of self, and therefore the experience of physiotherapy, is key to delivering individualised and responsive person-centred physiotherapy care.

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Appendices

Appendix I: Reflexivity as a researcher practitioner

What is reflexivity?

Higgs et al. (2008) write about reflexivity within the context of health professions clinical decision-making, and describe it as:

> The awareness of the process of decision-making and factors that influence one's decision making, capability to monitor and evaluate decision making throughout the process of making decisions and the capability to self-critique experience of and effectiveness of decision making and use this critique in the development of knowledge structures to inform future decision making. (p95)

Seale (2004) describes reflexivity in the context of research as:

> The capacity to reflect on our role in generating (research knowledge) [ ] the researcher asking themselves about their role in the research, involves acknowledging that that researcher approaches the research from a specific position and this affects the approach taken, the questions asked, and the analysis produced. (p184)

Etherington (2004) broadens the concept further and combines these definitions when describing reflexivity within the context of research and clinical practice as:

> An ability to notice our responses to the world around us, other people and events, and to use that knowledge to inform our actions, communications and understandings. (p19)

Etherington goes on to explain that in order to be reflexive, clinicians need to 'be aware of our personal responses and [ ] be able to make choices about how we use them', and also 'be aware of the personal, social and cultural contexts in which we live and work, and how to understand how these impact on the ways we interpret our world' (p19). Etherington explains that for some, 'reflexivity may represent a means of constructing a bridge between research and practice' (p31). This description characterises what I have personally experienced. However, I would add the unifying effect of reflexive research practice on knitting together aspects of myself as a person, researcher and practitioner. This enables me to optimise learning and self-development to deliver more confident, skilled and better informed physiotherapy. My understanding of what makes me a better physiotherapist has broadened to encompass learning more about myself and others, alongside increasing my knowledge, research and clinical skills.

These definitions make apparent the critical role of reflexivity for researcher practitioners in the continual evolution of clinical practice and research development. I had not anticipated the degree of reflexivity that would be involved in this research, nor that it would be so integral to improving both this research and my clinical practice. Ideally, I would have positioned this section in the introductory chapter to this thesis to demonstrate the importance of reflexivity in the growth of this research. My next choice was to incorporate reflexive commentary throughout this thesis to elucidate key reflexive processes that have affected this research. However, the limitations of word count resulted in this section being presented within the Appendices, but the practice of reflexivity has been instrumental throughout this research. Reflexivity continues to challenge my thinking and practice and develop my reasoning, analysis, and interpretation. I have included extracts from past assignments contributing to this professional doctorate and my research diary (extracts indicated by italics), to demonstrate the early inception of this research, and to give some insight into how reflexivity has changed both my practice and this research.

Reflexive section: initial research thoughts

Extract from Ideas and Questions assignment (part of the professional doctorate course) submitted August 2012: *As a neurological physiotherapist, I have worked with people who have MS, as well as people with other neurological conditions, for many years. I observe and listen to their strengths, struggles, hopes and fears and want to deliver a service that optimises their quality of life in its' fullest sense. As part of my job, I have attended many meetings and forums where certain criteria are identified as being indicative of improving physiotherapy services. I have been involved with a number of surveys and audits that ask explicit questions about people's experiences of physiotherapy, or ask patients to rate the importance of* *certain aspects of physiotherapy service delivery. Ideally, although not exclusively, this is carried out in partnership with the people who use the services. Yet, the discussions that I often have with people after a meeting, when leaving a room, or at the end of a phone call having completed the 'purpose' of the call, has often provided me with far more insight, challenging information and rich experience. It would be beneficial to my clinical practice to pause on some of these exchanges, and consider how they might affect my practice, and even (for us all) to be able to share this information with other people working in health care.*

Reflexive section: considering my practise

Extract from portfolio of professional and research practice (part of the professional doctorate course) submitted August 2013*: I am increasingly aware of the depth and range of emotions and reactions that I experience in my personal and professional life. I am now beginning to harness these, and use them to improve my practice through improving my ability to relate to others and engage in more meaningful interactions. Within my clinical role, I discuss with individuals how it feels for them to have been diagnosed with a progressive neurological condition- how it has affected their function, job, role within their family, the altered views that they have of themselves and their future as examples. Earlier in my practice, I would have listened to their feelings, acknowledged them, and then moved on to advise them about their condition and how physiotherapy may help them. I became a physiotherapist to help people, and physiotherapy is often about problem solving. However, I better recognise the respect and empathy that are provided to a person through listening and knowing when the person needs you to simply listen and try to understand rather than try to help them overcome or 'solve the problem'. This can lead to a more trusting open dialogue that later often enables you to help that person from a more practical perspective.*

In the past, I would have been hesitant to share personal experience or feelings, partly as I did not identify this had contributory value, and partly because I perceived this might blur the boundary I understood as separating professional and personal life. I now find myself listening, asking how people feel, being open about how I feel, and sharing some experiences of others. I decide which of these aspects to bring into conversation as the situation and person indicates, in order to open up an empathetic, reciprocal discussion about their responses and feelings. I am able to use how I have felt in certain situations, or during some experiences, to help identify with people and improve my care.

Reflexive section: my understanding of research

Clinical reflection 2014: *One of my patients with an aggressive form of motor neurone disease (a degenerative and terminal neurological condition) was explaining to me how she felt about having this condition, while we were discussing how physiotherapy might be able to help her. 'The thing that is hardest for me to cope with, the single hardest thing apart from watching my family suffer, is the knowledge that every day that I have, will be the best one that I am ever going to have again.' She went on to talk about seeing her time 'trickling away' and her wanting to 'capture and hold onto it' but 'knowing that (I) can't.' Although this conversation was personally upsetting, and so difficult to listen to, it improved my practice by providing me with a painfully penetrating insight that will never leave me. Her experience that she shared with me continues to drive me to provide the best service that I can with every patient. Her narrative often provides a frame of reference in my mind during decision making, reminding me that every interaction and moment counts for this person, at this time, regardless of how I am feeling that day.*

There are several examples that I could use to illustrate the deep affect that pivotal conversations have had on me. As I have spent more time considering the aims of this research, the aim of enabling other clinicians more shared experience with the people that we work with through listening to their words, seems increasingly paramount and pertinent. To improve my clinical practice, I read and develop my clinical expertise and knowledge on an ongoing basis, but how I apply and use that knowledge is driven and shaped by personal interaction, shared experience, and an ever increasing understanding of people (and an increasing understanding of how important this is to physiotherapy). An increased awareness of people and empathy towards their experiences can be gained through phenomenological research (Gee 2011; Smith et al., 2009). It is my hope that I can help to generate further meaning, context, relevance and empathy to physiotherapy practice through the interpretation and presentation of the experiences of these participants that will have significant and long lasting effect on clinical practice.

From research diary, March 2016: *My approach to clinical practice has altered significantly over sixteen years of being a physiotherapist. Prior to carrying out this research, I was aware that as I gained further life experience and clinical interaction (and all that entails in terms of wider enriched experience of people, situations and emotions), the importance of human interaction and shared understanding with my patients (and their families or carers) was increasingly critical to what I perceive effective physiotherapy to constitute. However, on reflection, my understanding of research and the context within which I understood and used research did not run in parallel with this development; my emphasis on improving my physiotherapy skills and knowledge remaining largely focused upon increased knowledge of conditions, interventions and studying quantitative research. I placed greater importance on increasing my clinical knowledge and skills than on the value of my increased ability to relate to and empathise with people that facilitated my helping people to manage their condition through physiotherapy.*

With a background of undergraduate and masters level study comprised predominantly of quantitative research, where the aim was to objectify findings as far as possible, I have found the transition into qualitative research surprisingly challenging, especially considering the paradigmatic shift within my clinical practice. I have also been surprised to realise the extent to which the background context of physiotherapy research being predominantly objective and outcome based, has affected the value that I have placed on my continually developing knowledge of human experience (particularly of living with a neurological condition). Whilst the ongoing improvement of my clinical factual knowledge remains a core aspect of delivering best practice, I now feel more empowered and comfortable to acknowledge and promote the value that my knowledge of human interaction and person-centred care has upon delivering best practice, and on effectively utilising technical knowledge or skills. Critiquing my use and understanding of research as part of becoming a researcher practitioner has synthesised and aligned the way I view myself as a practitioner within the context of physiotherapy research and delivery of evidence based practice.

Part of my professionalism and reflexive practice is the awareness of the specific situation that I and the other person are in, and the ability to make decisions based on this. I see reflexivity as an active skill and dynamic process that is developing my professional practice and my approach to research, and bringing the two aspects of my work closer together. I feel like I am beginning to approach both my research and my practice with ‘the same me’. This brings a sense of relief and ease by simply being me rather than representing the ‘professional me’ or the ‘researcher me,’ but it also brings some discomfort and unease by removing the distance, and anonymity this separation can provide.

Reflexive section: the research process for this study

Extract from Research diary, 2015:

Sample size: I found this element of IPA research difficult to reason through and justify to myself and others, having been surrounded by predominantly quantitative research for most of my study and career. I found myself justifying the sample size of my research when talking with colleagues. I considered increasing the number of participants simply to ‘prove’ the rigour and robustness of my work. I also found the concept of saturation challenging and confusing for this methodology: if I continued to collect data, then surely new themes would continue to be revealed as each individual would reveal unique experiences depending on so many factors. So why would more participants not result in further exploration of peoples’ experiences of physiotherapy? And if there were more themes, would the research not be more valid? Following a discussion about some of the findings from the interviews that I had carried out, I highlighted to my supervisor that I was concerned about my sample size being too small. I was asked why I thought that was the case, and why the data that I had was not enough. I found this a difficult question to answer, and it was only through returning to the philosophy and theories crucial to understanding the value of IPA that I started to feel more informed and confident that validity of IPA research lies within the effective and *thoroughness of the hermeneutic process of making sense of the persons' experience (rather than reporting it), within the context of my own experience. This understanding was reinforced by reading a range of IPA studies and recognising the impact that some of these had on me through the interpreted insights they offered, not through the number of themes highlighted.*

I found I had to keep returning to this throughout this research; I realised how established my own preconceptions about the purpose of research, and what it can demonstrate, actually were.

Reflexive thoughts on Interviewing:

Research diary 2015: *I found the experience of interviewing for this research more challenging than I anticipated. I had read so much about allowing the words of the participant to speak and not allowing my pre-conceptions or prior thoughts to affect their story-telling about their experience, that this was ever present in my head throughout the interviews. I was anxious about not posing leading questions, or putting words into people's mouths. This resulted in me feeling restricted at times during the interviews, and I can hear within the transcripts that often I hesitantly say less when I could have sought further clarification and further depth.*

Following a great deal more reading, and reviewing my own interview skills within this setting, I feel I should have been more confident in my own skills gained through therapeutic communication. I work as a physiotherapist in neurology, and help people with long term and progressive neurological conditions optimise their function. It is fundamental to therapy that I get to know the person, listen to their story, to enable us to discuss what is important to them, and how therapy can help them. I feel on reflection that I interviewed participants in an open and collaborative manner, and hopefully they felt empowered as the experts within the interview- they were sharing their experience to me. I feel a rapport was built effectively. I will discuss ways in which I would change the way I interview, and also some changes that I would make to the research method further in the discussion. Immediately following each interview, I began to form an opinion about how 'valuable' the interview was, how much 'it could tell me,' sometimes feeling I *could have probed further, or that I should continue to search for other participant accounts. However, as I read more IPA studies, I began to understand the methodology more, and, after repeatedly analysing the transcripts, I began to see that each participant experience was significant and meaningful, and provided far more insight than I had first anticipated.*

Gee (2011) ‘reminds first-timers to IPA neither to fear ‘mundanity’ nor conformity.’ When carrying out further IPA research in the future, I now have more confidence and knowledge that human experience is insightful, and the interpreter can illuminate and crystallise key ‘gems’ that enhance understanding of a phenomenon.

Extracts from reflective diary April 2015:

Peter & Mary

The interview with Peter and Mary was not an easy one- they had not had good experiences of physiotherapy and they felt frustrated and let down. This was sad to hear, and also made connecting with Peter challenging as Mary and Peter together presented a narrative of all the difficulties they had encountered, which was tough to penetrate. This was personally challenging, especially as I realised it was initially easier for me to feel empathy with other participants who had perhaps shared more of their story and were less critical of physiotherapy. This was an aspect of myself I felt uncomfortable with and was not aware of before carrying out this research.

However, as I spent more time in Peter’s story, repeating his brief but incisive words, I began to know him better, experiencing further insight into how MS had affected his and Mary’s lives. Seeing Peter smile as he talked about being in a pool trying to swim, allowed me to see Peter’s happiness. This provided me with the contrast; the reality was that his life was difficult, often sad, and his experiences of enjoyment were limited, effortful, and came at a sacrifice (like using the hoist). I recognised that I found it more difficult to communicate and even empathise with Peter and Mary as they were angry and critical. This made me feel *defensive (I wanted to explain why therapists might have made the decisions they had), guilty (physiotherapy had not provided them with what they needed) and sad. Taking time to listen to and reflect on what they were telling me, seeing how life was for them, allowed me to empathise and understand further; heightened awareness of my own reactions and feelings will improve my skills of communication and empathy.*

Bella

Perhaps because Bella was so positive throughout the interview, it allowed me to "rose tint" how Bella experienced and coped with her severe disability due to MS. She expressed 'and don't I wish I could go out and see (the outside world)' wistfully and I felt humbled, lucky, and, if I am honest, also relieved- I was able to walk away, to continue to experience all that was outside Bella's doors. I reflected that at times I find it easier to believe the façade or front that some patients' present- it is less painful and sad to think that people have accepted their situation and even found some contentment within it. However, even if this is the case to some extent, this final comment from Bella was a reminder to me that the loss encountered by PwMS should not be underestimated. Continuing to see the reality of that, helps drive the care I provide to patients.

Purpose of the research, a personal reflection

Extract from research diary following final analysis of data:

Prior to carrying out this research, I had expected the interviews to focus on what aspects of physiotherapy people had found particularly helpful, or unhelpful, and what their experiences of the service were. Certainly this did form part of discussions with each of the participants. However, I was surprised by the extent to which individuals spoke of how they felt about themselves in relation to physiotherapy, rather than how physiotherapy had made them feel. Also underpinning all participant discussions was just how much their physical condition and physical functioning affected their perception of themselves. I reflected on why I was surprised by this.

In my role as a physiotherapist, I listen to difficulties patients are experiencing, identifying and explaining the physical cause of these problems - in this context, how MS pathology is affecting a person's symptoms, and ultimately restricting their function and quality of life. I assess the physical condition and functioning of patients (the effect of the disease on their bodies and how it affects them). I understand that what they are experiencing, how it affects them, and what functioning means for each person is wholly individual and involves a complex number of variables. As long as I can remember, I have been able to see the impact that reduced function, and living with the symptoms of a range of conditions has on people's daily lives-affecting their participation in life in its broadest sense. I have seen the impact this has on how people feel about themselves. Therefore what was it surprising me in these words and further challenging my perceptions?

The words of these participants emotionally resonate and will remain with me, illustrating and reminding me of the effects of living with a condition such as MS, and how physiotherapy can have such a profound effect on a person's life. It has been perplexing and elusive to disentangle and grasp what this research was telling me that disconcerted me by my absence of understanding. I had not realised the extent to which experiencing a bodily change so fundamentally alters self-identity and the way a person feels about themselves. I have gained insight and clarity into recognising that it is not only change in function and the ability to do what people want to in life that affects the way they feel about themselves. The body is not viewed from the perspective of only a physical change (a change in their condition), it is viewed as a change in their whole self-identity. An explicit example of this is seen in Anna's statement; 'I tried to do my exercises the other day. Yesterday I just couldn't lift my leg. I couldn't. My balance was…oh…I was rubbish.' Anna was experiencing weakness in her leg and reduced balance due to her MS, and yet she explained this as 'I was rubbish.' I began to understand the extent to which various aspects, interactions and outcomes (in essence, the experiences) of physiotherapy impact on a person's sense of themselves. Peter describes an episode of physiotherapy where unreliable transport, poor communication, and lack of relevance had all contributed to his poor experience of physiotherapy (i.e. due to a lack in the service provided. However, when asked the *effect this had on Peter, he explained, 'it made me feel pointless really;' Not that the physiotherapy he had received was pointless.*

I thought back to times when I had been talking to patients who were concerned their symptoms were present because they were not trying hard enough, or because they had done something wrong (the perception of having done too much or too little exercise as an example). I had sought to explain that it was their condition that was causing what they were experiencing, not something that they had done- not because of who they were. I thought that it was possible to help people to see that their condition and symptoms were not who they were, but what their condition was. However, my insight and understanding has changed through listening to the experiences of these individuals. There is a connectivity between how people perceive themselves that cannot be separated from their condition, and physical changes and experiences relating to physiotherapy; they are intrinsic to a person's self-identity and perception themselves. Although this shift in perception may seem slight, I know this will improve my physiotherapy practice. As I write this, it seems rather obvious; any one of us feels differently about themselves when affected by any condition.

My training as a physiotherapist, and the continued focus on physical assessment may result in drawing a distinction between the person's sense of themselves, and their physical being, even if considered holistically. This is something I had not previously been as acutely aware of, particularly as I identify myself as adopting a person-centred approach to my practice. Physiotherapy involves a lot of problem solving- being able to treat a person's body is something that we can help with in a practical and tangible way. When I consider the devastating impact that MS has on a person's sense of self, it makes me feel deeply uncomfortable and sad- it is perhaps more manageable to think that I can more easily treat their physical person. In some ways the distinction seems subtle- having a condition such as MS fundamentally affects the way people view and feel about themselves, or that the condition and its affects (and so too the experiences of physiotherapy which affects their physicality) are wholly interconnected and synonymous with *themselves. This insight increases my understanding, awareness and empathy towards my patients, which will improve my physiotherapy practice.*

The interviews: A personal reflection

Each interview took on a different flow, shaped by many factors and impossible to capture without further in-depth discussion and analysis. I have provided a snapshot of each interview below, noting significant challenges or issues that affected the interview, with the aim of introducing participants to the reader, rather than to explore themes or present analytical interpretation.

Peter and Mary- Battling

Peter and Mary expressed the pain and anger they experienced as they felt they had to battle for the physiotherapy they understood to be vital for Peter. Mary, visibly upset and struggling to articulate and find her words, explained:

> …you know, erm…you are denied…you know…there is…physiotherapy could be thought of as a treatment for MS…and yet- it's not available. T1 L184/187.

They spoke evocatively of 'being denied', not being adequately supported or communicated with, or which, for Peter, 'just made life more difficult really' T1L53. They spoke of a range of experiences and how these experiences had affected Peter, 'it made me feel pointless really, because it wasn't helpful…' T1L33

This was a challenging interview. It was sad to see their anguish and resentment, with the battle they described fighting, their fears for the future and of the battles that were ahead for them. Mary, angry and upset, explained to me that they:

> Mary: were was so scared that [Peter] would lose what we had…what we had erm, erm… *(struggled to continue)*…
>
> Peter: built up
>
> Mary: yes, built up you see. T1L202/204

My initial perception was that Peter and Mary were presenting their story to me, a physiotherapist and researcher, as both a critical insight and as a challenge; "this is what we have had to experience from your profession. Can you make this any better?" However, this could have been a personal reaction, rather than their intention. This felt personal because of my role as both a physiotherapist and as clinical lead for the services they had received. This was the only interview carried out with a couple. I had arranged the interview with Peter, but Mary was there when I arrived and Peter asked Mary 'Well, you had better help tell my story…' T1L4. It did not feel right to ask Peter to interview on his own after he had expressed his preference. One of the difficulties with this was that Mary spoke for more of the interview than Peter, possibly as his speech was slower and more effortful and his memory impaired and Mary was trying to help him. It could have also been, even in part, that Mary wanted to explain the experience from her perspective. A significant part of the interview was Mary's experience and feelings regarding Peter's experience of Physiotherapy (and their experience as a couple), although there was mutual agreement and collaboration between them throughout the interview. Some of their experience of physiotherapy and of living with MS can be understood through the interaction between them, which provides valuable level insight.

Bella- I've totally got this

Bella's MS is advanced and severely affects her motor function and energy levels. Speech was effortful for her. She was able to speak slowly for one or two sentences but then became tired and needed to rest; the interview as a whole was physically and mentally effortful for her. Bella had arranged the interview by phone, and had not been required to talk for very long, before she handed over to her carer to arrange the details with me. Though it was clear that she had difficulty with her speech over the phone, the extent of her fatigue was not apparent. In light of this, I would consider some changes to the way that I recruited participants if I were to carry out this research again. I might have considered carrying out several short interviews as an example. I was aware of the potentially negative impact of the interview on Bella's fatigue, and how that might affect her later that day (as well as at the time), therefore her fatigue did affect how much I was able to question Bella. Her fatigue, and speech difficulties likely also affected her answers as it was difficult for her to explore some issues more fully because she was finding it so challenging to converse. Bella was determined throughout the interview to show me that despite the severity of her MS, she ‘was totally compos mentis’ T2 L30, fiercely independent, ‘all they had to do was explain it to me once, then I take it up from there’ T2 L32, and very positive, reporting that ‘all of [her] experiences have been good’ T2L2 and [she had] ‘had all the physiotherapy that [she] needed’ T2L3. She did allow me to briefly step a little further into her thoughts at points, but I could see that this was exhausting for her, ‘I get very physically tired…’ T2L42 and, as I was leaving:

> Me: Nice to meet you, and see the lovely place where you live…
>
> Bella: And, don’t I wish I could go out and see it…thank you for coming T2L87/88

Anna- the mind is willing

Anna entered easily and openly into conversation, sharing a lot about herself, her life and her experiences of physiotherapy. She talked about her experiences of physiotherapy in the way that she reflected on living with MS, overcoming many different situations that life had presented to her- with positivity, humour and resilience. Her memories were clear and abundant and she was able to describe her personal journey through various life transitions, battling with aspects of determination and acceptance, usually culminating in Anna finding resolution and fulfilment in the best way she could. Despite this, Anna was often quite critical of herself:

> But, I am still stupid…because, the mind is willing, but the body isn’t…and I keep telling people, listen to your body, listen…And, am I doing it? (Laughs)… Well, I’m not you see! T3L341/342.

Her ability to adapt to changes caused by her MS is illustrated when Anna describes how she felt when she was offered a walking frame in a physiotherapy session:

> [I thought] ‘this is not me, I am not an old woman,’ going round using a walker! (Laughs in mock outrage)
>
> Me: I can understand that. So, then you continued on using the stick?
>
> Anna: (laughs) Until whenever! (laughs). Now, I am using a walker (shrugs shoulders and raises her eyebrows) …I used it a lot once I started using it. I have used it an awful lot in the last few years. It’s been great. But it went all rickety…and so I have bought a new one myself…I call it my Jag! (laughs) T3L66/72.

She returns to this later and describes how she uses the walker to improve her quality of life:

> I still love going for walks over the pier. I love doing that. And, with this *(indicates her walker)*, I can do this. If I find, oh, I am getting wobbly, I can sit…Until I am OK, and then I can make my way to the end for my panad * and scone. I love doing that…yes…(smiles and seems to reflect)
>
> T3L212/214.

*tea in welsh

She highlights throughout the interview that she is a determined person, using completion of exercise programmes as one example:

> I have already done my exercises today, and my balance was super today…I do sit ups as well…I couldn't do them yesterday…but I did 20 today. I did my 20.
>
> Me: Great. I am very impressed!
>
> Anna: Well, the thing is that if I didn't do it, I would be in a corner- And I don't want to be in a corner. T3L346/350

Anna also provides insight into her fears of the future and of a possible future deterioration in her condition.

Fran

Fran had recently been diagnosed with MS and was interviewed following recovery from her first 2 relapses when physiotherapy had played a pivotal role in her emotional and physical rehabilitation:

> [ ] because I would say that it has made the difference between being back at work, and driving, and me not being back at work and driving T4L42/43.

Fran's feelings at the time of diagnosis, and the subsequent loss of being able to drive, work and function, were fresh and raw, and she explored the effect of her experiences of physiotherapy on her feelings:

> [ ] and actually just someone being there, and giving you the feedback, and somebody being interested… and actually being interested… (made such a difference) T4L152/155

> Fran: But I would use the physio advice about what was working, and how…If that makes sense?
>
> Me: It does make sense, yes…
>
> Fran:…erm, so, for me personally, it, the physios made the difference between me being able to walk and get up and down the stairs in this house, drive, work, and actually, because of how low all of that makes you feel when you have been

> reasonably functioning before, and you just can’t…like your world has changed, and you just can’t do anything… might even be why I am still here…T4L219/226

This was a difficult interview in confronting Fran’s directness about her feelings of desolation and loss of hope, particularly as my close family member has committed suicide. I appreciated and valued her honesty; the extent of devastation experienced through having a condition such as MS could not be more apparent, and this is something that will remain with me as I work alongside other people that have similar conditions. Despite it being deeply unsettling for me, it will ensure I have increased empathy and understanding with my patients.

Fran also explained her experiences of physiotherapy from a practical perspective:

> …and I had cut my hours, so she managed to see me on the whole where I didn’t need to take time off work to get to it…Which, you know, from my point of view, that was brilliant. T4L286/288

And from a physical perspective:

> And, so, even just getting stretches, to be able to get everything stretched, so you could actually be in a normal position…T4L133/134
>
> That, as I said, to be honest, would be, you couldn’t put a value on what that gave…But, if I was to say the one bit that has made a difference in all the treatment. The one bit that actually I want…But, err, the physio bit has made the difference between functioning and not.T4 L206/214

Fran works in healthcare. I considered whether she was more able to talk to me about certain aspects of her experience, relating to me as a fellow health professional. She was extremely insightful about service delivery and patient centred care and this was likely informed by her training and vocation. I found it surprising that Fran, as a health professional being treated in the NHS, did not expect person centred care, instead that she found it remarkable. I felt sad that something as simple as sharing conversation was an exception rather than an experienced expectation.

> And just things like you seeing a human being who was treating you like a human being. So, even when she (referring to the physio) was going on holiday, she said that she was going bird watching to see Condors. Actually, that’s nice, ‘cos that makes you feel like somebody actually…..it made me feel that somebody was actually treating me like a person T4L395/398

Clare

Clare worked as a volunteer for the local MS Society and was keen throughout the interview to discuss the value of the society and the exercise group that the local branch had set up:

> [Talking about her first experience of physiotherapy] '…and then just linked in with the same physio and the team really. And then I got involved with the local MS branch. And (local MS charity) were involved too, and that's how that class started off
>
> And that was good, because then was a, sort of…nucleus? Although there were lots of different symptoms, a lot of themes going on, I think it was good understanding…?
>
> Me: to be with other people who have MS?
>
> Clare: Yes, I felt that very very strongly. And other members of the group are saying the same things now. So that was good, and that seemed quite strong…T5L17/24

This formed a frame of reference for many aspects on the interview. My concern to allow participants to tell their story, to talk about their experiences, was prominent in my mind during interviewing. On reflection, and as a more skilled interviewer following some experience, I might have been able to find out more about Clare's experiences of physiotherapy if I initially explored her experiences of the MS Society and the class, and then moved on to ask more probing questions to develop discussions around physiotherapy. Clare talked about the need for feedback and education:

> I mean, when I came to see Catrina, and I thought that I was doing the exercises right, 'yeah, I am doing these exercises,' and Catrina just moved me slightly like that, and I thought 'I wasn't doing those exercises right!'
>
> It's having someone there just to correct things… T5L121/124

She also talked about the need for consistency, organisation and communication as being key to effective physiotherapy for her and explored issues around adherence and her ability to follow rehabilitation programme:

> It's great that I have been given the exercises, and I mean to do them more, but basically it just doesn't happen…So, this exercise class that runs weekly is essential. And, I've asked some of the others as well, and, they say, 'we mean to', 'we've got the thera-bands!'…but it just doesn't happen on your own. T5L53/56

> Clare: I think it's the continuity of the services and between services…it's good, but you are, sort of doing it on your own…but because they have to get you to do it on your own…they are all linked, but I just don't know how well they are followed through, if that makes sense?
>
> Me: The transition between services are not easy?
>
> Clare: I think the intentions are there to do it, but I'm not sure if there is a monitoring or feedback idea to see if it is really happening. T5L105/111

Clare talked in the abstract, or about a group of people rather than talking about herself. This might have made her feel more comfortable about discussing issues, as it made them less personal or identifiable to her. Or it might be her role in the MS Society made her feel that she should represent the group of people that she supported.

Julie

I had encountered Julie in many clinic settings and had also been her physiotherapist in the past. Initially Julie was keen to express to me that she was very happy with all the services that she had received, and I felt that Julie considered that this interview was something that she could do to help support me and show appreciation for the services that she had received:

> (when asked about her experience of physiotherapy)…well, very good. Very good! T6L5
>
> Even if I have gone to the doctor with something unrelated to MS that I need physio for, I have not had to wait that long. So, yeah, I am quite pleased about that. Well, I am very pleased with that. Erm. Yes, and everybody has been very courteous, they always treat you very…you know. Properly. So, yes, it's been a good experience…T6L10/15

However, as she relaxed into the interview, she started to talk more about living with MS, and arising from this, her experiences of physiotherapy, particularly in terms of helping her remain independent, and what this meant to her:

> And, you know, with the exercises that Lucy gave me, erm, sort of hints…you know if I fall or something…I had to get up. And there was nothing to pull up on. So, I just, sort of…lay there for a bit, and then I managed to, sort of, turn myself onto my bottom and shuffle to the chair where I could… (indicates getting onto knees and then up onto hands) you know? It wasn't that far to shuffle. But, before, I wouldn't have known how to get up. I would have thought 'oh no, what am I going to do…' you know? T6L57/70
>
> You know I am really independent, erm, that's a last, last resort (referring to a pendant alarm). But, you know, it's nice to have it there if I need it. But with the tools that Lucy has given me, then I can sort myself out! T6L90/93

Clare and Julie attended the same MS support group and exercise class, and Julie shared a lot of the thoughts and experiences that Clare had about compliance with rehabilitation and the benefits of group exercise:

> And I really look forwards to the meeting. Its' a chance to be with people, and it makes the physio easier to do…It's just an hour, but it's a chance to…to be with people. And it makes the physio easier to do, you know? And it makes me, just… 'oh come, you can do it, you've only got 3 more…' T6L98/102

> As I say, the group that I go to is brilliant, and it motivates people. And I really look forwards to going. You know? Plus, we have a laugh as well. And, you know what they say- that's the best medicine sometimes isn't it? T6L178/180

Julie talked openly about her experiences of using leisure centre services in a revealing dialogue that captured insight into Julie's self-identity as well as into her experiences of trying to live with MS within an environment that it not best suited for her needs.

Critical reflection on being a researcher practitioner

Research background:

I started this academic research journey by carrying out a masters in research. Up until this point, my experience with research was limited to an undergraduate physiotherapy degree, and a selection of masters' modules specific to neurological rehabilitation. I also read a considerable amount of research as part of my professional development. With a view to completing a master's degree, I studied a module in qualitative research methods at Glyndwr University, to include exploring the use of narratives in healthcare research. Until this point, my experience and knowledge was predominantly focused within quantitative research. The module on the use of narratives in healthcare engaged my interest, and coincided with being tasked with reviewing physiotherapy services for PwMS in North Wales as part of my job. Prompted by my expanded view of research methods, I looked to the research to see what was known about the experiences of physiotherapy for PwMS and was surprised by how little was known about this from a patient perspective. Following discussion with staff from Glyndwr University on the professional doctorate course, I decided to enrol on the professional doctorate programme. My aim was to explore and develop research that would facilitate improving physiotherapy services for PwMS in the geographical area through increasing my own research knowledge, and carrying out my own research. My starting premise was to find out what experiences of physiotherapy currently were for this population. From this point, I started the professional doctorate course and began to learn more about research methods and methodologies through various modules and lectures, culminating in the inception of this research in the form of a research proposal and poster presentation, with supporting information in a professional portfolio. How my research developed from the beginnings of this idea is described within chapter three.

I have been continually learning and reflecting throughout the course of this research. In the following section, I will discuss how my practice has changed through becoming a researcher practitioner, to include times when this has either created conflict, or married with my clinical practice. I will also explore some concepts I have found particularly challenging when carrying out this research.

Reflexivity as a researcher practitioner:

Colbourne & Sque (2004) suggest using a reflexive approach throughout a research study may not be easy, partly due to the concept being widely described, but less well defined within the literature, and also that knowing how to achieve it is difficult. I see reflexivity as an active skill and dynamic process that is continually developing my professional practice, my skills and approach to research and my knowledge of people and helps to bring these aspects closer together. Prior to this point, I viewed research as an adjunct to clinical practice and experience, viewing research with a different hat on to that needed for clinical practice. Synthesising my approach has allowed me to understand and utilise research with relevance to practice, while my clinical practice provides a lens through which I contextualise and understand research, making it more relevant and beneficial to patient care. Reflexivity has helped me challenge each of these aspects as I learned more about each of them (and about myself). I approach research and practice with 'the same me' far more than I have in the past. This suggestion is affirmed by Chesney (2000), 'with all practitioners undertaking research, their approach to the research process will have certain parallels with their practice' (p128).

As far as I was aware, person-centred care and adopting a holistic approach to physiotherapy was intrinsic to my practice for some time (I have been a physiotherapist for many years, and this approach to physiotherapy was adopted from when I first encountered physiotherapy, though within my level of knowledge and experience). What I found surprising upon early reflection in this research journey, is that I viewed this approach as being more relevant to clinical practice rather than research. When considering the research, I focused on trying to provide evidence based care for patients, targeting interventions that were shown to be effective, whilst trying to deliver them in a person-focused, individualised way.

Challenges of this research:

It has taken me to within weeks of completing this doctorate to come to a point where I feel wholly comfortable and confident in the research value gained through analysing the experiences of a small group of individuals to stand alongside a large multi-centred randomised controlled trial as an example, in terms of importance and contribution. The voices of people who have experienced living with conditions (or experiencing physiotherapy whilst living with a particular condition in this case) can have a potentially greater impact on practice through a more relevant and human connection. At the early stages of discussing my research with physiotherapy colleagues, I was reluctant to talk about the number of interviews I had carried out or that the interviews were unstructured and guided by participants, as examples of my lack of confidence this research would be accepted or respected within physiotherapy. As I progressed with this research, several IPA and other qualitative research I have read have made a lasting impact on me. More pertinently, experiencing the impact the participants in this study have had on myself and my practice, I increasingly understand and appreciate the philosophy behind this research. I feel more empowered to discuss the value and contribution this approach to research can make within healthcare and physiotherapy. I am a member of an online IPA forum, and this has further helped me to share experiences and views with a wide range of researchers using IPA to include novice researchers with minimal background in qualitative research such as myself. It has helped support my learning and development to hear questions that other researchers pose, as well as learn from the answers more experienced researchers provide.

There were various challenges and joys within my experience of interviewing. I felt honoured and thoroughly enjoyed getting to know these people in greater depth through their honest sharing. However, this revealed significant pain, anger and sadness in their lives that I found upsetting and difficult. I felt challenged in my professional role during some interviews, most markedly in the interview with Peter and Mary, where it was apparent that services had not met their needs and it felt like they wanted answers to these problems from me.

The presence of the researcher is intrinsic to IPA. Throughout this research, I have been aware of my lack of experience of IPA. It has taken some time to develop the confidence and belief that my interpretation of the words these people shared with me actually added value, when I felt that perhaps the strength of the research was simply in their (uninterpreted) words. I remember several times thinking that if I just typed up and shared the entire transcripts with colleagues, they would have significant impact and would reach out to the reader, as they had to me. However, I began to see that the words on the page meant more to me when I repeatedly read them and immersed myself in them, particularly as I was able to recall the participants' expressions, body language and emotion and understand the context and depth of the conversation. In this way, through detailed interpretation, I have been able to bring further depth and understanding to these transcripts, providing the reader with insight and knowledge through the lens of myself as a researcher practitioner (with all the clinical and research experience that entails). Immersion in the data, developing themes and then comparing and contrasting them between individuals further increased meaning and understanding into the experience of physiotherapy compared with reading the transcript without further analysis or interpretation would provide.

One of the challenges I experienced when writing up this research was finding myself drawn towards trying to 'back up' what the analysis of my research suggested, by using literature rather than the words of the participants. This illustrated to me that my preconceived ideas and experiences of research still remain with me to some extent, and I am continually challenging this.

Appendix II: Welsh speakers in North Wales

County in North Wales	**Percentage of welsh speakers (people over 3 years old)**
Anglesey	60.8
Gwynedd	71.1
Conwy	39.5
Denbighshire	35.9
Flintshire	19.7
Wrexham	25

TABLE SHOWING PERCENTAGE OF WELSH SPEAKERS IN NORTH WALES (WELSH GOVERNMENT, 2017)

Appendix III: Physiotherapy research utilising IPA

Table showing published physiotherapy research using IPA

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Arvinen-Barrow et al. 2010 *Psychology of Sport and Exercise journal*	UK chartered physiotherapists' personal experiences in using psychological interventions with injured athletes: An Interpretative Phenomenological Analysis	To explore physiotherapists' personal experiences in using psychological intervention techniques as part of sport injury rehabilitation	Semi-structured interviews with 7 physiotherapist participants, 1 detailed 'hand' analysis, the other analysed using computer software, verified by other researchers	Interpretive analysis supported by verbatim extracts. Detail of the individual as well as the overarching themes, looking for group themes. Synthesised descriptive interpretation	No reflexivity apparent within paper Clear link to practice 8 pages without references
Brazete Cruz et al. 2014 *Physiotherapy theory and practice*	A narrative reasoning course to promote patient-centred practice in a physiotherapy undergraduate programme: a qualitative study of final year students	To explore the students' perspectives about the contribution of a narrative reasoning course to promote patient-centred practice	Focus groups with 18 physiotherapy student participants	3 main themes generated and then discussed with support from verbatim extracts. Discussed in context with the literature in next section.	Minimal focus on the individual as the was co-constructed through focus group discussion Clear recommendations for practice and link to practice (education) based on findings 5 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Bulley et al. 2011 *Physiotherapy*	User experiences, preferences and choices relating to functional electrical stimulation and ankle foot orthoses for foot drop after stroke	Explore experiences, preferences and choices relating to the use of AFOs and functional electrical stimulation for foot drop by people who have suffered a stroke and their carers', with the aim of informing clinical decision-making	Semi-structured interviews with 13 patient participants Used NUD*IST for thematic analysis. Read like a thematic rather than an interpretive analysis.	Descriptions about preferring AFOs and preferring FES were presented with verbatim extracts supporting preferences. Factual account. Generated a table of positive and negative experiences, preferences and choices	'neutral' researcher, researcher not visible, no reflexivity demonstrated, Minimal interpretation clear link to clinical practice 7 pages without references
Cassidy et al. 2011 *Physiotherapy Theory and Practice*	Using interpretative phenomenological analysis to inform physiotherapy practice: An introduction with reference to the lived experience of cerebellar ataxia	To introduce IPA as an approach to qualitative research, and aims to show how it can help clinicians understand patients experiences and hope the findings might be used to inform physiotherapy practice	Semi-structured interviews with 12 patient participants Interpretation apparent and comprehensive as meets the aim of this research paper	No thematic findings as this paper is written to detail the approach rather than the findings There is a data analysis section and then a discussion	Data analysis comprehensive but written to explore IPA as a technique. Detailed interpretation Does have implications for practice from the data discussed 13 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Cassidy et al. 2018 *Disability and Rehabilitation*	The meanings of physiotherapy and exercise for people living with progressive cerebellar ataxia: an interpretative phenomenological analysis.	To understand the meanings of exercise and physiotherapy for people living with a progressive cerebellar ataxia	An interpretative phenomenological analysis was undertaken with 12 participants (4 women, 8 men) recruited via their membership of a national support group. Semi structured interviews were audio recorded and transcribed. Data were analysed using interpretivist methods	Two main themes: participants valued collaborative & supportive long-term therapeutic relationships with expert physiotherapists and were not necessarily looking to improve ataxia-related impairments; self-devised exercise conferred multiple psychosocial benefits that were largely absent from physiotherapist-prescribed home exercise programs	Rich interpretation and analysis clear link to clinical practice 10 pages without references
Connell et al. 2014 *Physiotherapy*	Stroke survivors' experiences of somatosensory impairment after stroke: an IPA	To **gain insight** into how stroke survivors experience somatosensory impairment after stroke	Semi-structured interviews with 5 patient participants Data analysis followed step by step guidelines of Smith et al. (2009)	3 superordinate themes identified- these were explored and illustrated with extracts and interpretation within the limitations of word count	Reflexivity is apparent and the context of the researchers is explained Clear link to clinical practice 5 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Dean et al. 2005 *Disability and Rehabilitation*	Managing time: An interpretative phenomenological analysis of patients' and physiotherapists' perceptions of adherence to therapeutic exercise for low back pain	To **explore** patients' and physiotherapists' perceptions about exercise adherence	Semi-structured interviews with 9 participant patients, 8 therapists	Interpretive analysis with verbatim extracts to support analysis Identifies aspects of patient centred care as identified by participants	In depth interpretive analysis in keeping with IPA Researcher not visible but reflexivity is apparent Clear link to clinical practice 11 pages without references
Karnad and McLean 2011 *International Journal of Physiotherapy and Research*	Physiotherapists' perceptions of patient adherence to home exercises in chronic musculoskeletal rehabilitation	To **explore** UK Physiotherapists' perceptions of exercise adherence and their interventions to tackle it in clinical practice	Semi-structured interviews with 5 physiotherapist participants	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	11 pages without references Reflexivity apparent and researcher contextualised and visible
Milligan 2014 *Nurse Education today*	Super-Human? Perceptions of accelerated students and graduates working in healthcare	To **explore** clinician's perceptions of accelerated pre-registration courses in physiotherapy	Semi-structured interviews with 14 physiotherapist participants	2 superordinate themes, 4 themes. Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	5 pages without references Clear link to practice within education

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Schofield and Horobin 2014 *Physiotherapy Theory and Practice*	Growing up with Primary Ciliary Dyskinesia in Bradford, UK: exploring patients experiences as a physiotherapist	To **explore** the physiotherapy experiences of patients and their parents. Also aimed to identify patients' needs and inform future service developments	Semi-structured interviews with 5 patient and carer participants	3 themes, Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	7 pages without references Discusses the contribution of IPA research to physio as well as making recommendations for clinical reflection and practice
Wickford 2014 *European Journal of Physiotherapy*	Conscious seeing: a description of a reflective framework used with final year Swedish physiotherapy students in the context of international clinical placement	This was a descriptive paper rather than research, describing a reflective framework used by physiotherapy students where they used IPA to analyse data from a reflective process	8 students and 2 supervisors used the framework	The outcomes were around learning experiences rather than themes generated from the data	The framework was the focus of this paper rather than IPA method which was only overviewed 7 pages without references
Wilkie et al 2012 Physiotherapy Theory and Practice	"Functional electrical stimulation (FES) impacted on important aspects of my life"—A qualitative exploration of chronic stroke patients' and carers' perceptions of FES in the management of dropped foot	Our purpose was to **explore** the impact of (FES), as applied in the management of dropped foot, on patients with chronic stroke and their carers.	13 patients and 9 carers	One main theme and 4 sub themes	Strong clinical impact and relevance 9 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings**	**Notes about the research**
Williamson et al. 2015 *Physiotherapy*	If I can get over that, I can get over anything- understanding how individuals with acute whiplash disorders form beliefs about pain and recovery: a qualitative study	To identify beliefs about pain and recovery present in the narratives of these individuals and to understand how and why individual's came to hold these beliefs	20 patient participants were part of an RCT and then interviewed afterwards	4 main themes, 8 sub-themes Descriptive and interpretive analysis in themes with verbatim extracts to support analysis Presented in tables	Clinical implications apparent Reflexivity recognised 8 pages without references
Wilson et al. 2016 *Physiotherapy*	Psychologically informed physiotherapy for chronic pain: patient experiences of treatment and therapeutic process	To investigate patients beliefs and experiences of this type of treatment, and helpful and unhelpful experiences	Semi-structured interviews with 8 patient participants interviewed following intervention- they were also assessed with a range of other outcomes	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis Four themes identified	?Focus was more on assessing the intervention rather than on participants experiences 7 pages without references
Wood et al. 2013 *Palliative Medicine*	Individual experiences and impacts of a physiotherapist-led, non-pharmacological breathlessness programme for patients with intra-thoracic malignancy: A qualitative study	To **evaluate** how patients with intra-thoracic malignancy undergoing the non-pharmacological breathlessness management programmes benefited from the programme	Semi-structured interviews 9 patient participants Phenomenological approach IPA	Termed results Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researchers job title mentioned no reflexivity demonstrated Clear link to clinical practice 8 pages without references

Table showing published physiotherapy research using IPA

Appendix IV: COREQ criteria

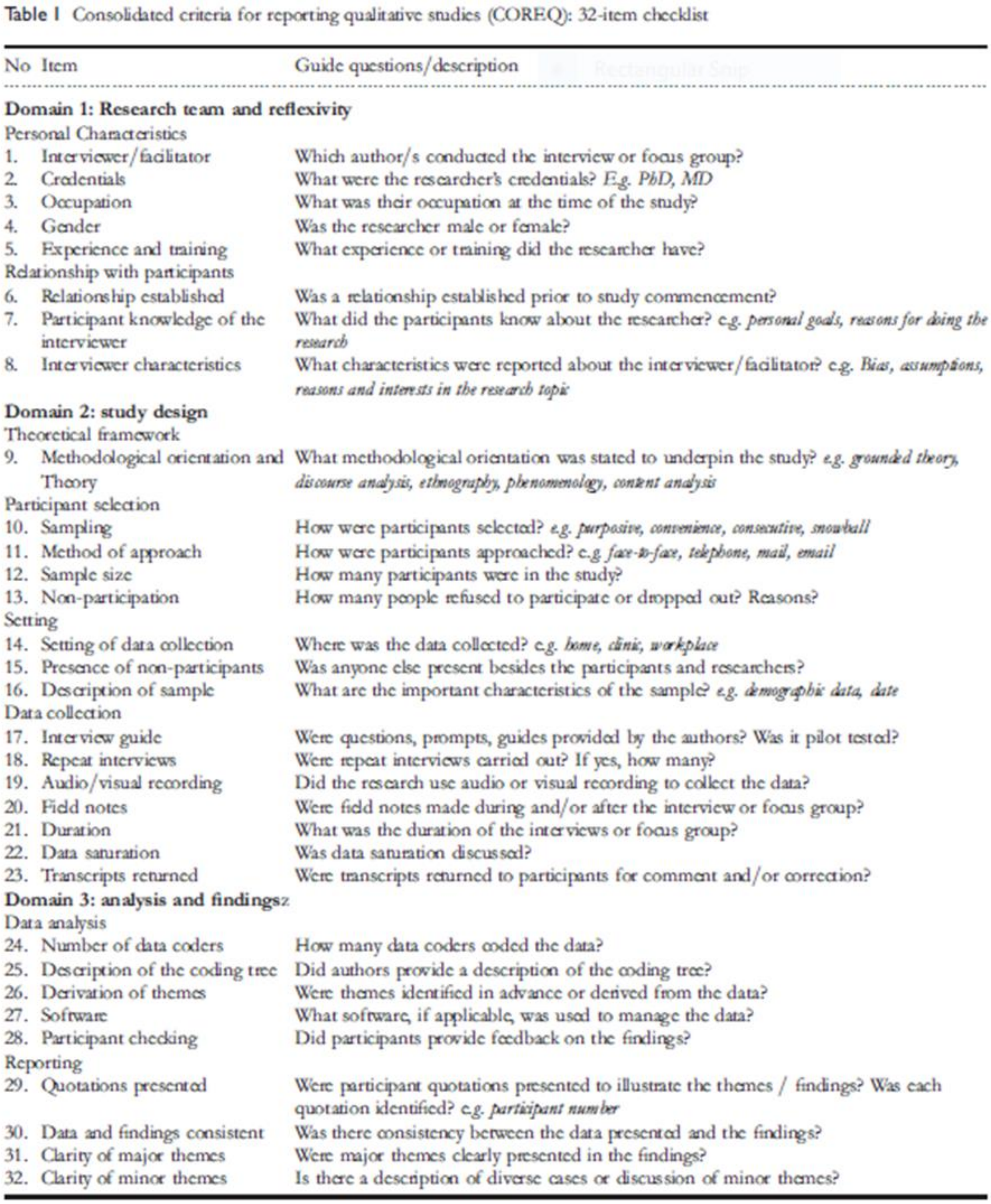

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.g *face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Table 1 from Tong, Sainsbury and Craig, 2007, p352, CRITERIA FOR REPORTING QUALITATIVE STUDIES (COREQ): 32 ITEM CHECKLIST

Appendix V: The lived experience of MS

Table A presenting published papers regarding lived experience of MS in the UK within the last 5 years

Authors & date of publication	Title	Methodology	Main themes
Browne et al. (2015)	Bladder dysfunction and quality of life for people with multiple sclerosis	19 PwMS, semi-structured interviews carried out by 3 different researchers (physiotherapy research students), audio recorded. Does not state where interviews were carried out. Thematic analysis- detailed description of process, coding and analysis carried out by all three authors, NVivo software used. Member checking was carried out by sending the key points from each person's own interview to them- no requests for revision were made Clear development of themes and representative use of participants and extracts to illustrate themes Reflexivity apparent and incorporated into research, researchers are described and situated	Disruption and loss Ways of knowing (trying to recognise their symptoms and trying to 'get a handle on it')
Davies et al. (2015)	'You are just left to get on with it': qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis (SPMS)	20 PwMS, 13 carers, semi-structured interviews, clear description of sample method. All interviews carried out by one experienced researcher who was not known to participants, audio recorded and subsequent focus groups conducted for interview content validation. Mostly interviewed at home but some chose to be interviewed at the hospital, and one at a coffee shop (Inductive) Thematic analysis- detailed description. NVivo software used. 2 authors made notes and read 4 interviews independently and a codebook was generated jointly. Then all scripts were coded by one author and themes generated were all discussed with second author Reflexivity not mentioned or apparent, researchers not described/situated	Themes around disease progression Realisation (they had MS) Reaction (response to this realisation) Realities (of living with SPMS) Recognising future challenges

Authors & date of publication	Title	Methodology	Main themes
Frost et al. (2017)	A qualitative investigation of lay perspectives of diagnosis and self-management strategies employed by people with progressive multiple sclerosis	14 PwMS, semi-structured interviews, clear description of sample method. Broad sample with wide representation. All interviews carried out by one researcher who was not known to participants, audio recorded. All interviewed at home. It was not mentioned that some participants were interviewed with their spouse but one extract had verbatim quotes that included the wife of PwMS Thematic analysis carried out initially by 2 authors and then then 3rd for further analysis- minimal/no description of this process except that NVivo software used. Reflexivity not mentioned or apparent, researchers not described/situated within text but biographies provided that were relevant to this research	The diagnostic process and certainty Sense making and uncertainty Self-management and management of self Fears for the future and death as the only certainty
Hardwick (2017)	Paul Ricoeur's theory of interpretation adapted as a method for narrative analysis to capture the existential realities expressed in stories from people living with Multiple Sclerosis	The study involved 10 PwMS but this article involved 2 PwMS and the wider study awaits publication. The recruitment of the 10 participants was through a regional therapy unit but no further detail was given about this process or about the participants. This study focuses on methodology of Ricoeur's theory of interpretation through the presentation of two narratives. The narrative interview was opened with asking participants to tell their story related to the onset of and adjustment to MS and the interaction was participant led thereafter. No further detail about the interview in terms of where it was carried out etc. was provided as the focus is then on the interpretation and the interpretive method	Themes identified in both narratives had different themes to include Time (past and present) powerlessness, Trauma/stress, acceptance and carrying on, the embodied self, being abandoned, alone & suffering in silence
Newton et al. (2016)	The experience of fatigue in MS- a thematic synthesis	Systematic review and thematic synthesis-the nine articles included in this synthesis were not within the inclusion criteria for this review, therefore this review has not been included within this section	

Authors & date of publication	Title	Methodology	Main themes
O'Loughlin et al. (2017)	The experience of transitioning from relapsing remitting to secondary progressive multiple sclerosis: views of patients and health professionals	Thematic analysis involving 9 PwMS in London and 7 specialised MS specialist health professionals participating in semi-structured interviews. Clear description of purposive sample method. All interviews carried out at participant homes, audio recorded. It is not clear who carried out the interviews. Sample of interview schedule included. Process of thematic analysis is detailed, NVivo software used. Carried out by key researcher but some sections were analysed by co-researchers to increase validation. Reflexivity is suggested in the methodology but not further expanded on or apparent.	Is this really happening? Becoming a reality A life of struggle Brushing oneself off and moving on Supported and well-illustrated by extracts
Preston et al. (2014)	Understanding the lived experience of people with MS and dysexecutive syndrome	IPA study, Purposive sample, 10 PwMS inclusion criteria- MS and have executive function deficits (as measured by the Behavioural Assessment of Dysexecutive Syndrome). Lack of clarity around recruitment process. Semi-structured interviews carried out by one researcher at the rehabilitation centre (at participants' request). Question: 'tell me about your experience of MS,' and then the interview continued through conversation. Use of IPA for analysis, described process clearly, reflexivity present. The author explained that this research article focused on the third theme as this was the predominant theme associated with Dysexecutive syndrome.	Three emergent constructs: gaining mastery of the disease, the reality of living with MS, the implications of MS for personal identity.
Soundy et al. (2016)	The Psychological Processes of Adaptation and Hope in Patients with Multiple Sclerosis: A Thematic Synthesis	Systematic review, critical appraisal and thematic synthesis-the 47 articles included in this synthesis were not within the inclusion criteria for this review, therefore this review has not been included within this section	

Authors & date of publication	Title	Methodology	Main themes
Strickland et al. (2016)	The liminal self in people with multiple sclerosis: an interpretative phenomenological exploration of being diagnosed	IPA study, Recruitment from a neurological clinic in Scotland- PwMS who had been diagnosed in the past 6 months. 10 participants interviewed in participants' homes, all by one researcher. 5 were interviewed with their nominated support person (participants could choose whether they were interviewed on their own or in a pair). Explained that this study was part of a larger one which also explored the views of support persons. Interviewed again in 6-12 months' time. Flexible interview guide, examples given. IPA analysis process explained and illustrated. Four transcripts were independently analysed by two other authors. Triangulation of data with supporter interview. Themes illustrated with extracts though only 5 participants used	Road to diagnosis The liminal self Learning to live with MS: an uncertain future

Table A presenting published papers regarding lived experience of MS in the UK within the last 5 years

Table B presenting published papers regarding lived experience of MS (internationally) within the last 5 years

Authors, date Country of research	**Title**	**Research Overview**
Asano et al., 2015, MS international, America & Canada	The lived experience of MS relapse: how adults with MS processed their relapse experience and evaluated their need for post relapse care	Experience of MS relapse 17 adults, semi-structured interview-questions focused on experience of relapse. Four relapse management patterns identified; Active Relapse Manager, Early-Stage Proactive Relapse Monitor, Adapted Passive Relapse Manager, and Passive Relapse Monitor. The relapse management patterns appeared to associate strongly with the appraisal of the experience.
Ghafari et al., 2015, Contemporary nurse, Iran	Patients' experiences of adapting to multiple sclerosis: a qualitative study	25 adults, semi-structured interviews Interviews and content analysis Themes: Religiosity, Information seeking Seeking support Maintaining hope Concealing the disease Emotional responses Fighting the disease and disability
Silverman et al., 2017, Disability and Rehabilitation USA	Bouncing back again, and again: a qualitative study of resilience in people with multiple sclerosis	The purpose of this study was to describe the meaning of resilience, factors facilitating resilience and barriers to resilience, from the perspective of persons with multiple sclerosis, their care partners and community stakeholders. Four focus groups. Psychological adaptation, social connection, life meaning, planning and physical wellness emerged as facilitators of resilience. Resilience depletion, negative thoughts and feelings, social limitations, social stigma and physical fatigue emerged as barriers to resilience

Authors, date Country of research	**Title**	**Research Overview**
Turpin et al., 2018 Australia	Understanding and living with MS fatigue	13 in depth semi-structured interviews with people who experience MS related fatigue. Existential approach to thematic analysis. Participants developed an understanding of multiple sclerosis fatigue through gaining awareness of its effect on their lives, seeking information themselves and being informed by health professionals. Participants described how they began to understand the effect of fatigue in their lives and make decisions about how to accommodate it. They discussed the challenges associated with helping others to understand their multiple sclerosis fatigue.
Pretorius & Joubert, 2014, Health SA Gesondheid South Africa	The experiences of individuals with MS in the Western Cape, South Africa	10, South Africa, Interviews and thematic analysis The focus of this study was on the challenges faced by individuals with MS, as well as the resources that help them to cope with MS The process of being diagnosed, daily life, invisible illness and medical aid schemes Coping: social support, mobility aids, religion and knowledge about MS

Table B presenting published papers regarding lived experience of MS (internationally) within the last 5 years

Table C presenting published papers regarding lived experience of MS prior to 2013 (UK and International)

Author, date and title	Participant number & place of residence, Method Focus	Themes
Barker-Collo et al 2006, Into the unknown: the experiences of individuals living with multiple sclerosis	16, New Zealand Interviews and thematic analysis The impact of the diagnostic process and of receiving the diagnosis	Pre-diagnosis: build-up of symptoms until threshold The Diagnostic Experience: powerlessness, readiness to hear about MS Reactions to Diagnosis: lesser of two evils Living with MS: the impact of disease course, challenges and changes, re-evaluating priorities and living life to the fullest.
Boeije et al 2002, Encountering the downward phase: biographical work in PwMS living at home	22 PwMS and 22 care givers, Netherlands and Belgium Interviews and Constant comparison analysis How individuals in the advanced stage of MS accommodate to their illness- included as also focused on broader experience of having MS	Body and performance failure Biographical time Conceptions of self
Dennison et al 2010 Experiences of adjusting to early stage MS	30, UK Interviews and thematic analysis regarding early MS	Early stage MS was typically considered difficult but manageable and was dealt with through positivity and practical strategies to preserve normal life. However, adjustment seemed precariously contingent on reasonable current and future health status. Participants described disinclination towards involvement in the stigmatized world of MS. Findings have implications for sensitive services for people with MS and question acceptance as a marker of appropriate adaptation.

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Douglas et al 2008 Understanding chronic pain complicating disability: Finding meaning through focus group methodology	Focus on understanding of chronic pain, 32 participants with MS. Focus group study, thematic analysis	Four broad conceptualizations of the experience of living with chronic MS-related pain. The first theme, pain is pervasive. The second theme resonated around feelings that nobody understands. The third theme, I'm fine, referred to the propensity of participants to keep pain private from others. Fourth theme, participants shared how MS had transformed their worlds into ones in which pain and discomfort had become a normal part of everyday life.
Edmonds et al 2007, Loss and change: experiences of people severely affected by multiple sclerosis	23 PwMS 17 carers, England Interviews and constant comparison analysis Can you tell me what things are most important to you about living with MS?	Physical abilities Independence Relationships Themes focused on loss
Fawcett and Lucas, 2006 Multiple sclerosis: living the reality	1, UK Phenomenological, hermeneutic analysis of narrative	Seemingly trivial symptoms took on a new and disturbing meaning to the point where, as someone newly diagnosed with MS, the potential challenges of the journey ahead have to be viewed with realism, optimism, and meaning

Author, date and title	Participant number & place of residence, Method Focus	Themes
Courts et al 2004, Focus Groups: The Lived Experience of Participants with Multiple Sclerosis	10, USA Focus groups study Questions were broad about experiences of MS and also asked 'what could HCPs do to make things better?'	Nobody's listening Symptom devastation (the devastation that symptoms cause to their lives) Pick and choose (exerting some control and choice despite MS) Fight your own fight (taking charge)
Flensner et al 2003, Lived experience of MS related fatigue- a phenomenological interview study	9, Sweden Open interviews, thematic analysis using meaning units	MS-related fatigue is living with a time-consuming and all absorbing phenomenon, involving the body and the whole human being. Fatigue is commonly non-constructively perceived and expressed in terms of energy loss, emotional afflictions, dependency and restrictions of life in general, however, it is also constructively perceived and involves a desire to accept life and strive for a better situation.
Grytten & Maseide, 2006, When I am together with them I feel more ill. The stigma of MS experienced in social relationships	14 PwMS and their relatives were interviewed, grounded theory analysis	Informants reported being ignored or, in contrast, having people overemphasize MS in interpersonal encounters. Although people tried to act tactfully, these acts were experienced as crucial stigmatizing. Informants were coping to counteract stigmatizing experiences in social relationships.
Hainsworth 1994 Living with Multiple Sclerosis: The Experience of Chronic Sorrow	Aimed to explore the experience of Chronic Sorrow in 10 PwMS. Interviewed using the Burke/NCRCS chronic sorrow questionnaire – 16 open ended questions	Feelings of chronic sorrow occurred periodically over a protracted span of time when some event reminded participants of their chronic situation.

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Isaksson & Ahlström 2006, From symptom to diagnosis: illness experiences of multiple sclerosis patients	61, Sweden Interviews and content analysis Part of a larger study Focus on experiences of symptoms occurring through to diagnosis (and the feelings after diagnosis)	From disablement to good health (conception of MS prior to diagnosis) Becoming vulnerable (12 categories of emotion described) From vulnerability to acquiring strength (emotional reactions and feelings of loss and abandonment)
Isaksson & Ahlström, 2008 Managing chronic sorrow: experiences of patients with multiple sclerosis	38, Sweden Interviews and content analysis	Discomfort resulted from ineffective management of chronic sorrow, reflecting the vulnerability these patients experience and the lack of understanding of their needs and appropriate support from family, friends, and healthcare personnel. In some cases, the losses and emotional distress caused by MS were managed effectively, which led to increased comfort through personal growth and a greater appreciation of life, greater confidence, and hope for the future
Johnson 2003 On receiving the diagnosis of multiple sclerosis: managing the transition	24, UK In depth interviews Analysis using a framework of data reduction and conclusion drawing	Intense feelings of abandonment and isolation were generated at the time of diagnosis and stayed with the person for many months or years. Differing expectations between patient and neurologist following confirmation of diagnosis could contribute to these findings

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Koopman & Schweitzer 1999 The journey to multiple sclerosis: a qualitative study	5, Canada Aimed to explore the experience of having symptoms for a period of time and then being told they have MS Phenomenological analysis	Four themes emerged: whispered beginnings, echoes of silence, the spoken words and recreating voice
Loveland 1999, The experiences of African Americans and Euro-Americans with MS	100, USA Interviews and thematic-type analysis. Focus-the impact of race and gender on people's interpretation of symptoms, access to medical care, diagnosis and adjustment to disability. Six questions were closed but one final question 'what is it like to have MS?' explored experience	Diagnosis Response to diagnosis Rationalisation and adjustment and acceptance (6 patterns discussed)
Malcomson et al 2009, What can we learn from the personal insights of individuals living and coping with Multiple Sclerosis?	13, Ireland Interviews and focus groups and thematic analysis	Learning something was wrong (pre-diagnosis) Getting a name (diagnosis) Lack of support Unchanging family relationships Adjustment to employment circumstances and social life Challenges Successful coping via proactivity Perspective an control (self-management technique) Advice for others Recommendations for how services could be improved

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Miller 1997, The lived experience of relapsing multiple sclerosis: a phenomenological study	10, USA Focus on relapsing MS, but inclusive question	social support, adjustment, coping, hope/hopelessness, control, conflict, relief with diagnosis, uncertainty, loss, fear, getting to know MS and revealing/concealing
Miller & Jezewski, 2006, Relapsing MS patients/ experiences with glatimer acetate treatment: a phenomenological study	20, Aimed to increase understanding of the experience of MS patients with glatimer acetate to provide an accurate foundation for patient education and counselling. Interviews, phenomenological analysis	The themes included choosing glatiramer acetate, self-managing care, injecting, healthy lifestyle, side effects, support, and participant advice to others.
Mohr et al, 1999, The psychosocial impact of multiple sclerosis: Exploring the patient's perspective	50 interviewed regarding the effects MS had on their lives and interpersonal relationships. These statements were collated and administered with a 5-point Likert scale to 94 MS patients	Three areas of subjective patient experience of the psychosocial consequences of MS emerged: demoralization, benefit-finding, and deteriorated relationships
Moriya and Suzuki 2011, A qualitative study relating to the experiences of PwMS: differences by disease severity	17, Japan Interviews and Constant comparison analysis. Structured questions focused on physical impairment, also change in experience depending on disease severity	Confusion before diagnosis Reaction to prognosis Disruption of rebuilding of life due to symptoms Modification and establishment of self-identity Planning ahead

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Mozo-Dutton, 2012 MS and Me: Exploring the impact of MS on perceptions of Self	12, England, IPA	Four themes were identified although for reasons of space and novelty three were discussed, (i) 'my body didn't belong to me': the changing relationship to body, (ii) 'I miss the way I feel about myself': the changing relationship to self and (iii) 'let's just try and live with it': incorporating yet separating MS from self
Olsson et al 2008, The meaning of women's experiences of living with MS	10, Sweden Interviews and phenomenological hermeneutic analysis Women's experiences of living with MS	An unrecognisable body (Being directed by the ill body, Having the will but finding it troublesome to perform, a feeling of being perceived as different). Trying to maintain power (Seeking answers to unpredictability, having the strength to fight, seeing possibilities in life)

Author, date and title	**Participant number & place of residence, Method** **Focus**	**Themes**
Reynolds and Prior 2003, Sticking Jewels in your life: exploring women's strategies for negotiating an acceptable quality of life with MS	27, England IPA Women's (with MS) strategies for coping and achieving QOL despite/with MS	Managing Illness and limiting its impact (looking after one's health, pacing and fatigue management, managing stress well, practising resistance and the fighting spirit) Maintaining and extending roles and occupations (engaging in meaningful roles and occupations, adapting pre-illness skills/interests to current levels of physical functioning,) Maintaining mutual relationships Clarifying personal beliefs and aspirations (articulating beliefs, retaining aspirations and confidence in personal goals,) Dealing with disabling social barrier (taking action on disability issues, finding a feasible way forwards) Consciously valuing and promoting the positive aspects of life (valuing positive moments, making constructive use fo precious timer and energy, finding positive aspects in diversity, enjoying fun and humour) Living with MS: The complexity of women's strategies and their change over times

Author, date and title	Participant number & place of residence, Method Focus	Themes
Stuifbergen & Rogers, 1997, The experience of fatigue and strategies of self-care among persons with MS	13, USA, Interviews and thematic analysis	Five themes were identified that describe the experience of fatigue for persons with MS. Categories of self-care strategies included energy conservation, recharge efforts, enhancing resistance to fatigue, and temperature control
Vickers 2012, Ante-narratives to inform health care research: exploring workplace illness disclosure for PwMS	20, Australia Interviews and analysis of antenarratives (relevant fragments of conversation) of the participants and of the researcher	Carol is losing her mind Jason doesn't take his cane Janet is independent Ned needs to prove himself Miranda regrets saying anything Glen finds support
Wright St-Clair 2003, Storymaking and Storytelling: Making Sense of Living with Multiple Sclerosis	16 women, New Zealand Focus group interview (6) and ten semi-structured individual interviews. Symbolic interactionism was used to build a theoretical foundation for interpreting the day-to-day dynamic relationship between the person, the symbolic meaning of their illness, and their occupations.	The women's engagement in the intuitive occupations of storymaking and storytelling reveals a rich use of analogies and metaphors to make meaning of and to develop occupational strategies for managing the intrusiveness of their illness in their everyday lived world. MS as an aggressor, a saviour, a guest, a partner, an adversary all explored

Author, date and title	Participant number & place of residence, Method Focus	Themes
Kolodziej 2012 The Lived Experience and Meaning of Living with Multiple Sclerosis: Suggestions from Anthropology for Policy Development - Dissertation	36, USA An ethnographic study of MS using qualitative interviews and illness narratives Constant comparative analysis was used.	Five predominant themes emerged from the data: influence on employment, power of positive outlook, time orientation, need for services and programs, and sense of independence. Each of the themes illustrated the influence of MS on the individual as well as on relationships with family and friends.

Table C presenting published papers regarding lived experience of MS (UK and International)

Appendix VI: Experience of Physiotherapy

Table A. Published physiotherapy research exploring patients' perceptions of specific aspects of physiotherapy

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Bulley, Shiels, Wilkie and Salisbury 2011 *Physiotherapy*	User experiences, preferences and choices relating to functional electrical stimulation and ankle foot orthoses for foot drop after stroke	**Explore** experiences, preferences and choices relating to the use of AFOs and functional electrical stimulation for foot drop by people who have suffered a stroke and their carers', **with the aim of informing clinical decision-making**	Semi-structured interviews 13 participants Phenomenological approach, used NUD*IST during thematic analysis. Read like a thematic rather than an interpretive analysis, IPA	Termed results Descriptions about preferring AFOs and preferring FES were presented with verbatim extracts supporting preferences	'neutral' researcher, researcher not visible, no reflexivity demonstrated Conclusion reached about preference of adjunct used for foot drop from this group of people Factual account. Generated a table of positive and negative experiences, preferences and choices Clear link to clinical practice Minimal/? No interpretation ? most appropriate method for this aim 7 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Campbell, Evans, Tucker, Quilty, Dieppe and Donovan 2001 *Journal of Epidemiology Community Health*	Why don't patients do their exercises? Understanding non-compliance with physiotherapy in patients with osteoarthritis of the knee	To **understand** reasons for compliance and non-compliance with a home based exercise regimen by patients with osteoarthritis of the knee	Semi-structured interviews 20 participants Thematic analysis	Termed results Linked physiotherapists findings of compliance to patients self-reporting of compliance through the interviews 4 main themes generated that affected compliance	Researcher described as 'mature and experienced,' no reflexivity demonstrated Analysis and interpretation of results in narrative discussion Clear link to clinical practice 6 pages without references
Carlesso, Cairney, Dolovich and Hoogenes 2011 *Manual therapy*	Defining adverse events in manual therapy: an exploratory qualitative analysis of the patient perspective	To **describe** how patients define adverse events associated with manual techniques	Semi-structured interviews 12 participants Thematic analysis	Thematic analysis developed 11 subthemes, each discussed and supported with verbatim comments	Specific questioning Researcher not apparent, no reflexivity demonstrated Discussion is interpretive Clear link to clinical practice 6 pages without references
Cooper, Smith and Hancock 2008 *Physiotherapy*	Patient-centeredness in physiotherapy from the perspective of the chronic low back pain patient	To **define** patient-centeredness from the patient's perspective in the context of physiotherapy management of chronic lower back pain	Semi-structured interviews 25 participants Thematic analysis	Descriptive analysis in themes with verbatim extracts to support analysis Identifies aspects of patient centred care as identified by participants	Discussion is descriptive in keeping with aim Researcher is described as a physiotherapist, no reflexivity demonstrated Clear link to clinical practice 8 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Dean et al. 2005 *Disability and Rehabilitation*	Managing time: An interpretative phenomenological analysis of patients' and physiotherapists' perceptions of adherence to therapeutic exercise for low back pain	To explore patients' and physiotherapists' perceptions about exercise adherence	Semi-structured interviews 9 participants Thematic analysis using IPA	Interpretive analysis with verbatim extracts to support analysis Identifies aspects of patient centred care as identified by participants	In depth interpretive analysis in keeping with IPA Researcher not visible but reflexivity is apparent Clear link to clinical practice 11 pages without references
Elena Del Bano-Aledo, Medina-Mirapeix, Escloar-Reina, Montiolla-Herrador and Collins 2013 *Physiotherapy*	Relevant patient perceptions and experiences for evaluating quality of interaction with physiotherapist during outpatient rehabilitation: a qualitative study	To **identify** elements of the physiotherapist-patient interaction considered by patients when they evaluate the quality of care in outpatient rehabilitation settings	Focus groups (9) 57 participants Thematic analysis	Descriptive analysis in themes with verbatim extracts to support analysis	Researcher not visible, no reflexivity demonstrated Discussion is descriptive in keeping with aim Clear link to clinical practice 6 pages without references
Hackman 2011 *Physiotherapy Research International*	What's the point? Exploring rehabilitation for people with primary central nervous system tumours using ethnography: patients perspectives	To **discover** the meaning of rehabilitation for people with this life limiting illness through ethnographic enquiry	Field work data, written narratives, interviews : ethnography 10 participants Thematic analysis	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Reflexivity apparent and integral to analysis Clear link to clinical practice 12 pages without references
Hale, Bennett, Bentley, Crawshaw and Davis *New Zealand Journal of Physiotherapy*	Stroke rehabilitation- Comparing hospital and home based physiotherapy: the patient's perception	To **explore** the perceptions of patients with stroke towards outpatient physiotherapy in the hospital and home based settings	Semi-structured interviews 6 participants Phenomenological thematic analysis approach	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Specific questioning Researcher not visible, no reflexivity demonstrated Clear link to clinical practice 13 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Kidd, Bond and Bell 2011 *Physiotherapy*	Patients perspectives of patient-centredness as important in musculoskeletal physiotherapy interactions: a qualitative study interactions	To **determine** patients perspectives of components of patient-centres physiotherapy and its essential elements	Semi-structured interviews 8 participants Thematic analysis	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researcher not visible, no reflexivity demonstrated Clear link to clinical practice 7 pages without references
May 2000 *Physiotherapy*	Patient satisfaction with management of back pain (1. What is satisfaction? 2. An explorative, qualitative study into patients' satisfaction with Physiotherapy)	To **describe** the aspects of physiotherapy care which back pain patients consider important	(Paper 1 explores the concept of patient satisfaction) Semi-structured interviews 34 participants Thematic analysis	Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researcher visible throughout, Clear link to clinical practice 9 pages without references
Pizzari, McBurney, Taylor and Feller 2002 *Journal of sports rehabilitation*	Adherence to anterior cruciate ligament rehabilitation: A qualitative analysis	To **investigate** the subjective experience of ACL rehabilitation and **identify** variables that influence adherence as perceived by ACL-reconstructed patients	Semi-structured interviews 11 participants Thematic analysis	Termed results Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	'The primary researcher was known to all participants but not involved in rehabilitation' Link to clinical practice in discussion but not separate section 12 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Sokunbi et al. 2010 *Manual therapy*	Experiences of individuals with chronic lower back pain during and after their participation in a spinal stabilisation exercise programme-a pilot qualitative study	To **explore** the experiences of a sample of individuals with chronic lower back pain who participated in a RCT investigating the most efficacious dosage and frequency of spinal stabilisation exercises	Focus groups 11 participants Thematic analysis	Termed findings Descriptive analysis in themes with verbatim extracts to support analysis	Researcher who did the focus groups was 'not involved in the procedural aspects of the RCT this research is associated with' Clear link to clinical practice 5 pages without reference
Soundy, Benson, Dawes, Smith, Collett and Meaney 2012, *Physiotherapy*	Understanding hope in patients with MS	To **understand** how patients with MS experience and express hope within a rehabilitation setting and use this information to help therapists in a clinical setting	Semi-structured interviews 11 participants Thematic analysis	Termed results Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researcher not visible, no reflexivity demonstrated Clear link to clinical practice 6 pages without references
Thomson and Hilton 2012 *Physiotherapy*	Service users perceptions regarding their involvement in a physiotherapy educational programme in the UK: a qualitative study	To **explore** service users' perspectives of their involvement in a UK based physiotherapy educational programme	Semi-structured interviews 8 participants Thematic analysis	Termed findings Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researcher not visible, no reflexivity demonstrated Clear link to practice 6 pages without references

Author and *Journal*	**Title**	**Aim**	**Methodology**	**Findings (methodological)**	**Notes about the research**
Underwood et al. 2006 *Rheumatology*	Patients perception of physiotherapy (within a trial for back pain treatments)	To **explore** the views of participants in a randomized controlled trial of physical treatments for low back pain about the treatment packages they received in the trial.	Open free-text question as part of RCT questionnaires 1334 patient participants Described as analysed using an adapted framework approach	Descriptive analysis- reporting of findings	Researcher not visible, no reflexivity demonstrated 5 pages without references
Wood, Connors, Dogan and Peel 2012 *Palliative Medicine*	Individual experiences and impacts of a physiotherapist-led, non-pharmacological breathlessness programme for patients with intra-thoracic malignancy: A qualitative study	To **evaluate** how patients with intra-thoracic malignancy undergoing the non-pharmacological breathlessness management programmes benefited from the programme	Semi-structured interviews 9 participants Phenomenological approach IPA	Termed results Descriptive and interpretive analysis in themes with verbatim extracts to support analysis	Researchers job title mentioned no reflexivity demonstrated Clear link to clinical practice 8 pages without references

Table A. Published physiotherapy research exploring patients' perceptions of specific aspects of physiotherapy

Table B. Published physiotherapy research exploring patients' experience of physiotherapy

Author **Year** **Country**	**Title**	**Methodology & focus (if more focused than title suggests)**
Bassett and Tango, 2002, New Zealand	Maori people's experience of being physiotherapy patients: a phenomenological study	Phenomenological approach In-depth guided conversation interviews, 6 participants. Focus on cultural interaction and context
Cassidy, Naylor and Reynolds, 2018, UK	The meanings of physiotherapy and exercise for people living with progressive cerebellar ataxia: an interpretative phenomenological analysis	IPA methodology, semi-structured interviews 12 participants
Daker-White, Greenfield and Ealing, 2013, UK	'Six sessions is a drop in the ocean': An exploratory study of neurological physiotherapy in idiopathic and inherited ataxias	Descriptive grounded theory analysis, semi-structured interviews with 38 people with ataxia and 8 physiotherapists as participants.
Dowswell, Dowswell, Lawler et al., 2002, UK	Patients' and caregivers' expectations and experiences of a physiotherapy intervention 1 year following stroke: A qualitative study.	Grounded theory analysis, semi-structured interviews carried out before and after intervention with 10 patient participants, 6 carer participants. Focused on expectations and outcome of a specific 3 month intervention.
Galvin, Cusack and Stokes, 2009, UK	Physiotherapy after stroke in Ireland: a qualitative insight into the patients' and physiotherapists' experience.	Grounded theory analysis, semi-structured interviews with 10 patients, focus groups with 10 physiotherapists. Focused on family involvement in rehabilitation.
Payton and Nelson 1996, USA	Patient perceptions of certain aspects of their physical therapy experience.	Descriptive study, semi-structured interviews, 20 patient participants. Focus on patients understanding of their role in therapy and goal setting
Potter, Gordon and Hamer, 2003, Australia	The physiotherapy experience for private practice patients: The patients' perspective	Nominal group technique to collect and rank/analyse data, focus groups with 26 patient participants
Wottrich, Stenstrom, Engardt et al., 2004 Sweden	Characteristics of physiotherapy sessions from the patient's and therapist's perspective	Descriptive comparative approach, Semi-structured interviews and observation 10 physiotherapist and 9 patient participants.

Appendix VII: Features of an ideal physiotherapy service

Extracted from Cassidy et al., 2018 and Daker-White et al., 2013

Features of an ideal neurological physiotherapy service for people with a progressive ataxia (taken from box 1, p339, Daker-White et al., 2013)	**Elements within themes generated and interpreted from participants (people with progressive ataxia) from the research by Cassidy et al., 2018**
Staffed by people who are confident and knowledgeable around ataxic patients	Increased knowledge about ataxia (and physiotherapy for people with ataxia) was regarded as important. However, physiotherapists improving their contextualised understanding of living with ataxia to enable delivery of more person-centred, meaningful physiotherapy was of greater value
Automatic therapeutic referral for any patient with a diagnosis of progressive ataxia (familial or sporadic)	Positive experiences of physiotherapy were associated with long term collaboration with continuity of care ideally with the same physiotherapist
Provide services both in the community and in clinic facilities	Person-centred care and collaborative working would guide where and how physiotherapy services would be best delivered for that individual, based on understanding the person's context, meaning and understanding of living with ataxia and of physiotherapy. People with ataxia identified the importance of having the support, advice and counsel of an understanding, responsive and empathetic physiotherapist
To offer a holistic service that may also include counselling, provision of information, referral and support	
To provide ongoing optional follow-up, monitoring and support over the long term	Long term collaborative physiotherapy that offers advice and on-going support should be offered in a flexible and responsive manner
To promote and engage in clinical research studies into what works in progressive ataxia	This study emphasised the importance of understanding physiotherapy and exercise for people with progressive ataxia from a phenomenological perspective. Physiotherapists are encouraged to explore this with each individual.
To make use of objective and subjective measures of functioning in order to measure improvement for patients	Outcomes should comprise patient-centred and quality of life measures that have meaning in the everyday lives of people living with a progressive ataxia. The approach advocated would operate at a local, personal, and relational level, a human scale based on an understanding of the phenomenological dimensions of long-term illness.

Features of an ideal neurological physiotherapy service for people with a progressive ataxia (taken from box 1, p339, Daker-White et al., 2013)	Elements within themes generated and interpreted from participants (people with progressive ataxia) from the research by Cassidy et al., 2018
To be mindful of the need to explore and engage patients around their expectations of therapy, adherence and degree of directed or hands-on therapy	Exercise and physiotherapy can make a positive contribution to living with ataxia. Expectations of physiotherapy were not found to be unrealistic (they were not looking for a cure). Negative appraisals of physiotherapy and home exercise programs were described when the complex and highly contextualized meaning of exercise and physiotherapy had not been adequately appreciated or considered for each individual. Physiotherapy and prescribed home exercise programs were understood to be primarily concerned with the impaired body. Self-directed exercise and activities that are enjoyable, challenging, meaningful and incorporate self-directed goals confer multiple benefits which helped participants sustain psychological well-being and reduce the salience of ataxia in their everyday lives.
To act as an information and training resource for other neurological physiotherapists (results not shown within this research)	Findings may provoke physiotherapists working with people living with a progressive ataxia to re-evaluate the meaning of physiotherapy and home exercise programs, and the ways in which physiotherapy services are provided from the patient perspective. In this way, people living with ataxia will provide crucial information and education for physiotherapists as well as information being shared between physiotherapists.

Appendix VIII: Experience of physiotherapy for PwMS

Author & Date	Title	Method (and aim)
Buckley, McLaughlin and Kennedy 2008	Physiotherapy services in Donegal: the perceptions of persons with MS. Focuses on service provision	Open response text section analysed (in addition to data analysis of questionnaire) 97 patient participants
Markwick, Singleton and Conduit 2014	The perceptions of PwMS about the NHS provision of physiotherapy services	The free text comments from an audit carried out in 2008 were used to perform content analysis on the views of PwMS, focusing on physiotherapy provision. 757 people commented on MS services, a further 41 commented on physiotherapy services
Normann, Moe, Salvesen et al 2012	Patient satisfaction and perception of change following single physiotherapy consultations in a hospital's outpatient clinic for PwMS	The aim of this study was to investigate satisfaction with physiotherapy and perception of change 72 patients completed the Outpatient Experience Questionnaire (OPEQ) to record satisfaction; the Patient Global Impression of Change (PGIC) and the Borg's Rating Scale of Perceived Exertion (BRSPE) were used to investigate perceived changes in standing up, sitting down, and walking following the consultation.
Normann, Sørgaard, Salvesen et al 2013	Contextualized perceptions of movement as a source of expanded insight: People with multiple sclerosis' experience with physiotherapy	Interviews carried out with 12 patients (observation sessions carried out with 7 of these patients) to specifically explore how PwMS perceive movement during sessions of physiotherapy in a hospital out-patient unit
Roush 1995	The satisfaction of patients with MS regarding services received from physical and occupational therapists	81 participants completed a therapist evaluation form to measure patient satisfaction which included 2 open ended questions: (a) things they would like to change in their relationship with their therapist and (b) the most positive thing in that relationship

Appendix IX: Wales Neurological Alliance recommendations

The Wales Neurological Alliance carried out a review in 2013 (Wales Neurological Alliance, 2013) and made ten recommendation following their review (see Appendix X). North Wales Neurosciences Network brought out 'Together for Health-Neurological conditions delivery plan in 2015 (Wales Neurological Alliance, 2015).

- Anyone with a neurological condition who would benefit from physiotherapy should be able to self-refer to local physiotherapy services
- Local Health Boards should organise specific neurological skills rehabilitation courses for generic physiotherapists in order to improve skills within the community and hospitals
- Evaluate and standardise the use of specialist equipment for patients with complex needs so a common level of service can be expected when patients transfer closer to home, or to their own home, for continued rehabilitation
- Provision of hydrotherapy and telemedicine should be considered, reviewed and expanded where appropriate to meet the needs of people with neurological conditions
- Heads of Therapies should promote the use of validated outcome measures so that physiotherapy for people living with neurological conditions is provided for the appropriate length of time that is commensurate to their needs
- The National Exercise Referral Scheme should be expanded into all neurological conditions to support individuals to self-manage their condition

Appendix X: Ethics Approval

PRIFYSGOL
glyndŵr
UNIVERSITY

Ein Cyf/Our Ref: 10004112_RDB1 approval URDC 2/19/2014

3rd June 2014

MRS L CAMPBELL
ABER HOUSE
CONWAY ROAD
PENMAENMAWR
GWYNEDD
LL34 6BD

Dear Leigh

Re: Confirmation of Research Degree Proposal

The University of Wales Degrees and Awards Board (DAAB) recently received your resubmitted *Research Degree Proposal, Learning Needs Analysis* forms and the *Ethical Statement,* and I am pleased to inform you that your programme of study is now formally confirmed.

Your supervision team is confirmed as follows:

Director of Studies: Dr Deborah Roberts
Supervisor: Dr Joanne Pike
Additional Second Supervisor: Dr Peter Gossman

Your research title is confirmed as follows:

Exploring the experiences of physiotherapy in North Wales for people with Multiple Sclerosis: informing service development and practice.

Should you wish to change your title at any stage, you will need to complete the *RDC12 (Application to Change the Title of a Research Project*) form and submit it to the Graduate School, for URDC approval. This, and other forms in respect of changes of registration, can be found via Moodle at: http://moodle.glyndwr.ac.uk/course/view.php?id=18&topic=5

Please note the following information regarding Ethical Approval:

If your proposed research involves human subjects, you will need to submit a GRESC1 application to the Glyndwr Research Ethics Standing Committee to seek ethical approval before starting any data collection.

If your proposed research involves non-human animal subjects, you will need to submit a GRESC3 application to the Glyndwr Research Ethics Standing Committee to seek ethical approval before starting any data collection.

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If your proposed research involves desk/lab based research, you will need to submit a GRESC2 application to your Supervisor to seek ethical approval before starting any data collection.

If your proposed research involves desk/lab based research, but also requires approval from an external ethics committee (e.g. NHS), you will need to submit a GRESC2 application to the Glyndwr Research Ethics Standing Committee to seek ethical approval, prior to any submission to an external committee and before starting any data collection.

For more information regarding how to proceed with your ethics application, please consult with your supervisor and read the following webpage: http://moodle.glyndwr.ac.uk/course/view.php?id=4968%2F%22%20target%3D%22_blank%22

May I take this opportunity to wish you all the best with your studies at Glyndŵr University.

Yours sincerely

Dr Alison Green
Associate Director: Graduate School / Cyfarwyddwr Cyswllt: Yr Ysgol i Raddedigion
Chair of University Research Degrees Committee / Cadeirydd Pwyllgor Graddau Ymchwil y Brifysgol

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cc Director of Studies: Dr Deborah Roberts
Supervisor: Dr Joanne Pike
Additional Second Supervisor: Dr Peter Gossman

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

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04 August 2014

Miss Leigh Campbell
Specialist Physiotherapist in Neurology
Betsi Cadwaladr University Health Board
Physiotherapy Dept
Glan Clwyd hospital
Bodelwyddan
LL18 5UJ

Dear Miss Campbell

Study title:	**Exploring the experiences of physiotherapy in North Wales for people with Multiple Sclerosis; informing service development and practice.**
REC reference:	**14/WA/1088**
IRAS project ID:	**148138**

The Proportionate Review Sub-committee of the Wales REC 6 reviewed the above application on 04 August 2014 (by correspondence).

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager Ms Penny Beresford, penny.beresford@wales.nhs.uk.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

GIG CYMRU NHS WALES | Bwrdd Iechyd Addysgu Powys | Powys Teaching Health Board

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

1. A statement and initial box to be included on the Consent Form with regard to audio recordings.

   Version number and date of the information sheet to be included in the first point on the Consent Form.

2. A statement regarding Lone Worker policy to be included in the information sheet.

   All researchers contact details to be mentioned to include work telephone numbers as well as email addresses.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Ethical review of research sites

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

Suitability of supporting information

The Committee noted it is mentioned with the information sheet that audio recordings will be taken, however, there was no provision for this on the Consent Form. It was also noted that the version number and date for the information sheet should be version linked on the consent form in point 1.

The committee would also like to see a statement regarding Lone Worker Policy conditions included in the information sheet along with details for the researchers to include their telephone numbers as well as email addresses.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [invite flier]	v1	03 March 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance certificate]	v1	
Participant consent form [participant consent form]	version 2	23 July 2014
Participant information sheet (PIS) [participant information sheet]	V1	03 March 2014
Participant information sheet (PIS) [participant information sheet]	2	23 July 2014
REC Application Form [REC_Form_23072014]		23 July 2014
Research protocol or project proposal [Research proposal]	V1	
Summary CV for Chief Investigator (CI) [CV]	v1	03 March 2014
Summary CV for student [Recent CV]	V1	01 July 2014

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

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

14/WA/1088 **Please quote this number on all correspondence**

Yours sincerely

Penny Beresford

pp
Roy L. Evans
Chairman

Email: penny.beresford@wales.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers" [SL-AR2]

Copy to: *Alison Green, Glyndwr University*
Mr Sion Lewis, Clinical academic office

Appendix XI: research flyer

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Do you have Multiple Sclerosis?

Have you accessed physiotherapy services within Betsi Cadwaladr University Health Board?

Would you be interested in discussing your experiences and thoughts?

If so, please contact: leigh.campbell@wales.nhs.uk or 01745 445867 for further information and discussion

glyndŵr UNIVERSITY

Appendix XII: Participant Information Sheet

06.08.14 V3

Participant Information Sheet

Study title: Exploring the experiences of physiotherapy in North Wales for people with Multiple Sclerosis (MS)

You are being invited to take part in a research study that is part of my professional doctorate study. Before you decide to do so, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with me if there is anything that is not clear, or if you would like any more information. Take time to discuss any aspect of the study to help you decide whether or not you wish to take part.

Part 1 tells you the purpose of this study and what will happen if you do decide to take part.

Part 2 gives you more detailed information about the conduct of the study

Part 1: The study

The aim of this study is to explore the experiences and thoughts of people with Multiple Sclerosis (MS) about physiotherapy in North Wales within the NHS. This will provide insight into patients' experiences, which will help to inform physiotherapy practice and service development.

Why you have been invited to participate:

You have been invited to participate because you have MS, and have experienced physiotherapy within BCUHB. We would like to hear your views.

Do I have to take part? Taking part in the study will be entirely voluntary. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way.

What will happen to me if I take part?

You are being invited to participate through answering some questions about your experiences and views of physiotherapy through one interview, lasting up to an hour.

Taking part in the project –things you should know:

Your comments will all be anonymous but may be used as direct quotes within the research

- The interview will cover topics such as: Tell me about your experience of Physiotherapy, How did/does physiotherapy affect you? What are your thoughts about physiotherapy?
- The interview will take place at a time, date and place of your convenience, and will arranged directly with the researcher. Transport will available if required.
- The interview will be recorded
- You can request an interpreter if you prefer to carry out the interview in a language other than English
- If you are unhappy with anything regarding the study, or the way that you have been treated at any stage, there are procedures in place to enable this to be addressed

What are the possible benefits of taking part?

Through taking part in this project you are helping to increase the understanding of the experiences and views regarding physiotherapy from PwMS.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. Detailed information regarding this is given in part 2.

Confidentiality:

If you consent to take part in this study all your details will be anonymised and all information will be stored in a secure, locked cabinet with access only to researchers in the project. All information collected will be kept strictly confidential, and ethical and legal practice will be followed at all times.

You do not have to take part. Even if you initially agreed to participate you may withdraw at any point without giving reasons. If that is the case, thank you for considering the invitation, and letting us know you no longer wish to be involved.

Part 2:

What happens if I don’t want to carry on with the study?

You can withdraw at any stage. If your interview has already been carried out, you can decide to withdraw this information at any stage prior to publication or submission.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions on 01745 534043. If you remains unhappy and wish to complain formally, you can do this through BCUHB complaints procedure. In the first instance, contact the concerns team on 01248 384194

Will my taking part in this study be kept confidential?

All personal information which is collected about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised.

What will happen to the results of the study?

The results will be interpreted and analysed. Some direct quotes or extracts from the interviews might be used as part of the analysis to illustrate an area of discussion: these will be anonymised at all times

Who is organising and funding the research?

This research is funded by BCUHB and organised by Glyndwr University

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and given favourable opinion by Glyndwr research ethics committee and Wales REC 6 research ethics committee.

Other

The health board has a lone worker policy that will be adhered to at all times by the researcher for the safety of both the researcher and the participant. Details of this policy can be found at www.wales.nhs.uk, or can be provided on request by the researcher

Further information and contact details:

Please contact Leigh Campbell for all information in the first instance:
leigh.campbell@wales.nhs.uk or work phone number 01745 534043

If you are happy to take part now having read this information, please sign the attached consent form and either return to the address below, hand to the researcher, or bring with you on the day of the interview that will be arranged at a time and place of your convenience. You will receive a copy of the signed consent form and will keep a copy of this information sheet.

Thank you for your time.

Leigh Campbell, Physiotherapist in BCUHB and professional doctorate student at Glyndwr University
leigh.campbell@wales.nhs.uk

Appendix XIII: Research participant consent form

06.08.14 V3

Research Participant Consent Form

Title of Project:

Exploring experiences of physiotherapy in North Wales for people with Multiple Sclerosis

Name of Researcher: Leigh Campbell

Participant identification number:

	Yes	No
❖ I **confirm that** have read and understood the information sheet (06.08.14 V3) for the above study and what my contribution will be		
❖ I have been given the opportunity to consider the information, ask questions (face to face, via telephone and e-mail), and have these answered satisfactorily		
❖ I understand that my participation is voluntary and that I can withdraw from the study at any time without giving any reason, without my medical care or legal rights being affected		
❖ I agree to take part in the study by participating in an interview that will be audio recorded		
❖ I understand that all members of the research team will need access to the information that I give the researcher, and I give these individuals permission to access these		
❖ I agree that any data that arises from my interview can be used anonymously in any future publications		

I agree to take part in the above study.

Name of Participant…………………………………………………………………..

Signature………………………………………..Date………………………………..

Name of researcher taking consent…………………………………………………

Signature………………………………………..Date………………………………..

Copy for participant, copy for researcher

Appendix XIV: example of theme generation

Original transcript interview 1:

I: I would like you to tell my about your experiences of Physiotherapy

P: How far do you want to go back?

I: As much as you can tell me

P: Well, (to wife) you had better help tell my story…I mean, there was a time when we didn't have any physio at all….that was when we had the council carers?

W: No, no, no…shall I, sort of?....(indicates with hand gestures that she will help facilitate conversation between Peter & I) We moved here about 11 years ago, Yes? (To P) And up until about 6 years ago, Peter was walking

P: uh huh

W: I can't remember……up until, you know you didn't have physio in London did you? (To P)

P: Yes

W: But you used to do your own exercises didn't you? (to P) He would go to the gym, and we had stairs in the house, so he was getting a lot of exercise (to I), em, you know, without needing medial physiotherapy really

I: yes…..

W: So, when the time came, when, you know, we thought that he needed physiotherapy, you were referred to XX hospital weren't you? (To P)

P: Yes

W:….and, I can't remember how long ago into moving here that that was…probably about 2 years, and so we are going back 8-9 years…..

I: uh-huh…..

W:….and, it was a system where they had 6 weeks on and 6 weeks off, and it was a group thing, in XX hospital

P: Yep

W:…so, that was your first experience of having MS related physiotherapy wasn't it?

P: Yep

I: (To P) And can you tell me about that experience?

P: Well, parts of it were good, and some weren't….like my went on that….(transport)….it was one royal fork out really….And, then I was on steroids then remember? (To W), and that helped for about….10 minutes….because, you know, it doesn't last long…so, anyway, that's all I remember of it….

I: So, what was the effect on your quality of life, or your life from that physiotherapy, if any?

P: It made me feel pointless really, because it wasn't helpful….

W: ….it wasn't consistent….it wasn't consistent…and what we found, was that very often, um, the 6 weeks, you know, you weren't called after 6 weeks, it would sometimes be 3 months, when his turn came up again, and, and that kind of experience. And, also, there was….I can't remember P, if it was before or after, the 6 week rota, I think it was before actually, you actually had some pool therapy in XX

P: oh, yes, right, swim, swimming

W: yes.

P: Yes

W: and that lasted, about a few weeks,

P: Yeh

W:….and then it never happened again, we were told, and I remember this actually now, you were told that, that, you were actually told, the gym based physio would be more beneficial for you, rather than going into the pool….

BOTH LOOKED AT I……..PAUSE

I: And did you find that to be the case?

P: No. Absolutely not.

I: OK

PAUSE. LOOKED AT I…..

I: so, in terms of how that made you feel….?

P: Well, it just made life more difficult really

I: So…..?

P: The lack of physio

I: The lack of physio made it more difficult. OK. And what was your next experience after that then?

P: Well, then it goes onto the dreaded council carers….

W: No, sweetheart, it doesn't…

P: It goes on to XX

W: No, no, no. Well, yes, eventually….but, what happened then, (PAUSE), what happened then, was that. Up until this time I am talking about now, you were able to walk. But, your walking ability was reducing pretty fast. OK? But, we kept going, didn't we? We kept going….like I would help P to the sink, to the toilet, and that would be the normal wouldn't it?

P: Yes.

W: You know? And, at that time, we only had one carer helping you…

P: Yeh

W:…and, it became…. Erm, evident, that she didn't feel confident dealing with P on her own, as it was getting more & more difficult for P to stand to stand at the sink and stuff…

I: uh-huh

W: so, we were at the stage now, when, I broke my foot. OK? So, then, I wasn't able to help him. And, it was then. Oh, and another thing, relating back, going back to the 6 week thing, another negative thing really, erm, it became so bad, that I wasn't able to help him into the car to go for physio. So, we started depending on transport. And that was very, very, erm…

P: Yeh….Yes.

W….erm fragmented…….so, erm, reliable. And I can remember counting one 6 week period. That he only had physio on 3 of the 6 episodes of physio that he was supposed to have it. So…..

I: Due to the transport?

W: Due to the transport.

W: So, that happened. And, then I broke my foot. And, of course, I stopped being able to help him

I: Yes

W: So, it was at that point, I think. That we started having primary care physio.

P: Yes

W: And that's when XX

P: Yes, yes

W:…when XX started coming

P: Yes. XX. And she was very good.

W: Yes, she was very good. And she used to come once a week. Ok? And, I can remember, because you weren't walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn't you?

P: Yes. Yeh.

W: And so what was said then, you see, 'cause I knew he could do it, you see, with the right, you know….you see, what was said then, was that the physio wanted consistency, so he needed to do that all the time for the physio to be effective. And, our argument was, you know, that we needed consistent physiotherapy really, for him to be able to have effect. Constant effect. You know it sort of went together really didn't it. Or that's what we felt.

P: Yes

PAUSE

So, we went, you know with XX, erm, for a long time, really

P: Yes

W:…and she was fantastic really, helping him to stand here (indicating their home). You eventually lost the ability to walk. (P nods yes) And I can't remember when that was. Probably about 6 years ago….

P: Yes…

I: uh huh.…

W: Yes

So, it's with determination really. We've had to…we've had to fight for physiotherapy. And P, although he has lost his ability to stand, err, to to walk. He can still stand. So, XX eventually went on maternity leave, didn't she?

P: Yes. Yes.

W: …and we were allocated a new physio….and the, the, PAUSE, what shall I say…a sort of. PAUSE….different perspective really of what you should be doing. And, umm, a lot of it was expected that P should be doing stuff on his own. Like, you know, like she suggested that a bag be put underneath his foot, and stuff like that. And that he should be doing that kind of stuff on his own.

Which was wrong really. Because, if he did that, and I wasn't here, he'd end up having a spasm and be down (indicating the floor). So, there was a bit of a safety issue there really. Emm. Yes

So, *eventually*, we got to the stage where. PAUSE. Erm.

Continuing health care agreed that P could have 5 hours of physiotherapy a week.

I: uh huh….

W: and that has been, the skill, physio skill has been transferred to the carers

So, every day now really….

P: Well…

W: you have exercises every day in the bed, umm, on non shower days, alternate days really, in the bed. Some of it is passive, and some of it is active. Erm, and you have standing exercises on 2 calls of the day…

P: Yes

W: And, if I'm not here, then you have 4 calls with carers a day. And then the 2 afternoon ones, both stands.

And you are still able to, for a certain length of time, able to take your legs away from the support of the turn-safe.

P: Yes. Yes.

W: And stand without support.

I: So what effect do you think that that has on you?

P: Well, it strengthens my legs, and balance you see

W: and it keeps, well, the beauty of it….. I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know? (directed to I)

That's how I feel. Erm, But, you know, he can't walk. He can still stand. And, having the physiotherapy keeps him going at that level. You know, you know, haven't become unable to…to…

P: No, no….

W: …to move…..and we are able to avoid using the hoist and that…..(Looks to I)

I: Which for you is significant? (To P)

P: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it's horrible. Horrible. The only time I have been in a hoist (and don't hate it) is in Penrhyn where we go sometimes on holiday, and they have a pool there, they can hoist me into the pool and I can try and swim in the pool, and I enjoy that

I: ….and so it's worth the hoist for the pool…(smiles)?

P: Yes, yes. I enjoy that

PAUSE

I: And have you interaction with physiotherapy now?

P: Well, only….

W: She comes, only…..Her, her, her… perspective has changed really, actually, because, erm, you know, from, from when we were…..

From when the physiotherapist changed, from when XX went on maternity leave….the…erm….PAUSE.

The attitude, I suppose.

Was very much, we haven't got time, we haven't got money. OK.

To now, probably about 2 or 3 years down the line….PAUSE…..she is saying….we must keep on with this as we are clearly doing something right….you know? (To I)

She said that herself last time she was here. (Looks to I)

I: uh huh

W: So, erm. The other thing, and I think this is important to say….is that the cycle thing in XX in the gym?

I: uh huh

W: Which is a good thing. But, it's very inflexible, in that, you know, we were given a half hour slot on a Friday morning. And that was not flexible at all. So, you know, if it was raining on a Friday, then we wouldn't go. And we couldn't change it to any other time. We couldn't, you know. I think, especially over the summer, if you could use it any time you felt like it, erm, we would you could use it more… you know?

P: Yes. yes

I: and so there's an inflexibility in a service that you want to access?

W: Yes

P: Yes

PAUSE

I: Thank you. You have given me a lot of information about the practical experience you have had about physiotherapy. Is there anything else that you would like to add? Perhaps about your experience of interaction with physio?

P: Well, there's not enough of it…..PAUSE

I: OK.

W: I feel, that, you know, MS as a condition, especially progressive MS. There isn't any other treatment to be had, other than, you know, what you get for anti-spasms and that kind of thing……

And, physiotherapy, is good for it.

And, you know, erm….LONG PAUSE…..

….You are denied…you know…there is…..

Physiotherapy could be thought of as a treatment for MS….

And yet, it's not available. That's what I am trying to say I suppose…….

I: Yes…..yes

That is very useful

P: yes. That's fine. Apart from do I want to mention the council thing? (To W)

W: Well, yes, that has nothing to do with it sweetheart…..

P:….well, I didn't have any physio! (emphatically)

W: yes, well, you see, for a while Leigh, what we have now are our own carers, yes?

I: Yes

W:…and, for a while, we had the council carers….and, erm, they refused point blank to transfer the skills, but I think, that that really…… for the future. Is not really going to be of value. As the council are giving up the care element of their services….

I: Yes

W: so, you see, I gave the physiotherapy while they were coming. Didn't I?

P: Yes, yes.

W: Every single day really. Erm, every day, every morning, whether it was shower day or not. Because I was so scared that he would lose what we had, what we had erm, erm…..

P: built up

W: yes, built up you see….the way, the way…. Perhaps I need to explain really. That the care company that we had, pulled out. And they did carry out the physio.

And so the council carers were a temporary measure until we were able to, erm, employ our own.

And that took 9 months right?

And so, for 9 months, you would have been without physio, if it hadn't been for me……

P: Yes, yes…

W: that's what you are trying to say isn't it?

P: Yes. Yes. Yes. Looks to I……

I: and what was the impact….?

P: a lot….a lot….I mean, she's working part time…….(Asked to stop recording)

Interview 1: Stage 1: Initial notes:

Initial notes, development of note-taking

Transcript	Notes *Descriptive* Linguistic **Conceptual**
(Chat about where they live)	

Me: I would like you to tell my about your experiences of Physiotherapy Peter: How far do you want to go back? Mary: As much as you can tell me	**Takes question as being a question about direct interaction with physio** (perhaps I could add examples to contextualise my question if I was to interview again)
Peter: Well, (to Mary) you had better help tell my story…I mean, **there was a time when we didn't have any physio at all**….that was when we had the council carers?	Sought assistance and affirmation from Mary (Peter struggles with timelines) *Initial focus on service delivery 'there was a time…'* This seemed to be the most pressing issue for Peter, and one that it seemed like he wanted to 'get out' right away
Mary: No, no, no…shall I, sort of?....We moved here about 11 years ago, Yes? (To Peter) **And up until about 6 years ago, Peter was walking**	'Let's start from the start' trying to 'get it clear' in their heads approach from Mary Affirmed and sought agreement from Peter (consistent interaction throughout the interview)
Peter: uh huh Mary: I can't remember……up until, you know you didn't have physio in London did you? (to Peter) Peter: Yes, I did	**Provided context of physical ability.** **Note the importance of this to Mary, but not mentioned by Peter as this stage** **Emphasis on walking function to provide context and highlighted as a significant event**
Mary: But you used to do your own exercises didn't you? (to Peter) He would go to the gym, and we had stairs in the house, so he was getting a lot of exercise (to me), em, you know, without needing medial physiotherapy really	**Mary not seeing Peter doing his own exercise as physiotherapy, ? Peter did, he answered 'Yes'**
Me: yes….. Mary: So, when the time came, when, you know, we thought that he needed physiotherapy, you were referred to XX hospital weren't you? (To Peter) Peter: Yes	? I should have/could have asked what was it that made them think that P needed physiotherapy at this point

Mary:….and, I can't remember how long ago into moving here that that was…probably about 2 years, and so we are going back 8-9 years…..	
Me: uh-huh…..	
Mary:….and, it was a system where they had 6 weeks on and 6 weeks off, and it was a group thing, in XX hospital	
Peter: Yep	
Mary:…so, that was your first experience of having MS related physiotherapy wasn't it?	**'system, group thing'. ? indicates no sense of belonging to this group, or taking part in it**
Peter: Yep	*Identified what Mary perceived as first (actual) experience of physiotherapy related to MS*
Me: (To Peter) And can you tell me about that experience?	
Peter: Well, parts of it were good, and some weren't….like my went on that….(transport)….it was one royal fork out really….And, then I was on steroids then remember? (To Mary), and that helped for about….10 minutes….(smirked/snorted in irony?) because, you know, it doesn't last long…so, anyway, that's all I remember of it….	**? the experience seemed separate to P 'it'** -struggled to describe frustrations, struggled to remember timelines -used sarcasm/humour to indicate frustration that available medical treatments did not help him and to and to express his dissatisfaction with this service -(some word finding problems- likely increased as Peter was agitated and upset when talking about this group set up and transport)
Me: So, what was the effect on your quality of life, or your life from that physiotherapy, if any?	
Peter: It made me feel pointless really, because it wasn't helpful….	*It made me feel pointless really* **Because the intervention was not helpful, made him feel pointless? Or made him feel the intervention was pointless?**
Mary: ….it wasn't consistent….it wasn't consistent…and what we found, was that very often, um, the 6 weeks, you know, you weren't called after 6 weeks, it would sometimes be 3 months, when his turn came up again, and, and that kind of experience.	*Peter described problems with the practicalities of the service in terms of transport, timing, regularity and how this made the experience 'pointless', but also that it made him feel pointless* (Mary tried to soften this statement? Aware that I was a therapist. Mary worked in health care- would

And, also, there was….I can't remember Peter, if it was before or after, the 6 week rota, I think it was before actually, you actually had some pool therapy in XX hospital	have some understanding of how I might feel listening to Peter's experience?)
Peter: oh, yes, right, swim, swimming	
Mary: yes.	
Peter: Yes	
Mary: and that lasted , about a few weeks,	
Peter: Yeh	
Mary:….and then it never happened again, we were told, and I remember this actually now, you were told that, that, you were actually told, the gym based physio would be more beneficial for you, rather than going into the pool….	(Looking at I in a challenging way) Challenging: Mary was angry, expressing that Peter had been offered this, trialled it, and was then told that it was not as helpful for him without his giving his opinion at all (Felt in interview that they wanted I to provide answers about this to them)
BOTH LOOKED AT Me……..(challenging/questioning look from both) LONG PAUSE…..continues to look to me for an answer	(Felt in interview that they wanted I to provide answers about this to them. Felt that I had to ask this question, tried to draw out how this affected Peter)
Me: And did you find that to be the case?	***They were not aware of having been involved in this decision***
Peter: No. Absolutely not.	Experience of having been offered classes, then stopped, hydro, and then stopped
Me: OK	
PAUSE. LOOKED AT I…..	
Me: so, in terms of how that made you feel….?	
Peter: Well, it just made life more difficult really	(tried to draw out how this affected Peter)
Me: So…..?	
Peter: The lack of physio	
Me: The lack of physio made it more difficult?	*? Highlighting that a lack of physio made life more difficult, ? or the changing of methods ? of not being consulted*
Peter: Yes	

Me: OK…….Pause (allowed time for Peter or Mary to talk)…	? I should have explored more ? in what way did it make your life more difficult
And what was your next experience after that then? Peter: Well, then it goes onto the dreaded council carers…. Mary: No, sweetheart, it doesn't… Peter: It goes on to Nicki (therapists name, changed for anonymity)	This was a statement- they did not seem to want to discuss this further, but to inform me about this
Mary: No, no, no. Well, yes, eventually….but, what happened then, (PAUSE), what happened then, was that. **Up until this time I am talking about now, you were able to walk**. But, your walking ability was reducing pretty fast. OK? **But, we kept going, didn't we? We kept going….**like I would help Peter to the sink, to the toilet, and that would be the normal wouldn't it?	**Again, emphasis on walking function to provide context and as a significant event**
Peter: Yes.	'we kept going' to each other. **Again reference to the fight/battle.** They describe the scenario of being left to manage- not having enough help, Mary having to help
Mary: You know? And, at that time, we only had one carer helping you… Peter: Yeh	Significant event- needing 1 carer only
Mary:…and, it became…. Erm, evident, that she didn't feel confident dealing with Peter on her own, as it was getting more & more difficult for Peter to stand to stand at the sink and stuff… Me: uh-huh..?	*-Came back to the 6 week on and 6 week off class intervention, described other practical barriers*
Mary: so, we were at the stage now, when, I broke my foot. OK? So, then, I wasn't able to help him. And, it was then. Oh, and another thing, relating back, going back to the 6 week thing, **another negative thing really, erm, it became so bad, that I wasn't able to help him into the car to go for physio.** So, we	-Mary really struggled to find the words to describe this service provision, angry and trying to express it politely? Significant event for them

started depending on transport. And that was very, very, erm…	
Peter: Yeh….Yes…	
Mary: ….erm fragmented…….so, erm, unreliable. And I can remember counting one 6 week period. That he only had physio on 3 of the 6 episodes of physio that he was supposed to have it. So…..long pause.	Became very emotional here Frustration and ineffectiveness of transport system described here
Me: Due to the transport?	
Mary: Due to the transport.	
Mary: So, that happened. And, then I broke my foot. And, of course, I stopped being able to help him	
Me: Yes	
Mary: So, it was at that point, I think. That we started having primary care physio.	
Peter: Yes	
Mary: And that's when Nicki…	
P: Yes, yes	
Mary:…when Nicki started coming	
Peter: Yes. Nicki. And she was very good. EXHALES Mary: Yes, she was very good. And she used to come once a week. Ok?	(Talked with a sense of relief about XX starting to see them. Exhales like marking a change in their story, things became better. Palpable change in atmosphere and tone of Mary)
And, I can remember, because you weren't walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn't you?	-description of walking as a significant event- something that made the physiotherapist they were discussing 'very good' - significance attached to the weekly attendance of the physiotherapist- also part of 'very good'
Peter: Yes. Yeh.	-again, challenging- a lot of reassurance and agreement being sought through eye contact

Mary: **And so what was said then, you see, ‘cause I knew he could do it, you see, with the right, you know….you see, what was said then, was that the physio wanted consistency,** so he needed to do that all the time for the physio to be effective. And, **our argument was**, you know, that we needed consistent physiotherapy really, for him to be able to have effect. Constant effect. You know it sort of went together really didn’t it? Pause….. Or that’s what we felt. Peter: Yes PAUSE So, we went, you know with Nicki, erm, for a long time, really Peter: Yes! Mary:…and she was fantastic really, helping him to stand here (indicating areas within their home). **You eventually lost the ability to walk.** (Peter nods yes) And I can’t remember when that was. Probably about 6 years ago…. Peter: Yes… Me: Mmm.… Mary: Yes **So, it’s with determination really. We’ve had to…we’ve had to fight for physiotherapy**. And Peter, although he has lost his ability to stand, err, to to walk. **He can still stand**. So, Nicki eventually went on maternity leave, didn’t she? Peter: Yes. Yes. Mary: …and we were allocated a new physio….and the, the, PAUSE, what shall I say…a sort of. PAUSE….different perspective really of what you should be doing. And, umm, a lot of it was expected that Peter should be doing stuff on his own.	-Mary talks of the desire and need for consistency **? perceptions of physiotherapy having to be carried out with a physiotherapist** -**Felt it was an argument, returns to the feeling of having to fight** (I could have explored this more. ‘…was fantastic really…’ Could have explored more about what constitutes this description) Reference point of walking used again here - description of a significant event, again, walking (whether functional or not did not seem relevant- important that Peter could do it at all). There was significance attached to the weekly attendance Mary talks of the desire and need for consistency ? perceptions of physiotherapy having to be carried out with a physiotherapist **Recurring theme of argument or having to fight** *-‘He can still stand’ reiterates this, affirms importance of this* **come back to the thought that P doing things on his own was not ‘proper physio’**

Like, you know, like she suggested that a bag be put underneath his foot, and stuff like that. And that he should be doing that kind of stuff on his own.	*'we kept going' to each other.* **Again reference to the fight/battle**
Which was wrong really. Because, if he did that, and I wasn't here, he'd end up having a spasm and be down (indicating the floor). So, there was a bit of a safety issue there really. Emm. Yes	'….which was wrong really…' Explore
So, ***eventually*****,** we got to the stage where. PAUSE. Erm.	
Continuing health care agreed that Peter could have 5 hours of physiotherapy a week.	
Me: uh huh….	
Mary: and that has been, the skill, physio skill has been transferred to the carers	*clear expression that Mary was exasperated/frustrated by length of time this took*
So, every day now really….	
Peter: Well…	**Felt it was an argument**
Mary: you have exercises every day in the bed, umm, on non-shower days, alternate days really, in the bed. Some of it is passive, and some of it is active. Erm, and you have standing exercises on 2 calls of the day…	**(Note that there is no awareness that this would have been highlighted and organised by the physiotherapist, which is a long process and does improve situation for Peter & Mary)**
Peter: Yes	
Mary: And, if I'm not here, then you have 4 calls with carers a day. And then the 2 afternoon ones, both stands.	'….which was wrong really…'
And you are still able to, for a certain length of time, able to take your legs away from the support of the turn-safe.	
Peter: Yes. Yes.	
Mary: **And stand without support**.	
Me: So what effect do you think that that has on you?	

Peter: Well, it strengthens my legs, and balance you see	
Mary: and it keeps, well, the beauty of it….. **I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know? (directed to me)**	-sense of regret ? more could have been done
That's how I feel. Erm, But, you know, he can't walk. He can still stand. And, having the physiotherapy keeps him going at that level. You know, you know, haven't become unable to…to… (becomes upset)	***-emphasis that he can still stand importance of this ability woven throughout narrative- used to pull it together***
Peter: No, no….(looks over to Mary and looks distressed himself)	*-able to describe the benefits to him what it means to him to have this physical ability and how it translates to independence and function*
Mary: …to move…..and we are able to avoid using the hoist and that…..(Looks to me) Exhales strongly. Pause	***-sense of regret-more could have been done***
Mary: Which for you is significant? (To Peter)	-looking to I for affirmation/explanation (Both became upset) I allowed some time to pass, Mary went over to Peter. When I felt they were ready, I asked the next question
Peter: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it's horrible. Horrible. The only time I have been in a hoist is in [place name] where we go sometimes on holiday, and they have a pool there, they can hoist me into the pool and I can try and swim in the pool, and I enjoy that	*-description about how he feels about being in a hoist.*
Me: ….and so it's worth the hoist for the pool…(smiles)?	**Links back to importance to Peter of being able to stand**
Peter: Yes, yes. I enjoy that	*Demeaning, horrible*

PAUSE	
Me: And have you interaction with physiotherapy now?	
Peter: Well, only….	
Mary: She comes, only…..Her, her, her… perspective has changed really, actually, because, erm, you know, from, from when we were…..	
From when the physiotherapist changed, from when Nicki went on maternity leave….the…erm….PAUSE.	
The attitude, I suppose. Was very much, we haven't got time, we haven't got money. OK.	*-highlighted an attitude that they perceived and ? that they felt that money & time were limiting factors to accessing physiotherapy*
To now, probably about 2 or 3 years down the line….PAUSE…..she is saying….we must keep on with this as we are clearly doing something right….you know? (To I)	-interesting that this is what the physio had said about working on his own, and that it has helped, but they see it as proving this to physio?
She said that herself last time she was here. (Looks to I)	
I: uh huh	
W: So, erm. The other thing, and I think this is important to say….is that the cycle thing in the gym?	**-expression of perception that it is them vs us?**
Me: uh huh?	
Mary: Which is a good thing. But, it's very inflexible, in that, you know, we were given a half hour slot on a Friday morning. And that was not flexible at all. So, you know, if it was raining on a Friday, then we wouldn't go. And we couldn't change it to any other time. We couldn't, you know. I think, especially over the summer, if you could use it any time you felt like it, erm, we would you could use it more… you know?	(challenging me?) *Refers to Moto-med bike* *Practicalities limit functionality of service*
Peter: Yes. yes	

Me: and so there's an inflexibility in a service that you want to access?	
Mary: Yes	
Peter: Yes	
PAUSE. Both look to me.	
Me: Thank you. You have given me a lot of information about the practical experience you have had about physiotherapy. Is there anything else that you would like to add? Perhaps about your experience of your interactions with physio?	
Peter: **Well, there's not enough of it**…..PAUSE	***-consistent theme throughout interview: there's not enough of it***
Me: OK.	
Mary: I feel, that, you know, MS as a condition, especially progressive MS. There isn't any other treatment to be had, other than, you know, what you get for anti-spasms and that kind of thing…… And, physiotherapy, is good for it. And, you know, erm….LONG PAUSE….. ….You are denied…you know…there is….. Physiotherapy could be thought of as a treatment for MS…. **And yet, it's not available**. That's what I am trying to say I suppose…….	***- identification of the thought that the only thing that gives (them) hope, or that actually helps with MS is physiotherapy***
Me: Yes…..yes That is very useful to hear…	*'….you are denied…'*
Peter: yes. That's fine. Apart from do I want to mention the council thing? (To Mary)	

Mary: Well, yes, that has nothing to do with it sweetheart…..	***
Peter:….**well, I didn't have any physio! (emphatically)**	
Mary: yes, well, you see, for a while Leigh, what we have now are our own carers, yes?	
Me: Yes	
Mary:…and, for a while, we had the council carers….and, erm, they refused point blank to transfer the skills, but I think, that that really…… for the future. Is not really going to be of value. As the council are giving up the care element of their services….	-issues regarding transference of handling skills and therapy from therapy to carers caused distress for P. Mentioned a few times in the interview. Peter seemed very upset about this time in their lives as Mary had to do a lot for Peter? He is angry that the service was not provided *-expression of how exhausting it was for W to carry out physiotherapy with P*
Me: Yes	*-expression from P about how worried it made him for W*
Mary: so, you see, I gave the physiotherapy while they were coming. Didn't I?	*coming back to being denied, not enough/any physio*
Peter: Yes, yes.	*-both of them are angry- each aware of the effects on the other*
Mary: Every single day really. Erm, every day, every morning, whether it was shower day or not. Because I was so scared that he would lose what we had, what we had erm, erm…..(became upset)	Important to Peter- keeps returning to this
Peter: built up	-Peter looking to me to emphasis the impact of this on their lives.
Mary: yes, built up you see….the way, the way…. Perhaps I need to explain really. That the care company that we had, pulled out. And they did carry out the physio.	*-coming back to something they had fought for and do not want to lose*
And so the council carers were a temporary measure until we were able to, erm, employ our own.	*-importance of physical independence and ability*
And that took 9 months right?	
And so, for 9 months, **you would have been without physio, if it hadn't been for me……**	-issues regarding transference of handling skills and therapy from therapy to carers caused distress for Peter Mentioned a few times in the interview.
Peter: Yes, yes…	

Mary: that's what you are trying to say isn't it?	
Peter: Yes. Yes. Yes. Looks to I……	-here Peter fills in for Mary when she struggles to express what she wants to say and becomes upset
Me: and what was the impact….? Pause	
Peter: a lot….a lot….I mean, she's still working part time…….	-expression of how exhausting it was for Mary to carry out physiotherapy with Peter -expression from Peter about how worried it made him for Mary
Stopped recording at this point as Mary indicated me to do so, as Peter became upset about the impact that his MS has upon Mary, particularly when reflecting on this time of their lives	-coming back to being denied, not enough/any physio -both of them are angry- each aware of the effects on the other
	-Peter looking to me (look that was full of sadness, desperation) to emphasis the impact of this on their lives. Peter was clearly distressed about this

Peter comes back to throughout the interview was the time when they had 9 months without any therapy and without their own carers. The council carers that they had were unable/did not carry out physical activity/exercise with P. Therefore Mary had to carry this out every day with Peter during this time and this was something that he was both upset and angry

- Discussed that effects that not having physiotherapy had on them but did not articulate what benefits it did have to them
- No ownership of physio
- Other notes: W worked in the same health board- knew the system, expressed that people with other conditions 'got more', expressed frustration at the system ++

At time of interview: Functional ability: Able to stand with equipment and assistance, requires care, unable to walk. Peter is able to stand with assistance and a transfer aid. Able to use arms for some tasks. Lives with his wife. Able to self-propel or use electric WC independently

Third stage: Emerging themes:

Emergent themes	Transcript (W= wife of P) P= ‘Peter’ W= ‘Mary’	Notes *Descriptive* Linguistic **Conceptual**
	(Chat about where they live)	
	Me: I would like you to tell my about your experiences of Physiotherapy	
	Peter: How far do you want to go back?	
	Mary: As much as you can tell me	
Absence of physio- a practical issue but also a resounding theme	Peter: Well, (to Mary) you had better help tell my story…I mean, **there was a time when we didn’t have any physio at all**….that was when we had the council carers?	Sought assistance and affirmation from Mary (struggles with timelines) **Initial focus on service delivery** ***
Reference point and importance of functional ability	Mary: No, no, no…shall I, sort of?....We moved here about 11 years ago, Yes? (To Peter) **And up until about 6 years ago, Peter was walking**	Affirmed and sought agreement from Peter (consistent interaction throughout the interview) *Provided context of physical ability.* *Note the importance of this to Mary, but not mentioned by Peter* **Emphasis on walking function to provide context and highlighted as a significant event**
Peter seemed to perceive this a therapy ‘Yes’, whereas Mary did not	Peter: uh huh Mary: I can’t remember……up until, you know you didn’t have physio in London did you? (to Peter) Peter: Yes, I did Mary: But you used to do your own exercises didn’t you? (to Peter) He would go to the gym, and we had stairs in the house, so he was getting a lot of exercise (to	**Mary not seeing Peter doing his own exercise**

	me), em, you know, without needing medial physiotherapy really	**as physiotherapy, whereas Peter did 'Yes'**
	Me: yes…..	
	Mary: So, when the time came, when, you know, we thought that he needed physiotherapy, you were referred to XX hospital weren't you? (To Peter)	
	Peter: Yes	? I should have/could have asked what was it that made them think that Peter needed physiotherapy at this point
	Mary:….and, I can't remember how long ago into moving here that that was…probably about 2 years, and so we are going back 8-9 years…..	
	Me: uh-huh…..	
	Mary:….and, it was a system where they had 6 weeks on and 6 weeks off, and it was a group thing, in XX hospital	
	Peter: Yep	
	Mary:…so, that was your first experience of having MS related physiotherapy wasn't it?	
	Peter: Yep	**'system, group thing'. ? indicates no sense of belonging to this group, or taking part in it**
Lack of involvement- being done to,	Me: (To Peter) And can you tell me about that experience?	*Identified what Mary perceived as first experience of physiotherapy related to MS*
Use of humour to enable coping	Peter: Well, parts of it were good, and some weren't….like my went on that….(transport)….it was one royal fork out really….And, then I was on steroids then remember? (To Mary), and that helped for about….10 minutes….(smirked/snorted in irony?) because, you know, it doesn't last long…so, anyway, that's all I remember of it….	**? seems separate to Peter 'it'** -struggled to describe frustrations, struggled to remember timelines
	Me: So, what was the effect on your quality of life, or your life from that physiotherapy, if any?	-used sarcasm/humour to indicate frustration that available medical
	Peter: It made me feel pointless really, because it wasn't helpful….	

Lack of communication and lack of consistency ? lack of being involved in person centred care results in feeling of pointless ness, making life more difficult ‘you were told that, you were actually TOLD’ highlights lack of control and involvement	Mary: ….it wasn’t consistent….it wasn’t consistent…and what we found, was that very often, um, the 6 weeks, you know, you weren’t called after 6 weeks, it would sometimes be 3 months, when his turn came up again, and, and that kind of experience. And, also, there was….I can’t remember Peter, if it was before or after, the 6 week rota, I think it was before actually, you actually had some pool therapy in XX hospital Peter: oh, yes, right, swim, swimming Mary: yes. Peter: Yes Mary: and that lasted , about a few weeks, Peter: Yeh Mary:….and then it never happened again, we were told, and I remember this actually now, you were told that, that, you were actually told, the gym based physio would be more beneficial for you, rather than going into the pool…. BOTH LOOKED AT Me……..(challenging/questioning look from both) LONG PAUSE…..continues to look to me for an answer Me: And did you find that to be the case? Peter: No. Absolutely not. Me: OK PAUSE. LOOKED AT I…..	treatments did not help him **It made me feel pointless really** **Because the intervention was not helpful, made him feel pointless? Or made him feel the intervention was pointless?** *Mary described problems with the practicalities of the service in terms of transport, timing, regularity* (Looking at I in a challenging way- expectation of me as a therapist) Challenging: expressed that Peter felt that he had been offered this, trialled it, and was then told that it was not as helpful for him (Felt in interview that they wanted I to provide answers about this to them)

	Me: so, in terms of how that made you feel….? Peter: Well, it just made life more difficult really	**They were not aware of having been involved in this decision**
	Me: So…..? Peter: The lack of physio Me: The lack of physio made it more difficult?	Experience of having been offered classes, then stopped, hydro, and then stopped
	Peter: Yes Me: OK…….Pause (allowed time for Peter or Mary to talk)…	**? Highlighting that a lack of physio made life more difficult, ? or the changing of methods ? of not being consulted**
	And what was your next experience after that then?	***
Reference point and importance of functional ability	Peter: Well, then it goes onto the dreaded council carers…. Mary: No, sweetheart, it doesn't…	? I should have explored more ? in what way did it make your life more difficult
Use of functional level as a reference point to each scenario told- emphasising importance of this to them both Another theme: we kept going, fighting, battle	Peter: It goes on to Nicki (therapists name, changed for anonymity) Mary: No, no, no. Well, yes, eventually….but, what happened then, (PAUSE), what happened then, was that. **Up until this time I am talking about now, you were able to walk**. But, your walking ability was reducing pretty fast. OK? **But, we kept going, didn't we? We kept going….**like I would help Peter to the sink, to the toilet, and that would be the normal wouldn't it?	**Again, emphasis on walking function to provide context and as a significant event** 'we kept going' to each other. Again reference to the fight/battle
	Peter: Yes. Mary: You know? And, at that time, we only had one carer helping you… Peter: Yeh Mary:…and, it became…. Erm, evident, that she didn't feel confident dealing with Peter on her own, as it was getting more &	Significant event- needing 1 carer only

Facilities and practicalities made accessing physio difficult Which made their lives more difficult *Repeated phrases. Affirmation. They both emphasise the importance of having a therapist come that they felt 'was good'* What defined 'good' physio for them? -Physio should be carried out by a physio -consistency -function	more difficult for Peter to stand to stand at the sink and stuff… Me: uh-huh..? Mary: so, we were at the stage now, when, I broke my foot. OK? So, then, I wasn't able to help him. And, it was then. Oh, and another thing, relating back, going back to the 6 week thing, **another negative thing really, erm, it became so bad, that I wasn't able to help him into the car to go for physio.** So, we started depending on transport. And that was very, very, erm… Peter: Yeh….Yes… Mary: ….erm fragmented…….so, erm, unreliable. And I can remember counting one 6 week period. That he only had physio on 3 of the 6 episodes of physio that he was supposed to have it. So…..long pause. Me: Due to the transport? Mary: Due to the transport. Mary: So, that happened. And, then I broke my foot. And, of course, I stopped being able to help him Me: Yes Mary: So, it was at that point, I think. That we started having primary care physio. Peter: Yes Mary: And that's when Nicki… P: Yes, yes Mary:…when Nicki started coming Peter: Yes. Nicki. And she was very good. EXHALES Mary: Yes, she was very good. And she used to come once a week. Ok?	-Came back to the 6 week on and 6 week off class intervention, described other practical barriers Significant event for them Became very emotional here Frustration and ineffectiveness of transport system described here **Can see myself step into 'work mode' looking for what the problems were** Another significant event- need for community physio (Talked with a sense of relief about XX starting to see them) -I could have asked what they meant by 'very good' -description of a significant event, again, walking (whether functional or not did not seem relevant- important that Peter could do it at

Seems to say this to me with some challenge- see, we have got here despite being denied *And 'it was expected that….' By stating this, suggests that Mary does not expect this?*	And, I can remember, because you weren't walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn't you? Peter: Yes. Yeh. Mary: **And so what was said then, you see, 'cause I knew he could do it, you see, with the right, you know….you see, what was said then, was that the physio wanted consistency,** so he needed to do that all the time for the physio to be effective. And, **our argument was**, you know, that we needed consistent physiotherapy really, for him to be able to have effect. Constant effect. You know it sort of went together really didn't it? Pause….. Or that's what we felt. Peter: Yes PAUSE So, we went, you know with Nicki, erm, for a long time, really Peter: Yes! Mary:…and she was fantastic really, helping him to stand here (indicating areas within their home). **You eventually lost the ability to walk.** (Peter nods yes) And I can't remember when that was. Probably about 6 years ago…. Peter: Yes… Me: Mmm…. Mary: Yes **So, it's with determination really. We've had to…we've had to fight for physiotherapy**. And Peter, although he has lost his ability to stand, err, to to walk. **He can still stand**. So, Nicki	all). There was significance attached to the weekly attendance Mary talks of the desire and need for consistency ? perceptions of physiotherapy having to be carried out with a physiotherapist Felt it was an argument/battle (I could have explored this more. '…was fantastic really…' Could have explored more about what constitutes this description) Reference point of walking used again here Recurring theme of argument or having to fight 'He can still stand' Importance of functional ability -come back to the thought that Peter doing things on his own was not 'proper physio'

	eventually went on maternity leave, didn't she?	'….which was wrong really…'
	Peter: Yes. Yes.	
-Fight	Mary: …and we were allocated a new physio….and the, the, PAUSE, what shall I say…a sort of. PAUSE….different perspective really of what you should be doing. And, umm, a lot of it was expected that Peter should be doing stuff on his own. Like, you know, like she suggested that a bag be put underneath his foot, and stuff like that. And that he should be doing that kind of stuff on his own.	*** (Note that there is no awareness that this would have been highlighted, organised and applied for by the physiotherapist. And the physio would have trained the carers)
Theme from above- what this therapist did was actually set up a programme to enable Peter to carry out programme with the carers daily- to practise functional task consistently yet not described as 'good' as physio was not carrying this out	Which was wrong really. Because, if he did that, and I wasn't here, he'd end up having a spasm and be down (indicating the floor). So, there was a bit of a safety issue there really. Emm. Yes	
	So, ***eventually***, we got to the stage where. PAUSE. Erm.	
	Continuing health care agreed that Peter could have 5 hours of physiotherapy a week.	
	Me: uh huh….	
	Mary: and that has been, the skill, physio skill has been transferred to the carers	
	So, every day now really….	
	Peter: Well…	
Functional ability highlighted, Repeated.	Mary: you have exercises every day in the bed, umm, on non-shower days, alternate days really, in the bed. Some of it is passive, and some of it is active. Erm, and you have standing exercises on 2 calls of the day…	
	Peter: Yes	
Sense of regret- 'if he had this kind of physio when he needed it…'	Mary: And, if I'm not here, then you have 4 calls with carers a day. And then the 2 afternoon ones, both stands.	

Might help with feelings of anger, acceptance if this was something that they could talk through, or something that therapists talked through- to help people to understand that the condition is degenerative and so deterioration is not necessarily due to anything that was done or not done	**And you are still able to, for a certain length of time, able to take your legs away from the support of the turn-safe**. Peter: Yes. Yes. Mary: **And stand without support**. Me: So what effect do you think that that has on you? Peter: Well, it strengthens my legs, and balance you see	-emphasis that he can still stand to I -able to describe the benefits to him -sense of regret
Functional ability repeated.	Mary: and it keeps, well, the beauty of it….. **I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know? (directed to me)**	-looking to I for affirmation/explanation
Hope that continuing physiotherapy will maintain function	**That's how I feel. Erm, But, you know, he can't walk. He can still stand. And, having the physiotherapy keeps him going at that level. You know, you know, haven't become unable to…to… (becomes upset)**	(Both became upset) difficult to articulate
There is a juxtaposition in this interview. Clear view that they need more physio, and physio needs to be consistent. Physiotherapist had been instrumental in setting up a comprehensive care package to include daily physio. Neither Peter nor Mary seem to see this as physio (nor see the role of the physio in setting this up), though they do note the value of this programme several times (but see it separate to physio). Perhaps more work around explaining the role of the physio in assessing and then prescribing a	Peter: No, no….(looks over to Mary and looks distressed himself) Mary: …to move…..and we are able to avoid using the hoist and that…..(Looks to me) Exhales strongly. Pause Mary: Which for you is significant? (To Peter) Peter: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it's horrible. Horrible. The only time I have been in a hoist is in [place name] where we go sometimes	-description about how he feels about being in a hoist. Links back to importance to Peter of being able to stand -repetition of her- struggles to find the words

programme and then the consistency is through carrying this programme out. Seemed to prefer seeing the PT weekly rather than daily PT with carers?	on holiday, and they have a pool there, they can hoist me into the pool and I can try and swim in the pool, and I enjoy that Me: ….and so it's worth the hoist for the pool…(smiles)? Peter: Yes, yes. I enjoy that PAUSE	
	Me: And have you interaction with physiotherapy now? Peter: Well, only…. Mary: She comes, only…..Her, her, her… perspective has changed really, actually, because, erm, you know, from, from when we were…..	-highlighted an attitude that they perceived and that they felt the money & time were limiting factors to accessing physiotherapy
	From when the physiotherapist changed, from when Nicki went on maternity leave….the…erm….PAUSE.	-interesting that this is what the physio had said about working on his own, and that it has helped, but they see it as proving this to physio?
	The attitude, I suppose. Was very much, we haven't got time, we haven't got money. OK.	-expression of perception that it is them vs us?
Again, that sense of battle, and having to fight	To now, probably about 2 or 3 years down the line….PAUSE…..she is saying….we must keep on with this as we are clearly doing something right….you know? (To I)	
	She said that herself last time she was here. (Looks to I)	(challenging?)
	I: uh huh	Moto-med
	W: So, erm. The other thing, and I think this is important to say….is that the cycle thing in the gym?	Practicalities limit functionality of service -consistent theme throughout interview: there's not enough of it
	Me: uh huh?	
Facilities and access, inflexibility	Mary: Which is a good thing. But, it's very inflexible, in that, you know, we were given a half hour slot on a Friday morning. And that was not flexible at all. So, you know, if it was raining on a Friday, then we wouldn't go. And we	-identification of the thought that the only

Need for a physio to carry out physio. Still reporting this as their experience despite hour a day therapy as part of care package *Hope in physiotherapy* Not enough of it Battle 'you are denied' *Throughout the interview with Mary and Peter, they return to their feelings of being denied physiotherapy- something that they identified as being helpful*	couldn't change it to any other time. We couldn't, you know. I think, especially over the summer, if you could use it any time you felt like it, erm, we would you could use it more… you know? Peter: Yes. yes Me: and so there's an inflexibility in a service that you want to access? Mary: Yes Peter: Yes PAUSE. Both look to me. Me: Thank you. You have given me a lot of information about the practical experience you have had about physiotherapy. Is there anything else that you would like to add? Perhaps about your experience of your interactions with physio? Peter: **Well, there's not enough of it**…..PAUSE Me: OK. Mary: I feel, that, you know, MS as a condition, especially progressive MS. There isn't any other treatment to be had, other than, you know, what you get for anti-spasms and that kind of thing…… And, physiotherapy, is good for it. And, you know, erm….LONG PAUSE….. ….You are denied…you know…there is….. Physiotherapy could be thought of as a treatment for MS…. **And yet, it's not available**. That's what I am trying to say I suppose…….	thing that gives (them) hope is physiotherapy '….you are denied…' *** Important to Peter- keeps returning to this -issues regarding transference of handling skills and therapy from therapy to carers caused distress for Peter Mentioned a few times in the interview. -expression of how exhausting it was for Mary to carry out physiotherapy with Peter -expression from Peter about how worried it made him for Mary -Peter looking to I to emphasis the impact of this on their lives. Peter

	Me: Yes…..yes That is very useful to hear…	was clearly distressed about this
	Peter: yes. That's fine. Apart from do I want to mention the council thing? (To Mary) Mary: Well, yes, that has nothing to do with it sweetheart….. Peter:….**well, I didn't have any physio! (emphatically)** Mary: yes, well, you see, for a while Leigh, what we have now are our own carers, yes? Me: Yes	Stopped recording at this point as Mary asked me to as Peter became upset about the impact that his MS has upon Mary
The stress that the carer carrying out therapy has on the person and the carer. That seemed why this episode of his life was so important to Peter- it was the affect on Mary	Mary:…and, for a while, we had the council carers….and, erm, they refused point blank to transfer the skills, but I think, that that really…… for the future. Is not really going to be of value. As the council are giving up the care element of their services…. Me: Yes Mary: so, you see, I gave the physiotherapy while they were coming. Didn't I?	
Peter became very upset about this- felt that he had been trying to talk about this throughout the interview. There seemed to be some release when he said it and he became very upset. Sadly Mary discontinued the interview at this stage.	Peter: Yes, yes. Mary: Every single day really. Erm, every day, every morning, whether it was shower day or not. Because I was so scared that he would lose what we had, what we had erm, erm…..(became upset) Peter: built up Mary: yes, built up you see….the way, the way…. Perhaps I need to explain really. That the care company that we had, pulled out. And they did carry out the physio. And so the council carers were a temporary measure until we were able to, erm, employ our own. And that took 9 months right?	

	And so, for 9 months, **you would have been without physio, if it hadn't been for me……** Peter: Yes, yes… Mary: that's what you are trying to say isn't it? Peter: Yes. Yes. Yes. Looks to I…… Me: and what was the impact….? Pause Peter: a lot….a lot….I mean, she's still working part time……. *Stopped recording at this point as Mary indicated me to do so, as Peter became upset about the impact that his MS has upon Mary, particularly when reflecting on this time of their lives*	

Interview 1: Development of themes:

subsumption & abstraction, bringing together of themes

Carried out on paper, notes on computer

<u>The importance of functional ability of daily tasks</u>

- Important to Mary > Peter?
- Used as a reference point to time, significant life events
- the use of this as a challenge
- the use of this as an achievement, demonstration of 'battle won', A badge?

- Mary: And up until about 6 years ago, Peter was walking 6/7

- Mary: Up until this time I am talking about now, you were able to walk. But, your walking ability was reducing pretty fast 60/61

- Mary: Yes, she was very good. And she used to come once a week. Ok? And, I can remember, because you weren't walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn't you

Peter: Yes. Yeh 86/91

- Mary: And Peter, although he has lost his ability to stand, err, to to walk. He can still stand 107/8

- Mary: And you are still able to, for a certain length of time, able to take your legs away from the support of the turn-safe
  Peter: Yes…Yes
  Mary: And stand without support 129/132

- Mary: But, you know, he can't walk. He can still stand. And, having the physiotherapy keeps him going at that level 139/140

<u>Service delivery</u>

<u>Lack of involvement in therapy</u>

- being done to
- being told to
- Mary: …….we were told, and I remember this actually now, you were told that, that, you were actually told, the gym based physio would be more beneficial for you, rather than going into the pool….
  BOTH LOOKED AT I……..PAUSE
  I: And did you find that to be the case?
  Peter: No. Absolutely not 44/48

- Lack of communication
- ? lack of being involved in person centred care results in feeling of pointlessness, making life more difficult

<u>Effectiveness</u>

- lack of consistency

- Mary:….and, it was a system where they had 6 weeks on and 6 weeks off, and it was a group thing, in XX hospital
  Peter: Yep
  Mary:…so, that was your first experience of having MS related physiotherapy wasn't it?
  P: Yep
  I: (To Peter) And can you tell me about that experience?
  Peter: Well, parts of it were good, and some weren't….like my went on that….(transport)….it was one royal fork out really….And, then I was on steroids then remember? (To W), and that helped for about….10 minutes….because, you know, it doesn't last long…so, anyway, that's all I remember of it….
  I: So, what was the effect on your quality of life, or your life from that physiotherapy, if any?
  Peter: It made me feel pointless really, because it wasn't helpful 21/32 (? Was this because he was not involved in the process)
- Mary: ….it wasn't consistent….it wasn't consistent…and what we found, was that very often, um, the 6 weeks, you know, you weren't called after 6 weeks, it would sometimes be 3 months, when his turn came up again, and, and that kind of experience 33/35
- Mary: you actually had some pool therapy in XX hospital
  Peter: oh, yes, right, swim, swimming
  Mary: yes

Peter: Yes
Mary: and that lasted, about a few weeks
Peter: Yeh…
Mary:…..and then it never happened again 36/42

- Mary: And stand without support
  I: So what effect do you think that that has on you?
  Peter: Well, it strengthens my legs, and balance you see 132/134

Facilities and practicalities made accessing physio difficult

- Which made their lives more difficult
- Facilities and access, inflexibility

- Mary:….and, it was a system where they had 6 weeks on and 6 weeks off, and it was a group thing, in XX hospital 21/22
- Mary: going back to the 6 week thing, another negative thing really, erm, it became so bad, that I wasn't able to help him into the car to go for physio. So, we started depending on transport. And that was very, very, erm…
  Peter: Yeh….Yes.
  Mary….erm fragmented…….so, erm, reliable. And I can remember counting one 6 week period. That he only had physio on 3 of the 6 episodes of physio that he was supposed to have it. So…..
  I: Due to the transport?
  Mary: Due to the transport 70/76
- Mary: …… the cycle thing in XX in the gym?
  I: uh huh
  Mary: Which is a good thing. But, it's very inflexible, in that, you know, we were given a half hour slot on a Friday morning. And that was not flexible at all. So, you know, if it was raining on a Friday, then we wouldn't go. And we couldn't change it to any other time. We couldn't, you know. I think, especially over the summer, if you could use it any time you felt like it, erm, we would you could use it more… you know? 162/169

Not enough physio

- The stress that the carer carrying out therapy has on the person and the carer. That seemed why this episode of his life was so important to Peter- it was the affect on Mary

- Peter……I mean, there was a time when we didn't have any physio at all….4/5 (first statement ? indicative of importance level)
- I: so, in terms of how that made you feel….?
  Peter: Well, it just made life more difficult really
  I: So…..?
  Peter: The lack of physio
  I: The lack of physio made it more difficult. OK. 51/55
- Mary: So, it's with determination really. We've had to…we've had to fight for physiotherapy 107
- Mary: The attitude, I suppose. Was very much, we haven't got time, we haven't got money. OK. 156/157
- Mary: I feel, that, you know, MS as a condition, especially progressive MS. There isn't any other treatment to be had, other than, you know, what you get for anti-spasms and that kind of thing… And, physiotherapy, is good for it. And, you know, erm….LONG PAUSE….You are denied…you know…there is…..Physiotherapy could be thought of as a treatment for MS….And yet, it's not available. That's what I am trying to say I suppose…….180/186
- I: Is there anything else that you would like to add? Perhaps about your experience of interaction with physio? Peter: Well, there's not enough of it…..PAUSE 176/178

(What defines/what is perceived as) ‘good’ physio ? What is understood to be physio?

- Physio should be carried out by a physio

- Mary: …..up until, you know you didn’t have physio in London did you? (To Peter)
  Peter: Yes
  Mary: But you used to do your own exercises didn’t you? 9/11
- consistency
- function
- what this therapist did was actually set up a programme to enable Peter to carry out programme with the carers daily- to practise functional task consistently yet not described as ‘good’ as physio was not carrying this out
- Need for a physio to carry out physio. Still reporting this as their experience despite hour a day therapy as part of care package
- Theme from above- what this therapist did was actually set up a programme to enable Peter to carry out programme with the carers daily- to practise functional task consistently yet not described as ‘good’ as physio was not carrying this out
- Peter: Yes. XX. And she was very good.
  Mary: Yes, she was very good. And she used to come once a week. Ok? And, I can remember, because you weren’t walking brilliantly then, but I can remember a day when I was in the office, and I could hear the zimmer-frame coming along. And he had actually walked from the other end of the house. And, that was, you know, umm, unusual really, as he had been for weeks without walking at all. Hadn’t you?
  Peter: Yes. Yeh.
  Mary: And so what was said then, you see, ‘cause I knew he could do it, you see, with the right, you know….you see, what was said then, was that the physio wanted consistency, so he needed to do that all the time for the physio to be effective. And, our argument was, you know, that we needed consistent physiotherapy really, for him to be able to have effect. Constant effect. You know it sort of went together really didn’t it. Or that’s what we felt 85/96
- Mary: …and we were allocated a new physio….and the, the, PAUSE, what shall I say…a sort of. PAUSE….different perspective really of what you should be doing. And, umm, a lot of it was expected that P should be doing stuff on his own 111/113
- Mary: Continuing health care agreed that P could have 5 hours of physiotherapy a week 118
  you have exercises every day in the bed, umm, on non shower days, alternate days really, in the bed. Some of it is passive, and some of it is active. Erm, and you have standing exercises on 2 calls of the day…124/126
- Mary: and it keeps, well, the beauty of it….. I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know? (directed to I)
  That’s how I feel. Erm, But, you know, he can’t walk. He can still stand. And, having the physiotherapy keeps him going at that level 136/140

We kept going, fighting, battle

- Mary: Up until this time I am talking about now, you were able to walk. But, your walking ability was reducing pretty fast. OK? But, we kept going, didn’t we? We kept going….60/61
- Mary: So, it’s with determination really. We’ve had to…we’ve had to fight for physiotherapy 107
- Mary: The attitude, I suppose. Was very much, we haven’t got time, we haven’t got money. OK. 156/157
- Mary: I feel, that, you know, MS as a condition, especially progressive MS. There isn’t any other treatment to be had, other than, you know, what you get for anti-

spasms and that kind of thing… And, physiotherapy, is good for it. And, you know, erm….LONG PAUSE….You are denied…you know…there is…..Physiotherapy could be thought of as a treatment for MS….And yet, it's not available. That's what I am trying to say I suppose…….180/186

- Mary: Every single day really. Erm, every day, every morning, whether it was shower day or not. Because I was so scared that he would lose what we had, what we had erm, erm…..
  Peter: built up
  Mary: yes, built up you see 200/202

Hope/Fear/Regret

that continuing physiotherapy will maintain function

- Mary: Erm, But, you know, he can't walk. He can still stand. And, having the physiotherapy keeps him going at that level. You know, you know, haven't become unable to…to…
  Peter: No, no…
  Mary: …to move…..and we are able to avoid using the hoist and that…..(Looks to I)
  I: (to Peter) Which for you is significant?
  Peter: Oh, it is. There is nothing more demeaning than being in a hoist. I mean, you know, it's horrible. Horrible. 138/144

Sense of regret

- 'if he had this kind of physio when he needed it…'
- Mary: and it keeps, well, the beauty of it….. I feel, that perhaps if he had had this kind of physiotherapy when he needed it, when he was walking, that perhaps he might still be walking. Do you know? (directed to I) 135

Effect on carers

- Mary:…and, for a while, we had the council carers….and, erm, they refused point blank to transfer the skills, but I think, that that really…… for the future. Is not really going to be of value. As the council are giving up the care element of their services….
  I: Yes
  Mary: so, you see, I gave the physiotherapy while they were coming. Didn't I?
  Peter: Yes, yes
  Mary: Every single day really. Erm, every day, every morning, whether it was shower day or not. Because I was so scared that he would lose what we had, what we had erm, erm…..
  Peter: built up
  Mary: yes, built up you see….the way, the way…. Perhaps I need to explain really. That the care company that we had, pulled out. And they did carry out the physio. And so the council carers were a temporary measure until we were able to, erm, employ our own. And that took 9 months right? And so, for 9 months, you would have been without physio, if it hadn't been for me……
  Peter: Yes, yes…
  Mary: that's what you are trying to say isn't it?
  Peter: Yes. Yes. Yes. Looks to I……
  I: and what was the impact….?
  Peter: a lot….a lot….I mean, she's working part time……** Peter became upset and Mary asked for the interview to be stopped 194/212

Other: Mary leads a lot of the interview

Mary: No, no, no…shall I, sort of?....6 (And various other examples)

OVERVIEW TABLE OF THEMES

Theme one: Sense of self

Emerging themes	Sub-themes
Pride in achievements vs feelings of uselessness, loss of confidence, critical of self, unimportant, undeserving (not wanting to bother anyone)	Participants' feelings about themselves (in relation to their experience of physiotherapy, their physical function, and in relation to having MS)
The physical effects of MS (over time), Effect on loved ones, working life,	MS effects on lives of participants & their loved ones
The fight (of MS/ for Physiotherapy); participants expressed the daily fight against the effects of MS, the fight for maintaining quality of life and independence despite MS, the fight against loss (using a walking aid for example), the internal fight- what participants felt they should do and what they could do and what they actually do.	**Loss of confidence in self, Loss of sense of self**
(Having to fight to get physiotherapy)	**Fighting with MS**
Change in function and ability changed the way participants viewed themselves	Loss of confidence in self, Loss of sense of self

Theme two: The embodied experience of physiotherapy

Emerging themes	Sub-themes
Hospital transport issues are problematic, creating barriers to therapy and causing anxiety to users Car parking is situated too far from the department, causing fatigue, distress and anxiety Disabled-friendly access to the physiotherapy department and toilet facilities are important for usability, reducing anxiety, fatigue management and maintaining independence and dignity Personalised timing and flexibility of appointments improve work-life balance and facilitate better fatigue management Self-referral to physiotherapy is valuable and assists PwMS to self-manage their condition Continuity of physiotherapy is important Some participants felt they had to fight to get and maintain physiotherapy input	Suitable transport, car parking, accessible facilities and toilets, flexible appointments and the ability to self-refer to physiotherapy all impact on participants' ability to attend and participate in physiotherapy sessions, affecting participants' dignity, , how participants feel about themselves (sense of self)independence, anxiety, fatigue and quality of life **Practical aspects of service delivery affect the lived experience of physiotherapy (and of living with MS)**
What physiotherapy means and constitutes to participants: Exercise- part of their daily routine, helps to improve function, identification that they need help to get their exercise technique right Education, advice, teaching, (to include advice about walking aids) Something that you carry out on your own? (Self-management) Something that a physiotherapist carries out with you? What makes a 'good' physiotherapist?	Exercise is understood as a key component of physiotherapy and of most participants management of their MS The physical effects of physiotherapy were discussed Education, advice and teaching (including feedback) provided enablement and increased ability to self-manage, as well as increasing confidence and independence. What makes a 'good' physiotherapist Participants' understanding and perception of physiotherapy varied between participants **What is Physiotherapy?**
Factors affecting self-management and participants' ability to follow programmes (and what affects these): Adherence, time management, fatigue levels, motivation Independence, confidence Group work (to exercise) and Community support (MS support group)	Factors affecting self-management The importance of self-management and independence **Self-management**

Consistency, regular reviews beneficial to ensure that participants knew what physiotherapy/exercise to do and how	
A person-centred approach to physiotherapy is beneficial: listening, providing knowledge, emotional support and reassurance, involving patients in decision making, communicating effectively across and between services, were all identified as being important physiotherapist skills that overwhelmingly improved the experience of physiotherapy and of living with MS, to include how participants felt about themselves	Person-centred care and effective communication (to include partnership working and decision making) is pivotal for effective physiotherapy **Person centred care and communication**

Theme three: The embodied experience of living with MS

Emerging themes	Sub-themes
Hope and hopelessness- the balance can be affected by physiotherapy, regret and loss associated with having MS, but also if 'denied' physiotherapy Joy and happiness as fragile concepts, perhaps more difficult to find when living with the effects of MS. Identified as being important for quality of life- doing things that are meaningful and enhance life Exercise and physiotherapy offer hope and helps to manage fear (of condition getting worse) Restricting physiotherapy/not being able to access physiotherapy restricts hope, increases anxiety and fears	Emotional effects: Hope Regret Happiness and fulfilment Fear and loss The balance between maintaining hope and managing/preventing fear was present and important to all participants

Appendix XV: Theme generation

Ways of looking for connections across emergent themes	
Abstraction	Putting like with like to develop super-ordinate theme
Subsumption	An emergent super-ordinate theme brings together a series of related themes
Polarisation	Looking for differences, oppositional relationships in themes within transcripts
Contextualisation	Organising themes from looking at the context of the transcript, for example, relating to key events in the participants life
Numeration	Frequency with which the theme is supported in the narrative
Function	Themes can be examined for their specific function within the transcript, for example, if the participant uses certain language to represent a particular thing, or position themselves in a particular way

Table showing techniques and descriptors for searching for connections across emergent themes.

Appendix XVI: What makes a good physiotherapist?

Mary:…and she was fantastic really (T1L102)

Yes, she was very good. And she used to come once a week. Okay? (T1L118)

Bella: All I have to say is that all of my experiences have been good. I have had all the physiotherapy that I need (T2L2/3)

Anna: Well, I have had good experiences of physio (T3L29)

Fran: I mean, I'm, I've got nothing but praise for the physio that I had (T4L41)

Clare: Well, I hope that this is going to be helpful as, actually, all my experiences have been good…(T5L6/7)

But, as far as physio, I have been very happy with everyone I have been involved with (T5L146)

Julie: (I had asked her to tell me about her experiences of physiotherapy) Well, very good. Very good! (T6L5)

Table: Extract selection where physiotherapy is described as good

Enablement (enabling independence enabling function education and advice)	**Mary:…**and she was fantastic really, helping him to stand here (indicating their home) (T1L102) **Anna:** And she was good. She gave me all kinds of exercises that I could be doing. (T3L40/41) **'**and Laura was very good while I was there. Laura was very good with me. She told me what to do, all the exercises (T3L49/50) '…and another thing that she said….'heel toe and up' I say, right. I say, when I can feel it dragging, I think of Laura and I say 'heel, toe and up'…..you know the things that Laura was saying. Gosh! She was good (T3L224/226) **Fran:** ….I mean, I'm, I've got nothing but praise for the physio that I had. Because I would say that it has made the difference between being back at work, and driving, and me not being back at work and driving (T4L41/42) I had been more impressed by how she, how the physio has been interested in preventing disability rather than "making your nerves work" (T4L63/65) And, and Megan has been great. So, each week, she gave, sort of, me enough time, and looked at something, suggested something (T4L142) But, err, the physio bit has made the difference between functioning and not. Probably more so than the steroids. The steroids were

Hope	magic, but they also turned you balloon faced, …and made other bits not…(T4L214) ‘you know, she could just spot things like that from the way you walked in. ‘Cos she is a good experienced physio you know. So, you can walk in, and she says… ‘have you been doing such and such…?’ Laughs (T4L372/382) **Julie:** [talks about a fall that she had and how she managed to get up herself, using technique shown by the physiotherapist] So, what I am saying is, I can get out of these situations now, because Brenda has told me what to do, you know? …..so that is brilliant, brilliant. So, yeah, I am really really pleased with that ‘cos I am not sort lying there, helplessly thinking ‘Ohhhhhhh’ (T6L85/90) **Fran:** And, actually, that in itself was, you know, probably……I mean, functionally, I would not be functioning this well without physio. Definitely. But, I think the fact they were also able to give you a bit of hope…(T4L181/186)
Person-centred approach, joint discussion and communication listening	**Anna:** She is very very good for me. I told her, I can feel that one leg is longer than the other. And she said ‘we’ll measure it, we’ll measure it then’…And they were both the same! (Laughs) (T3L52/54) **Fran:** [ ] the first time she just listened to me for about an hour, about what had been going on. And, in a sense, I know that isn’t specifically physio…but that was the first time that anyone had done that…. And it was the first time that someone had listened to how the illness had affected me…(T3L58/61) **Fran:** And just things like you seeing a human being who was treating you like a human being. [ ] Actually, that’s nice, ‘cos that makes you feel like somebody actually, it made me feel that somebody was actually treating me like a person (T4L395/398) The personal bit helped me a lot (T4L411/414)

Table: Extract selection where physiotherapy is described as good with a description about why this is the case

Appendix XVII: IPA course

Aston University
Life & Health Sciences

Professional Development Course

This is to certify that

Leigh Campbell

has attended a 1 day
Interpretative Phenomenological Analysis Workshop

16th May 2014

FORWARD

Dr Julia Y Brown
Head of External Relations

Aston University
Birmingham

INTRODUCTION TO INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS: THEORY & ANALYSIS

DR RACHEL SHAW

16TH MAY 2014, ASTON UNIVERSITY

This workshop is for those who are new to IPA and those who need more formal guidance on the practicalities of doing IPA. There is an introduction to the theoretical background of IPA at the beginning but the majority of the day is organized to give delegates plenty of time to practise their IPA skills, share their experiences in small group work and to seek advice from the facilitator. Issues of reflexivity and quality will be covered briefly at the close. References are provided including key text books, research articles using IPA and other methodological articles about IPA.

TIME	ACTIVITY
9.15-9.30	Registration & refreshments
9.30-10.00	Introductions
10.00-11.00	What is IPA? **I** – idiography & interpretation; hermeneutic cycle; **P** – phenomenology; **A** – analysis (a series of steps)
11.00-11.15	Refreshments
11.15-11.30	Exercise 1: Initial reading
11.30-12.30	Exercise 2: Phenomenological coding
12.30-13.15	Lunch
13.15-14.15	Exercise 3: Interpretative coding
14.15-14.45	Exercise 4: Identifying themes
14.45-15.00	Integrative analysis
15.00-15.15	Refreshments
15.15-16.00	Being reflexive; thinking about quality
16.00-16.15	Questions & feedback

Appendix XVIII: IPA quality evaluation

Acceptable

The paper meets the following four criteria:
- Clearly subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic.
- Sufficiently transparent so reader can see what was done.
- Coherent, plausible and interesting analysis.
- Sufficient sampling from corpus to show density of evidence for each theme:

N1-3: extracts from every participant for each theme
N4-8: extracts from at least three participants for each theme and
N-8: extracts from at least three participants for each theme-measure of prevalence of themes, or extracts from half the sample for each theme.

Overall the paper is judged sufficiently trustworthy to accept for publication and include in a systematic review.

Caveats

Compensation. Evidence base and interest factors considered together so that, e.g., a paper with particularly interesting data may gain compensation for a less than ideal evidence base.
Partial acceptability. A paper may be deemed acceptable if it has partial but discrete pockets of acceptable, e.g.,
1. Paper may present four themes, two of which are interesting and well evidenced while two of them are not. In this case, the paper can be considered acceptable as the two good themes make a sufficient contribution in their own right.
2. Paper may have number of themes but evidence each with data from the same single participant. This paper may be considered acceptable if the account of the individual is sufficiently coherent that it can be read as an interesting idiographic case-study.
3. Paper may present data from two participant groups, e.g., males and females and be deemed acceptable for one participant group but not the other.
Safe or borderline? A paper showing sufficient sampling as described above is deemed safe. A paper with a sample over eight with extracts from enough participants to illustrate variation but without detail of prevalence or enough evidence of density of themes is deemed borderline. See text for more details.

Unacceptable

The paper fails on one of the four criteria for acceptable. It may be:
- not consistent with theoretical principles of IPA
- insufficiently transparent for reader to see what was done
- not of sufficient interest
- poorly evidenced.

Predominantly what lets a paper down is the poor evidence base. Typical ways this can occur:
- large number of descriptive/superficial themes from a large number of participants
- each theme has short summary and one or two extracts without interpretation
- insufficient extracts from participants to support the themes being illustrated
- no explanation for how prevalence of the themes was determined
- analysis is crude, lacks nuance.

Overall the paper is not trustworthy and would not be judged acceptable for publication.

Good

Paper must clearly meet all the criteria for acceptable. It then offers these three extra things:
- well focused, offering an in-depth analysis of a specific topic
- data and interpretation are strong
- reader is engaged and finds it particularly enlightening.

Overall the paper could be recommended to a novice as a good exemplar of IPA.

Table: IPA quality evaluation guide. P17 Smith 2011

The paper should have a clear focus. Papers providing detail of a particular aspect rather than a broad reconnaissance are more likely to be of high quality. This focus may be determined at the outset or emerge during analysis. This focus is apparent in many of the good IPA papers illustrated, for example, Chapman et al. (2007) examine the impact of one particular technology in heart disease. Turner et al. (2002) sample one specific group of ex-professional sports players.

The paper will have strong data. Most IPA is derived from interviews and this means that, for the most part, getting good data requires doing good interviewing. This is a particular skill that must not be underestimated. The quality of the interview data obtained sets a cap on how good a paper can subsequently be. Examples of good data are given in many of the summaries of good papers presented earlier. High-quality data is integral to the success of these papers.

The paper should be rigorous. One should aim to give some measure of prevalence for a theme and the corpus should be well represented in the analysis. Extracts should be selected to give some indication of convergence and divergence, representativeness and variability. This way the reader gets to see the breadth and depth of the theme. For papers with small sample sizes (1-3), each theme should be supported with extracts from each participant. For papers with sample sizes of 4-8, in general, extracts from half the participants should be provided as evidence. For larger sample sizes, researchers should give illustrations from at least three or four participants per theme and also provide some indication of how prevalence of a theme is determined. The two papers on chronic fatigue syndrome by Dickson et al. (2007, 2008) have, for IPA, a relatively large sample size. Their persuasiveness is enhanced by careful articulation of measures of prevalence. The overall corpus should also be proportionately sampled. In other words, the evidence base, when assessed in the round, should not be drawn from just a small proportion of participants.

Sufficient space must be given to the elaboration of each theme. In certain circumstances it may well be better to present a subset of the emergent themes so there is room to do justice to each, rather than presenting all themes but doing so superficially. The French et al. (2005) paper on patient explanations for heart attack is enhanced by having an extended and elaborate account of one of the emergent themes.

The analysis should be interpretative not just descriptive. An interpretative commentary should follow each of the extracts presented. The author is thereby showing the particular ways extracts are contributing to the unfurling theme. In order to do this the researcher is engaging in the double hermeneutic: trying to make sense of the participant and trying to making sense of their experience. For further discussion on pushing interpretation deeper, see Smith (2004).

The analysis should be pointing to both convergence and divergence. Where an IPA study reports data from more than one participant, there should be a skilful demonstration of both patterns of similarity among participants as well as the uniqueness of the individual experience. The unfolding narrative for a theme thus provides a careful interpretative analysis of how participants manifest the same theme in particular and different ways. This nuanced capturing of similarity and difference, convergence and divergence is the hallmark of good IPA work.

The paper needs to be carefully written. Good qualitative work always requires good writing.

The reader will feel engaged by a well-wrought, sustained narrative. As a result, he/she will consider they have learned in detail about the participants' experience of the phenomenon under investigation.

Table: What makes a good IPA paper? P24 Smith