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EXPLORING OCCUPATIONAL THERAPY INTERVENTIONS FOR PEOPLE WITH MULTIPLE SCLEROSIS WITHIN INSTRUMENTAL ACTIVITIES OF DAILY LIVING

CHRISTOPHER EDWARD WALSHAW

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

University of Huddersfield

NOV 2020

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Abstract

Introduction

Multiple Sclerosis (MS) is an unpredictable progressive neurological condition that has a profound impact on the ability of people to engage and participation in occupations from onset which often occurs in early adulthood. At this stage of life Instrumental Activities of Daily Living (IADL), based in domestic and community contexts, constitute a complex and demanding group of occupations that contribute to occupational identity. Occupational therapy interventions have a complex role in enabling people with MS to engage and participate in purposeful and meaningful occupations such as IADL. Adopting a person-centred theoretical lens, the study reported in this thesis explored the experiences and perceptions of IADL and the occupational therapy interventions of five people with multiple sclerosis in the practice context of a community neurology team.

Methods

The research design consisted of a multiple case study incorporating mixed methods to collect predominantly qualitative data. A novel methodological approach adopted a world view influenced by pragmatism and critical realism. The Assessment of Motor and Process Skills (AMPS) providing case attributes that measured occupational performance in IADL. Semi-structured interviews were then conducted with the people with MS, their carers, occupational therapist, and other healthcare professionals. A questionnaire was also administered to the occupational therapists. The framework approach was applied to analyse the data systematically and robustly. Computer assisted qualitative data analysis software (NVivo) was used to manage data. Presentation of the framework analysis was supplemented by case summaries illuminating the narratives of the five people with MS.

Findings

Four core concepts were identified. *The Person Living with MS* represented the understanding of the impact of MS on occupational performance in IADL. *The Occupations* core concept demonstrated the variety of IADL participation and linkage to other groups of occupations. *Occupational Therapy Interventions for People with MS* revealed professional reasoning and featured fatigue management strategies, environmental interventions, and psychological interventions. The social context of *Inter-relationships* with other significant people and the MDT to support and enhance occupational performance was also identified. Development of a therapeutic partnership, that listens to and respects the diagnostic narrative of the person with MS, enables personalised interventions to support and empower participation in IADL and other occupations. The contemporary MS person-centred occupational therapy (MS-PcOT) practice model was constructed as a synthesis of the findings.

Conclusion

Occupational therapy interventions have a multi-faceted role in enabling people with MS to participate in occupations they want, need, and expect to do. The findings contribute new knowledge of professional reasoning in occupational therapy practice for people with MS. The findings also contribute to the understanding of experiences and perception of occupations in the domestic lives of people with MS. The MS-PcOT practice model is a person-centred and occupation based guide for occupational therapy practice. The model incorporates integrated and coordinated interdisciplinary practice to support people with MS in their daily occupations and maintain health and well-being.

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List of abbreviations

ADL (Activities of Daily Living)

AHP (Allied Health Profession)

AOTA (American Occupational Therapy Association)

AMPS (Assessment of Motor and Process Skills)

ANOVA (Analysis of variance)

BADL (Basic Activities of Daily Living)

BI (Barthel Index)

COMP (Canadian Occupational Performance Measure)

COPD (Chronic Obstructive Pulmonary Disease)

CMOP (Canadian Model of Occupational Performance)

CNT (Community Neurology Team)

CAQDAS (Computer assisted qualitative data analysis software)

EAT (Electronic assistive technology)

EDSS (Expanded Disability Status Scale)

FAM (Functional Assessment Measure)

FIM (Functional Independence Measure)

HCPs (Healthcare Professionals)

HRA (Health Research Authority)

IT (Information Technology)

IRAS (Integrated Research Application System)

ICF (International Classification of Functioning, Disability and Health)

IADL (Instrumental Activity of Daily Living)

JHREAT (John Hopkins research evaluation appraisal tool)

MOHO (Model of Human Occupation)

MS (Multiple Sclerosis)

MS-PcOT (MS Person-centred Occupational Therapy Practice Model)

MDT (Multi-disciplinary Team)

NHS (National Health Service)

NICE (National Institute for Health and Clinical Excellence)

OT (Occupational therapist)

PADL (Personal Activities of Daily Living)

PDA (Personal Digital Assistant)

PEOP (People Environment Occupational Performance)

PPMS (Primary Progressive Multiple Sclerosis)

REC (Research Ethics Committee)

RCT (Randomized Controlled Trial)

RBMT (Rivermead Behavioural Memory Test)

RCOT (Royal College of Occupational Therapist)

RRMS (Relapsing Remitting Multiple Sclerosis)

SREP (School Research Ethics Committee)

SPMS (Secondary Progressive Multiple Sclerosis)

UK **(**United Kingdom)

WHO (World Health Organization)

Chapter One

Background and context

---

1. Introduction

This PhD thesis is concerned with exploring how occupational therapy interventions contribute to the ability of people with Multiple Sclerosis (MS) to perform Instrumental Activities of Daily Living (IADL). MS is a progressive and unpredictable neurological condition with onset often in early adulthood. Occupational therapy is a client-centred health profession that aims to enable people to participate in activities of everyday life. Occupational therapists work to enhance a person's ability to engage in the occupations they want, need, or expect to do (World Federation of Occupational Therapists [WFOT], 2012a). Occupational therapy interventions have a constructive contribution to make to the lives and wellbeing of people with MS. This research sets out to explore the IADL occupations of five people with MS and the occupational therapy they received.

This introductory chapter presents an overview of the subject area considering the background issues and contexts that confront people with MS when they engage in IADL. The motivation for undertaking the research is detailed from a personal and reflexive viewpoint in the following section. The policy framework and context for the provision of occupational therapy services for people with MS are considered next. The impact of MS as a complex progressive neurological condition upon the person is then discussed in relation to the pathology, epidemiology, clinical course, and clinical features of the condition. The core sets of categories from the International Classification of Functioning, Disability and Health (ICF) are then considered for MS (World Health Organisation [WHO], 2001). The definition and classification of IADL is discussed from the perspective of the Occupational Therapy Practice Framework (American Occupational Therapy Association [AOTA], 2014). Research into IADL for people with MS is reviewed and the range of occupational therapy interventions for people with MS considered. Finally, an overview of the thesis and the research approach will be presented. The purpose of this research project and its rationale for generating new knowledge, is to explore the perceptions and experiences of people with MS in IADL and the contribution occupational therapy interventions delivered in a community neurology service make to maintaining and enhancing ability to perform these occupations.

1.1 Personal interest and development of the research

The initial idea, which led to this research project, developed following the invitation to contribute a study session for an electronic learning project. The *ebrain* project is a collection of resources aimed at developing knowledge and skills for health care professionals in the clinical neurosciences. The resulting session aimed to provide clinicians with a basic and general introduction to the maintenance of activities of daily life for people with MS (Walshaw, 2011). How people maintain engagement and competency in occupations such as Activities of Daily Living (ADL) and IADL is a core concern and focus for occupational therapy intervention (AOTA, 2014; Meriano & Latella, 2016).

The preparation of the learning session led to reflection on my clinical experiences with people with MS and the occupations that appeared meaningful and purposeful for them. MS is a complex and challenging condition for the person, their family, and carers with the clinical features of fatigue, muscle weakness, ataxia, cognitive impairment, sensory, and visual impairments being prominent. The profound existential impact for the individual diagnosed with MS in the early stages can lead to disruption of the body and life context that necessitates renegotiation of identity, relations with others, and future plans (Finlay, 2003). As I encountered people with MS in my own occupational therapy practice, this impact of disruption in the person's life was familiar. The person with MS experiences an individual combination of these symptoms resulting in unique challenges to engagement in occupations. The onset and diagnosis of MS often occurs at a crucial stage of early adult life. At this time, there are great occupational demands, which follow the making of relationships and beginning of family life. This stage of life had personal resonance as a parent of two children and the associated occupational demands of family life, work, and study.

A fundamental influence on the development of this research was recognition of the importance of hearing the voices of people with MS and their carers with regards to their experiences in IADL occupations and their views of the occupational therapy interventions they received. Representing the real world perceptions of people with MS by inviting them to have their say was an essential element of this research.

The decision to conduct research with people with MS was also influenced by my clinical practice experiences. I have regular ongoing clinical contact as an occupational therapy practitioner in an acute tertiary hospital setting with this client group. Throughout my career, my practice has included working with people with MS and their carers in the in-patient and out-patients clinical setting. This context has been useful in giving me the chance to critically

consider the needs of people with MS and occupational therapy interventions in my own practice. I have been inquisitive to learn more beyond my own experiences in the acute hospital setting and explore the wider community practice setting. The needs of patients at times seemed unmet or untimely. My occupational therapy colleagues working in the community context have many skills and knowledge to offer people with MS and their carers.

Reading relevant literature for the e-brain learning session indicated a lack of research and evidence related to these ADL specific occupations for people with MS and the clinical effectiveness of occupational therapy interventions. This then led to the questioning of the relationship between people with MS and not only ADL but also the more complex occupations that constitute IADL. The role of occupational therapy in effectively intervening with people with MS to maintain occupational performance in these activities was also questioned. This was an introduction to the confusing terminology associated with ADL and IADL. My experience in clinical practice indicated that these occupations were often of significant concern in the day-to-day lives of people with MS, their families, and carers. IADL are occupations that constitute a key part of people's domestic lives and can be viewed as more complex and meaningful than mere obligatory chores. They are involved in maintaining a home, fulfilling occupational roles such as being a parent within a household, and are highly valued contributing to the essentials of a personal lifestyle.

Following the preparation of the e-brain study session, the opportunity arose to commence doctoral research at the University of Huddersfield, initially on the Professional Doctorate programme (2010) and subsequently transferring to the PhD pathway (2015). The gap identified in the literature regarding how occupational therapy interventions support people with MS to engage, perform, and participate in IADL, developed into the idea that led to the research proposal. Beginning a doctoral programme of study with institutional guidance gave me the prospect of developing research skills. The challenge of finding a suitable methodology to explore the issues led to the initial consideration of quantitative methods and the clinical effectiveness of occupational therapy interventions. The realisation that qualitative methods were also valuable and able to play a role led to deeper consideration of the issues. Reviewing the literature resulted in a move towards a person-centred consideration of the experiences and perceptions of occupational therapy interventions. A methodological approach was identified that combined both quantitative and qualitative research in mixed methods and case study research. Pragmatism and critical realism have provided philosophical influences on the research project as it has evolved. The collection of empirical data from the real world context of occupational therapy practice for people with MS, in the form of an ethical and in-depth

research project, has given me the opportunity to contribute new knowledge to the occupational therapy profession and wider academia. The next section will examine the policy context influencing the practice of neurological occupational therapy services for people with MS.

1.2 Policy context of occupational therapy services

The background context of this research is situated in the health policy of the National Health Service (NHS) in the UK. The interventions and service provision for people with MS by key health professional such as nurses, medics, physiotherapists, occupational therapists, and other Allied Health Professionals (AHPs) are set within the wider framework of relevant policy documents. The NHS long-term plan establishes the agenda for the future of health services in the UK over the ten-year period to 2028 (NHS England, 2019). This represents a key policy document looking towards the future and setting aspirations for the health and wellbeing of the nation. Prior to this the National Service Framework for Long-term Conditions set service standards for people with neurological conditions (Department of Health, 2005). The National Institute for Health and Care Excellence (NICE) clinical guideline (CG 186) for management of MS in adults, identifies evidence-based advice for service provision to people with MS (NICE, 2016). Professional guidance for occupational therapist working with people with MS is provided by the Royal College of Occupational Therapist (RCOT) and the MS Society (Harrison, 2007; MS Society 2009). This section sets out to consider concepts of person-centred and holistic care that are embedded in policy and relevant for people with long-term conditions such as MS. A discussion of occupational therapy in neurological practice and the importance of this practice being based upon research evidence will be made. Occupational therapists provide services to people experiencing a wide range of neurological conditions and constitutes a specialist area of practice. The significance of MS as a long-term neurological condition in occupational therapy practice is also examined.

In the UK services for people with MS are mainly provided by the NHS, but may also be provided by charities, social enterprises, and private providers. NHS services are based in acute hospitals, rehabilitation units, out-patient departments, and out-reach settings. Other services are community based. These can be condition specific for MS or part of a general community neurological rehabilitation service provided by Community Health Trusts or other healthcare providers. Services are contracted by the local Clinical Commissioning Groups (CCGs) (Davis, Lister, & Wrigley, 2015). Other related services where occupational therapists are employed are wheelchair services and local authority care services focusing on providing assistive technology in the form of equipment and home adaptations.

The NHS long-term plan has the objective of improving outcomes and the quality of care for patients through financial commitment to specific health priorities and a new model of timely and coordinated care by health care professionals in the appropriate setting (NHS England, 2019). An integrated care system is proposed to meet the needs of individuals and the complex demands on the NHS. Commitment to community based provision of services, personal health budgets, and social prescribing has been made to help people live independently at home for longer. The development of such services has been welcomed but seen as a great challenge to deliver primarily due to workforce shortfalls (The Kings Fund, 2019). The NHS long-term plan also identifies a need for a fundamental shift to collaborative working between the NHS and patients through the delivery of *person-centred care*. To understand how the aspiration for this transformation in service emphasis is to be met, a closer examination of the conceptual basis of person-centred care is necessary.

1.2.1 Person-centred care

The concept of person-centred care has been identified as a key quality indicator in health care provision (Slater, McCance, and McCormack, 2017). The growing demands and pressures on the NHS have focused the attention of policy makers on concerns for the quality of care. This culminated in the Darzi Report identifying the need for high quality care for all (Darzi, 2010). The crucial importance of care quality was also emphasised by the tragic consequences of poor quality of care at the Mid Staffordshire NHS Trust and the recommendations of the public inquiry detailed in the Francis Report (Francis, 2013).

Internationally the meaning of person-centred care as a concept is evolving as debate proceeds over the attributes of numerous definitions and frameworks that have been put forward (Delaney, 2018; Santana et al., 2018; van de Cingel et al., 2016). Four principles of person-centred care have been identified in the provision of healthcare services in the UK (The Health Foundation, 2016). The first principle concentrates on affording people dignity, compassion, and respect in healthcare. The second principle identifies coordination and third personalisation in care, support, or treatment. The final principle is concerned with enabling people to realise their own strengths and abilities in living independently and experiencing satisfactory lives.

In nursing practice an influential theoretical framework for person-centred care has been proposed (McCormack & McCancel, 2010). This framework comprises of the following four constructs:

1) Prerequisites that focus on attributes of the nurse such as professional competency, interpersonal skills, job commitment, and clarity of beliefs and knowledge.
2) Care environment focusing on the context of care delivery including the skills mix, shared decision making, effective staff relationships, supportive organisational systems, power sharing and potential for innovations, and risk taking.
3) Person-centred processes focus on delivery of care through a range of activities including working with patients' beliefs and values, engagement, sympathetic presence, shared decision making and providing for physical needs.
4) Outcomes as the central component of the framework as the result of person-centred nursing including satisfaction with care, involvement in care, feeling of wellbeing, and creating a therapeutic environment.

Person-centred care has gaining influence in the wider provision of healthcare services in UK. This is reflected in the inclusion and centrality of person-centred care in the various policy documents referred to. At the base of person-centred care is respect for the human rights of the individual.

The concepts of person-centred care are familiar as core values and beliefs for occupational therapy with elements influencing the development of the profession (Jackson, 2015). The origins of person-centred care are based in the humanistic psychology of theorists such as Carl Rogers who placed emphasis on trusting, genuine and open relationships, unconditional positive self-regard, and self-actualisation in psychotherapy (Chapman, 2017; Kirschenbaum & Henderson, 1990). Such humanistic psychology is influential in occupational therapy, particularly in mental health practice. The term *client-centred practice,* however, has more commonly been used in occupational therapy. Indeed, occupational therapy, as indicated in the introduction to this chapter, identifies and defines itself as a client-centred healthcare profession. The development of ideas related to client-centred occupational therapy practice has been particularly significant in Canada (McCormack & Collins, 2010). Five core elements of client-centred practice of occupational therapy have been identified which support a fundamental partnership between the occupational therapist and the client (Sumsion & Law, 2006):

1) Balance of power between the occupational therapist and client.
2) The balance of power can be balanced by listening and communication by the occupational therapist.
3) Partnership respecting the client's experiences.
4) Choice consistent with the client's values and preferences.

5) Hope and a spiritual perspective on their wellness.

In the reality of occupational therapy practice settings barriers exist in attempting to provide person-centred care services or client-centred practice. The expectation and pressures of the demands for economic efficiency can force a reductionist approach to practice (Jones et al., 2016). Services are provided in target driven cultures where metrics are important, and lack of resources concentrate practitioners on maintaining minimal standards at the cost of quality. In the UK occupational therapist are employed in target driven health and social care organisations with demands for economic efficiency and pressure on practitioners' time. There is also difficulty in providing client-centred practice when the person has cognitive impairment, and they are unable to understand and express their needs (Pierce, 2003).

1.2.2 Holistic care for people with long-term conditions

The drive of the NHS long-term plan is not only towards person-centred care, but also holistic care. In terms of healthcare, holism has been defined as embracing all aspects of a person's functioning to meet their needs and expectations (Margereson & Trenoweth, 2010). This includes the physical, psychological, emotional, and social aspects of the person and the personal meanings associated with lived experiences of health and illness. These lived aspects are interrelated and integral to the wholeness of healthcare. Holistic healthcare, therefore, does not focus narrowly on a person's health condition and symptoms but considers their preferences, wellbeing, social, and cultural context (The Health Foundation, 2014). Holistic care aims to meet the needs of the whole person. These attributes are true to the history, philosophy, and aspirations of occupational therapy with its commitment to health, well-being, and participation through intervening in the contexts of environmental, physical, psychological, and social factors to facilitate engagement in a person's chosen occupations (AOTA, 2016; Gentry et al., 2018). The unique contribution of occupational therapy should also be seen within the wider integration of health and well-being provision, associated with the interventions and outcomes of other professions in a multi-disciplinary context.

MS can be viewed as a long-term neurological condition. The term *long-term conditions* has been applied to a wide range of health conditions including diabetes, coronary artery disease, respiratory disorders such as asthma and COPD, mental health conditions, conditions related to aging, cancer, and renal conditions (Margereson & Trenoweth, 2010). Long-term conditions may involve co-morbidities and have complex implications for a person's function. The care needs of people with long-term conditions are by nature ongoing in terms of interventions and relationships. The chronic nature of long-term conditions contrasts with acute health

conditions where effective resolution of issues is possible. Long-term conditions also extend into issues at the end of life and palliative care.

A national service framework for long-term conditions (NSF) in the UK has been established with the aim of improving the lives of people experiencing conditions such as MS (Department of Health, 2005). The NSF by provided best practice guidance and was based on evidence from services for people with neurological conditions and aimed at establishing quality requirements in key areas of the care pathway. These included person-centred services, early and specialist rehabilitation, community and vocational rehabilitation, providing equipment and accommodation, and palliative care. The quality requirements were to be in place by 2015 and provide ongoing standards for service provision. The NSF for long-term is relevant to people with other long-term conditions such as those itemised above.

1.2.3 Neurological practice of occupational therapy

In neurological practice the occupational therapist is working with people who experience a wide range of varied and complex conditions. This practice draws on a particular set of knowledge and skills required to enable occupational performance for people with complex issues resulting from the impact of disease or injury to the central nervous system (CNS). Occupational performance is concerned with the doing process in relation to a desired outcome (Reed, 2015). The role of occupational therapy interventions with people with neurological conditions is to enable the person to engage, perform, and participate in the daily occupations they need or chosen to do. This is achieved through exploiting the person's existing skills and resources, remediating maladaptive responses, and developing new adaptations in occupational performance (Edmans & Preston, 2016).

Occupation has been defined in terms of physical, mental and social health as a multidimensional and complex concept of doing, being, belonging and becoming (Wilcock & Hocking, 2015). The doing dimension involves actions and activities that may be individual or collective. The being element of occupation is associated with quieter times of reflection when occupational roles, such as being a gardener, may be considered by the person. Belonging is concerned with humans as social beings through shared occupations with family, groups, and community. The becoming dimension in this definition of occupation relates to the person's change, transformation, and development. Occupation also has personal meaning in what the individual needs, wants or is obliged to do. Occupation is the central domain of interest for occupational therapy (WFOT, 2012b). For people with neurological conditions such as MS occupational therapy aims to enable participation in their personal occupations.

Neurological conditions can affect a person across the lifespan from childhood through adulthood to old age. Some conditions, such as cerebral palsy, have onset at birth or during infancy and childhood whereas, other conditions are more prevalent in adulthood such as stroke and Parkinson's disease. Neurological conditions can be grouped into categories by epidemiology and clinical course. Some neurological conditions such as stroke and trauma to the brain or spine in traumatic brain injury and spinal cord injury have a sudden onset and may involve life-saving medical interventions and neurosurgery (Lindsay, Bone, and Fuller, 2010). Neurological conditions caused by infections such as Guillian-Barré syndrome and encephalitis similarly have an acute on-set. Neuro-oncological conditions involving cancer effecting the CNS where tumours occur in the brain or spinal cord are another area of neurological occupational therapy practice where issues of limited life expectancy are also encountered.

All these neurological conditions can cause severe and multiple impairments result in; challenges to survival, may involve prolonged disorders of consciousness, and necessitate prolonged rehabilitation to regaining function in the long-term. These neurological conditions can have major impacts on motor movement and process skills and thus occupational performance reflecting the fundamental functions of the CNS. Varied impairments to motor, sensory, behaviour, and psychological function have impacts on occupational performance. These conditions can challenge the person's ability to engage in occupation and often fundamentally alter the course of a person's life. The pathway for the person in recovery and adaptation to neurological conditions can include periods in critical care environments, acute and rehabilitation in-patient treatment and involve MDT interventions to facilitate recover and rehabilitation.

Other neurological conditions such as MS, Parkinson's disease, Motor Neurone Disease, and Huntington's disease can be considered as progressive in nature (Allen & Lueck, 2002). In these conditions a degenerative disease processes cause damage to the CNS. Progressive conditions present the challenges to occupational therapy practice in their variability and ongoing deterioration (Jain, Kings, & Playford, 2005). MS has a prolonged impact on occupational performance from onset in early adulthood into old age which will be considered in more detail in the following section.

Neurological practice of occupational therapy can be based in hospital settings such as critical care units, acute wards, and in-patient rehabilitation. Occupational therapy for people with neurological conditions is also provided as community base rehabilitation, in home environment adaptation, and wheelchair services. Neurological practice requires knowledge

and skills in physical rehabilitation, approaches to movement therapies and management of altered muscle tone and spasticity. Methods and techniques in fatigue management, cognitive rehabilitation, and behaviour management are equally important. These practices are based on neurodevelopmental, motor behavioural and cognitive rehabilitation models and theory (Baum, Bass, and Christiansen, 2015). Occupational therapy interventions in neurological practice have been grouped into ADL interventions, cognitive rehabilitation and management of fatigue, anxiety, falls, tremor, and pain (Edmans & Preston, 2016). These address impairments and ADL but also need to look to engagement and participation in wider activities and occupations such as IADL, work, and leisure for people with neurological conditions.

The importance of occupational therapy practice being based on research evidence has been driven from the development and influence of evidence-based medicine in the wider healthcare environment over the past two decades (Sackett et al., 1996). This draws on legal parallels in process, involves making professional judgement, and the experience of practice to decide what constitutes reasonable interventions and involves behavioural change in professional practice towards best practice (Hicks, 1997). Evidence based practice in healthcare involves a process of decision making where due weight is accorded to all valid and relevant information. The drive to embed research culture in AHPs has been ongoing and a strategic objective of the NHS. AHPs, including occupational therapy, are seen as having an important role in translating research evidence into clinical practice in health and social care (Slade, Philips, & Morris, 2018). Occupational therapists' practice in a dynamic economic environment with limited resources where expectations of clinical and cost effectiveness are high (Green & Lambert, 2017). Justification for the commissioning of services is based on proof of value and effectiveness, considering the evidence base of interventions.

Occupational therapists are also charged with a professional duty to base their practice on and contribute to the generation of research evidence. Section six of the *Code of Ethics and Professional Conduct* is concerning with developing and using the profession's evidence base (RCOT, 2015). This emphasises the value and importance of research as the basis for the profession's evidence base. Best practice should be based on evidence and not on traditional practices or anecdote (Greenhaugh, 2014). It is necessary to secure the resources to further develop the profession's research capabilities and capacity to build on current research evidence (RCOT, 2019). The strategy of the profession is to build research capacity so that clinical and cost effectiveness can be demonstrated. Development of the profession's research capacity to deliver what is considered high quality quantitative research, such as multi-centred Randomized Controlled Trials (RCTs), however is questionable due to the

resources required. Also debates that surround questions of the nature of evidence in healthcare and the value and contribution of qualitative methodologies to the evidence for best practice are ongoing and of particular importance to occupational therapy (Greenhaugh et al., 2016).

1.2.4 Occupational therapy practice for people with MS

People with MS experience the most common progressive neurological condition affecting younger adults and form an important group of clients for occupational therapists working in neurological practice (MS Trust, 2018). MS results in particular and complex service needs from diagnosis onwards as physiological and psychosocial impairments impact on the individual's occupational performance abilities. The onset of MS is typically during the early adulthood stage of life. People with MS subsequently live with the condition for most of their adult lives and into older age. The person with MS may have ongoing and long-term need for occupational therapy services. Despite the impact of MS on occupational performance throughout the disease process occupational therapy provision tends to occur later in the progression of the disease and focus on ADL (Finlayson, Garcia, & Cho, 2008).

People with MS encounter occupational therapists in various clinical and community settings as the condition progresses. An initial need for occupational therapy may take the form of support in the workplace in the form of vocational rehabilitation (Sweetland, Riazi, & Playford, 2007; Hayward, Mateen, Playford, & Eva, 2019). Later as the increase in disease severity takes place during the progressive phase of MS, movement and musculoskeletal more difficulties in ADL performance may be encountered. Hospital admission may follow such periods of relapse or disease progression where a change in the person's function occurs or as a result of a fall or inter-current medical condition such as an infection. In hospital and community settings referral to occupational therapy may occur at a time when strategic provision of equipment or adaptation to the home environment is required. Occupational therapy may also be initiated by referral to a multi-disciplinary community based rehabilitation team. Occupational therapists provide essential service components in the overall management for people with MS through reducing the impact of impairments to enable participation in meaningful occupation (Preston, Haslam, & Lamont, 2012). This is reflected in the inclusion of occupational therapy as a core component of the multi-disciplinary team (MDT) for people with MS (NICE, 2016).

Current rehabilitation practice for people with MS in the UK should involve interventions by an MDT featuring coordinated care that includes occupational therapy. The MS quality standards

recommend occupational therapy involvement for people with MS by including professional representation in the MDT with expertise in MS alongside a consultant neurologist, MS nurse, and physiotherapist (NICE, 2016). A single point of contact should coordinate access to the MDT. Occupational therapist and physiotherapists are the AHPs most likely to be seen by people with MS with their professional expertise being recognised and valued by the MS Trust (Dix & Green, 2013). Occupational therapy brings a unique contribution to the MDT with its focus on enabling participation in occupations.

In the UK NICE set standards for the provision of healthcare services. Clinical Guideline 186 provides evidence based guidance on the management of MS in primary and secondary care settings and takes into consideration contributions from people with MS and healthcare professionals (HCPs) including occupational therapists (NICE, 2014). The guideline covers diagnosis and management of MS in adults with the aims of improving the quality of life by the promotion of symptoms management, comprehensive review, and effective relapse treatment. The guideline is produced for the use of people with MS their families and carers, health and social care professionals, commissioners, and service providers. If a person with MS or a professional wishes to use the guideline, it is the duty and responsibility of the local CCG and healthcare provider to enable the application of the guideline within the context of funding priorities and service development (NICE, 2016). The guidance identified key priorities of; diagnosis of MS, information and support, coordination of care, MS symptoms management and rehabilitation, and treating acute relapse of MS with steroids. The directions given by the guideline are general. Some recommendations are directly relevant to this research, such as the assessment and treatment of fatigue and anxiety. Participation and access to daily activities, driving and access to transport are also included. Research recommendations are made to improve the guideline and patient care for the future. The effectiveness of cognitive rehabilitation is prominent and specifically related to the problems people with MS encounter with their ability to carry out everyday activities and household tasks. This research sets out to address these priorities for people with MS.

The RCOT provides guidance to occupational therapists on interventions with people with MS. Specific guidance to occupational therapists on the use of fatigue management for people with MS has been produced (Harrison, 2007). This gives information on specific approaches and programmes of fatigue management and energy conservation. The difficulty people with MS experience maintaining independence and balance in everyday living is acknowledged. Practical advice is also offered on fatigue management during participation in domestic activities, meal preparation, shopping, laundry, cleaning, childcare and community mobility.

These suggestions relate to IADL and are based on expert opinions but not research evidence. A guide containing resources for interpreting NICE and NSF guidance for occupational therapy practice has been produced (MS Society, 2009). This aims to support clinical decision-making within the everyday practice of occupational therapists. Although this document has a section related to ADL the key reflections and audit statements provided are general in nature giving broad direction on assessment and assisting the person with MS to identify priorities. More detailed and holistic guidance on the wide-ranging interventions used in occupational therapy practice for people with MS is lacking. The following section will consider the background of the impact of MS as a progressive neurological condition.

1.3 The Impact of MS

The person with MS must contend with a chronic and progressive neurological condition resulting from an autoimmune process that causes damage to the CNS. The individual clinical presentation is unique to the person. The clinical course of the disease is unpredictable with variable clinical features and uncertain prognosis (Confavreux & Compston, 2006). Key clinical features associated with MS include fatigue, muscle weakness, tremor, pain, sensory loss, visual disturbance, and cognitive dysfunction (Asano, Preissner, Duffy, & Meixell, 2015; NICE, 2014; Yu & Mathiowetz, 2014b) These clinical features have a major and complex impact on the person's ability to engage, participate, and perform occupations. The unpredictable nature of MS means the person has to adapt to the progressive disease impact resulting from this range of clinical features (Lexell, Lund, & Iwarsson, 2009). The following section will discuss the pathology and epidemiology of the MS disease process.

1.3.1 Pathology and epidemiology

In MS damage to the CNS is thought to be caused by an autoimmune response where the immune system targets myelin protein (Milo & Miller, 2014). The precise pathophysiology involved, and why immune responses commence in the CNS, is not fully understood (Thompson, Baranzini, Geurts, Hemmer, & Ciccarelli, 2018). T-lymphocytes and B-lymphocytes in the adaptive immune system target antigens that are present in the CNS. Two models for the initiation of the immune response have been proposed (Hemmer, Kerschensteiner, & Korn, 2015). The intrinsic model suggests the process starts in the CNS whereas the extrinsic model hypothesises emphasises events external to the CNS such as a systemic infection resulting in an autoimmune response within the CNS (Thompson, Baranzini, et al., 2018). The protective blood brain barrier of the CNS also becomes compromised during the disease process (Wekerle & Lassmann, 2006). MS is characterised

by neurodegeneration in the CNS with multiple lesions occurring throughout the brain and spinal cord. At the cellular level MS pathology involves; axonal and neural loss, demyelination and astrocytic gliosis which disrupts and slows the function of nerve fibres (Thompson, Baranzini, et al., 2018). The inflammatory cascade of the autoimmune process causes demyelination. Gliosis leads to a lack of trophic support in the brain and spinal cord and results in scaring of the CNS known as plaques (Milo & Miller, 2014). Neurodegeneration results in brain atrophy and decreased brain volume of between 0.5-1.5% per year (Eshaghi et al., 2018). Increased energy demands also occur due to changes in mitochondria affected neurones. The location of lesions in the CNS accounts for the individualised clinical features experienced by the person with MS. The impact of the MS disease process is complex and not fully understood. Acute episodes or relapses are followed by remission where a process of re-myelination occurs. During the progressive phase of MS lack of trophic support and mitochondrial dysfunction result in chronic axonal demyelination.

The aetiology of MS is attributable to a combination of environmental factors, life style, and genetic susceptibility (Compston & Coles, 2008; Olsson, Barcellos, & Alfredsson, 2016). The underlying role of the environment is thought to be larger than the genetic aspects (Thompson, Baranzini, et al., 2018). Environmental factors include Vitamin D levels from sunlight, cigarette smoking, diet, and obesity in early life. Genetic studies of MS implicate the genes associated with immunological processes and regulatory areas of the human genome (Sawcer, Franklin, & Ban, 2014). Research, however, is ongoing into the genetics of MS with only a proportion of the genetic variants of heritability being currently explained.

The person receiving a diagnosis of MS is often a young adult typically in their late 20's (NICE, 2016). The average onset of MS and medical diagnosis occurs in people aged 20-40 years and represents a significant cause of disability in young people (Confavreux & Compston, 2006; Lindsay et al., 2010).

Globally it is estimated that 2-3 million people have MS, with prevalence rates varying between 50-300 per 100,000 population (Thompson et al., 2018). The distribution of MS shows a noticeable geography with the condition occurring more commonly in higher latitudes such as Scotland, the Nordic countries and Canada. The influence of ethnicity and genetic susceptibility has been suggested to account for higher prevalence in northern Europe compared to Asia and the rare occurrence in Africa (Compston & Wekerle, 2006). The influence of environmental factors such as vitamin D deficiency from low sunlight exposure in high latitudes may also account for this distribution. Studies of migrants indicate MS is a

disease acquired early in life and linked to environmental factors whereas studies of indigenous populations provide evidence of genetic factors being influential (Compston & Confavreux, 2006).

A survey of the UK General Practice Research Database between 1990 and 2010 estimated 126,669 people were living with MS in the UK (203 per 100,000). An incidence of 6,003 new cases were found to be diagnosed each year (9.7 per 100,000 per year) (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan, 2014). A distinctive gender difference in the prevalence of MS was demonstrated in this survey with 113 per 100,000 for men and 286 per 100,000 for women representing a male to female gender ratio of 1:2.5. Men are more likely to experience the primary progressive form of MS (Thompson, Baranzini, et al., 2018). The reason for this gender imbalance may reflect similar differences in other autoimmune diseases, which are more common in females. A genetic explanation proposed is that this is related to the interaction between endocrine factors and the immune system (Compston & Wekerle, 2006). This contrasts with research evidence in Canada where the gender ratio has been shown to be rising to 1:3.2 with an increasing incidence for females over a 50 year period (Orton et al., 2006). Unknown environmental factors were proposed as a reason for this rapid change. In Sweden, however, a national study of sex ratio in MS over time has shown no change (Boström, Stawiarz, & Landtblom, 2013). The issue is clearly complex with an interaction between environmental factors and genetic susceptibility possible. Full scientific explanations of the pathology and epidemiology associated with MS from which treatments are based, are not currently available. This contributes to the uncertain future faced by the person diagnosed with MS.

1.3.2 Clinical course and clinical features

For the person with MS the initial diagnosis is often made following a period of concern and anxiety over the developing symptoms associated with the condition. The diagnosis of MS is made by clinical expertise, MRI findings and laboratory results demonstrating CSF abnormalities (Thompson, Baranzini, et al., 2018). The outcome can be difficult news for the person from the neurologist. Diagnosing MS is made by using the McDonald criteria which was most recently updated in 2017 (Thompson et al., 2018). MS is only confirmed if a clinical isolated syndrome is followed by a second episode of symptoms with a 30 day separation between events (Brex & Williams, 2018).

Types of MS have been classified by their initial course into relapsing remitting onset (85%) and progressive onset (Confavreux & Compston, 2006). Four forms of MS have been defined

based on description of dissemination in time (Lubin & Reingold, 1996). In Relapsing Remitting MS (RRMS) relapses are followed by periods of either full recovery or residual deficits. The disease does not progress between the relapses. A relapse is an acute episode of neurological deficits that is experienced in the early stages of MS. During the periods of relapse remyelination and cortical plasticity occurs following neural loss and function is maintained (Thompson, Baranzini, et al., 2018). RRMS is a stage that 70% of people with MS pass through before going onto develop a progressive form of MS (Lindsay et al., 2010). Secondary Progressive MS (SPMS) begins with the RRMS course and is followed by progression. Occasional relapses, minor remission and plateaus may occur. In the progressive forms, disease progression is from the onset. For Primary Progressive MS (PPMS) occasional plateaus and temporary minor improvements may take place whereas in the Progressive Relapsing form of MS (PRMS) clear acute relapses occur where there may be recovery but periods between relapses show a continued progression. This terminology has been criticised as not providing information regarding the pathophysiology of MS. The definitions only describing activity, relapses, progression with the support of MRI to demonstrate new lesions, atrophy and advancing neurodegeneration (Thompson, Baranzini, et al., 2018). In the later stages of MS, the consequences of lesions to the CNS are multiple impairments and associated disabilities.

The clinical features of MS have a significant impact on the person's ability to function in their everyday lives. The impact of MS on the functions of the person's body is wide ranging and varied reflecting the importance of the CNS in occupational performance. Each person with MS will experience a personal combination of symptoms. The most prominent clinical features are fatigue, muscle weakness, tremor, pain, altered sensation, visual disturbance, impaired cognitive function, and changes to emotional function.

The impact of MS on the body's motor system can be widespread. This is in response to involvement in the CNS of the corticospinal, corticobulbar, vestibulospinal, cerebellar and sensory pathways (McDonald & Compston, 2006). Muscle weakness is experienced by people with MS and is a sign of upper motor neuron lesion. In the upper limbs, lack of muscle power function has an impact on grip strength and dexterity. Weakness can also be accompanied by limb stiffness and spasticity which affect 30% of people with MS (Morley, Tod, Cramp, & Mawson, 2013). The experience of troublesome and painful spasms can be distressing and psychologically detrimental.

For many people with MS, fatigue is the most common and limiting of symptoms (Asano et al., 2015). This is the subjective feeling of tiredness that is caused by primary MS pathophysiology

of neurodegeneration and secondary complications such as pain, musculoskeletal problems, sleep disturbance and depression (Bogdan, Cercignani, & Rashid, 2017). The precise cause of fatigue is poorly understood. Theories of fatigue causation based on the subjective feelings have suggested an inflammation induced sickness behaviour (Hanken, Eling, & Hildebrandt, 2014). Failure of the function of the basal ganglia has also been implicated in accounting for MS related fatigue (Chaudhuri & Behan, 2000). When the person comes to engage in occupations, they lack the energy and drive required. For the person with MS managing fatigue is a fundamental strategy but also difficult and challenging due to the necessity for radical behavioural changes that are often required (Bogdan et al., 2017). People with MS have to develop an understanding of how fatigue effects them, help others to understand their fatigue and accommodate its impact in their daily lives (Turpin et al., 2018).

Ataxia is a common symptom of MS resulting from the cerebellar and sensory dysfunction which leads to in-coordination of movement (Mills, Yap, & Ca, 2007). One feature of ataxia is tremor which can affect between 25% and 58% of people with MS (Rinker et al., 2015). It is described as involuntary rhythmic movements most frequently affecting the upper limbs and results in difficulties performing ADL such as eating, drinking, and self-care (Teufl, Preston, Wijck, & Stansfield, 2017). Tremor is often not an isolated symptom of MS and is extremely disabling in terms of ADL (Feys, Romberg, Ruutiainen, & Ketelaer, 2003). Tremor, together with muscle weakness and spasticity, can significantly impact on motor control. This is a concern for the person with MS and their quality of life as handling task objects when engaging in occupations becomes difficult due to tremor.

The process of inflammatory demyelination can lead to lesions of the optic nerve known as optic neuritis (Thompson, Baranzini, et al., 2018). Acute visual loss is usually temporary with the recovery of most vision occurring and oral steroid treatment being indicated (Lindsay et al., 2010). Disturbance of ocular movement such as diplopia and nystagmus can also occur. One feature of MS that can cause short-term variations in the experience of symptoms is Uhthoff's syndrome. This is an implication of the body struggling to regulate temperature. A minor rise in core body temperature can lead to exacerbation of symptoms (Kalb, Holland, & Giesser, 2007). An increase in body temperature for example due to warm weather or gentle exercise can result in a deterioration of symptoms of optic neuritis (Smith, McDonald, Miller, & Lassmann, 2006). Cooling the body with a cold bath or an iced drink can relieve this temporary exacerbation of symptoms.

Alteration to the processing of sensory information occurs in all forms of MS due to changes to the thalamus and associated structures (Colbeck, 2018). The interpretation and processing

of afferent information to the CNS from the environment is impaired. Low registration of sensory information, sensory sensitivity and avoidance of sensory stimuli has an impact on the person's quality of life. At the onset of symptoms and in early RRMS abnormal sensation of tingling and numbness can be experienced. Sensory changes in the upper limbs and hands can crucially lead to reduced coordination and calibration of hand function (McDonald & Compston, 2006).

Cognitive impairment has been demonstrated to be experienced by 40-65% of people with MS (Amato, Zipoli, & Portaccio, 2006). Several aspects of cognitive function are involved including memory, sustained attention, visuospatial ability, executive function, and processing speed (McDonald & Compston, 2006; Preston, Hammersley, & Gallagher, 2013). The degree of executive dysfunction, with domains of volition, planning, purposeful action, and effective performance, has been shown to impact on everyday activities for people with MS. For people with MS this leads to concerns regarding withdrawal from former occupational roles, perceptions of failure within existing roles, and feelings of loss to self-worth and self-esteem (Preston, Ballinger, & Gallagher, 2014). The frequency of depression for people with MS is high with a lifetime prevalence of 50% (McDonald & Compston, 2006).

Medical treatments for MS, in the form of pharmacological options, have advanced greatly over the past 25 years particularly for RRMS. Since the 1990's the advent of the interferon group of medication treatment (such as Beta-interferon) has advanced the range of approved disease modifying options. These treatments act on neuro-inflammation to indirectly reduce neurodegeneration with the selection of the appropriate medications forming a complex process with risks of adverse events (Thompson, Baranzini, et al., 2018). Despite these promising developments, options are more limited for the progressive forms of the condition with only one medication (ocrelizumab) shown to be effective. The level of disability in the later stages of SPMS is significant with little long term effect of the previous drug treatments (Cree et al., 2016). Developments in medication for the future are aimed at promoting neuroprotection and remyelination alongside the personalisation of treatments. A cure for MS, however, remains elusive (Thompson, Baranzini, et al., 2018).

MS is a significant cause of impairments and disability for young and middle aged adults but also into older age. Improving longevity of people with MS has been demonstrated (Finlayson, Garcia, & Cho, 2008). In the UK the increasing aging of people with MS has been attributed to improvements in care and has major implicates for the allocation of resources (Mackenzie et al., 2014). People with MS are living longer but with the burden of disability, uncertainty, and unpredictability associated with the condition. A large role therefore exists for rehabilitation

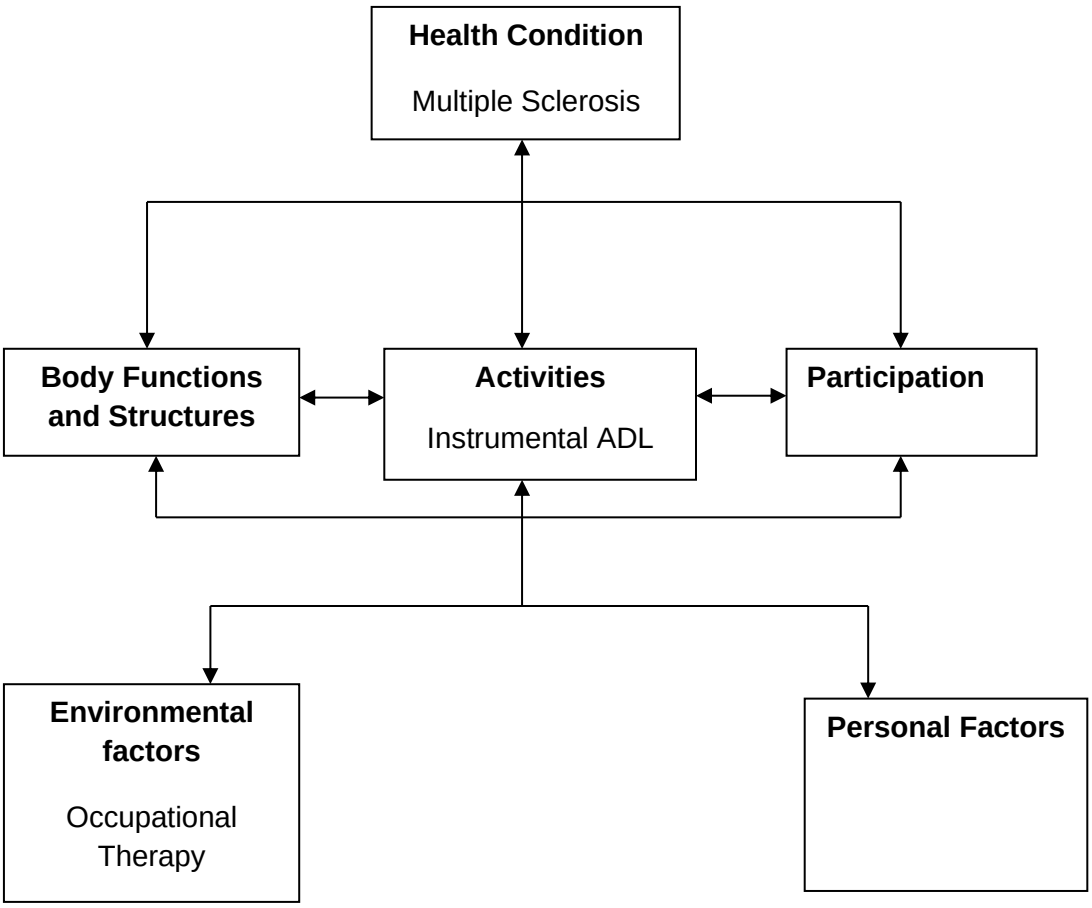
medicine and the associated professions in the management of disability and assisting the person with MS to reach their own potential function and participation in life. Occupational therapy is one of the key professions with the range of interventions to realise this potential. The impact of MS on the person in terms of impairments, functioning in activities, and participation will be considered in the following section.

1.3.3 International Classification of Functioning, Disability and Health

The World Health Organisation (WHO) published the International Classification of Functioning, Disability and Health (ICF) to provide a framework to categorise functioning and disability in health conditions (WHO, 2001). The ICF provides international standards for description and measurement of health and functioning (COT, 2004). Figure 1 illustrates the interaction between the domains of body functions and structure, activities, and participation for a particular health condition in the context of the individual's environmental and personal factors. This is based on a bio-psycho-social model of disability that is person-centred with activity central to the framework. Important objectives of the ICF are to provide structure for research and facilitate communication between professionals within MDTs by providing uniform terminology. Functioning is seen as an interaction between a health condition such as MS and contextual factors. The interaction of the body's functions and structures with personal factors impacts on activities and participation. The concern of the research is with MS as a health condition and how occupational therapy as a contextual and social environmental factor effects specific activities i.e. IADL. The research also considered how activities and impairments interact with the influence of contextual factors.

In the case of MS, a consensus process has been undertaken to systematically review research studies and consider expert opinion in order to identify core sets of relevant ICF categories for MS (Coenen et al., 2011; Khan & Pallant, 2007). This process allows MS to be mapped onto the ICF framework. A brief core set of ICF categories and a more detailed comprehensive core set have been produced (Coenen et al., 2011). Table 1 shows the brief core sets with the relevant comprehensive set for carrying out daily routine. This indicates the impact of MS on body structures and body functions. Body structures of the brain and spinal cord are affected by MS. Body functions identified in the brief core set are muscle power, energy and drive, seeing, sensation of pain, emotional, higher-level cognitive, gait pattern, and urination. These categories are consistent with the clinical features discussed above in section 1.3.2. Activities and participation identified are solving problems, walking, family relationships, and remunerative employment. Carrying out daily routines is considered of particular interest

Figure 1. WHO International Classification of Functioning, Disability, and Health (ICF)



to the research as this relates to IADL. Important environmental factors included immediate family and the individual's attitude to them and health services such as occupational therapy (Coenen et al., 2011). On closer examination the comprehensive core set contains categories related to IADL such as using transport, driving, acquisition of goods and services, preparing meals, doing housework, caring for household objects, and assisting others. This is evidence of the importance of Instrumental ADL to people with MS. The ICF provides a useful framework to conceptualise the relationships between functioning, disability, and health. It does not however, employ the specific term IADL as a category of activity. Some interpretation is therefore necessary to provide an occupational therapy perspective of the categories used in the ICF with regards to IADL. Clarification and a more detailed discussion of an operational definition of IADL with reference to the Occupational Therapy Practice Framework and the professional and conceptual language of occupation follows in the next section.

Table 1. Relevant Core Sets of ICF Categories for Multiple Sclerosis (Coenen et al., 2011)

Body Function and Structures domain	**Activities and participation domain**	**Environmental factors domain**	**IADL related** (Comprehensive set)
Structure of the brain	Carrying out daily routine	Immediate family	Moving around in different locations
Spinal cord and related structures	Solving problems	Health professionals	Moving around using equipment
Muscle power functions	Walking	Individual attitudes of immediate family members	Using transport
Energy and drive functions	Family relationships	Health services, systems, and policies	Driving
Seeing functions	Remunerative employment		Acquisition of goods and services
Sensation of pain			Preparing meals
Emotional functions			Doing housework
Higher-level cognitive functions			Caring for household objects
Gait pattern functions			Assisting others
Urination functions			

1.4 Instrumental Activities of Daily Living

Historically defining *Activities of Daily Living* as a conceptual term in occupational therapy has been problematic and confusing. Numerous terms and definitions have been offered. These ranging from lists of tasks to considering those everyday life demands deemed necessary for participation in social life, work roles, and independent living (Reed, 2015). Sidney Katz at Benjamin Rose Hospital, Cleveland, Ohio, made an early use of the term activities of daily living in a multi-disciplinary rehabilitation setting during the 1950's. The Katz Index of Independence in ADL was designed to measure six functions; bathing, dressing, toileting, transfers, continence, and feeding (Noelker & Browdie, 2014). ADL are associated with care of one's own body and are also termed *Basic Activities of Daily Living* (BADL) or *Personal Activities of Daily Living* (PADL). In the rehabilitation literature a variety of other terms are synonymous with ADL such as self-care, personal care, and self-maintenance (Reed, 2005). *Extended Activities of Daily Living* is another term used in the rehabilitation literature that is associated with ADL. An example of the use of Extended ADL is the inclusion the UK Functional Assessment Measure (FAM) (Turner-Stokes & Siegert, 2013)**.** This outcome measure is used in rehabilitation units in the UK. It includes six items relating to Extended ADL: meal preparation, laundry, housework, shopping, home finances, and work/education. The final category of work and education in this list would be considered in a separate domains within the occupational therapy practice framework (AOTA , 2014).

The origins of the term *Instrumental Activities of Daily Living* can be traced back to its use in an assessment of function for older people (Lawton & Brody, 1969). This was an assessment of tasks that had not previously been included in other ADL assessments. The Instrumental Activities of Daily Living Scale aimed to measure competencies in complex tasks such as shopping, cooking, laundry, using money, and using transportation. Since this time, IADL has been adopted into the professional language of occupational therapy. Table 2 summarises definition of IADL in the occupational therapy literature. The definitions vary in emphasis and do not agree in content. IADL are optional activities that may be delegated to others and are directed towards complex interaction with the environment within the home and community (Preretti & Umphred, 1996). They require a higher level of cognitive skills than ADL and are required for independent community living (Reed, 2015). IADL are often defined as being exclusive from ADL i.e. activities that are not ADL (Piersol & Ehrlich, 2000; AOTA, 2014). In IADL a key point is that the range and types of activities a person engages in is related to their occupational roles (Reed, 2015). Occupational role is concerned with being able to complete

Table 2. Instrumental Activities of Daily Living (Reed, 2015)

Authors	Definition	Comment
Pedretti and Umphed (1996)	IADL involve "more advanced problem-solving skills, social skills and complex environmental interactions such as home management and community living skills, health management and safety preparedness" p463	Includes skills and complex environmental interactions
Jackson and Banks (1997)	Define IADL "higher order activities that support independence, including household duties, shopping, budgeting and money management" p460	Independence features
Unsworth (1999)	IADL are "domestic and community activities of daily living, such as cleaning, shopping and driving" p478	Defined by groups of activities
Piersol and Ehrich (2000)	IADL are "activities other than basic activities of daily living (ADL) that relate to the ability to manage independently at home e.g. laundry, shopping, and money management" p200	Exclusive of ADL, independence
Stein & Roose (2000)	Define IADL as "tasks that involve participation of a client with the physical and/or social environment, including home management, money management, communication, safety, community living skills, work and leisure activities" p130	Includes work and leisure
American Occupational Therapy Association, (2014)	"Activities to support daily life within the home and community that often require more complex interactions than those used in ADLs." pS19	Comprehensive 12 categories proposed see Appendix 1 for fuller details

with satisfaction the occupations that are central to the person's role (Christiansen & Baum, 2005).

For the purpose of this research, an operationally definition of IADL was made in accordance with the classification of the Occupational Therapy Practice Framework (AOTA, 2014). The occupational therapy practice framework is a key document for the research which summaries the interrelated constructs that apply to occupational therapy practice. It has defined and refined the domains of practice, occupations, performance skills, and performance patterns to produce a uniformed professional language. The Occupational Therapy Practice Framework defines IADL as:

> Activities to support daily life within the home and community that often require more complex interactions than those used in ADLs (AOTA, 2014). pS19

In addition the practice framework provides the most comprehensive guide to the twelve occupations categorised as IADL (AOTA, 2014). Table 3 lists the twelve occupations. Full descriptions of the occupations are given in Appendix 1. These full descriptions of IADL provided a basis for the research design, methods used and data analysis process. The Occupational Therapy Practice Framework pays reference to the ICF but goes far beyond in defining terminology specifically for occupational therapy practice.

IADL is a dynamic concept, however, with an evolution of meaning and inclusion taking place between the second and third editions of the Occupational Therapy Practice Framework. Although the revision was broadly similar, two additional categories of occupations were added to IADL. These were firstly health management and maintenance, and secondly religious and spiritual activities and expression. The definition of the concept and categorisation of occupations must also be able to accommodate changes in lifestyles. An example is technological change. Once communication with information technologies simply involved using a landline phone. This has been transformed as the more complex and pervasive use of various devices such as smart phones and tablet computers have entered the home and domestic daily life. These twelve occupations were used to interpret the findings of the ICF brief and comprehensive core sets for people with MS discussed in section 1.3.3. Therefore, categories in the ICF, such as preparing meals, doing housework, assisting others, using transport, and driving, were all interpreted as IADL.

Once occupational roles are taken into consideration, the real life complexity of classification of IADL emerges. Gender roles and economic factors can be influential. An individual's

Table 3. Occupations Classified as Instrumental ADLs (AOTA, 2014)

IADL Occupations Activities to support daily life within the home and community that often require more complex interactions than those used in ADLs	
Caring for others	Health management and maintenance
Care of pets	Home establishment and maintenance
Child rearing	Meal preparation and clean-up
Communication management	Religious and spiritual activities and expression
Driving and community mobility	Safety and emergency maintenance
Financial management	Shopping

interpretation and meaning of IADL occupations such as housework may range from; work, a chore and an obligation to; a leisure providing pleasure and accomplishment. A person may choose to have a cleaner if they are financially able to, or paint and decorate their own home if they have the necessary skills. This may be influenced by gender roles. A feminist perspective may emphasise economic inequality and work (Primeau, 1996). The total gross value added to the UK economy in 2014 of home production including; household housing services, adult and child care, private transport, clothing and laundry was £1,018.9bn (Webber, Payne, Mallett, & Weedon, 2016). These all could be considered as IADL.

1.5 IADL performance by people with MS

A limited amount of research has been undertaken to investigate how people with MS are able to perform IADL. The ability to function competently in the community has been studied for 22 people with mild to moderate impairments due to MS compared with a matched control group (Doble, Fisk, Fisher, Ritvo, & Murray, 1994). The *Assessment of Motor and Process Skills* (AMPS) was used as a measure of functional competency in IADL task performance (Fisher

& Jones, 2010). The AMPS was compared with the *Expanded Disability Status Scale* (EDSS), a measure of neurological impairment (Kurtzke, 1983) and a health profile measure, the *Sickness Impact Profile* (SIP) (Bergner, Battit, & Pollard, 1976). The findings indicated that the group of people with MS had poorer functional competences than the control group although a quarter of the MS sample had motor and processing skills scores in the range of the control group indicating their competency. The study also found that some people with MS had IADL performance deficits due to motor and process skills whereas for others deficient process skills alone accounted for difficulties in task performance. This is clear evidence of impairments due to MS having an impact on task performance in IADL. The relationship between impairment and performance, however, would appear complex and raise questions of which variables accounted for the different performance groups within the MS sample.

The performance of ADL and IADL has also been studied in 44 individuals with moderate to severe MS (Månsson & Lexell, 2004). The *Functional Independence Measure* (FIM), and AMPS were used as measures of performance in ADL and IADL (Granger, Hamilton, Linacre, Heinemann, & Wright, 1993). This study demonstrated that the impact of MS for this sample group is to reduce the ability to perform both ADL and IADL. This confirms another epidemiological study that indicated that only a third of people with MS were independent in ADL activities related to self-care (McDonnell & Hawkins, 2001). The Månsson and Lexell (2004) study also distinguished individuals that were independent in ADL but still unable to perform IADL satisfactorily. Occupations related to IADL, such as meal preparation, child rearing, and shopping may be of great importance for this group of people with MS. The demands of IADL occupations are particularly great in the early and mid-adulthood stage of life.

More recent studies have considered occupational performance for people with MS in cooking, money management, and Information Technology (IT) use. One study has examined the association between cognitive function and limitations in cooking ability for 72 people with MS (Goverover, Strober, Chiaravalloti, & Deluca, 2015). A non-standardised measure of cooking ability was used by asking questions on participation in the preparation of cooked breakfast. The research assignment subjects to “active cookers” and “non-active cookers” categories. A battery of cognitive measures was also administered with the people with MS. The cooking ability was found to be associated with higher functioning of working memory, verbal memory, and in particular processing speed.

Money management activities have also been examined by considering problems with financial management in 30 people with MS in comparison to a control group (Goverover, Hass, & DeLuca, 2016). This IADL occupation was again compared with cognitive function.

Money management ability was measured using a self-reported questionnaire of money management and cognitive function measured by administration of a battery of neuropsychological tests. The findings demonstrated that the people with MS recruited to the study had more problems and made more errors with money management. Significant correlation between cognitive impairment and self-reported money management skills was presented in the results. The importance of having adequate processing speed, attention, and executive abilities was emphasised by this study. The findings may be accepted with caution however, due to the questionable validity of the self-reported measure of money management skills employed.

Qualitative methods have been employed to study the use of everyday technology by three men with MS from an occupational perspective (Stern & Goverover, 2018). An interpretative phenomenological approach to conceptualise the lived experience of the men was used to arrive at three themes and occupational dimensions. The use of online search engines to research and manage MS as a condition was a means of learning and suggested to be a doing occupation. The connections with other people through social networks constituted a belonging theme. Seeing the present and the future was identified as a being and becoming theme (Wilcock & Hocking, 2015). Considerations of masculinity and disability were also influential in using everyday technology. Caution, however, in generalising to the wider population of men with MS from this research study may be necessary as this report is informative of these three individual's experiences.

In this section the research evidence on the ability of people with MS to engage and participate in IADL has considered and indicates that cognition, motor skills and process skills are key factors in occupational performance in IADL. The next section will discuss occupational therapy interventions for people with MS.

1.6 Occupational therapy interventions

Improvements in activity and participation for people with MS have been demonstrated in multidisciplinary rehabilitation by a review of seven Randomised Controlled Trials (RCTs) and a Controlled Clinical Trial for the Cochrane Collaboration (Khan, et al., 2007). The review indicated evidence for out-patient and home based multidisciplinary rehabilitation programmes producing improvements in symptoms, activity, participation, and quality of life for both the short and long-term. Amongst the recommendations were the need for research into the effectiveness of specific interventions and rehabilitation components such as occupational therapy. However, a more recent overview of Cochrane reviews of MS assigned a very low

grading to occupational therapy reflecting the limited research base (Amatya, Khan, & Galea, 2019).

Occupational therapy, is an integral component of multidisciplinary rehabilitation for people with MS (Yu & Mathiowetz, 2014a; NICE, 2016). Occupational therapy is one of the professions identified by the MS Trust as having a special interest and involvement in the management of people with MS (Dix & Green, 2013). Identifying the particular contribution of occupational therapy to the rehabilitation of people with MS has been less clear than for multidisciplinary rehabilitation. The effectiveness of physical, psychological, and functional occupational therapy related interventions has also been reviewed. A meta-analysis of twenty-three articles suggested effectiveness at task and activity levels. Overall, a medium size effect was reported (r = 0.52) (Baker and Tickle-Degnen, 2001). The findings should be considered with caution, however, as none of the studies involved occupational therapy specifically. Occupational therapy interventions were embedded with other multidisciplinary interventions. Other rehabilitation co-interventions by physiotherapy, nursing, speech therapy, medicine, or psychology may also have contributed to efficacy. The appropriateness of using a meta-analysis methodology is questionable where there is such a diversity of research subjects, interventions, and outcome measures. (Steultjens, Dekker, Bouter, Leemrijse, & van den Ende, 2005)

Another review for the Cochrane Collaboration evaluated the effectiveness of occupational therapy interventions for people with MS considered only three studies. A qualitative best evidence synthesis was applied to the studies that met stringent criteria for methodological quality (Steultjens et al., 2005). Two studies evaluated energy conservation but were regarded as having poor methodological quality and small sample sizes (Mathiowetz, Matuska, & Murphy, 2001; Vanage, Gilbertson, & Mathiowetz, 2003). An RCT considered to have high methodological quality, examined counseling on self-care strategies (O'Hara, Cadbury, De Souza, & Ide, 2002). This study concerning professionally guided self-care reported non-significant results (see section 2.2.5 for critical discussion). The Cochrane review drew no conclusion on the efficacy of occupational therapy in improving outcomes for people with MS (Steultjens et al., 2005).

Systematic reviews of the effectiveness of occupational therapy interventions for people with MS have been completed. A review of activity and participation indicated benefits from individualized, goal-directed interventions promoting occupational performance and participation (Yu & Mathiowetz, 2014a). This review confirms the utility of face-to-face and long-distance fatigue management in decreasing the impact of fatigue. The importance of promoting a balance between engagement in occupations and the environment is also

confirmed. This paper recommends more studies of the short-term and long-term effects of occupational therapy at the activity and participation level to establish the unique contribution the profession makes to multidisciplinary rehabilitation. This confirms that evidence is lacking for the effectiveness of the occupational therapy contribution to multidisciplinary rehabilitation for people with MS. No specific review of studies of occupational therapy interventions relating to IADL could be found for occupational therapy.

The review of occupational therapy interventions related to impairment resulting from MS emphasized the use of cognitive rehabilitation approaches (Yu & Mathiowetz, 2014b). Occupational therapy practitioners were advised to assist their clients to develop strategies for memory impairment and use cognitive behavioural therapy based interventions incorporating goal setting in a multidisciplinary team (MDT) context, to improve depression and self-efficacy in participation.

The contribution of fatigue management as an effective occupational therapy intervention for people with MS has been established based on robust research evidence (Yu & Mathiowetz, 2014a). Indeed operational guidance for fatigue management programmes has been produced by the RCOT (Harrison, 2007). The contribution of fatigue management by occupational therapy has been recognised as a non-pharmacological treatment in the latest seminal review of MS published in the Lancet medical journal (Thompson, Baranzini, et al., 2018). Despite a large number of studies that have considered the efficacy of fatigue management strategies, such as energy conservation courses, none have made links to IADL (e.g. Finlayson, Impey, Nicolle, & Edwards, 1998; Vanage et al., 2003; Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Matuska, Mathiowetz, & Finlayson, 2007; García, Lennon, Peoples, Murphy, & Lowe-Strong, 2012 and Van Heest, Mogush, & Mathiowetz, 2017). Fatigue is a significant impairment reported by people with MS (Bogdan et al., 2017) (see section 1.3.2). The lack of energy associated with fatigue impacts on occupational performance resulting in difficulties completing activities and tasks. Energy conservation is an intervention aimed at helping people with MS to manage their fatigue. Some of the studies are of high methodological quality and report significant benefits to their experimental groups in reducing the impact of fatigue and improved health-related quality of life (Mathiowetz et al., 2005). One study of fatigue management related to goal achievement following a teleconference-delivered fatigue management program, is reviewed in greater detail in the following chapter (Asano et al., 2015) (see section 2.2.4).

Fatigue management courses can be delivered face-to-face or remotely over long distances by teleconferencing. An RCT involving 169 people with MS considered the effectiveness of an energy conservation course taught by occupational therapists (Mathiowetz et al., 2005). The researchers reported significant positive effects on fatigue impact, self-efficacy, and some

aspects of quality of life. The more specific relationship between energy conservation and occupational performance in IADL, however, has not been researched for people with MS.

The profession of occupational therapy has an important and defining role in supporting engagement in the individual's chosen and obligatory occupations which include IADL (WFOT, 2012). A core concern for occupational therapists in their practice is to facilitate the person's functional independence in IADL and participate in occupational roles to appropriate level of skills (Van Oss, 2016). The role of occupational therapy in MS practice is centred on enabling the person with MS to engage and participate in the important, valued, and necessary occupations that make up the person's everyday life. This includes the wide range of activities and occupations that constitute a person's lifestyle from the young adult stage of life. Occupational therapy interventions for people with MS have been previously been limited in focus on ADL in the later stages of the disease process (Asano et al. 2015; Finlayson et al., 2008). The scope of occupational therapy practice should be holistic and person-centred through the expansion into confronting the complexity of interventions to support IADL. Important components of rehabilitation undertaken by occupational therapy have been based on fatigue management, and cognitive rehabilitation. The connection between these components of rehabilitation and participation at the impairment level in participation in everyday life activities is under researched and represents a gap in knowledge. The relationship of minimising impairment and enabling occupational performance requires further investigation (Preston, et al., 2012). From this limited research base occupational therapy interventions can be seen to offer the potential to contribute a complex multi-faceted role to support people with MS to complete their IADLs. The following section provides a summary and overview of the thesis.

1.7 Summary and overview of the thesis

This chapter has introduced the background and influences involved in the development of this research project. The policy background of occupational therapy services has also been considered. MS is a progressive neurological condition, which results in an unpredictable and unique impact on the person. The clinical features of MS such as fatigue, muscle weakness, tremor, visual impairment, sensory loss, and cognitive dysfunction have a far-reaching influence on occupational performance. Onset of the condition is often in early adulthood, a stage of life when the demands of IADL occupations can be great and have an important bearing on occupational identity. IADL have been operationally defined in accordance with the Occupational Therapy Practice Framework as activities supporting daily life within the home and community that are more complex than ADL (AOTA, 2014). The core sets of ICF categories for MS have been considered in relation to IADL despite this term not occurring in

the classification. Occupational therapy interventions for people with MS, particularly in fatigue management, have been discussed but these do not tend to relate to IADL. A scoping review of the research literature relating to occupational therapy and other MDT interventions for people with MS within IADL will be presented in the next chapter.

This research sets out to explore how occupational therapy interventions contribute to the ability of people with MS to perform IADL. The remainder of the dissertation consists of the presentation of the research approach, which assumes a stance based on pragmatism and critical realism, in Chapter Three: Methodology and methods. The theoretical lens through which occupational therapy practice is viewed is grounded in the concepts and theories of person-centred care. These influences have been developed throughout the research process. Occupational therapy is practiced within the real world context of health services and the lives of people with MS. This practice is aimed at enabling engagement and participation in purposeful and meaningful occupations. The researcher's personal clinical experience and desire to include the voices, experiences, perceptions, and opinions of people with MS and their carers has also influenced the development of the project. Chapter Three also considers the methods employed in the research by explaining and justifying the selection of a multiple case study research design incorporating mixed methods of data collection to investigate the IADL occupations of five people with MS. This research aims to contribute to occupational therapy practice knowledge by exploring how the multi-faceted role of occupational therapy practice can enable the ability of people with MS to perform IADL. The findings and their discussion are presented in Chapters Four and Five with conclusions drawn in Chapter Six.

Chapter Two

Review of the Literature

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2. Introduction

In Chapter Two the wider background and context of this research project will be considered in relation to previously published research. The purpose of this scoping literature review is to establish a critical frame of reference for the research that subsequently explores occupational therapy interventions for people with MS within IADL (Rugg & Petre, 2004). This is the basis for the aim of making an insightful and original contribution to knowledge for occupational therapy practice (Hart, 1998). The methodology employed in conducting the literature review is presented and the findings critically reviewed and discussed. An ongoing iterative process of literature search and review took place throughout the research project which developed from considering ADL and then more specifically IADL. The methodology of this scoping literature review is detailed in the following section.

13 papers met the criteria for review. The methodologies of these studies varied in quality. These research studies were categorized into themes. The six key themes arising from the literature review contributed to establishing the background and context of the research project. In the reviewed research papers, an identified gender imbalance is discussed with reference to including a male perspective on IADL in this author's research. The scarcity of research into occupational therapy interventions in IADL for people with MS demonstrated in the literature review accounts for a notable gap in knowledge and provides justification for undertaking this explorative research project. The literature review findings are discussed and form the basis for the development of the research question, objectives, methodology and data collection methods.

Although an ongoing iterative process of literature review proceeded throughout the research, two more concentrated periods of literature review were also undertaken. At an early point in the research an initial literature review was completed with the aim of establishing the clinical effectiveness of occupational therapy interventions in ADL for people with MS (Walshaw & Kirshbaum, 2012). As the research question was refined and developed the emphasis shifted from ADL to IADL and a second period of literature review took place. Justification for considering IADL as oppose to ADL was made as these activities are more complex and demanding on occupational performance. Clinical practice experiences indicated that there would be a stage in the clinical course of MS, particularly in the relapsing-remitting form of the condition, when IADL became more prominent for people with MS. This may be as the person

experiences more difficulty at work with productivity occupations. Research evidence has been published that analysed the goals set by people with MS following a teleconference delivered fatigue management programme (Asano et al., 2015). This research emphasised the importance of IADL to people with MS and recommended occupational therapy practitioners focus fatigue management on IADL as oppose to ADL. This confirmed and validated the author's development of a more specific and focused interest in IADL for people with MS. IADL were also perceived as being of core importance to occupational therapy and particularly relevant to community-based services.

2.1 Literature Review Methodology

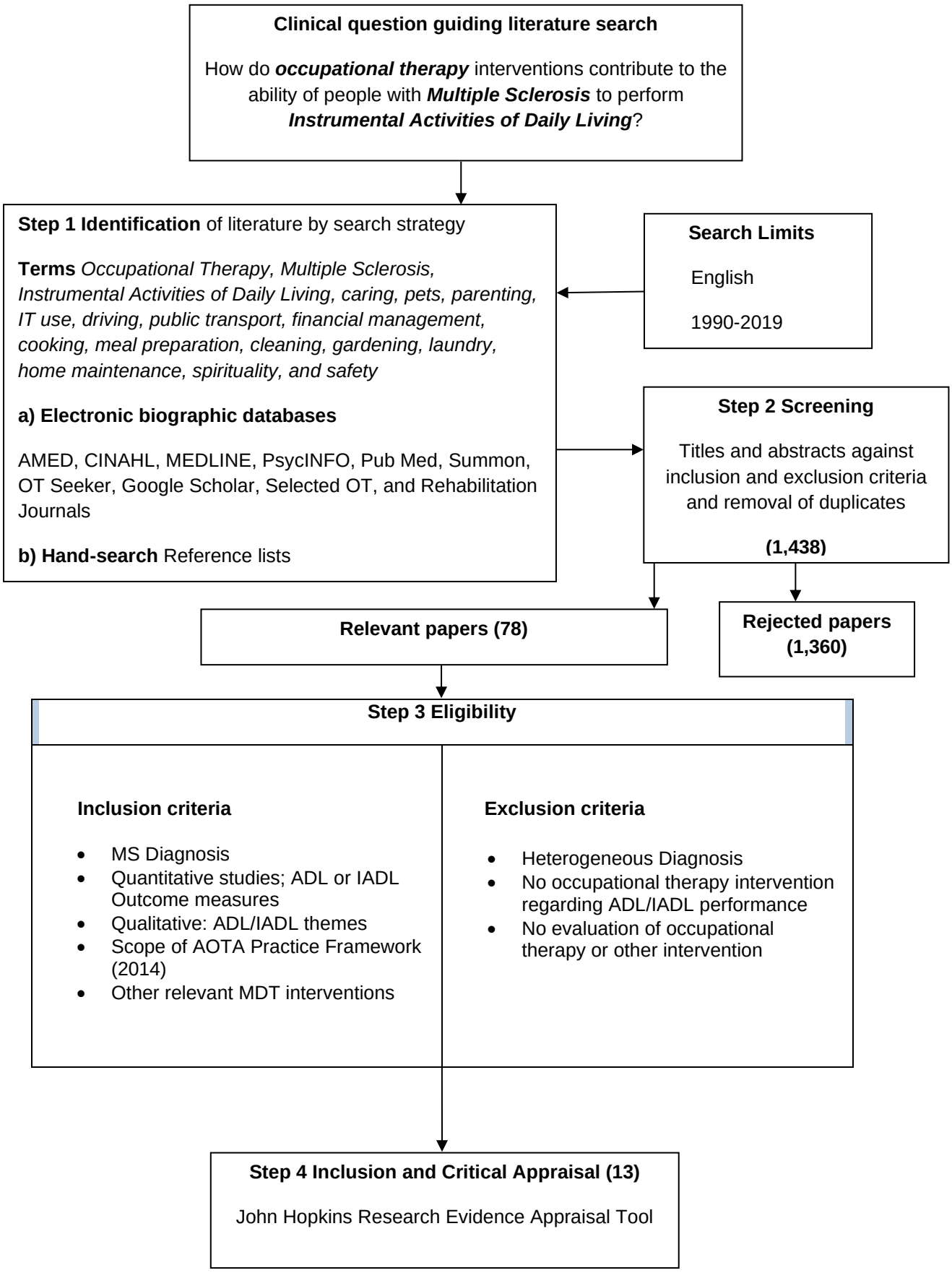
A scoping review approach was used to search, select, and appraise the literature. Scoping reviews involve a knowledge synthesis where a systematic approach is used to chart evidence on a subject and identify concepts, theories, and gaps in knowledge (Harms & Goodwin, 2019; Tricco et al., 2018). Figure 2 illustrates the literature review process. An evidence-based practice frame of reference provided the grounding for this literature review. This involved the use of current best evidence in clinical decision making integrating clinical expertise and evidence from systematic research (Bury, 1998; Greenhalgh, 2019). The starting point for evidence-based practice is identifying a clear research question:

> *How do occupational therapy interventions contribute to the ability of people with MS to perform IADL?*

The research question was used to guide the literature search. The key search terms of; *Occupational Therapy, Multiple Sclerosis and Instrumental Activities of Daily Living* were identified from the research question. Additionally the IADL terms; *caring, pets, parenting, information technology use, driving, public transport, financial management, money management, cooking, meal preparation, cleaning, gardening, laundry, home maintenance, spirituality, and safety* were used to identified the wide range of daily activities that people with MS engage in.

The first step in the process consisted of the search strategy. Literature was identified through searching the following electronic databases; AMED, CINAL, MEDLINE, PsycINFO, and Pub Med. *Summon*, the search engine of the University of Huddersfield resources and the *OT Seeker* database, were also consulted. The searches were limited to resources in English between 1990 and 2019. Selected occupational therapy and rehabilitation journals were also electronically searched. The thesis collection of the RCOT was also consulted. The reference lists of relevant papers were hand searched to identify additional studies. This search process resulted in 1438 citations being retrieved. The scoping review also included the contribution to

Figure 2. Literature search and review methodology



IADL performance of other professions such as physiotherapy, medicine, nursing, and clinical psychology.

The second step consisted of screening titles and abstracts against the inclusion and exclusion criteria and the removal of duplicates. 78 relevant papers were identified to which more detailed application of the inclusion and exclusion criteria was made. The selection inclusion criteria consisted of:

a) Diagnosis of Multiple Sclerosis for participants in studies.

b) Quantitative studies including an ADL or IADL outcome.

c) Qualitative studies with ADL or IADL themes.

d) Occupational therapy within the scope of the Occupational Therapy Practice Framework (AOTA, 2014).

e) Other relevant MDT professions' interventions.

The exclusion criteria were:

a) Heterogeneous diagnosis.

b) No occupational therapy intervention regarding ADL or IADL.

c) No evaluation of the occupational therapy or other interventions.

The inclusion and exclusion criteria set boundaries for the search. Research papers were included for review where participants were identified as people with MS. Studies with participants of heterogeneous diagnoses that included other conditions were excluded. Other long-term neurological conditions such as stroke, traumatic brain, and spinal cord injury or long-term conditions such as respiratory conditions, cancer, and mental health conditions, were not included to focus the search on the specific needs of people with MS. The inclusion criteria also identified studies with ADL or IADL outcomes or themes and interventions by occupational therapists or other professionals within the scope of the Occupational Therapy Practice Framework (AOTA, 2014).

The final step in the review process consisted in the critical appraisal of the 13 papers identified from these selection criteria. The 13 papers were grouped into six themes related to the conceptual and theoretical content. The methodological quality of studies was graded according to the John Hopkins Research Evidence Appraisal Tool (JHREAT) (Dang & Dearholt, 2017). This critical appraisal tool uses an evaluation checklist to assess the design

of the research study and assign an evidence level and a quality rating score. Table 4 summarises the JHREAT evidence levels and quality ratings. A rating score is provided for quantitative, qualitative, and mixed methods studies. It also rates systematic and other literature reviews of research evidence. As most of the studies reviewed were quantitative in design they were assigned a quality rating score of either: A - high quality, B - good quality, and C - low quality/major flaws.

Table 4. John Hopkins Research Evidence Appraisal Tool (Dang & Dearholt, 2017)

Evidence Level	Quality Rating
Level I experimental studies RCT, Systematic review of RCTs, mixed methods with RCT	A - High quality, B – Good quality, C – low quality/major flaws
Level II quasi-experimental	A - High quality, B – Good quality, C – low quality/major flaws
Level III non-experimental Descriptive, comparative and correlation studies. Qualitative studies	Quantitative studies A - High quality, B – Good quality, C – low quality/major flaws Qualitative studies A/B – High/Good quality, C – Low quality
Level IV opinion of respected authorities Guidelines	A - High quality, B – Good quality, C – low quality/major flaws
Level V experiential and non-research evidence Integrative reviews and literature reviews	Organizational experience A - High quality, B – Good quality, C – low quality/major flaws Integrative review and literature reviews A - High quality, B – Good quality, C – low quality/major flaws

2.2 Literature review findings

A summary of the literature review findings is presented in Table 5. This details of the aims, methods, sample, key findings, critically appraisal, and JHREAT score of the 13 studies that were accepted for review. A total of 1,932 people with MS participated in the studies reviewed. The studies were conducted by international centres mostly in North America (eight) and Europe (five) with one in Turkey.

Table 5. Overview of literature review findings

Authors	Theme	Study aims	Methods *(qualitative / quantitative)*	Participant numbers Gender ratio	Key findings, critique and JHREAT score
Akinwuntan, et al., 2014 (US)	Assistive technology Driving simulator	To determine the potential to improve driving-related skills using a simulator-based programme in persons with RRMS	Quantitative Pre-post intervention design	30 people with RRMS 6 control group with RRMS Male 6 Female 30 Ratio 1:5	• No significant difference between training and control group before after on road test • Descriptive statistics show trends towards improvements in visual, physical, and cognitive function • Inclusion criteria bias to well performing drivers, not representative of wider MS population • Small sample size, no randomization • Level II C
Asano et al., 2015 (US)	Fatigue management	To describe the focus of goals set by people with MS after a teleconference-delivered fatigue management programme. To evaluate goal achievement	Quantitative Data analysis from RCT evaluation of efficacy and effectiveness of teleconference	81 Male 13 Female 68 Ratio 1:5.2	• IADL the most common type of goal achieved • Emphasis on strategies in the application of fatigue management for people with MS to perform IADL • Examples goals used in programme bias to IADL as oppose to work, leisure or ADL • Questionable sample bias to cognitively more able people with MS • Level III B
Flensner and Lindencrona, 1999 (Sweden)	Assistive technology Cooling-suit	To gain information on the effects of an assistive device, the cooling-suit, on MS-patients' self-care ability and practical implications.	Quantitative [mixed methods] A single-case approach was adopted in a quasi- experimental before-and-after study Outcome: MS Self-Care ADL scale and open-ended interviews	10 Male 3 Female 10 Ratio 1: 3.3	• Increase in self-care ability • Themes of self-care ability, performance, and social activities • Limited sample size prevented statistical analysis • Possible placebo effect of wearing cooling-suit • Level III B

Table 5. Overview of literature review findings (continued)

Authors	Theme	Study aims	Methods *(qualitative / quantitative)*	Participant numbers Gender ratio	Key findings, critique and JHREAT score
Finlayson et al., 2008 (US)	Service user perspective	To examine the use of occupational therapy services in a sample of people aging with MS	Quantitative Telephone interviews to identify unmet health-related service needs. Occupational therapy was 1 of 22 services examined. Proportional odds models were used to examine factors associated with how recently services were used.	1,282 Male 333 Female 949 Ratio 1:2.8	• High importance and satisfaction for those using services recently. • Occupational therapy services more involved once occupational performance has declined in ADL • Data not collected on types of intervention or outcomes of service use • Level III B
Gentry, 2008 (US)	Assistive technology: Personal Digital Assistant	To evaluation the effects of an occupational therapy training protocol using personal digital assistants (PDAs) as assistive technology for people with cognitive impairment related to MS.	Quantitative Quasi-experimental study A-B-C repeat measure design; Assessments of functional performance. A. Start of an 8-week pre-treatment period B. Beginning and end of training, C. 8 weeks after the conclusion of training. Outcomes: RBMT, CHART, COPM	20 Male 4 Female 16 Ratio 1:4	• Participants were able to learn to use basic PDA functions and retain learning. Functional performance increased significantly. • Training with PDAs as a compensation for cognitive deficits was effective. • No control group • Possible recruitment and rater bias • Level II B
Gillen, 2002 (US)	Assistive technology: Electric Wheelchair System	To describe the occupational therapy interventions focused on improving mobility and community access for a 40-year-old man with multiple sclerosis.	Qualitative Case report Outcome FIM	1 (Male)	• FIM Outdoor mobility subscale increased • Improvement maintained at one-year follow-up • IADL goal to visit family and friends in community • Limitation of generalisability to wider population of people with MS • No report of case selection • Level III C

Table 5. Overview of literature review findings (continued)

Authors	Theme	Study aims	Methods *(qualitative / quantitative)*	Participant numbers Gender ratio	Key findings, critique and JHREAT score
Goverover, Chiaravalloti, and DeLuca, 2008 (US)	Cognitive rehabilitation Self-generation	To examine the utility of using a self-generation strategy to improve learning and performance of everyday functional tasks in persons with multiple sclerosis	Quantitative Within- and between-subject factor design. Outcome: Correct recall and step sequence	20 people with MS 18 healthy controls Male 5 Female 15 Ratio: 1:3	• Self-generation conditions significantly improved recall and step sequence in meal preparation and financial management tasks • Small sample, not representative of wider cognitive impairments in people with MS • No randomization • Questionable evidence for impact on IADL function • Level II B
Goverover and DeLuca, 2018 (US)	Cognitive rehabilitation Actual reality assessment tool	To establish validity and reliability to a performance-based assessment of everyday life activities called actual reality	Quantitative Repeated measure design With three-week interval Outcomes: Neuropsychological battery for people with MS, Functional Behavioural Scale, Lawton and Brody IADL scale	30 people with MS 30 healthy controls Male 7 Female 23 Ratio 1:3.2	• Accessible assessment only needing internet use to carry out three on-line shopping tasks • Moderate to large interrater reliability, discriminatory and concurrent validity • Small sample, not matched to healthy control group challenge generalisability to wider population of people with MS • Questionable generalisation to other IADL tasks • No consideration to other observational measures of IADL such as AMPS as a gold standard for comparison • Level II B

Table 5. Overview of literature review findings (continue)

Authors	Theme	Study aims	Methods *(qualitative / quantitative)*	Participant numbers Gender ratio	Key findings, critique and JHREAT score
Lexell, Fansbjer, and Lexell, 2014 (Sweden)	In-patient rehabilitation Performance and satisfaction following interdisciplinary rehabilitation	To assess self-perceived performance and satisfaction with performance of daily activities in persons with MS on admission to and at discharge from interdisciplinary rehabilitation	Quantitative Retrospective study with a pre-post design Outcome measure; COPM	43 people with MS Male 16 Female 27 Ratio 1:1.7	• Three quarters of problematic activities identified in self-care, household management and functional mobility • Significant correlation between changes in performance and satisfaction at admission and discharge • No control group • In-patient environmental context greatly different from home • Level III B
Maitra et al., 2010 (US)	In-patient rehabilitation Occupational therapy interventions and ADL categories	To understand how occupational therapy interventions, enable goals attained for inpatients in a rehabilitation setting.	Quantitative, Retrospective analysis of five years past medical records. Descriptive statistics and correlation analysis identifying variables associated with positive outcomes of FIM.	193 people with MS Male 45 Female 148 Ratio 1:3.3	• Occupational therapy was associated with positive outcomes • Significant correlation with positive changes in; cognitive skills training, community reintegration and self-care • Useful description of occupational therapy intervention categories • MDT rehab, difficult to isolate occupational therapy contribution • Some intervention categories ambiguous • Level III B
O'Hara et al., 2002 (UK)	Guided self-care programme	To assess the efficacy of a patient-focused professionally guided self-care programme	Quantitative Single-blind RCT Outcome: Postal Barthel Index Two level, mixed design ANOVA	169 people with MS Intervention 73 Control 96 Male 51 Female 118 Ratio 1:2.3	• ADL ability maintained in experimental group compared with decline in control group at follow-up • Included in Cochrane review of occupational therapy and MS, however occupational therapists not involved with study. • Relevant to occupational therapy practice • Limited to ADL not considering more complex IADL occupations • Level I A

Table 5. Overview of literature review findings (continued)

Authors	Theme	Study aims	Methods *(qualitative / quantitative)*	Participant numbers Gender ratio	Key findings, critique and JHREAT score
Özkan, Tuncay, and Mollaoğlu, 2017 (Turkey)	Assistive technology Cooling-suit	To determine the effects of cooling suit on fatigue and activities of daily living of individuals with MS	Quantitative, RCT; study used a two sample, control group design. Outcome: Modified Barthel Index	35 people with MS Male 8 Female 27 Ratio 1:3.4 40 control group matched for clinical and socio-economic characteristics	• Significant Improvement in ADL independence on Modified Barthel Index for experimental group • Decreased level of fatigue • Uhthoff's syndrome, other theories of MS fatigue or limitations of the research are not discussed • Level I B
Reilly and Hynes, 2018 (Ireland)	Cognitive rehabilitation cognitive occupation-based programme	To assess effectiveness of a cognitive occupation-based programme for improving daily life and cognitive impairment	Quantitative, Experimental pre-test/post-test design Outcomes: GAS and COB-MS	12 People with MS Male 1 Female 11 Ratio 1:11	• Statistically significant improvements in GAS and some cognitive measures verbal memory, short and long delay free recall • Occupational competency in daily living skills (OSA-DLS) measure clinical improvement • Small sample and only one male participant limit generalisability to wider population of people with MS • Examples of goal setting process not reported • Level III B

Table 6 shows the six themes the studies were grouped into. In-patient rehabilitation forms the first theme and is based on two studies of outcomes in relation to ADL. Occupational therapists are key members of multidisciplinary teams in such hospital settings. Assistive technology formed the second theme with studies considering Personal Digital Assistants (PDAs), a wheelchair system, driving simulator use, and two studies of the effect of cooling-suits on performance in ADL. The third theme was based on the concept and theories of cognitive rehabilitation. This included three studies of self-generation, actual reality, and a cognitive occupation programme. The remaining themes all consisted of single studies concerning fatigue management, professionally guided self-care, and service user perspective. The methodologies of these studies were predominantly quantitative in design and varied in quality as rated on the JHREAT. One of the cooling-suit studies used mixed methods. These themes are considered in more detail in the following sub-sections.

2.2.1 In-patient rehabilitation

Occupational therapy interventions for people with MS can often take place in the context of the hospital in-patient ward. An admission may typically follow a relapse in the condition or a fall and require a period of multidisciplinary rehabilitation. Two studies identified in the review considered interventions for people with MS in the in-patient setting. A secondary analysis of documentation in Chicago considered occupational therapy outcomes for people with MS over a five year time frame (Maitra et al., 2010). A retrospective method was also used to study the perceived performance and satisfaction with performance of daily living activities following interdisciplinary in-patient rehabilitation in Sweden (Lexell, Flansbjer, & Lexell, 2014).

The aim of the research into occupational therapy outcomes was to comprehend how occupational therapy interventions enabled goals to be attained for in-patients in a rehabilitation setting (Maitra et al., 2010). The rehabilitation centre used the Functional Independence Measure (FIM) as an outcome measure. This research is included in this literature review as a number of motor items included in the FIM are directly related to ADL, eating, grooming, bathing, dressing upper body, dressing lower body, toileting and bowel management, transfers to bed/chair and tub/shower, walking/wheelchair, and stair climbing (Granger et al., 1993).

Table 6. Literature review themes

Theme	Description	Papers	Subject	JHREAT score
In-patient rehabilitation	Interventions related to IADL that take place for people with MS in the context of an in-patient hospital setting.	• Maitra et al, 2010 • Lexell, Fansbjer, and Lexell, 2014	• Occupational therapy interventions and ADL categories • Performance and satisfaction following interdisciplinary rehabilitation	• III B • III B
Assistive technology	Interventions related to IADL that involve low- and high-tech devices that maintain and improve functional capabilities and the services to provide such devices.	• Akinwuntan, et al., 2014 • Flensner and Lindencrona, 1999 • Gentry, 2008 • Gillen, 2002 • Özkan Tuncay, and Mollaoğlu, 2017	• Driving simulator • Cooling-suit • Personal Digital Assistant • Electric Wheelchair System • Cooling-suit	• II C • III B • II B • III C • I B
Cognitive rehabilitation	Interventions that use compensation and restorative approaches to address cognitive impairments in the context of IADL performance.	• Goverover, Chiaravalloti, and DeLuca, 2008 • Goverover and DeLuca, 2018 • Reilly and Hynes, 2018	• Self-generation • Actual reality assessment tool • cognitive occupation-based programme	• II B • II B • III B
Fatigue management	Interventions related to IADL involving management of fatigue.	• Asano et al., 2015	• Goals set	• III B
Professionally guided self-care	Interventions related to ADL guided by professionals.	• O'Hara et al., 2002	• Guided self-care programme	• I A
Service user perspective	Service users views of importance and satisfactions of occupational therapy	• Finlayson et al., 2008	• Occupational Therapy service use	• III B

A sample of 193 people with a diagnosis of MS or related disorders had their initial and discharge FIM scores compared using paired t-test. In the ADL areas of transfers, toileting, dressing, and bathing, FIM scores were reported to increase but not at significant levels. A Pearson's correlation analysis between occupational therapy intensity and changes in FIM scores was used to test the efficacy of intervention. Therapeutic intensity had a significant correlation with the FIM category of upper-extremity dressing ($r = 0.15$, $p < 0.05$). The self-care training category demonstrated significant correlation with ADL categories of upper-extremity dressing ($r = 0.24$, $p < 0.01$) and toilet transfers ($r = 0.15$, $p < 0.05$). An indication to the importance of specific practice of ADL tasks can be seen if these findings are contrasted with the therapeutic activities category. A significant negative correlation was found between therapeutic activities and the categories of lower-extremity dressing ($r = -0.17$, $p = 0.05$) and tub transfers ($r = 0.21$, $p < 0.01$). The authors suggest practicing self-care tasks is more effective in promoting independence in ADL than spending time on therapeutic activities.

Undertaking a retrospective study of intervention documentation is a cost-effective research methodology which places a low burden on participants. A lack of control over the data, however, can introduce bias and confounding factors to the research (Classen, 2006). As the research took place in a rehabilitation centre, interventions by other disciplines may have acted to confound the findings. The research had no control over this, and occupational therapy interventions may not solely account for FIM score changes. Definitive clarity of some of the intervention categories such as therapeutic activities and therapeutic exercises was not possible leaving ambiguity during coding. Changes to documentation procedures also led to difficulties deciphering units of intervention. An under representation of men in the study is also noted with women accounting for 76.7% of the sample, a male: female ratio of 1:3.3. As a correlation study this also does not indicate proof of cause and effect between the occupational therapy intervention and changes in FIM scores. When considered on the JHREAT this study was scored at level III B.

This retrospective study of a five-year period of documentation records for in-patient rehabilitation outcomes gives some useful description of occupational therapy interventions categories. The coding categories used are instructive as they give an indication of the occupational therapy interventions that take place in an in-patient rehabilitation centre. These included hot-cold packs, sensory integration, manual therapy, massage, contrast baths, orthotic fitting, cognitive skills, neuromuscular re-education, community reintegration, self-care, occupational-based therapeutic activities, therapeutic exercises, evaluation, re-evaluation, and group. The most common interventions were self-care, therapeutic exercise, and occupation-based therapeutic activities. These intervention categories are wide ranging and give some insight to occupational therapy in an in-patient rehabilitation context. The study

does not, however, give an indication to the measurement and intervention aimed at preparing the people with MS to perform the more complex and occupational performance demanding IADL in the home setting upon discharge.

A second study involving people with MS in the in-patient setting considered the self-perceived performance and satisfaction with daily activities following interdisciplinary rehabilitation (Lexell et al., 2014). This retrospective study with pre-post design included occupational therapists within the interdisciplinary team. The study aimed to reveal if and how activities changed following rehabilitation interventions. A sample of 43 people with MS living in the community consisting of 27 women and 16 men were studied. This represented a male female ratio of 1:1.7. The Canadian Occupational Performance Measure (COPM) was administered on admission and discharge from the rehabilitation unit (Law et al., 2004). As the study included the COPM it was accepted for review. COPM is a self-rated performance and satisfaction scale that includes a self-care area of occupational performance.

Of the 216 activities identified as problematic approximately three quarters were in personal care, household management and functional mobility. This gives an indication of the importance of ADL and IADL to the people with MS. A difference in the self-rating of 2.0 points on COPM was identified as clinically significant (Finlayson, Månsson Lexell & Forwell, 2012). At discharge 42% of participants rated performance and 56% rated satisfaction with performance as increasing by the clinically significant 2.0 points improvement. A significant correlation was reported between changes in performance and satisfaction compared between admission and discharge ($\rho=0.85; p<0.001$). The conclusion was drawn that using a patient-reported outcome such as COPM broadened understanding of the benefits of interdisciplinary rehabilitation. Use of a control group within the design of the study was rejected as not appropriate. This research does not distinguish the elements of occupational therapy contributing to the interdisciplinary interventions. The in-patient context is very different from the home environment where other interventions that support ADL and IADL take place such as provision of equipment and adaptation of the environment. The quality of this research was rated as level III B on the JHREAT.

2.2.2 Assistive technology

Occupational therapists are often involved in the assessment and provision of various assistive technologies to enable occupational performance for people with MS. Assistive technology is characteristically wide ranging and has been defined as concerning both low- and high-tech devices that maintain and improve functional capabilities and the services to provide such devices (Blake & Bodine, 2002).

The contribution of assistive technology to maintaining occupational performance in IADL has been examined in several studies. The use of information technology by people with MS was considered in a quasi-experimental study of PDAs as a compensation for cognitive deficits and reported improvement in performance and satisfaction with ADL (Gentry, 2008). The use of technologies to facilitate community mobility were researched in two studies. One study reports the occupational therapy interventions involved in providing a wheelchair system for a man with MS (Gillen, 2002). A second study examined a programme to improve driving performance through use of a driving simulator (Akinwuntan, et al., 2014). The use of cooling-suits as an adjunctive intervention and the impact on ADL function was also considered in two studies (Flensner & Lindencrona, 1999; Özkan, Tuncay, & Mollaoğlu, 2017).

The effectiveness of an occupational therapy training protocol using personal PDAs has been researched. This was in relation to functional performance for people with MS who experience symptoms of cognitive impairment (Gentry, 2008). The study examined the value of assistive technology available on devices such as palm held computers and mobile phones. A lack of ecologically valid studies of cognitive rehabilitation for people with MS justified the study. A quasi-experimental methodology was employed consisting of A-B-C repeat measures design. Outcome measures were taken at pre-treatment phase (A), treatment phase (B) and post-treatment (C). Four measurement tools were used; Rivermead Behavioural Memory Test (RBMT) (Wilson, Cockburn, & Baddelay, 1985), Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, Charlifie, Gerhart, Overholser, & Richardson, 1992), COPM and a PDA check list demonstrated use and logging of PDA entries. The intervention consisted of training the research subjects to use a PDA as a cognitive aid over a ten-week period.

The reported results include repeat measures ANOVA for mean scores on COPM. The statistical analysis indicates significant improvements on performance ($F = 96.02$, $p < 0.001$, $df = 1.13$, $\eta^2 = 0.83$) and satisfaction ($F = 104.916$, $p < 0.001$, $df = 1.14$, $\eta^2 = 0.847$). Post hoc comparison using the Bonferroni adjustment indicated significant changes during the treatment period with large effect size for performance (M = 4.008, SE = 0.390, $p > 0.001$, $r = 0.76$) and satisfaction (M = 4.435, SE = 0.408, $r = 0.81$). The conclusion was drawn that training with PDAs as a compensation for cognitive deficits was effective and had real world importance.

The study can be criticised from several perspectives. The sample size was small consisting of 20 individuals. No power calculations were completed prior to the study. The genders ratio of the sample is biased in favour of women with 4 men to 16 women, a ratio of 1:4. The sample involved recruitment of volunteers from a MS clinic and a MS Society membership. This could

result in a biased towards those involved in these services and may not represent the wider MS population. Transferring conclusions to the general MS population must be made with caution. There was no randomisation of the sample and no control group as comparison. The use of a control group would appear feasible and ethical. As this was a novel treatment intervention, a control group would have received the standard treatment approaches. The study investigator conducted the assessments leaving the possibility for rater bias in outcome measurement. From the viewpoint of this review it is also not possible to fully analyse and separate the ADL occupational performance area (self-care). The improvements in COPM performance and satisfaction include the other occupational performance areas of productivity and leisure. This quasi-experimental methodology was rated at level II B on the JHREAT.

A second research study involving assistive technology consisted of a case report describing a task orientated approach to occupational therapy interventions for a 40-year-old man with MS who experienced severe ataxia and lower limb weakness (Gillen, 2002). Treatment interventions included prescription of an electric powered wheelchair system with a 20° backward tilt. Interventions occurred in an in-patient rehabilitation context where the goal was to improve ADL and mobility skills. A description of the assessment procedures, professional reasoning and intervention planning is reported. Assistive technology was also used to adapt the joystick control and compensate for the effect of tremor. Positioning in the wheelchair was improved by providing a pressure relieving gel cushion and lateral trunk supports. Orthotic prescription of a volar wrist support and adaptation of movement patterns to facilitate control of the joystick in right, left, forward, and reverse directions. Once the wheelchair was prescribed ten training sessions of 30 minutes took place in hospital, home, and community environmental contexts. During the in-patient period daily sessions of occupational therapy lasted for 90 minutes.

The FIM was employed as a standardised outcome measure. On the indoor powered wheelchair mobility sub-scale, the score increased from 4 (minimal assistance) to 6 (modified independent). On the outdoor mobility sub-scale, the score increased from 1 (total assist) to 5 (requires only supervision). This improvement was maintained at 1-year follow-up. Indeed, outdoor mobility was scored at 6 (modified independent) suggesting progress continued.

An obvious limitation is the relevance and generalisability of the results to other people with MS (Barlow & Hersen, 1984). No information on the nature of selection of the case report is reported. Justification for the selection of case study is not provided. It appears that a convenient subject is described. The single sample size only permits descriptive as opposed to analytic statistics to be employed. The report does describe co-interventions during the

period of in-patient rehabilitation. Multidisciplinary interventions included an initial period of drug treatment by medics, physical therapy sessions of 90 minutes daily, speech therapy, and therapeutic recreation. Physical therapy initially focused on the goal of walking, but this proved unrealistic. Subsequent treatments aimed to improve endurance, sitting balance and strength. The issue of co-intervention effects is discussed with regards to tremor-dampening agents which had a positive effect on functional activities in conjunction with the occupational therapy intervention. With regards to an occupational perspective the man chose the IADL goal of community mobility, as being able to travel to visit family and friends in his community was highly meaningful. In other areas of ADL, for example feeding, he needed substantial assistance due to persistent ataxia. Despite giving insight into occupational therapy interventions this study is of low methodological quality. When considered on the JHREAT this study was scored at Level III C.

A pilot study investigated the use of a driving simulator programme to improve the driving skills in people with RRMS (Akinwuntan et al, 2014). Driving is a complex IADL that holds importance for people with MS in relation to community mobility, independence, and autonomy. The research involved a driving simulator that provided an immersive environment to train driving skills for people with MS and actual driving of a vehicle. The programme involved 5 hours of training over 5 weeks and included navigating scenarios in the driving simulator and production of an individualise training programme. The training was based on motor learning with contextual, task specific, and repetitive training emphasised. A sample of 36 participants with RRMS undertook the training programme. Six participants, however, were unable to complete this due to simulator sickness and these participants became a control group. 30 of the participants were women and six were men representing a ratio of 1:5. The outcomes measured driving performance on an on-road test at pre-training and post-training. A varied battery of psychological tests including visual and cognitive function was also administered.

The results, however, did not show significant difference between the training and control group before and after the training programme for the on-road test. Evidence to support the potential benefits of the driving simulator interventions relied upon descriptive statistics with general trends towards improvements in some visual, physical, and cognitive tests. Limitations to the design of the study could account for these findings. The small sample size and the very small control group meant the study was under-powered. Allocation to the control group was not randomized but by natural selection due to their experience of simulator sickness problems. The inclusion criteria showed bias towards recruitment of people with RRMS who were well performing drivers. This group was not representative of the wider

population of people with MS and their driving abilities. Due to these methodological limitations the study was scored at level II C on the JHREAT.

Two studies from the nursing literature considered the effect of wearing a cooling-suit on function in ADL. One study of ten people with MS in Sweden considered their experiences in daily life when using a cooling suit (Flensner & Lindencrona, 1999). The second in Turkey reported an RCT to study the effects of cooling-suit on fatigue and ADL (Özkan et al., 2017). The concept of the cooling-suit was developed in the US in the 1990s as an assistive device to reduce body temperature and relieve symptom exacerbation due to heat-sensitivity. Both these studies considered ADL of people in their own homes. The study in Sweden used a single case quasi-experimental approach to collect mixed methods data before and after application of a cooling-suit. Open-ended interviews were carried out alongside the MS Self-Care ADL scale outcome measure (Gulick, 1988). The quantitative results showed increase in self-care ability through descriptive statistics as the sample of ten people with MS was too small to test variance. Content analysis of the qualitative interview data produced three themes: self-care ability, performance, and social activities. The possible impact of a placebo effect occurring due to wearing a special cooling-suit was not discussed in the paper. Due to the research methodology and small sample the authors caution against generalisation of the findings to a larger population of people with MS. The case study methodology does, however, point towards generation of theoretical explanations from the findings. As a mixed methods study this was rated as Level III B on the JHREAT.

An RCT has also considered the effect of a cooling suit for people with MS on fatigue and ADL in Turkey (Özkan et al., 2017). The study sample of 75 people with MS was recruited from an out-patient clinic. An experimental group of 35 people with MS were matched to a control group of 40 people with MS by clinical and socio-economic characteristics. The cooling suit treatment consisted of a vest containing ice packs which reduce body temperature by 0.5-1.0 °C. The cooling suit was worn daily for 40 minutes over four weeks in the home setting. Three outcome measures, the Fatigue Impact Scale (Armutlu, Keser, Korkmaz, et al., 2007), Fatigue Severity Scale (Armutlu, Korkmaz, Keser, et al., 2007), and Modified Barthel Index (Küçükdeveci et al., 2000) were administrated at the start, after four weeks and eight weeks. These measures are validated for the Turkish population.

The reported results indicate significant improvements for the experimental group in levels of fatigue and independence in ADL as measured by the Modified Barthel Index. Indeed, these improvements continued at eight-week follow-up. Limitations, however, of the research are not discussed by the authors. The limitations may be related to other variables such as the seasonal variation in ambient domestic temperature in Turkey and cooling intervention

methods such as drinks, showers, or air conditioning. The data collection was completed by the authors which introduced a risk of bias. No introductory discussion of other theories of MS fatigue or use the term Uhthoff's syndrome is made in the paper. As an RCT this research into the effect of a cooling suit treatment was rated as Level I B on the JHREAT.

2.2.3 Cognitive rehabilitation

Cognitive training and rehabilitation interventions have been found to improve attention and memory function for people with MS (Rosti-Otajärvi & Hämäläinen, 2014). Cognitive rehabilitation has been described as interventions that use compensation and restorative approaches to address cognitive impairments (Pierson and Griffith, 2006). Three studies were included in the review that considered elements of cognitive rehabilitation in relation to IADL for people with MS.

One study set out to consider the usefulness of a self-generation strategy to learn and perform two meal preparation and two financial management tasks in people with MS (Goverover, Chiaravalloti, & DeLuca, 2008). Self-generation uses the person's own words, concepts, and personal references to improve memory and learning. This research emphasised an approach that addressed the key cognitive problem of learning in people with MS. A sample of 20 participants with MS and 18 healthy control participants were recruited. The ratio of male to female participants with MS was 1:3. The design involved within and between subject comparison with one task in each IADL group presented with self-generated conditions and one with provided conditions. The four IADL tasks were divided into 12 steps with instruction either pre-set or with missing words for participants to generate themselves. The outcomes of recall and step sequence were recorded at three intervals: immediate verbal recall following presentation of the conditions, after a 30 minute period, and performance of the IADL tasks and one week after initial presentation.

The results demonstrated that for the meal preparation and financial management tasks the self-generated conditions significantly improved new learning and memory for participants with MS and the control group. ANOVA of the generated versus provided conditions showed a medium effect size ($F=28.1$, $P<.001$; $\eta^2=.43$). The authors concluded that self-generation enhanced new learning and memory for function in IADLs in both people with MS and healthy participants. A stronger effect was reported for the meal preparation tasks compared with the financial management tasks. This was explained as possibly related to the meaningfulness of the real meal task versus the simulated financial tasks.

The study was limited by the small sample size and lacked representation of the cognitive impairments of the wider population of people with MS. The robustness of the study procedure

could have been improved by using random assignment to the conditions as oppose to alternate assignment. This study focused on recall and learning functions as outcome measures but only directly observed task performance at the second data collection point 30 minutes after the initial presentation of the conditions. Observation of the task performance at one week could have provided more robust results for task performance than verbal recall by telephone call. Critical appraisal of this research into self-generation as a method of cognitive rehabilitation on the JHREAT was rated at Level II B.

A feasibility study set out to establish the effectiveness of a cognitive occupation-based programme for people with MS (COB-MS) in improving daily life and cognition (Reilly & Hynes, 2018). The eight 60-minute session programme employed a holistic approach to cognitive rehabilitation which emphasised education, remediation, and adaptation. This was integrated towards daily occupations in contexts and aimed at facilitating the meeting of self-determined goals. A small convenience sample of 12 people with MS, including just one male, participated in the programme. The primary outcome measure used was Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968). Secondary outcome measures included tests of cognitive domains and the Occupational Self-Assessment-Daily Living Scales (OSA-DLS) a measure of occupational competency (Scott, 2016). Data was collected at three intervals, a week before the programme, a week after completion, and at eight weeks follow-up.

The results indicated statistically significant improvement in GAS scores (z=-3.061, p=0.002) but only clinical improvements in occupational competency. Outcome measures considering cognition were statistically significant in verbal memory, short and long delay free recall. Limitations of this research study include issues of selection bias, as participants were self-selected, and practice effects in the secondary cognitive outcome measures. The small sample with only one male participant recruited also limits the generalisability of the findings to the wider population of people with MS. The brief programme content report does not detail or use examples of the goal setting process making the precise cognitive rehabilitation techniques difficult to delineate. The impact and relationship with fatigue on cognitive function and occupational performance is also not considered in this research study. This research was assigned a quality rating at Level III B on the JHREAT.

The development of an assessment of everyday life function involving the use of information technology to carry out on-line shopping tasks was included in the review as a potential component within the scope of occupational therapy interventions process (AOTA, 2014). The study aimed to establish the psychometric properties of validity and reliability of the *actual reality* approach to assessing everyday functioning (Goverover & DeLuca, 2018). The sample consisted of 30 people with MS and a control group of 30 healthy people. The actual reality

assessment consisted of completing three internet shopping tasks: booking an airline ticket, purchasing decorative cookies (biscuits) and purchasing a pizza. Each task involved 32 steps which are observed and scored for task independence, cognitive capacity, and time. A repeated measure design was employed by administering the tasks twice at a three-week time interval. Neuropsychological assessment was carried out using a cognitive battery for people with MS. Daily living function was assessed using two self-reported measures, the Functional Behavioural Scale (Baum et al., 1993) and the Lawton and Brody IADL Scale, an outcome measure of eight IADL domains (Graf, 2008).

The results indicate moderate to large interrater reliability, discriminatory and concurrent validity of the actual reality assessment. The assessment was proposed as an advance in the measuring functional cognitive outcomes and the assessment of IADL. The limitations of this research lie in generalisability to a wider population of people with MS from this small sample. On-line shopping may not be a representative construct of other IADL task. The raters were not blinded to healthy control group and MS groups and the groups were not matched. There is no consideration or discussion of the merits of comparison with other behavioural observation measures in IADL such as AMPS as a gold standard for measurement (Fisher & Jones, 2014). This research paper was appraised as Level II B on JHREAT.

2.2.4 Fatigue management

The role of fatigue management as a well-accepted occupational therapy intervention within multi-disciplinary rehabilitation is established (see section 1.6). Of the many studies related to fatigue management screened during the literature review process, only one was included in the review of literature. The setting and achievement of goals by people with MS was studied after the completion of a teleconference-delivered fatigue management program (Asano et al., 2015). Goal setting aims to encourage behavioural changes as part of self-management programmes. The data was collected as part of an RCT with people with MS of the effectiveness and efficacy of a teleconference-delivered fatigue management programme (Finlayson, Preissner, Cho, & Plow, 2011). The programme consisted of six weekly calls lasting 70 minutes which introduced 14 energy conservation and management strategies to a group of people with MS. The sessions were facilitated by a qualified occupational therapist. This quantitative research set out to examine the 485 goals set at the end of the programme by 81 participants of whom 13 were males and 68 females, a ratio of 1:5.2. Goals were coded to categories based on the eight occupations described in the Occupational Therapy Practice Framework (AOTA, 2014). This research used descriptive statistics to analyse data on the attainment of goals using a Likert-type self-rating scale ranging from (1-10) designed for the study. As this study identified ADL and three IADL goal categories, and measured goal

attainment as an intervention outcome it met the inclusion criteria for the literature review. The quality of this research was graded at Level III B on the JHREAT.

Some critical points can be made regarding this research into goal attainment. The discussion indicates that only limited examples of goals were demonstrated during the intervention programme and these were related to IADL occupations. This may have led to bias in the choice away from other occupations for example related to work, leisure, and indeed ADL. Only 81 of the 181 participants (44.8%) submitted goals. Some of the submitted goals were not able to be coded to occupation categories. The people with MS who did not submit goals may have found the process more difficult due to cognitive impairments associated with the condition or required more ongoing individual and face-to-face support to complete goals than was available through the teleconferencing programme.

The results of the analysis are highly significant for this thesis. The most popular goals set by the people with MS were coded to the IADL categories. Indeed, during the goal coding process, the researchers decided to sub-divide and extend the IADL category into; IADLs Home (n = 136; 28%), IADLs Health (n = 96; 19.8%) and IADLs Other (n = 48; 9.9%). IADL goals were also the most common to be achieved. Short term goals were more likely to be achieved which was accounted for by the unpredictable nature of MS symptoms affecting intermediate and long term goals. As the participants were setting their own goals this is evidence providing insight into the priorities and motives of the people with MS in the rehabilitation process. In the acute hospital setting in-patient rehabilitation is focused on ADL goals (Maitra et al., 2010) (see section 2.2.1). The participants involved in this research project were all community based. The researchers concluded that occupational therapists should concentrate on targeting fatigue management strategies for people with MS towards IADL rather than ADL. This paper directly complemented the premise of the importance of IADL for people with MS identified in this thesis. It was published at the time when data collection was ongoing and confirmed the value of researching how occupational therapy interventions contribute to the ability of people with MS to perform IADL.

2.2.5 Professionally guided self-care

A limited number of studies relate to occupational therapy interventions in ADL for people with MS have been completed. Of these studies a well-designed RCT considered the effectiveness of a low intensity professionally guided self-care programme for people with MS living in the community in the UK (O'Hara et al 2002). The intervention programme consisted of a discussion of self-care strategies followed by the support of an information booklet developed for the study and based on the priorities of people with MS.

Of the 183 people with MS who began the study 169 completed it, an attrition rate of 8%. Individuals were randomly assigned by an independent person to an intervention group (n = 73) who received the intervention programme or a control group (n = 96) who did not receive the intervention. The gender ratio of male to female participants in this study was 1:2.3. The assessors and health professional undertaking the intervention were blinded to the randomised allocation process. A power calculation indicated that a sample of 180 participants would indicate changes between the groups on a mobility scale outcome measure (De Souza, 1999). A postal version of the Barthel Index (BI) was administered at baseline and six months later. In rehabilitation the BI is a widely used and valid ADL outcome measure (Gomperzt, Pound, & Ebrahim, 1994). The ADL categories measured consist of bowel and bladder management, grooming, toileting, feeding, transfers, mobility, dressing, stairs, and bathing. A criticism that can be made of the postal BI is that as a self-reported measure its validity as an objective measure of occupational performance in ADL is questionable.

Analysis of variance (ANOVA) for the BI scores provides interesting evidence to the relative potential efficacy of the intervention programme. The baseline scores in ADL between the experimental group and the control group showed no significant difference in independence (Mann-Whitney U =3459.50, Z = -0.14, p = 0.89). Analysis of baseline and follow-up BI scores for the intervention group indicated no significant difference (z = -0.49, p = 0.62). This would indicate ADL ability did not improve or deteriorate but was maintained. The comparison of baseline and follow-up BI scores for control group, in contrast, showed a significant negative difference (z = -3.41, p = 0.001). The ADL independence level for the control group had deteriorated. Considering the nature of MS as a progressive condition this is an important finding. The results showed that for the group receiving the programme, ADL outcome scores were maintained. By contrast the control group experienced a significant decline in their scores.

Experimental designs such as an RCT set out to establish evidence for causality, i.e. that an intervention has an effect on an outcome (Nelson, 2006). This study is of high methodological quality and was rated at level I A on the JHREAT. The rationale was to address the perceived gap in provision of services addressing daily living in the community. Rather frustratingly the study report does not specifically identify the health professional administering the programme as an occupational therapist. Indirect evidence of occupational therapy intervention is offered by the scope of the programme, its location partly at local therapy centres and the study's inclusion in the Cochrane review on occupational therapy and MS (Steultjens et al., 2005). It is possible that another professional such as a MS nurse specialist was involved in administer the program. With these caveats the study was included in this review as the intervention was

judged to be within the scope of interventions made by occupational therapy. Correspondence with the authors confirmed that the programme was actually delivered by a physiotherapist and a nurse (De Souza, 2012). This somewhat undermines the inclusion of this research study in the Cochrane Collaboration review of occupational therapy for people with MS (Steultjens et al., 2005). The content of the intervention programme, however, is highly relevant to occupational therapy practice with people with MS. This could be delivered by occupational therapists working in a community based multidisciplinary team. The research only considers ADL and does not consider more complex occupations such as IADL.

2.2.6 Service user perspective

Knowledge and use of occupational therapy services by people with MS is crucial to developing effective interventions that people with MS will engage with. There should be congruence between the interventions offered by occupational therapy services and the perceived needs of the people with MS and their carers (Preston, Haslam, & Lamont, 2012). The literature review identified one study that examined the use of occupational therapy services by people aging with MS (Finlayson, Garcia, & Cho, 2008). The views of people with MS on their occupational therapy services are highly relevant if research of interventions to support performance in IADL are to be based on principles of person-centred care. The relationship between the person with MS and the occupational therapist should be collaborative and based on the personalised goals of the person with MS.

A survey of occupational therapy services used by a sample of people aging with MS in five states of the US has been reported (Finlayson et al., 2008). This was structured using the Occupational Therapy Practice Framework (second edition) (Youngstrom et al., 2002). The rationale of the study was to identify areas of difference between service use patterns and the scope of occupational therapy. In this study participants were aged over 45 years and reported themselves as having a diagnosis of MS. Recruitment was made from various sources including the US National MS Society. A sample of 1,282 individuals were interviewed by telephone: 557 aged 45 to 64 years 725 aged 65 years and above. The ratio of male to female participants was 1:2.8 in this study. Interview questions included asking participants about their ability to perform 11 ADL tasks and seven IADL tasks. The responses were scored on the Self-reported Functional Scale (Hoenig, Hoff, McIntyre, & Branch, 2001). Occupational therapy service users were categorised into a) never user b) former users c) recent user. A majority of 61.8% had never used occupational therapy services. Analysis of the data used proportionate odds models for ordinal level data.

The reported results indicated that decreased self-reported ADL ability was strongly associated with use of occupational therapy services. People with maximal ADL limitations were significantly more likely to have recently seen occupational therapy services than those in the moderate, minimal and no limitations categories (p = 0.001). This suggests that occupational therapy services are more involved with people once their occupational performance has declined in ADL. Results for importance and satisfaction with the occupational services were high in the people recently using the services.

This study provides some insight into the perception of people with MS with regards to the importance and satisfaction with occupational therapy services. Their perceptions of the service were that it was important and valued (Finlayson, Garcia, & Cho, 2008). The study did not, however, consider occupational therapy interventions below the service use level. No detailed data on occupational therapy interventions were collected or outcomes of service use. This is weak evidence for the efficacy of occupational therapy. People with MS voiced their satisfaction with and expressed the importance of occupational therapy interventions and that they were important. Whether this can imply that the interventions are effective is questionable. This study was rated at level III B on the JHREAT.

2.3 Gender balance

A gap in knowledge concerning the male perspective of occupational performance in IADL has been identified. MS is a major cause of disability for young adults. In the UK, the prevalence of MS is 80 per 100,000 of the population, with annual incidence of 5 per 100,000. Figures for male: female ratio range from 1:1.5 (Allen & Lueck, 2002), 1:2.5 (Khan et al., 2008) and 1:3.2 (Orton et al., 2006). The sample populations of the reviewed studies tend to a gender bias towards women with MS. The gender ratios range from 1:1.7 (Lexell, et al., 2014) to 1:11 (Reilly & Hynes, 2018) (see Table 5). Recruitment bias towards female participants may account for this imbalance. The research offered the opportunity for exploration of the theme of the male experiences of occupational therapy interventions in IADL through the inclusion not only of female but also male cases.

2.4 Discussion

This scoping review of the literature identified the current evidence indicating the nature of interventions within the scope of occupational therapy practice with people with MS related to ADL and IADL. This body of knowledge is based on quantitative studies of varied design quality. This literature will now be discussed with reference to the identification of gaps where this thesis contributes to occupational therapy practice knowledge.

The literature review led to a shift in emphasis from ADL to focus on the importance of IADL for people with MS. In-patient occupational therapy interventions in the hospital context emphasise ADL outcomes (Lexell et al., 2014; Maitra et al., 2010). These interventions occur at a time when the occupational performance of the person with MS is compromised due to medical issues and intense multi-disciplinary rehabilitation is required. This does not, however, represent the usual context for people with MS who are living at home with family or alone and are attempting to balance occupations such as home management, caring for families, work, and leisure. For these people, the environmental context of home, community, and workplace where people with MS perform occupations are more relevant than the hospital setting.

One premise of this thesis, that IADL are key occupations for people with MS, is confirmed in the advocacy that the target of fatigue management interventions by occupational therapists should shift from ADL towards IADL (Asano et al., 2015). Previous research effort by occupational therapy into fatigue management has concentrated at the impairment level and neglected making connections with activities and participation. Only this single study relates fatigue management to ADL or IADL. Evidence supporting the importance of IADL is also provided by the problematic activities of household management and functional mobility identified by people with MS in their daily lives (Lexell et al., 2014).

The role of providing assistive technologies in supporting occupational performance for people with MS is core to occupational therapy practice. The studies reviewed here only touch on this area of intervention. The use of everyday technology has become pervasive in society and central to many people's daily lives (Stern & Goverover, 2018). The potential of Electronic Assistive Technology (EAT) to benefit people with MS as a compensation for cognitive impairment in a real world setting has been demonstrated (Gentry, 2008). This study emphasises that cognitive impairments are a significant area for intervention. Further investigation is required into how cognitive impairments related to MS impact on occupational performance in IADL.

The importance of facilitating community mobility through an electric powered wheelchair system has also been reported although the study design was of poor quality (Gillen, 2002). This is of real world relevance and importance to people with MS. The mobility of people with MS is detrimentally affected by impairments to physical, cognitive, and visual functioning (Van der Feen et al., 2019). Limited community mobility impacts on participation in wider society and quality of life. The potential use of a driving simulator to promote on-road driving skills was not well supported by the findings of a poorly designed pilot study (Akinwuntan et al, 2014). This is disappointing as occupational therapists are employed at mobility and driving centres for people with disabilities in the UK. The benefits of wearing a cooling-suit are based

on more robust evidence from a mixed methods study and an RCT (Flensner & Lindencrona, 1999; Özkan et al., 2017). Occupational therapy practice could benefit from the use of such technologies if they are shown to be effective. The utilisation of assistive technologies in occupational therapy interventions requires further exploration and investigation.

This scoping review revealed several examples of assistive technologies that could be used in occupational therapy practice. The wider use of assistive equipment in ADL and IADL along with provision of adaptations to the home environment for people with MS and its impact on occupational performance has had no research attention. The process of clinical decision making by occupational therapist with assistive technologies has similarly not been studied.

The importance of cognitive impairment as a significant area of occupational therapy intervention to support IADL has been recognised in some research. Two studies have considered specific cognitive rehabilitation approaches in occupational therapy interventions. The use of self-generation techniques to improve recall and step sequence of IADL tasks has great apparent potential in occupational therapy practice (Goverover et al., 2008). The methodology, however, gave weak evidence that self-generation directly improved occupational performance in IADL. The actual reality assessment process used a structured assessment procedure to measure occupational performance in IADL. (Goverover and DeLuca, 2018) This was not, however, developed as an intervention aimed to improve occupational performance, but as an assessment tool and measure. The utility was limited to IT use as generalizability to other IADL was questionable. Comprehensive and holistic occupational therapy interventions would be expected to take cognition and processing skills into account. Wider research to identify the nature and use of cognitive rehabilitation-based approaches to occupational therapy interventions in IADL is potentially fruitful direction of exploration.

Viewing occupational therapy interventions from the perspective of the person with MS was partially achieved by a large quantitative survey of occupational therapy service users (Finlayson et al., 2008). Although this gives some indication of the value and satisfaction held by people with MS for occupational therapy interventions, it does not consider the detail, depth, and complexity below the service provision level. These nuances of intervention experience and perception are lacking from the quantitative studies reviewed. No qualitative designed research studies emerge from the literature review. Only research into the effect of using a cooling-suit employed mixed methods that incorporated open ended interviews as qualitative data collected method (Flensner & Lindencrona, 1999). Qualitative research methodologies could explore the experiences and perceptions by representing the voices of the people with MS, their carers, the occupational therapists delivering the interventions and other

professionals within a real world context. Qualitative research methods are also aligned with the principles of person-centred care.

This literature review has highlighted a further issue of relevance to the thesis. Analysis of the gender ratios of the studies indicate a tendency to a bias towards female participant compared with the general gender difference in the incidence of MS. Research should include analysis of male perspectives on their experiences of occupational therapy interventions.

A holistic view of the scope of occupational therapy practice with people with MS and its impact on ability to perform IADL needs to be established. From the perspective of cognitive rehabilitation this has been attempted by the COB-MS programme (Reilly & Hynes, 2018). The combination of addressing cognitive impairments with an occupation-based programme to improve daily living tasks had promising outcomes in this pilot study. Justification of an exploration of occupational therapy interventions comes from the gaps in knowledge identified by the literature review. These include research into the relationships between the impairments experienced by people with MS, their engagement in occupations and the effect of occupational therapy interventions on performance in IADL. An example of this would be exploring the effect of fatigue management on performance in IADL.

The effectiveness of professionally guided self-care in maintaining abilities in ADL in community settings is strong evidence to the contents of one element of a comprehensive occupational therapy intervention for people with MS (O'Hara et al., 2002). This approach did not, however, consider IADL. Expanding such guidance by professional to IADL occupations would be beneficial to occupational therapy practice.

The literature review stage of the research influenced the shift in research methodology consideration from an evidence-based practice frame of reference towards a real world mixed methods approaches that combined quantitative and qualitative approaches. Considering the limited research identified in the literature review the aim of the research was to understand how occupational therapy interventions contribute to the ability of people with MS to perform their meaningful IADL occupations. This should listen to the voices of people with MS and consider them in their own real world setting and contexts.

In summary this scoping review has identified a limited number and range of studies that provide descriptions, examinations, and evaluations of occupational therapy interventions for people with MS related to ADL and IADL. Identifying and researching through exploring the nature of clinical interventions for people with MS that support IADL is important in providing a holistic and person-centred premise to the evidence based of occupational therapy services. The sparseness of research into how occupational therapists intervene to support people with

MS in IADL and the varied quality of design provided justification for undertaking this study. Indeed, a broader exploration using qualitative methods is required to establish the full composition of occupational therapy interventions and their impact for people with MS in IADL. Exploring the experiences and perceptions of these interventions by the person with MS, their carer and the occupational therapist addresses these gaps in knowledge and contribute to person-centred care. The following section states the research question and objectives of the study.

2.5 Research question and objectives

The research question evolved from an initial research topic concerning ADL towards the significance of IADL for people with MS. The rationale of the research question emerged from an interest in how people with MS engage in IADL. As a deeper understanding of the crucial occupational role of IADL developed, particularly at an earlier stage in the progression of the condition, the role of occupational therapy intervention with these occupations became more prominent. Further refinement of the question to take in methodological considerations followed. The context of the research taking place with a community service was also important. The research set out as an exploration to discover what occupational therapy could offer people with MS and their carers as interventions to specifically support IADL occupations.

The literature review informed the design of the research question by identifying the gaps in knowledge. The research question that the project set out to answer:

> *How do occupational therapy interventions contribute to the ability of people with Multiple Sclerosis to perform Instrumental Activities of Daily Living?*

The elements of the question aimed to address the gaps in knowledge. This question addresses specifically the importance of IADL to people with MS identified in the studies such as Asano et al., (2015) and Lexell et al., (2014). IADL are wide ranging, complex in nature and important to individual lifestyles. The core of the research explores how occupational therapy interventions support people with MS to engage and participate in these occupations. The practicalities of how occupational therapy interventions are designed and conducted for people with MS has not previously been addressed. To obtain a holistic and person-centred view of occupational therapy interventions it is essential to consider the experience and perception of the people with MS. A predominantly qualitative interpretation of the question was assumed. Qualitative research is flexible and more open to an explorative approach (Robson & McCartan, 2016). This contrasts with the fixed methods used in the quantitative studies appraised in this chapter.

When reflecting on the research question useful comparisons and contrasts can be made with other research studies. Two previous literature review questions that have investigated occupational therapy interventions for people with MS are instructive. One review for the Cochrane collaboration of occupational therapy for multiple sclerosis considered whether occupational therapy interventions improved outcomes on functional abilities, social participation, and health related quality of life (Steultjens et al, 2003). This is focused on the clinical efficacy of interventions. At this stage, however, the strict limitations of the systematic review resulted in only three papers being reviewed. Another systematic review critically appraised evidence for the effectiveness of interventions within the scope of occupational therapy for people with MS (Yu & Mathiowetz, 2014a). This provided a general mapping of interventions and appraisal of their clinical effectiveness but not specifically to a group of occupations.

Such an approach, in considering clinical efficacy and effectiveness, necessitates the analysis of quantitative evidence to make recommendations to clinical practice. This can, however, either down-play or neglect the contribution that qualitative based research evidence has to contribute. Occupational therapy has a tradition of investigating practice through both quantitative and qualitative methods. Indeed research topics such as clinical decision making and observing effects of interventions cannot be understood through quantitative methods alone (Greenhalgh et al., 2016). Complementary perspectives on evidence are provided by consideration of the differing research designs of quantitative, qualitative, and mixed methods.

In comparison with research questions in other reviews of studies of occupational therapy interventions for people with MS where the focus has been effectiveness and efficacy, this question differs in that it provides the opportunity to focus on a group of occupations of importance to people with MS and the occupational therapy they receive. The question also permits a different methodological approach to investigate IADL for people with MS and the occupational therapy they receive from a person-centred and holistic perspective by using qualitative methods. The literature review informed the methodology by identifying this gap in the contribution of knowledge from a qualitative perspective by focusing on the experiences and perceptions of people with MS. This led to the development of a multiple case study research design that incorporated predominantly qualitative data collection methods in the form of semi-structured interviews and a quantitative measure of occupational performance from the multiple perspectives of the person with MS, carer, occupational therapist and other HCPs.

The objectives of the investigation were designed around firstly benchmarking occupational performance in IADL. This establishes the level of performance and the impact of MS on each

person with MS. The next four objectives set out to identify the experience and perceptions of the occupational therapy interventions from the perspectives of significant people involved in the cases: the person with MS, the occupational therapist, the carer, and other Health Care Professional (HCPs). The final objective looked to draw the analysis together and guide occupational therapy practice.

The research set out to meet the following objectives:

1) To measure occupational performance in IADL during occupational therapy intervention.

2) To identify the experiences and perceptions of occupational therapy interventions from the perspective of the person with MS.

3) To identify the experiences and perceptions of occupational therapy interventions from the perspective of the carer.

4) To identify the experiences and perceptions of occupational therapy interventions from the perspective of the occupational therapist.

5) To identify the experiences and perceptions of occupational therapy interventions from the perspective of other significant professionals such as physiotherapists, MS specialist nurses and speech and language therapists.

6) To synthesise and analyse the data to produce evidence-based guidance for occupational therapy intervention.

2.6 Summary

Chapter Two has presented a review of the previous relevant research into occupational therapy interventions for people with MS in IADL. A scoping review process of searching and screening against eligibility criteria was used. Thirteen research studies employing quantitative methodologies of varying quality were reviewed. Within this body of research, the review identified six themes of: in-patient rehabilitation, assistive technology, cognitive rehabilitation, fatigue management, professionally guided self-care, and service user perspective. The limited research into the occupational therapy interventions for people with MS in IADL provides justification for undertaking a study using qualitative methods to explore in depth the experiences and perception of people with MS, carers, occupational therapist, and other HCPs. The research question and objects have also been stated in this chapter. The next chapter provides justification for the methodological approach adopted and the data collection methods employed.

Chapter Three

Methodology design and methods

3. Introduction

Chapter Three starts by introducing the context of the research study which was the occupational therapy service provision in a multi-disciplinary Community Neurology Team. The methodology underpinning the research design is then presented by introducing the influences of pragmatism and critical realism within the research approach. The previous chapter sets out an appraisal of the current literature and presented the research question and objectives. The purpose of the research reported in this thesis is to explore how occupational therapy interventions contribute to the ability of people with MS to perform IADL. Figure 3 illustrates the levels of research study development, thus providing an overview of the methodological approach adopted in the research. A paradigm world view influenced by pragmatism and critical realism is discussed in this chapter. Consideration is then made of the theoretical lens through which the research phenomena are viewed. This is positioned in the relevant concepts, theories, and models of person-centred care. Consideration of several possible alternative methodologies from quantitative and qualitative approaches is critically discussed and the rationale for their rejection explained. Justifications for the chosen design of a multiple case study which incorporates mixed methods are then presented.

The research methods employed in the project were designed to gather data on how occupational therapy interventions for people with MS contribute to the ability to perform IADL. The context of the study, the occupational therapy service provision in a multi-disciplinary Community Neurology Team (CNT), is described and the process of gaining ethical approval explained with reference to the ethical issues related to the design. The participant recruitment process and sampling strategy are considered, and data collection methods justified. The data analysis process is then detailed. This followed a seven stage framework analysis approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Data management utilised NVivo software. Finally issues of research quality are discussed at the end of the chapter.

The research methodology led to the selection of a multiple case study approach with mixed methods of data collection. Each case unit of analysis was centred on a person with MS. The qualitative methods of data collection were semi-structured interviews, a questionnaire and field notes. Quantitative data measuring the occupational performance in IADL for the person with MS was also collected using the Assessment of Motor and Process Skills (AMPS) as an essential element of this mixed methods study. This three-stage data collection process

occurred over a four-month period between June and September 2015. The pilot stage trialled the collection of AMPS and interview data. The AMPS was administered with the person with MS (Case 1). Separate interviews then took place with the person with MS, the carer, and the occupational therapist. A questionnaire to the occupational therapist followed this. Field notes supplemented the data to provide context and opportunity for researcher reflexivity. This data collection process was then repeated in the second multiple case stage for a further four people with MS. The final stage consisted of interviews with four HCPs who worked in close association with the occupational therapists. In total data collected for the five cases consisted of, five AMPS, 19 semi-structured interviews and five questionnaires. Discussion of the methodology and research methods begins with a brief introduction to the service provision context of the research site.

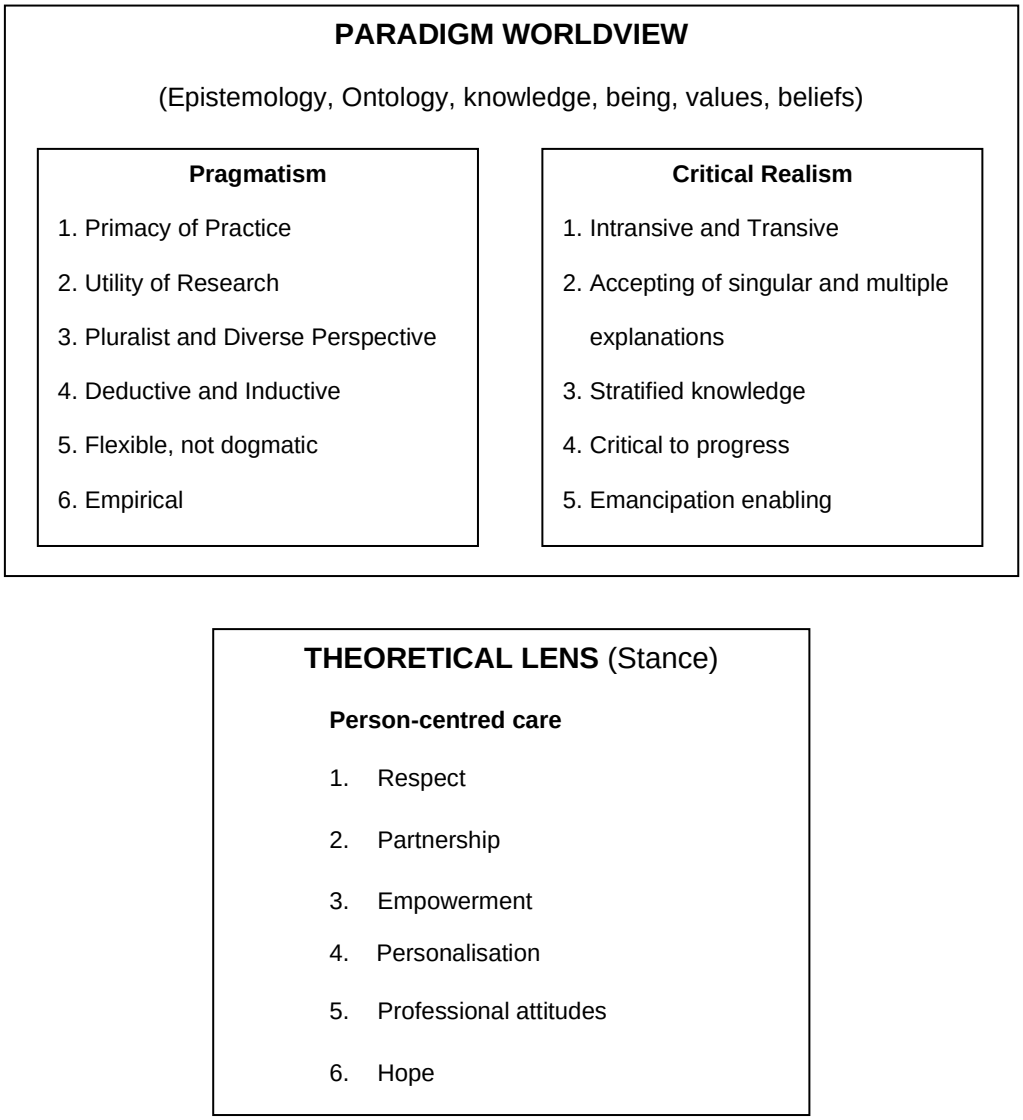
3.1 Study context

The context of the study consisted of occupational therapy practice for people with MS in a CNT based at a local district hospital in the north of England. In 2014 health services were provided to a multi-cultural population of approximately 240,000 spread between a large town and smaller urban and rural communities in the surrounding area. Occupational therapy is an integral professional service within a multi-disciplinary team. Other disciplines in the MDT included physiotherapy, speech and language therapy, dietetics, and orthotics. Rehabilitation assistants also work within the MDT and provide professionally guided therapy interventions. Close links are maintained with other key professionals in particular the consultant neurologist and MS specialist nurse, the later contributing a key source of referrals to the CNT. Referrals to and clinical relationships are maintained with a wide range of other related services including clinical psychology, counselling, and community occupational therapy for equipment and home adaptations. The referral process for the person with MS to receive the CNT service was primarily initiated from the General Practitioner (GP) via the consultant neurologist in Out-Patient clinic with a MS nurse in attendance. Self-referral was also permitted within a period of two years following the end of an episode of care, allowing the person with MS to re-engage with the MDT as their needs indicated. Interventions by the CNT took place in a variety of settings: the person's home, workplace, community, or clinic.

3.2 Methodology

An overview of the philosophical, theoretical, and methodological influences on the research design and methods employed is illustrated in Figure 3. Four key elements in the development of a research design have been identified (Creswell & Plano Clark, 2011). At the broadest philosophical level, the paradigm worldview of the research has been guided by pragmatism and critical realism. The epistemology and ontology that form the basis for these worldviews

Figure 3. Levels of Research Study Development (Creswell & Plano Clark, 2011)



and their compatibility will subsequently be discussed. The second key element is the role of theory in relation to the research topic which forms a particular view or theoretical lens (see section 3.3). In this research of occupational therapy practice as applied with people with MS engaging in IADL, consideration has been made of the stance of person-centred care for occupational therapy practice. This forms the theoretical lens through which the research is viewed. The third element is the methodological approach is a multiple case study incorporating mixed methods. The fourth element of research design is the methods of data collection and analysis. Primarily qualitative data was collected through the methods of semi-structures interviews, a questionnaire and field notes. A quantitative data collection method was also included as a measure to benchmark occupational performance in IADL for the people with MS. The methods are discussed in greater detail in section 3.7.

3.2.1 Pragmatism

The pragmatist tradition in philosophy is concerned with everyday practicalities and what works in the real world. Establishing what works involves an emphasis on enquiry through practical empiricism. Pragmatism has been used as an approach to social research where the complexities of the real world are encountered (Robson & McCartan, 2016). This is close not only to the subject matter of the research question, but also central to the nature of occupational therapy (Cutchin, 2013). The research question is concerned with the real world of occupational therapy interventions and the practices of occupational therapists with people with MS doing their everyday activities and occupations. This involves a core concern of occupational therapy practice; solving problems to enable participation in the practicalities of a person's daily life (Jones & Hocking, 2015). Pragmatism values the world of such human experience in action (Johnson & Onwuegbuzie, 2004). Pragmatism also emphasises the utility of the research (Feilzer, 2009). This research has the practical objective of contributing to the development of occupational therapy practice. The essence of what matters to the research is *what works* in the occupational therapy intervention for the person with MS. Practicing occupational therapists are concerned with solving problems for clients and what works during intervention. Pragmatism views theories as instrumentally true based on how predictable and applicable they are (Osbourne, 1992).

Pragmatism developed into a philosophical worldview in North America during the late 19th and early 20th Centuries. Prominent thinkers in this tradition included; Charles S. Pierce (1839-1914), William James (1842-1910) and John Dewey (1859-1952) (Osbourne, 1992). Although having diverse viewpoints, interests and approaches their work established a philosophical movement in the American cultural context of the time. The foundation and development of occupational therapy as a profession was established in the same cultural milieu of early 20th

Century North America (Wilcock, 2002). The influence of pragmatism and in particular the work of John Dewey is significant for occupational therapy. Dewey had developed ideas related to occupation prior to the formation of the profession. These ideas have been revisited more recently in the consideration of his conceptualisation of occupation (Cutchin, 2013).

With regards to human enquiry Dewey justified using *warranted assertibilty* where a proposition gains standing through a continuous process of enquiry to establish knowledge and meaning (Blackburn, 2008). What is done in day-to-day life as we interact with the environment is viewed as being analogous to experimental and scientific inquiry (Johnson & Onwuegbuzie, 2004). This is related to basic and practical experiences and is fallible, therefore being provisional as research findings are often open to criticism and may be flawed. The result is that meaning and knowledge change over time. In terms of the research question and the design of the inquiry, the contribution of occupational therapy interventions to the ability of people with MS to perform IADL has been examined through an ongoing dynamic data analysis process provided by the framework approach. Pragmatism has therefore influenced how the research data has been collected and analysed. The underpinning philosophy of the framework approach is based on a pragmatic world view (Ormston, Spencer, Barnard, & Snape, 2014).

Pragmatism has seen a resurgence of interest and influence in social research through the work of a broad group of more contemporary philosophers such as Richard Rorty (1931-2007) and Nicholas Rescher (b.1928) (Bertstein, 1992). Again, the concern with the practical, utility and the primacy of practice have been emphasised. This neopragmatism has assumed an influence on research into professional practice such as nursing and management (Marsonet, 2008). This complements the objective of providing guidance for the practice-based discipline of occupational therapy as the research findings have utility for wider professional practice. Data for this research project was collected by AMPS, semi-structured interviews, a questionnaire, and field notes as research methods. These were effective and practical methods in the real world context of the research study to answer the research question. This was within the context of a researcher practitioner collecting data from people with MS, carers, occupational therapists, and professional colleagues in the home environment and practice setting. The roles and relationships between the researcher and these participants in the research process are also accepted as influential (Robson & McCartan, 2016). The selection of a multiple case study approach as a methodology assumes a pragmatic decision that is the most suitable route to explore the five people with MS in their daily lives and activities (Jones & Hocking, 2015). Justification for an eclectic choice of case study design and mixed methods also lies in pragmatism and the acceptance of complementary views of knowledge.

The ontological position adopted in pragmatism assumes the acceptance of both singular and multiple realities (Creswell & Plano Clark, 2011). This pluralist perspective, flexible and acceptant of diversity, has influenced the selection of both case study method and mixed methods to answer the research question. This exploration of occupational therapy intervention on IADL for people with MS has proceeded taking the theories and concepts of person-centred care into account. A pragmatic approach also permits the use of both deductive and inductive reasoning where most suitable. In the research design deductive reasoning informed the development of the semi-structures interview questions. The literature reviewed and the clinical and professional experience of the researcher provided themes for the questions. Inductive reasoning from the research data has been employed in the analysis of qualitative data in the form of the framework approach to identify themes and core concepts. The underpinning philosophy of the framework approach to data analysis is pragmatic and accepting of inductive and deductive reasoning (Ormston et al., 2014). There is more than one viewpoint depending on the type of phenomenon and knowledge. This permits the researcher to adopt multiple stances and perspectives such as considering a biased and unbiased view (Creswell & Plano Clark, 2011). This has been used to justify using not only qualitative data collection methods but also AMPS quantitative measure of occupational performance in IADL through mixed methods.

However, for all the attractions of the common sense involved in pragmatism this world view has been summarised as being almost an anti-philosophy (Robson & McCartan, 2016). Pragmatism has been criticised as an assortment of ideas that can lead to the dangers of a relativist position (Russell, 1979). An insistence on the importance of the practical can reduce ideas to just the expediency of actions. If an idea works it does not necessarily follow that it is true (Cherryholmes, 1992). Pragmatism is therefore not alone in influencing the development of the research. It was necessary also to consider the contribution that realism as a philosophy could make to the development of the research design. The compatibility of pragmatism with realism will be discussed in the following section.

3.2.2 Critical Realism

Realist approaches to science and research emphasise that knowledge is theory laden, disputable, and a product of history and society (Robson and McCartan, 2016). A real world does exist and is independent of human perceptions and knowledge (Sayer, 2000). The aim of science is to produce theory to explain this real world. The key features of a critical realist worldview that have influenced the research study development are illustrated in Figure 3. These are the division between transive and intransive knowledge, the acceptance of singular

and multiple explanations of phenomena, the stratification of knowledge, for science to progress it should be critical, and an emancipatory and enabling nature.

Critical realism holds the ontological stance that external reality exists and is knowable through the human mind and involves socially constructed meanings (Ormston et al., 2014). A distinction in the dimensions of knowledge between 'intransive' and 'transive' objects has been proposed (Bhaskar, 1978). Science is concerned with the study of both these objects of knowledge; physical and social phenomena constituting the intransive dimension that remain unchanged whereas concepts, models, theories and discourses form the transive dimension that are liable to change over time as research knowledge progresses (Sayer, 2000).

With regards to the nature of the research from a critical realist view point some components of the exploration are more intransive such as the impact of the underlying pathology in MS on the CNS of the person, the biomechanics acting on the person's body during activity or the psychological responses of the person with MS. Occupational performance is a measurable phenomenon and an attribute of the people with MS (Fisher & Jones, 2010). Transive objects of human constructed knowledge can be viewed as the theories, concepts and models proposed in occupational therapy. The findings of the research and their interpretation are therefore viewed as transive objects and aim to contribute scientifically to explaining the effect in the real world of occupational therapy interventions for people with MS.

Critical realism also views the knowledge of the complex real world as stratified or layered (Sayer, 1992). The social world is therefore structured. This differentiation of knowledge into layers is useful when analysing research data as the process of identification of core concepts and themes in the framework approach to data analysis proceeds to produce abstraction and interpretation of descriptive and explanatory accounts (Spencer, Ritchie, Ormston, O'Connor, & Barnard, 2014). For knowledge to progress social science should also be critical (Sayer, 2000). The research subject must be considered critically to produce comprehension and explanation (Easton, 2010). Some features of critical realism share similarities with pragmatism such as the acceptance of multiple and singular explanations of phenomena. This eclectic and multi-faceted view again has been taken, with the influence of theories from person-centred care on the research development and the selection of a mixed methods design including qualitative and quantitative data collection methods. Critical realism also accepts that language can be used to describe the world thus justifying the selection of semi-structured interviews as a data collection method. (Sayer, 2000).

An attractive aspect of critical realism is the emancipatory nature that is emphasised (Bhaskar, 1978; Easton, 2010). Consideration of factors of constraint and enablement are particularly relevant to the research (Archer, 2003). The person with MS must contend with constraints

such as the clinical features of the condition, the impact of these features on their occupational performance and the demands of occupational roles. The occupational therapy interventions should be critically examined to determine the contribution made in enabling occupational performance in IADL. Hearing the voices of the research participants within the research and making interpretations of their perceptions were also key values of the research development. The use of interviews as qualitative methods gives that opportunity for the voices of the people with MS and their carers to be heard and analysed. The selection of a multiple case study method to explore occupational therapy interventions for people with MS also permits the use of critical realism as an orientation and approach to the data analysis process. The use of the person with MS as the unit of analysis in the multiple case study also means the research is person centred.

In summary, five features of critical realism have influenced the research: a distinction between intransive and transive factors, accepting singular and multiple explanations, structured knowledge, criticism for progress, and emancipator nature of critical realism. The compatibility of pragmatism and realism has been argued for by neopragmatists such as Rescher (2000) and propose a pragmatic scientific realism. This accepts pragmatism is essentially a realist philosophy. The features of the critical realist worldview and its position recognize the influence of context in the exploration and interpretation of the lives of the people with MS considered in the multiple case study (King & Horrocks, 2010). Critical realism enables the research to find explanations to questions and approach data collection in the real world where uncontrolled situations occur in contexts such as professional practices (Robson & McCartan, 2016).

3.3 Theoretical lens

The theoretical lens of the research is provided by the humanistic principles of person-centred care that were introduced in relation to the policy context (see section 1.2). The theoretical foundation of a research project directs the nature of the research question, the design of methods, phases of data collection, and data analysis (Creswell & Plano Clark, 2011). Throughout the development of this research project a fundamental consideration has been made of the position of the person with MS. Section 1.1 introduced the author's personal interest and development of the research which is based within a person-centred care frame of reference. Person-centred care has also influenced the formulation of the research design and methods used. As this research concerns occupational performance within IADL and occupational therapy interventions the conceptual basis is located in the components of client-centred occupational therapy practice. This forms the theoretical lens level of research study development illustrated in Figure 3. Exploring occupational therapy interventions for people

with MS within IADL by taking multiple concepts and theories into account allows for theory crystallization during data analysis to increase the rigour of the research. Care must be taken however, to avoid discrepancies and contradictions between selected theories (Robson & McCartan, 2016).

The philosophy of person-centred care is increasingly influential and widely accepted in achieving high quality healthcare across the world (Jesus et al., 2016). Several conceptual components are bound up in person-centred care. The theoretical lens of this research identifies six key conceptual components of person-centred care: respect, personalisation, partnership, empowerment, professional attitudes, and hope. These components have influenced and directed the research question, objectives design and selection of methods.

In discussing application of person-centred care, it is helpful firstly to clarify the meaning of the *person*. The person may not simply refer to the individual alone (Mroz, Pitonyak, Fogelberg, & Leland, 2015). In the context of rehabilitation, person-centred care goes beyond considering just the person experiencing the medical condition (Jesus et al., 2016). This is particularly the situation for people with long-term conditions such as MS where care and support from other close and significant people such as partners, family members, carers and friends facilitate successful engagement in occupations. Other key people around the person with MS are important to considered in person-centred care.

Difficulties have been encountered in agreeing a definition of person-centred care and operationalising its use. The interchangeable use of the terms person-centred, patient-centred, and client-centred can be confusing and makes defining person-centred care problematic (Sliva, 2014). In occupational therapy client-centred care has been a prominent term used. A starting point in identifying the concepts involved in the theoretical lens is consideration of client-centred practice of occupational therapy. Occupational therapy carries client-centred care in its definition and ethical codes (WFOT, 2012a; RCOT, 2015). The meaning of client-centred care, however, is not elaborated upon in these statements. A definition of client-centred practice in occupational therapy from a British perspective has been developed (Sumsion, 2000). Information from focus groups of occupational therapists identified:

> Client-centred occupational therapy is a partnership between the client and the therapist that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments. The client participates actively in negotiating goals which are given priority and are at the centre of assessment, intervention, and evaluation. Throughout the process the therapist listens to and respects the client's values, adapts the interventions to meet the client's needs and enables the client to make informed decisions. (Sumsion, 2000 p. 208)

In this definition the two key features of *respect* for the person and *partnership* between the occupational therapist and client are emphasised. Respect for the beliefs, values, experiences, and context of the person is a common conceptual component of person-centred care models and definitions (McCormack and McCancel, 2010; Mroz et al., 2015; Sumsion & Law, 2006). This respect for the person affords dignity and compassion in healthcare (The Health Foundation, 2016). For the occupational therapist this involves the validation of the person's experiences and formation of a partnership that is dynamic and supports occupational performance (Mroz et al., 2015). The partnership should involve engagement between the person and the occupational therapist that is collaborative and involve joint decision making (Jesus et al., 2016; Mroz et al., 2015). Full involvement of the person's perspective in their care and therapy is important in informing the collaborative planning and implementation of interventions. This contrasts with care and therapy that is done to and not with the person (Jesus et al., 2016).

The balance of power between the occupational therapist and the person is a key element in client-centred occupational therapy practice (Sumsion and Law, 2006). Ensuring a balance of power, so the client becomes an equal partner and power is shifted from the professional, gives the client more control over their own health. From a balance of power *empowerment* can enable the person to realise their potential in living independently and achieving satisfaction in life (The Health Foundation, 2016). This establishes the foundations for full involvement of the person with MS in occupational therapy interventions (Jesus et al., 2016). Empowerment is also achieved through support in the self-management of problems with occupational performance as an outcome (Mroz, et al., 2015). *Personalisation* of occupational therapy interventions follows respect for the person's beliefs and experiences and a balanced partnership with the occupational therapist. Enabling preferences and choice that is consistent with the person's values ensures their needs are met (Jesus, et al., 2016; Sumsion & Law, 2006).

Certain *professional attitudes* are necessary on the part of the occupational therapist to implement person-centred interventions. This element has not been identified as part of client-centred occupational therapy practice but is part of person-centred care models (McCormack and McCancel, 2010). Interpersonal communication skills are necessary that are open and involving active listening, sharing of information and decision making (Mroz et al., 2015). This enables the occupational therapist to achieve a balance of power within the partnership (Sumsion & Law, 2006). Communication with other professionals in the MDT also contributes to the coordination of care (The Health Foundation, 2016). Also linked to the professional competencies and clarity of beliefs and knowledge of the occupational therapist (McCormack and McCancel, 2010). In researching occupational therapy interventions, the methods involve

semi-interviews that listening, hearing, and interpreting the views and perceptions of the experiences of people with MS.

The concept of maintaining *hope* throughout the client-centred partnership has been identified as important in occupational therapy (Sumsion and Law, 2004). Hope involves a positive orientation towards the future and is associated with health and well-being (Lohne & Severinsson, 2004). This is based on an optimistic understanding and a belief in what is possible. Hope may be focused on specific gaols or be global and include an acknowledgement of the importance of spiritual dimensions and perspective for some people in coping with the challenges of illness and disease. Hopes for people and families may involve exploring new activities and roles. Nurturing realistic hope for people with long-term conditions to realise wellbeing requires a careful and holistic communication process (Mroz et al., 2015).

The six concepts of respect, partnership, empowerment, personalisation, professional attitudes, and hope that comprise theoretical lens of person-centred care are positioned at the core of the overall development of the research study. This theoretical lens influenced the development of the research question, study design, and methods. Facilitating high quality care through person-centred occupational therapy practice requires skilful decision making on the part of professionals in combining these conceptual components at the point of care for the person.

3.4 Research Design

At an early stage in the research design development, a variety of possible research methodologies were considered to answer an evolving research question. The quantitative research approaches of randomised controlled trail and single case experimental design were considered along with pure qualitative methodologies based on grounded theory, phenomenology, and ethnography. A brief discussion of these possible methodologies is presented in this section with reasons for their rejection. A pragmatic and realistic world view was adopted to arrive at the eventual selection of a multiple case study methodology which incorporated mixed methods. This diverse approach was considered to align with the research question and to be practicable in the context of people with MS living and receiving occupational therapy interventions in a community setting. This section sets out to describe, explain, and justify the research design employed in the collection and analysis of data. A mixed methods approach was applied to collect firstly quantitative data through the AMPS to provide a benchmark measure of occupational performance in IADL as an attribute of each person with MS. The use of mixed methods and the acceptance of diversity were important to the researcher as an occupational therapy practitioner from a pragmatic and critical realist perspective. The use of AMPS allowed the elements of the research question associated with

the ability of people with MS to perform IADL to be addressed. This quantitative method was complemented by qualitative data related to the experiences and perceptions of participants of IADL and occupational therapy interventions through semi-structured interviews, field notes, and a questionnaire. The qualitative data collection methods and analysis addressed the research question by carefully listening to and then analysing the views of the participants. These qualitative methods addressed the research objective associated with the experiences and perception of the participants. This was all set within a multiple case study methodological approach with the unit of analysis based around the person with MS.

3.4.1 Alternative methodologies

An overview of five alternative methodology options; randomised controlled trial, single case experimental design, grounded theory, phenomenology, and ethnography are considered here. The reasons and justification for rejecting these pure quantitative and qualitative methodologies at an early stage of research development are briefly discussed.

Taking a positivist approach to the research subject could have considered the clinical effectiveness of a specific occupational therapy intervention for people with MS. This may have used quantitative methods in an experimental research strategy (Robson & McCartan, 2016). An example of this methodology was employed in the study of a guided self-care programme with people with MS reviewed in the previous chapter (see section 2.2.5) (O'Hara, et al., 2002). A randomised controlled trial (RCT) could have considered occupational performance in IADL as the dependant variable and an occupational therapy intervention such as fatigue management as the independent variable with the population people with MS. This would involve potentially measurement of occupational performance in IADL before and after the occupational therapy intervention with an experimental group and a control group. Several potential problems with this approach were identified. There would be difficulty isolating these variables and controlling other variables, for example the impact of MS pathology as a deteriorating condition on the participant's occupational performance, so as not to confound the results. The real world of occupational therapy practice for people with MS is more complex and involves multiple individualised variables within a social context. Rejecting a null hypothesis using statistical analysis would involve a sufficiently large sample size. The possibilities of recruiting an experimental and control group with 30 or more participants in each group were not seen as viable with the resources at the disposal of the researcher. The use of a control group not receiving an intervention is also ethically questionable. A pragmatic view was taken that an RCT would be unworkable.

Another methodology that would be based on a quantitative approach is the single subject experimental design (Deitz, 2006). In this a similar positivist approach is assumed to RCT but

using just one person as their own control and repeated measurements of variables take place over time. The aim is reproducible and replication to other single subjects in other settings. This methodology would have problems of generalisability to wider population of people with MS. These quantitative approaches featuring experimental designs of RCT and single subject experimental design were therefore rejected on grounds that in the real world the context of occupational therapy interventions with people with MS in IADL are complex and a positivist scientific view of objectivism is naïve (King & Horrocks, 2010). A purely quantitative research design did not seem relevant, was limited as an exploration and impracticable for the project as the research question developed considered three main elements of occupational therapy interventions for people with MS within IADL.

Consideration of a variety of qualitative approaches to research methodologies was made. In grounded theory approaches theory is generated through inductive reasoning and emerges from data as the study proceeds (Glaser & Strauss, 1967; Robson & McCartan, 2016). Data is analysed through systematic and structured methods to generate categories and relationships until saturation is reached and no data is added to the theory (Spencer, Ritchie, Ormston, et al., 2014). Grounded theory approaches could have been used to design the research to study the experiences and perceptions of the occupational therapists' view of their interventions with people with MS in IADL. This would not have included the views of other stakeholders and in particular the people with MS. A grounded theory methodology was also rejected on grounds that the research subject was not completely novel, unknown, or un-researched. The professional knowledge and experience of the researcher along with review of the literature guided the design and contributed deductive reasoning to the research design. Research theories from person-centred care have also acted as a theoretical lens and contributed to the development of the semi-structured interviews and the framework approach to analysis.

A phenomenological approach could have been taken with the objective of understanding the experiences of either the occupational therapists or the people with MS in relation to occupational therapy interventions within IADL. The researcher concentrates on describing and interpreting the everyday life experiences of the participants (Luborsky & Lysack, 2006). Revealing understanding of the deep meanings of these individual's experiences is the purpose of research using phenomenological methods whilst acknowledging the bias of the researcher (Smith, Flowers, & Larkin, 2009; Shinebourne, 2011). The concerns of an ethnographical approach to research are similar and aim to understand the social world of people through immersion in their communities and description of lives (Robson & McCartan, 2016). Although the researcher is an occupational therapist and has some insight to occupational therapy interventions as an insider the experiences of people with MS would be

harder to become immersed in during the research. Generating theory from the descriptive results may also be problematic.

These quantitative and qualitative methodological approaches were not considered appropriate for revealing the fuller picture of how occupational therapy interventions contribute to the ability of people with MS to perform IADL. In the early stages of research development, a transition in methodology influence occurred. This saw a shift from quantitative approaches, influenced by evidence-based practice considering clinical effectiveness, to a recognition of the equal value of qualitative methodologies to explore the research phenomenon. A pragmatic approach would allow methods derived from both quantitative and qualitative research to be mixed. Collecting data by observing people doing tasks as well as interviewing them was important to the researcher in this exploration.

3.4.2 Mixed methods

Once the final research question was constructed it was decided that the predominant methodology should involve qualitative methods. Justification, however, was also made for the inclusion of a quantitative measure on pragmatic grounds and this constituted a mixed methods approach. This would add valuable data as an attribute for each person with MS and provide additional explanations during data analysis. The first research objective, of measuring occupational performance in IADL during occupational therapy intervention, would also be met. The use of a quantitative data collection method aimed to improve practical data collection and understanding of the research subject for the people with MS. The AMPS scores for each person with MS added a benchmark of occupational performance and allowed for analysis of the relationship between the impact of MS on IADL performance and the influence of occupational therapy interventions.

The rationale for employing qualitative methods in the research design was to find answers to the research question through the production of deep, nuanced and contextual knowledge of the complex phenomena of perceptions and experiences of the participants and their interactions (Robson & McCartan, 2016). Other important and relevant features of qualitative research are a concern for the lived everyday worlds of the participants, a reflexive approach which acknowledges the position of the researcher and analysis that is open to emergent categories and theories (Luborsky & Lysack, 2006; Ormston et al., 2014). It is the people with MS who experience the occupational therapy interventions so understanding what they have to say about the subject is important as well as the occupational therapists, the carers, and other HCPs in the MDT. A qualitative research design provides the methods to gather data that describes, explores, and understands the perceptions of people with MS in their experiences of occupational therapy interventions in IADL. People's lives are varied, and

complex so qualitative methods are most appropriate to research experiences. Hearing and listening to the voices of the people with MS is vital in gathering rich and in-depth data to analyse in the exploration of the contribution of occupational therapy interventions. The research design therefore adopted a predominantly qualitative approach to data collection and analysis. These qualitative research methods allowed the realisation of research objectives 2-5 of identifying the experiences and perceptions of occupational therapy interventions from the multiple perspectives of the person with MS, the carer, the occupational therapist, and other significant professionals.

An entirely qualitative approach did not offer the full potential to follow other explanations for how occupational therapy interventions contribute to the ability of people with MS to perform IADL i.e. the research question. Knowledge of the objective level of performance for people with MS through structured observation is clearly also relevant and of crucially value. It was decided therefore to employ mixed methods in answering the research question.

Paradigms have been proposed as a concept when considering predominant research world views in the development of scientific knowledge (Khun, 1996). The development of qualitative research methods resulted from a critical response to the quantitative paradigm. Qualitative methods were based on radically differing epistemologies and that produced an intense debate (Teddlie & Tashakkori, 2003). During the last 20 year however, the progress of mixed methods as a third paradigm for research designs in health and social science has become acknowledged and influential (Creswell & Plano Clark, 2011). A mixed methods approach is based on pragmatism, looks for what works and accepts that there is compatibility between qualitative and qualitative research methods. Mixed methods attempts a synthesis in research practice between qualitative and quantitative approaches to research aiming for deep understanding (Johnson, Onwuegbuzie, & Turner, 2007). In mixed methods research the concept of methodological triangulation is important in reducing single methodology bias (Bowling, 1998). Research in occupational therapy draws from varied methodologies including both quantitative and qualitative paradigms (Corcoran, 2006). Mixed methods research designs have been widely employed previously in occupational therapy (Mortenson & Oliffe, 2007). This research aligns with a mixed methods enquiry because the research knowledge base for occupational therapy interventions for people with MS in relation to IADL is poorly described and is unexamined. An in-depth exploration from several differing viewpoints has therefore been undertaken.

This study focused not only on the perceptions of effect of occupational therapy intervention from different views within the therapeutic relationship but also the direct measurement of function in IADL. This measure of the occupational performance level in IADL gives a valuable

attribute to the cases (Bazeley & Jackson, 2013). The quantitative use of an objective measure of function as a benchmark is combined with the subjective perspectives of the person with MS, the carer, the occupational therapist and other HCPs such as a physiotherapist, MS specialist nurse, rehabilitation assistant, and the service manager.

Typologies of mixed methods suggest a spectrum between degrees of pure qualitative, pure mixed methods, and pure quantitative (Johnson et al., 2007). Qualitative research methods are predominant and core in this research. The quantitative data added a supplementary element for analysis. The sequence of data collection involved the collection of the quantitative measure followed by qualitative data collection by semi-structured interviews and a questionnaire. These methods will be explained further in the following chapter on methods. The methodological approach adopted aims to take the best assets from both quantitative and quantitative methods to produce what works to answer the research question (Curry & Nunez-Smith, 2015).

3.4.3 Case study research

The research project employed a multiple case study design incorporating mixed methods (Yin, 2014). The methodology was selected with the purpose of providing an in-depth exploration of occupational therapy intervention from multiple perspectives in the unique context of a community rehabilitation team. This section identifies case study research as an appropriate approach to the research design.

Case study research has its origins in the disciplines of sociology and psychology developing in late 19th Century United States of America under the influence of pragmatism (Salminen, Harra, & Lautamo, 2006). Despite being unfavoured as a research methodology between the 1950s and 1980s case study research has subsequently seen a resurgence in interest in the wider social sciences (Platt, 1992; Yin, 2014). Case study research involves the in-depth explorative investigation of unique and complex situations such as professional practice in a real world context (Simons, 2009). Case study research values the particular and how this can contribute to generalisation and theory building (Stake, 2005). Some authors emphasise the subjective uniqueness of the case and the science of the singular or particular (Simons, 2009; Abma & Stake, 2014). The strengths of case study research as a flexible research design are that it permits exploration of the viewpoints of key people in real world situations (Simons, 2009). It is suitable for answering how and why research questions (Yin, 2014). Illuminatory explanations can be obtained in thick and rich descriptions of the process and dynamics of the phenomenon within its own context.

A formal two part operational definition of case study research, from a position of when it is appropriate to be used as a method, has been proposed (Yin, 2014). Firstly, the scope of a case study is concerned with an in-depth empirical inquiry investigating contemporary phenomena related to the real world context. The borders between the phenomena and context may not be apparent.

Secondly regarding features of a case study:

> A case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis. (Yin, 2014, p. 17)

These features emphasise the importance of crystallisation of diverse data sources and the deductive reasoning of a priori knowledge and theory in the analysis process. Although triangulation is often used in qualitative research as a quality measure to verify data findings the term is less appropriate when the complexities of more than three data sources and perspectives are being considered (Ritchie & Ormston, 2014). The term crystallisation is therefore more fitting where the multiple facets of a research phenomenon is being investigated (Sandelowski, 1995; Denzin & Lincoln, 2008). The experiences and perceptions of occupational therapy interventions for people with MS are here viewed rigorously from the multiple perspectives of the participants contributed data sources in the form of the AMPS, semi-structured interviews, and questionnaires. The perspective of the research also adds to the crystallisation process through the interpretations made and documented in field notes, annotations on data, memos, and a reflexive journal. The crystallisation process involved in this case study research therefore contributes to the validity of the interpretation of the findings. The final research objective of synthesising and analyse the data to produce evidence-based guidance for occupational therapy intervention is addressed through this process in the production of an occupational therapy practice model.

Case study research has been categorised into intrinsic, instrumental and multiple case study types (Stake, 2005). The principal concept in using a multiple case study design was to explore diversity in the data (Jones & Hocking, 2015). This allows for comparisons and contrasts across the cases to be made that determine how themes interact and contribute to building theory. The research design involved five people with MS and aimed at providing insight into the issue of experiences and perceptions of occupational therapy interventions and aims to draw analytical generalisation (Stake, 2005). Analytical inferences are more powerful if they are reproduced in several cases (Yin 2009). Despite being associated with a purely qualitative

choice of methods, case study research can also include quantitative evidence in a mixed methods approach (Yin, 2014).

The Case study approach as a research methodology has been used in diverse disciplines such as psychology, education, social work, and nursing (Yin, 2014). Case study research design has been used in occupational therapy but not extensively (Salminen, et al., 2006). Examples include a study of the unique pattern of occupations for children following traumatic brain injury in New Zealand (Jones & Hocking, 2015), community participation in food security programmes in Canada (Hyett, Kenny, & Dickson-Swift, 2017) and everyday experiences of pleasure, productivity and restoration also in Canada (Hyett et al., 2017). In relation to the research topic a study in Ireland considered the Kawa practice model in guiding occupational therapy intervention employed a case study methodology and collected data through semi-structured interviews for two people with MS (Carmody et al., 2007). These studies confirmed the validity and practicability of using case study as a research method.

The case study took place in a community neurological rehabilitation team with the purpose of examining the effect of occupational therapy interventions on function for people with MS within IADL (Yin, 2014). Occupational therapy interventions were made by practitioners in the real world context of a multi-disciplinary team (MDT) in the natural settings of the home, workplace, and wider community. This case study is concerned with providing conceptual and theoretical insight into the issue of the experiences and perceptions of IADL and occupational therapy interventions, and aims to draw analytical inferences (Stake, 2005). The case study methodology also draws data together centred on the person with MS to meet the final research objective of synthesising and analyse the data to produce evidence-based guidance for occupational therapy intervention.

The case study unit of analysis is centred on individuals with MS who received occupational therapy interventions from an established community neurological rehabilitation team. The unit of analysis aims towards completeness and integrity of data collection and analysis. The phenomenon of study is the experiences and perceptions of occupational therapy interventions for people with MS in IADL (Yin, 2009). In the case the core individuals closest to the research phenomenon are the person with MS who experiences the interventions and the occupational therapist designing and delivering the interventions. The carer was included as another perspective of the day to day impact of the interventions. The wider perspective of other HCPs was added to the design to investigate how the occupational therapy interventions sit within the wider rehabilitation programme. The case study boundaries are defined by the operational definitions of IADL and occupational therapy interventions (see sections 1.4 and 1.6). This multiple case study design facilitated an exploratory investigation of occupational

therapy interventions in IADL for people with MS from multiple viewpoints (Salminen, et al., 2006).

3.5 Ethical issues and approval

Several specific ethical issues were considered during the development and design of the research project. Ethical research in health and the social sciences demands that participation is voluntary and the study recruits on the principle of informed consent (Mitscherlich and Mielke, 1949). People with MS can be considered a vulnerable group particularly due to the cognitive difficulties associated with the condition. The Mental Capacity Act (2005) established the legal framework for decision making for people who lack capacity to make their own decisions (Dixon-Woods & Angell, 2009). Consideration was taken therefore to ensure the people with MS participating in the research study were identified as having the cognitive and communication skills required to engage in an interview and the Assessment of Motor and Process Skills (AMPS). The first recruitment exclusion criterion prevented those people with such cognitive impairments form being included in the research. During the recruitment process the issue of the cognitive function and mental capacity of potential participants was discussed with the CNT at the researcher confirmation stage (see Figure 5). For one participant the issue of cognitive impairment was identified, and a discussion of capacity took place. The outcome was that the person had capacity so was approached and recruited as a participant. The process excluded others who were not approached. The participant information sheet (Appendix 3) and consent form (Appendix 4) included information on the aims, methods, and expected benefits of the research.

Justification for undertaking the research rested on the objective of providing new knowledge on the experiences and perceptions of occupational therapy treatment for people with MS. The benefits of the research must outweigh the burden placed on the individual participant in the research project (Derenzo and Moss 2006). As this was a case study design the burden to the participants of engagement in an interview and outcome measure, in the form of the AMPS, were carefully considered. This was a particular issue to consider where fatigue was present. The administration of these tools must minimise the potential impact of fatigue causing a reduction in physical function. Data collection took place during two separate appointments at an optimal time of day chosen by the person with MS. Reassurance was given that the interview or assessment would stop if the person with MS felt excessively tired. Indeed, in the pilot case the person with MS requested the research interview be postponed due to an episode of intense fatigue. After a two week period the participant was contacted to arrange the interview which was agreed and tool place. The option for withdraw from the project remained throughout the collection of data. Data collection occurred in the participant's

home to avoid fatiguing journeys for the people with MS. The research project also considered the possibility that expectations of additional beneficial interventions were raised for the participants with MS and their carers. The information sheet clearly explained that the project was researching previous and current interventions and did not include additional therapy.

A further issue of non-maleficence relates to the psychological wellbeing of all the individuals who are to be interviewed (Lee, 2009). There may have been potential for an emotional response during an interview when discussing a progressive and deteriorating condition. The identification of carer strain during interview was also possible. Research must aim to avoid harm, distress, anxiety, or negative feelings (Oliver, 2003). The research project therefore considered contingencies for management of such situations by psychologically supporting the individuals and allowing the person to withdraw from the research. A referral for psychological support by the community neurology team would have been made if necessary and the GP informed by letter. Contingencies were in place to minimise risks to emotional well-being. The participants were also briefed before the interview to reiterate the right to withdraw. Participation was voluntary and the recruitment design was careful to protect against coercion. Once a potential participant was identified a scripted statement was read by a member of the community neurology team at the research site inviting participation.

The case study design involved the collection of qualitative data through interview from an occupational therapist. This presented a potential ethical issue concerning consent and the dependent relationship between the senior practitioner (the researcher) and a more junior occupational therapist (World Medical Organisation, 1996). To reduce the potential risk of exploitation of this relationship the research took place outside the researcher's own organisation and locality. The research site was convenient enough to facilitate data collection but beyond the practice community and professional network of the researcher. The confidentiality of the professionals interviewed was safeguarded by ensuring interview appointments were booked in a suitable and private room on NHS premises. During one interview with a professional the confidentiality of an interview was challenged by disturbance which necessitated moving to a more private room. One interview with a carer took place in a venue away from the home. Again, interruption resulted in the interview being interrupted and another room found to ensure confidentiality was maintained.

Confidentiality should be safeguarded during the research process to maintain the integrity of the individuals (World Medical Organisation, 1996). Precautions were taken to make data unidentifiable and stored in accordance with the Data Protection Act (1998). Names of participants and other personal identifiable information was no longer used once data was collected. Transcribed interview scripts substituted participant's names for pseudonyms.

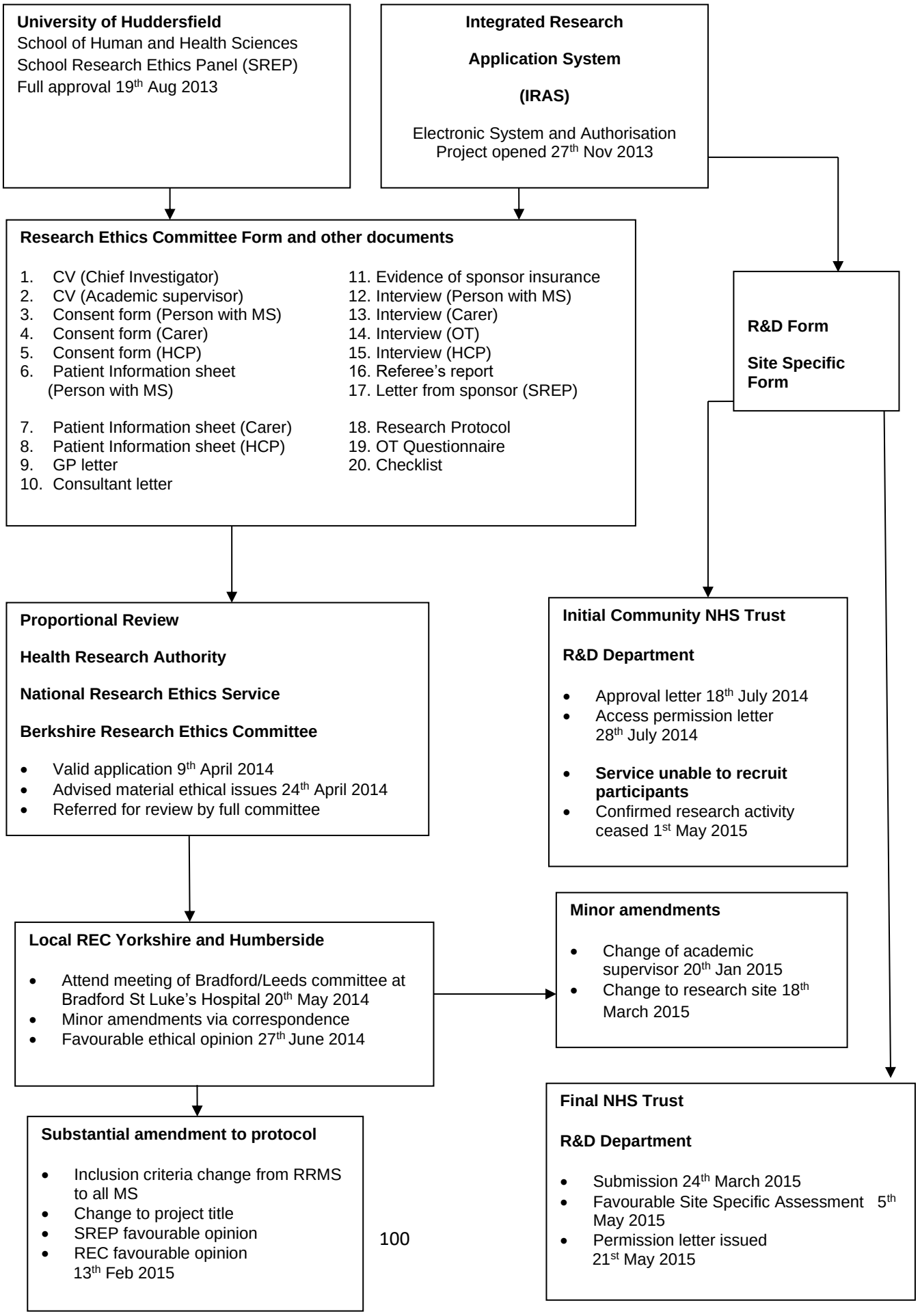
Identifiable documents such as consent forms, letters and other data were stored in locked metal filing cabinets on NHS premises. Electronic data was password protected and stored at the University of Huddersfield. Letters were sent to all participants thanking them for contributing to the project.

The process of obtaining ethical approval and local research and development permission is illustrated in Figure 4. This involved an initial application to the University of Huddersfield School of Human and Health Sciences School Research and Ethics Panel (SREP). Full approval was confirmed by SREP on 19th August 2013. A second stage of ethical approval consisted of obtaining a favourable ethical opinion from the National Research Ethics Service (NRES reference: 14/YH/0168) (Health Research Authority, 2015). Despite meeting the criteria of the No Material Ethical Issues Tool (NMEIT) proportionate review completed by the Berkshire NHS Research Ethics Committee identified material ethical issues requiring review at a full Research Ethics Committee (REC) meeting. The NRES Committee Yorkshire and Humberside – Bradford Leeds meeting was attended at St Luke's Hospital, Bradford on 20th May 2014. A favourable ethical opinion was obtained on 27th June 2014 following the satisfactory provision of further information. Research and Development approval for the initial research site was gained on 18th July 2014 and a permission letter issued on the 28th July 2014.

Recruitment of participants at this research site unfortunately proved unachievable. To increase the probability of recruitment a pragmatic decision was made to amend the protocol to include not only participants with RRMS, but also the progressive forms of MS. Relaxing the criteria opened the research to an increased number of potential participants. The original justification for this criterion was that people with RRMS are more likely to be performing IADL. This issue was, however, addressed from a perspective of function as opposed to impairment by another inclusion criterion, IADL undertaken as part of routine (see section 3.6). This constituted a major revision to the project as it necessitated a change to the criteria and title of the project despite the operational ethical practices of the research project remaining the same. Such a substantial amendment to the research protocol required a resubmission to SREP and the REC through IRAS. Approval of this substantial amendment was gained on the 13th February 2015. Despite these actions a combination of ongoing service restructuring, staff vacancies and commitments to other research projects resulted in unfavourable prospect for recruitment. An expedient strategy was taken to negotiate towards a transfer of the project to a neighbouring service.

At the eventual research site, the NHS Trust granted permission with the research and development department acting as the gatekeeper on 21st May 2015. This allowed research

Figure 4. Ethical approval and Research and Development permission processes



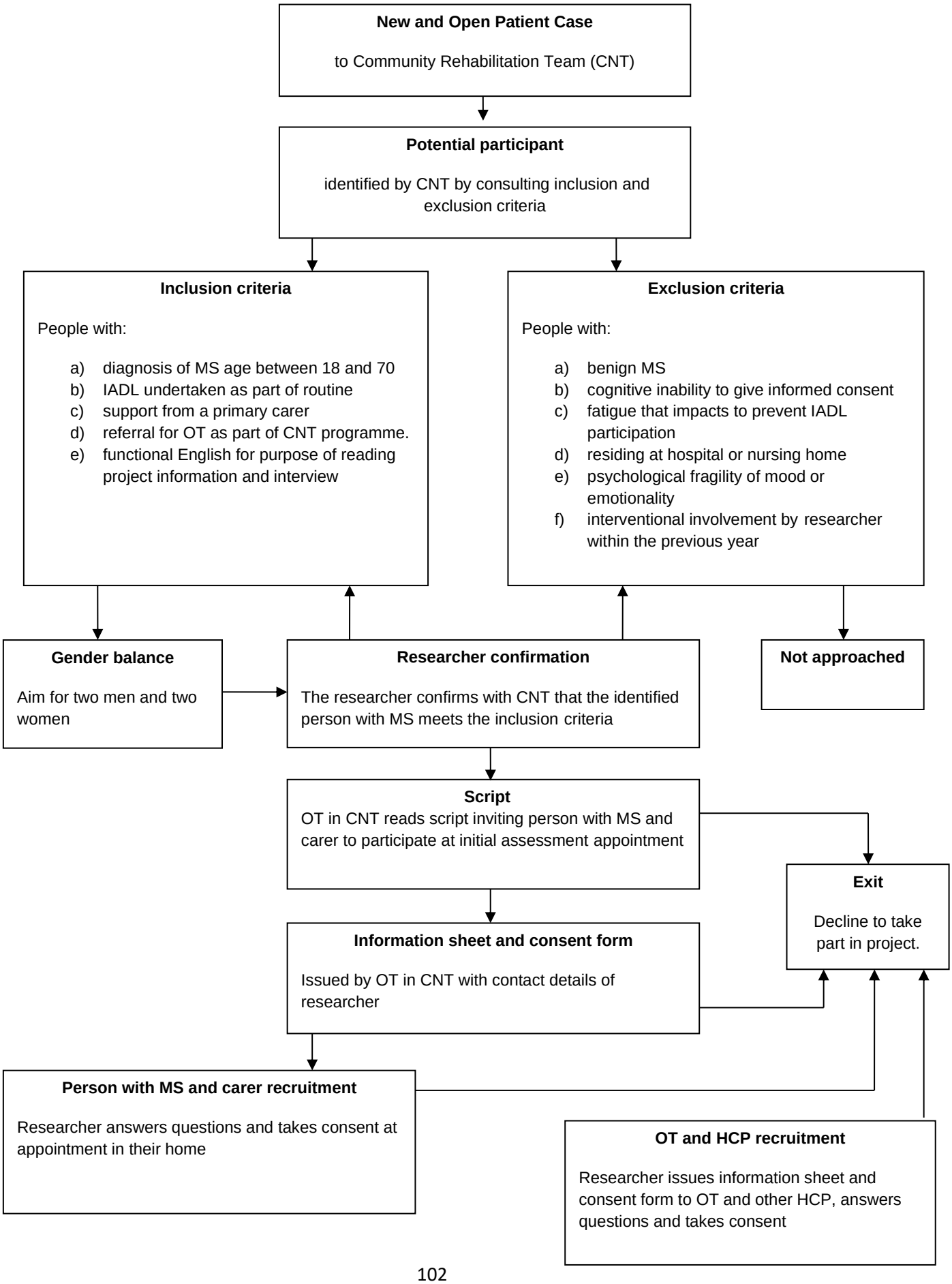
access to take place between May 2015 and April 2016. The problems recruiting participants at the initial site, the prolonged process of transferring the research site, and the substantially amendment to the research protocol caused a significant delay to data collection. Data collection eventually commencing in June 2015. The next section will present the processes of sampling and participant recruitment.

3.6 Sampling and participant recruitment process

The purpose of the study was to recruit people with MS, their carers, and occupational therapists, all of whom were able to illuminate the experiences and perceptions of occupational therapy interventions on occupational performance in IADL. Qualitative research sampling can be categorized into the three approaches of theoretical, convenience and purposive sampling (Ritchie, Lewis, Elam, Tennant, & Rahim, 2014). Theoretical sampling is associated with grounded theory and involves participants being recruited through an iterative process related to the emergent theoretical constructs (Ritchie et al., 2014). Convenience sampling involves selection of the most accessible and convenient participants for the study and is considered an unsatisfactory approach due to the possibility of unspecified biases such as pre-existing relationships (Robson & McCartan, 2016). In purposive sampling the researcher selects participants with a purpose that is based on criteria to set parameters (Silverman, 2011). Within the criteria the sample of five cases looked to select a variety of cases to compare. The sample also permitted the identification and exploration of common themes across cases during the analysis process (Ritchie et al., 2014). The diversity of recruitment also aimed to explore and explain differences of experiences and perceptions by participants in their IADL and occupational therapy interventions. (King & Horrocks, 2010). For this research, a careful recruitment process of five cases was undertaken with inclusion and exclusion criteria providing a purposive sample of participants. The sampling strategy aimed to represent characteristics of the population of people with MS (Ritchie et al., 2014). People with both RRMS and SPMS were included although nobody with PPMS was recruited. The recruitment process also took the gender of the people with MS into account to ensure the inclusion of men in the research project.

At an early stage in access at the research site the research protocol was explained to the CNT in meetings with the research collaborator and CNT service manager. The research collaborator was the official research representative for the NHS Trust within the CNT for the research and acted as access gatekeeper for recruitment. A folder containing the research protocol document, participant identification sheets, participant information sheets and completed consent forms was held at the CNT's NHS hospital base for access and reference

Figure 5. Participant recruitment process



by the research collaborator, CNT service manager and the research and development department. The participant recruitment process is illustrated in Figure 5. Routine new referrals and open cases to the Community Neurology Team (CNT) were identified as potential participants by the site collaborator who consulted the inclusion and exclusion criteria.

The Inclusion criteria consist of people with the following:

a) diagnosis of MS
b) age between 18 and 70
c) IADL undertaken as part of their routine
d) support from a primary carer
e) functional English for purposes of reading project information and interviews
f) referral for occupational therapy as part of the community rehabilitation programme.

The recruitment process was open to people with a diagnosis of MS of both relapsing-remitting and the progressive forms of the condition. The age range was limited to people between 18 and 70. This was primarily to exclude people aging with the condition and encountering co-morbidities and age related impairments to occupational performance (Finlayson et al., 2008). The recruitment of a primary carer who could provide interview data from a different viewpoint than the person with MS or professionals was important in providing triangulation of data sources. A carer was identified as someone providing paid or unpaid support to a person with MS who cannot fully care for themselves (College Occupational Therapists, 2017). All five carers who participated in the research were spouses to the people with MS. For purposes of reading and understanding project information and taking part in interviews the participants were required to have functional English. This was determined by the CNT during the research recruitment process. The research project resources were limited and not able to commission interpretation services. This was acknowledged however, as a potential limitation to the diversity of participants in a multi-cultural community. The final inclusion criterion was that occupational therapy had been part of the community rehabilitation programme.

The exclusion criteria consist of people with the following:

a) Benign MS
b) cognitive inability to give informed consent to participate in the research project
c) fatigue that impacts to prevent participation in IADL
d) psychological fragility of mood or emotionality
e) a home not based in a community context
f) interventional involvement by the researcher in a clinical role with the researcher employing NHS Trust within the previous year.

People with the benign form of MS were excluded as they were seen as having minimal impairment caused by the disease and this would not warrant occupational therapy intervention. There was an ethical responsibility not to include people whose cognitive impairment prevented them from giving informed consent to participate in the research. As fatigue is a well-recognised symptom of MS that limits participation in activity this was used as an exclusion criterion to prevent the interviews and AMPS causing excessive and harmful fatigue. People with MS can also be at risk of changed mood or emotionality so was identified as an exclusion criterion again to protect participants from harm. The impact of fatigue and mood were discussed during the recruitment process with the research collaborator. The location of the person living in a residential care or nursing home was also an exclusion criterion as level of care and environment would indicate less engagement in and variety of IADL. The final exclusion criteria accounted for a small possibility that the researcher could previously have made clinical interventions with the person with MS as part of his substantive NHS role at a tertiary hospital.

Identification of participants took place in two stages. The participant identification sheet used by the CNT is contained in Appendix 2. Discussion between the researcher the research collaborator and the CNT confirmed the suitable of each person with MS to participate in the research by considering the inclusion and exclusion criteria. The discussion considered factors such as if the participant was appropriate to answer the research questions and provide rich data on their experience and perceptions. At this point case gender was balanced as recruitment proceeded by ensuring the five cases comprised of at least two women with MS and two men with MS. They were then approached by a member of the CNT who read a script to the person with MS and the carer inviting participation in the research. If in agreement the information sheet and consent form was issued with the contact details of the researcher. Examples of the information sheet and consent form for the people with MS are attached in Appendices 3 and 4. Similar information sheets and consent forms were issued to the carers and HCPs recruited to the research project. An appointment was then made between the researcher, the person with MS, and the carer, at which any questions regarding the research project were answered and formal consent then taken from both the person with MS and their carer. The occupational therapists and other HCPs were recruited by issuing information sheets and consent forms. A meeting with all participants took place to answer questions about the research and take formal consent to participate. A letter of thanks was issued to all participants at the completion of data collection.

3.7 Data collection methods

The multiple case study design incorporating mixed methods collected data using four methods. The mixed methods research design predominantly collected qualitative data but began by gathering quantitative AMPS data as analysis 1 in the case studies (see Figure 6). The case study therefore had multiple data points and aimed towards description and explanation within the unit of analysis (Yin, 2014). The data sources were carefully selected in the design of the research to ensure integrity and facilitate convergence during the data analysis process.

The Assessment of Motor and Process Skills (AMPS) is a quantitative measure of occupational performance ability in IADL. It gave a benchmark for each case and a practically introduction to the concept of IADL to each person with MS. Semi-structured interviews were conducted separately with the person with MS, their carer, the occupational therapist, and Health Care Professionals. A total of 19 interviews generated the main body of qualitative data. Field notes were made following all data collection appointments. These field notes provided supplementary data to the interviews and on the context of home environment where IADL were performed. The field notes also involved a reflexive process on behalf of the researcher. The fourth data source consisted of a brief questionnaire administered to the occupational therapists with the objective of gathering in-depth data on the professional opinions of the cases.

3.7.1 Assessment of Motor and Process Skills

The Assessment of Motor and Process Skills (AMPS) is a standardised observational tool used by occupational therapists with the purpose of evaluating the quality of a person's performance in ADL and IADL (Fisher & Jones, 2010). AMPS measures occupational performance in natural task related environments and has the benefit of being occupation based. The person chooses to perform two relevant tasks from a list 110 tasks (93 IADL and 17 ADL) that are of appropriate challenge. The occupational therapist collects and scores raw observed data on performance in 16 motor and 20 process skills (Gillen, 2009). The AMPS scoring software computes overall, linear ADL motor and ADL process ability measures. Each of these skills is carefully and specifically defined in the AMPS (Fisher & Jones, 2010). This psychometrically robust and sensitive observational tool was administered with the person with MS as the first data collection point and formed the quantitative data of this mixed methods multiple case study (Choo et al., 2018). AMPS has been influential in the wider occupational therapy profession with the terminology and definitions of motor and process skills being adopted into the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2014). Collection of AMPS data took place in the home

environment of the person with MS at a separate appointment to avoid causing unnecessary fatigue to the people with MS.

The purpose of using AMPS in this research project was threefold. First to establish a diagnostic benchmark of occupational performance in motor and process skills for each person with MS. A score in equal interval measuring units called logits is generated for motor and process skills by AMPS. The logit scores are categorised into overall quality of ADL task performance (Fisher & Jones, 2010). These scores would provide valuable attributes for comparison between the cases during data analysis. Cross-referencing can then be made to other qualitative data points. As a trained and calibrated AMPS user the researcher was able to provide unbiased and valid observational data on occupational performance in IADL.

AMPS introduced the concept of IADL to the people with MS. The administration of AMPS involves establishing rapport and a collaborative relationship through a brief interview to identify relevant ADL tasks within the occupational performance context of the person with MS (Fisher, 2009). This provided an important introductory discussion on IADL for the person with MS. Undertaking the AMPS is also a practical process involving doing tasks. The subsequent semi-structured interview was not then centre on IADL as a new and abstract concept. The interview could be based on and use examples of the tasks and activities previously completed in the evaluation. AMPS was also integral to the design of the semi-structured interviews. Motor skills and process skills formed two of the interview topics in the guide (see Table 7).

The third purpose was concerned with the integrity of the researcher as an occupational therapy practitioner being involved with observing and assessing the person with MS performing tasks. It was important that the researcher collected data on the occupational performance of each of the five cases. This data point formed a background basis and informed focus for the semi-structured interview. The researcher has maintained AMPS rater training and software calibration within his practice so this formed a conceptual framework for the consideration of occupational performance in IADL.

Although AMPS can be considered a powerful measurement tool with the advantages of validity and reliability from a qualitative perspective criticism can be made in terms of its accessibility to the wider occupational therapy practice community. Despite uptake on an international basis the occupational therapists in the CNT were not AMPS trained and had not used it as an outcome measure. The training commitment in terms of resources is significant. The financial cost and the time involved in attending a 5 day training course can be barriers to using the tool. The demanding course also does not guarantee that the occupational therapist will be able to meet the requirements of validation and calibration. Use of AMPS is also reliant on the ability to offer a range of tasks in an appropriate environment to give true choice.

3.7.2 Semi-structured interviews

Collecting data through interviews is a favoured qualitative research method (King & Horrocks, 2010). This accessible method permitted the researcher to ask questions directly to the participants about their experiences, perceptions, and opinions of occupational therapy interventions for people with MS in IADL. Interviewing is a collaborative process with the involvement of active participants (Silverman, 2011). Interviews involve a meaningful relationship between the interviewer and the interviewee where the individual's personalities have an influence on the questioning and data collection process (Rubin & Rubin, 2012). For the people with MS and carers the interview took place on the third visit by the researcher following the initial meeting to take consent and the AMPS data collection. Over these meetings a relationship was built between the researcher and the participants based upon the process of administering AMPS and the interview. The relationship with the occupational therapist who provided four interviews became deeper as shared clinical knowledge and experience was revealed in the interview process.

Criticism of interviewing as a research methodology has been made. The validity of interview data has been questioned and how close to truth it can reach (Robson & McCartan, 2016). Interviews are also seen as being over-used in society generally. Despite this criticism interviewing does reflect experiences of the participants and has value but requires careful data interpretation (Yoe et al., 2014).

Types of research interview range from fully structured formats with fixed wording of pre-set questions to unstructured interviews where an informal conversation is undertaken on general research topics (Robson & McCartan, 2016). In this research 19 semi-structured interviews were employed with the purpose of collecting in-depth data on the experiences and perspectives of the participants (Rubin & Rubin, 2012). Semi-structured interviews were chosen to ensure the interview remained focused on the research topic of occupational therapy intervention and IADL but were not too rigid to permit the flexibility involved in natural conversation. The preparation and pre-planning involved in the interview guide aimed to maintain some control of the interview content and data.

During semi-structured interviewing the researcher requires a particular set of communication and management skills related to a complex social interaction (Robson & McCartan, 2016). Key skills include establishing a good quality of rapport and trust with the interviewee, active listening during the interview interaction, demonstrating knowledge of the research topic, and judging which questions and follow-up questions to ask as the conversation proceeds (Yoe et al., 2014).

The researcher aimed for a responsive interview style. This involves the establishment of a conversational partnerships with the interviewees with an outcome of the collection of vivid and detailed data (Rubin & Rubin, 2012). Collecting qualitative data through semi-structured interviews provide the benefits of being able to set a list of issues to be considered with the flexibility of follow-up questions and probes to pursue informative lines of inquiry (Thomas, 2016).

Six stages have been suggested to occur during a research interview (Yoe et al., 2014). The researcher was firstly careful at the initial arrival to introduce himself and build further rapport upon the previous meetings with participants when consent had been taken and for the people with MS the previous meeting when AMPS data had been collected. The recording equipment was also set up at this initial stage. Secondly the core interview subject of how the occupational therapy interventions affected the ability of person with MS to perform IADL was introduced by reading a passage (see Appendix 5). As IADL is an abstract conceptual term used by occupational therapists and other healthcare professions, it was important to explain IADL occupations in meaningful language to the participants especially the people with MS and the carers. The activities were introduced by giving examples of IADL occupations such as making meals, caring for children, and shopping in the contexts of the home and community. The third interview stage consisted of the beginning of the interview and this involved the first question which invited the participant to explain how MS affects how they do these activities. The next stage involved preceding though the schedule of questions based on key themes where most of the talking was done by the participants. At the end of the interview the recorder was switched off which marked the end of an apparent official stage of the interview although more was often said after and thanks was offered to the participant. The sixth and final stage involved making field notes as soon as practicable after the interview was completed.

An example of the interview guide used for the person with MS illustrating the topics and questions is presented in Table 7. The structure of the interview questions involved a limited number of main question on each theme, follow up questions and probes to encourage a continuation of the conversation in answering (Rubin & Rubin, 2012). A brief introduction to the research was given to clarify the purpose to the participant and emphasise the type of occupations involved in IADL (see appendix 5). It was identified that the impact of MS, and the metaphorical journey the person with MS had experienced in relation to participating in IADL, was an appropriate starting point. There then followed questions on the other two main concerns of the research: IADL and occupational therapy interventions. The literature review contributed to the identification of fatigue management and assistive technology as important topics to include in the interview. The interview topics also were influenced by AMPS which provided the themes of motor and process skills. A final question asked about any other

Table 7. Interview Guide: Topics and Questions (Person with MS)

Topic	Main Question	Follow-up questions	Probe
1. MS Journey and impact on occupational performance in IADL	Tell me how your MS affects how you do these activities?	What was your function like in these activities a year ago? How have you been able to do these tasks over the last year? How did you do these activities in the past? How does this contrast with now? How well do you do these activities now? Has this affected how much help you need from others? Which activities do you want to continue doing? How do you see the future?	That's interesting can you tell me more? Go on ... Can you give me an example? Use body language and gestures to encourage continuation of conversation
2. Meaning of IADL to the person with MS	What do these activities mean to you?	How important are these activities to you?	Same probes
3. Occupational therapy intervention Occupation based intervention, doing the activities, top-down. Time spent doing these tasks or assessing them. Assessing how you do these tasks	Tell me what you did with the occupational therapist?	Tell me about the last time you saw the OT. What happened? What did they do? Have you changed how you do these activities? Did you change which activities you do? What did the OT do with regards to this? Have you had OT before?	Same probes

Table 7. Interview Guide: Topics and Questions, Person with MS (continued)

Topic	Main Question	Follow-up questions
3. Occupational therapy intervention Continued	Tell me what you did with the occupational therapist?	Did the OT spend time assessing how you did these activities? How meaningful to you were the activities the OT did with you? Was this purposeful to you? What would you suggest would be a better way to help you?
4. Motor skills	'Tell me about your movements and strength before OT ... and after OT.'	Tell me how this has affected how you do these activities. How well did this work for you? How did they do this?
5. Fatigue management	Tell me about your tiredness and fatigue before OT ... and after OT.	What did the OT do with regards to your tiredness? Did the OT help you to overcome tiredness related to doing IADL How did this work for you? What did this involve?
6. Assistive technology	Do you use equipment to do these activities?	Tell me more about the equipment. What equipment did the OT use with you? Was any electronic equipment used? Did they use equipment or a technology to help you with these activities? What about a wheelchair?

Table 7. Interview Guide: Topics and Questions, Person with MS (continued)

Topic	Main Question	Follow-up questions	Probe
7. Process skills	Does your thinking, memory or vision affect how you do these activities?	What did the OT do with regards to this? Was any technology used?	Same probes
8. Other interventions Orthotics fitting, contrast baths, sensory integration, sensory - vision	Was there anything else the OT did with these activities that you would like to tell me about?	Did the OT make a splint? Tell me about the splint	Same probes

interventions the occupational therapist may have made. During the interview, the prior completion of the AMPS allowed the researcher to refer to a practical experience of doing IADL. The same interview structure of topics and questions were used with the different groups of participants, people with MS, carer, occupational therapist, and HCP. The interviews with the person with MS and their carer were scheduled to take place in their home at their convenience and comfort. This was considered an ecologically appropriate interview setting.

The semi-structured Interview data was collected by audio recording. A procedure was established to familiarise the research participants with the recorder. This attempted to reduce the intrusive nature of being recorded and reducing anxiety for the interviewee (King & Horrocks, 2010). The recorder was introduced at the start of the interview with a short sentence saying that this was a test recording and the day, date, and year. The aim was for the recorder to become part of the background environment for the participants thus reducing their anxiety and to ensure the equipment was working. This procedure was successful apart from during one interview where battery failure resulted in the loss of a section of interview data.

3.7.3 Field notes

Field notes were made by the researcher after each data collection appointment. The initial hand written notes were word processed into a Microsoft Word document within 24 hours to establish more formal field notes (Yin, 2014). This also facilitated the management of the data with information technology and the subsequent data analysis process with NVivo. During the process of AMPS data collection notes were also made regarding the context of relevant task selection and occupational performance in the selected IADL (Fisher & Jones, 2010). These notes were also added to the field note documents for the people with MS.

The purpose of keeping field notes was to supplement the other data collection methods, provide context to the cases and a basis for the ongoing reflexivity by the researcher (Arthur, Mitchell, Lewis, & McNaughton Nicholls, 2014). The field notes documented data from observations in the interviews that were not captured by the audio recordings (Flick, 2014). These observations included what went well in the interviews but also difficulties and tensions with the research topic. Examples of the additional contextual data collected were details of the home environment and material culture of the people with MS. The reflections involved in the field notes also assisted the refinement of data collection including the presentation of the researcher. During the data analysis stage, the field notes contributed depth and vividness to the accounts contained in the case summaries (see section 4.1). The reflexions involved in processing the field notes can be seen as an early stage in the development of data interpretation and analysis as ideas and issues were identified (Arthur et al., 2014).

3.7.4 Questionnaire

A questionnaire was issued to the occupational therapists following their interview. The realist perspective of the research used this as part of the method triangulation with the aim of increasing the confidence of the findings (Robson & McCartan, 2016). The objective of the questionnaire was to gather additional data by asking a different set of questions to obtain a deeper level of insight. These included questions on occupational therapy concepts, theory, and models as well as engagement in interventions and adaptation to the condition. It also offered the occupational therapists an opportunity to express opinions when not in direct contact with the researcher. The questionnaire gave the option to say more by writing in private. Appendix 6 contains the open questions asked in the questionnaire completed by the occupational therapists. The written form of questions aimed to encourage open responses to supplement the interview data from the occupational therapists (Thomas, 2016). The real world of the research project, however, resulted in the questionnaire being issued immediately following the interview with the occupational therapist. This was a pragmatic decision made once the research access period had been curtailed. The questionnaire formed the final data collection in the unit of analysis for the five cases.

3.8 Data collection

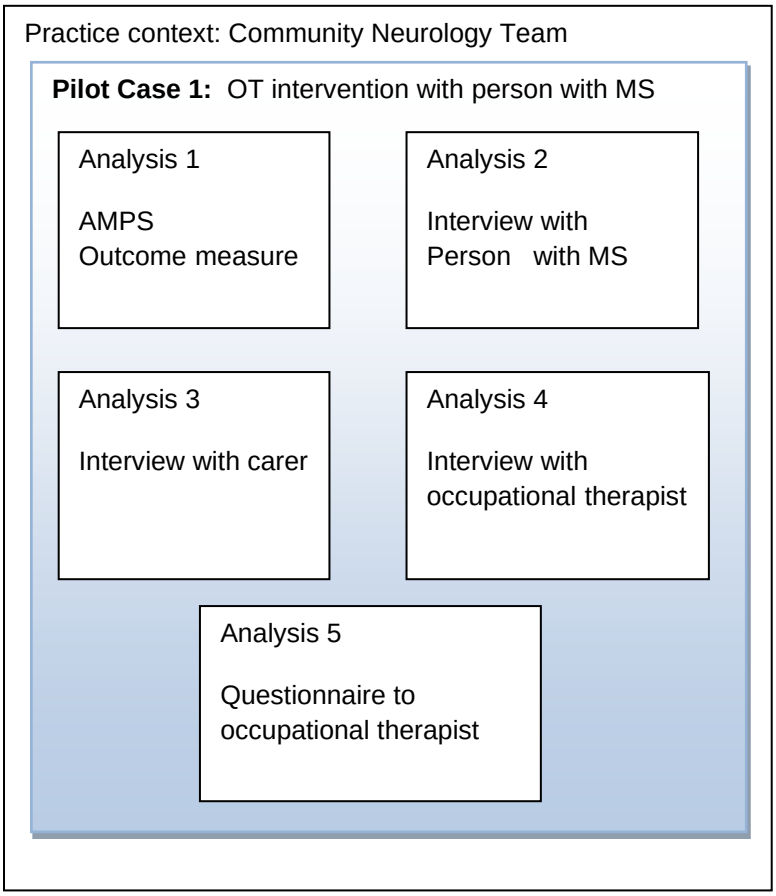
Data collection proceeded over three stages: a pilot case stage, a multiple case stage, and an HCP stakeholder stage. In total the data sources for all five cases consisted of five AMPS, nineteen semi-structured interviews and five questionnaire responses from the occupational therapists. The intended timetable for the data collection was planned to take place over a period of six months. This consisted of a one-month period of the pilot phase, followed by four months for the multiple case stage and one month for the HCP stakeholder stage. Data collection occurred during an intensive four-month period between June and September 2015. Restructuring of the CNT service at the research site resulted in the period of data collection being reduced from the planned six months to four months. Although some indication of a potential change in the project timetable was given at the research site, official notification that data collect would have to end was only received two months into the project. There followed a period of intense data collection which demanded tight planning and flexibility from the researcher. Emphasis had to be shifted to carefully scheduling recruitment, making of appointments, and data collection. The plan to transcribe data as data collection ensued and initiate the analysis was not possible as the focus of attention centred on preparation for the appointments with participants, collecting audio recordings, and making field notes. The circumstances left dissatisfaction for the researcher as data collection and data analysis could not be integrated. There was also a lack of time to reflect on and adjust data collection by

considering the interviews by participants in each case. This was, however, a real world research context where services are dynamic and change due to the prevailing demands of the health and social care systems.

3.8.1 Stage 1: Pilot case

The research involved an initial pilot case of a person with MS who had received occupational therapy interventions from the CNT. The aim of the pilot case was to trial and assist refinement of further data collection (Yin, 2009). Figure 6 illustrates the unit of analysis for this first pilot case which consisted of the occupational therapy intervention with person with MS. Data was collected from five sources within the unit of analysis.

Figure 6. Pilot Case Stage Unit of Analysis (adapted from Yin 2009)



Analysis 1 consisted of the quantitative data in this mixed methods research and was gathered through the AMPS. This was introduced to the person with MS at the first appointment with the researcher when consent had been taken. At this first meeting the person with MS chose the two AMPS tasks to undertake at a subsequent appointment. The researcher observed the person with MS completing the two tasks and gathered the AMPS data in the home setting at

this second meeting. At a third meeting the semi-structured interviews were conducted with the person with MS and their carer. Individual interviews were undertaken to give the opportunity for the separate voices and perspectives of the person with MS and the carer to be heard in the research (Kendall et al., 2009). By interviewing the carer separately in private and with the assurance of confidentiality, the opportunity was offered to give sensitive or personal information that may not have been disclosed in a joint interview. The carer may be more willing to talk about sensitive or personal information such as not coping with the burden of care or problems with communication. Protecting the interviewees information added potential depth to the interview data (DiCicco-Bloom & Crabtree, 2006). In joint interviews with patients and carers, researchers have found carer participants often take the opportunity to speak individually to the researcher informally (Kendall et al., 2009). Joint interviews also have the disadvantage of introducing more complex dynamics between the interviewer and two interviewees (Morris, 2001).

Qualitative data from these interviews constituted data analysis 2 and 3. Analysis 4 drew on data from a semi-structured interview with the occupational therapist. All interviews with the occupational therapists and other health care professionals took place in a suitable setting on NHS premises. A final data source was collected from a brief questionnaire that the occupational therapists were asked to complete following the interviews. Field notes were also made soon after each data collection appointment to provide additional context to the data collection and aid the research reflexivity process.

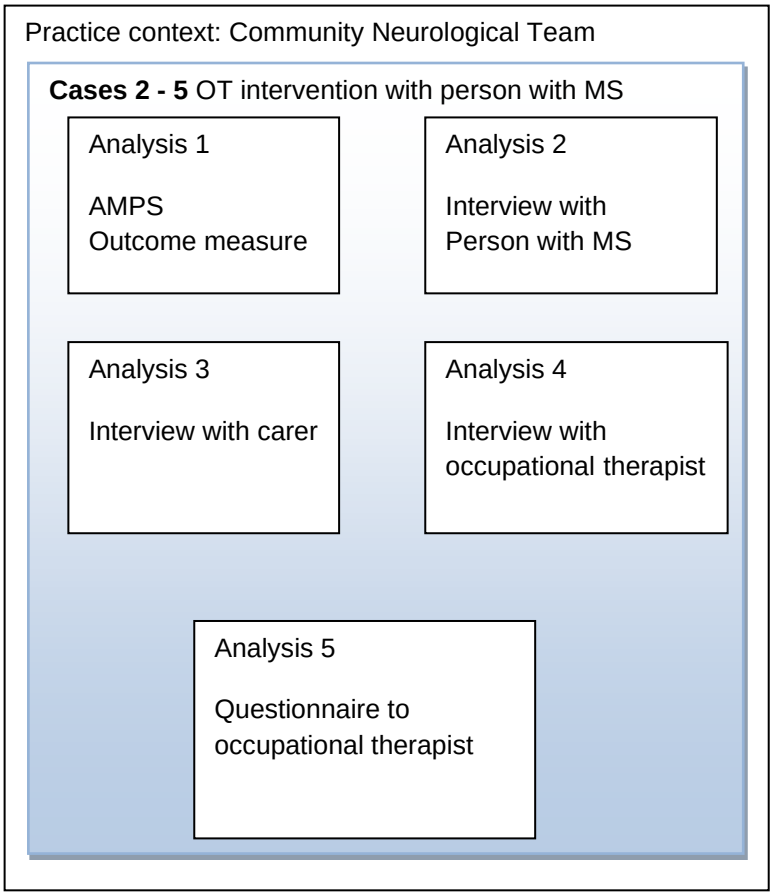
The pilot case provided confirmation of the suitability and practicality of the data collection methods. No changes to the process were considered necessary and data from the subsequent cases used this procedure. The data collected in the pilot phase contributed to the overall analysis in the study.

3.8.2 Stage 2: Multiple case stage

Figure 7 illustrates the multiple case stage involving a further four cases which followed the initial pilot case stage. These cases all repeated the data collection procedure piloted with the first case. The AMPS data was collected in the home environmental context for each of the people with MS's at a pre-appointed meeting. The semi-structured interviews with the four people with MS and their carers also took place in their homes. The exception was one interview with a carer which took place in a different venue at their request and convenience. Participants with MS were given the option to finish their interview after 45 minutes and the interviews overall were concluded before 60 minutes. An exception was the interview with Case 3 which lasted 65 minutes.

The research design and the context of the CNT service had an implication for the number of occupational therapists who could potentially be involved in the research. It was possible for between one and five different occupational therapists to have been recruited depending on which occupational therapist had treated the person with MS. In the real world context of the CNT the recruitment process, however, resulted in two occupational therapists participating. It was not possible to influence and balance this as only five people with MS met the recruitment criteria and consented to participate in the research during the limited period of research access to the CNT service. The result was that one occupational therapist provided interviews concerning the occupational therapy interventions for four of the cases and a second occupational therapist an interview for the remaining case. The structure of occupational therapy in the CNT also influenced participation. The occupational therapist providing four interviews was a clinical specialist occupational therapist with a special interest in MS and taking a clinical lead in practice for people with MS within the CNT. The occupational

Figure 7. Multiple Case Stage Unit of Analysis (adapted from Yin 2009)



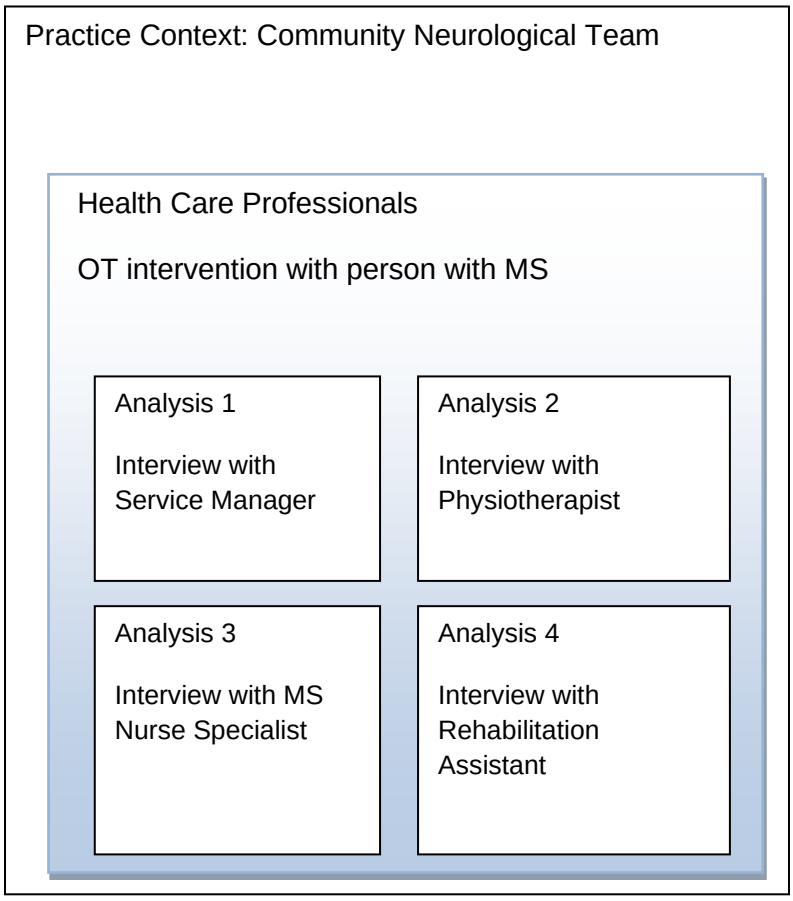
therapy interview data therefore was provided mostly by a highly experienced, innovative, and knowledgeable clinician. Within the case study as a whole this has the advantage of collecting

data from an expert occupational therapy practitioner source and contributing a significant exemplary element to the case study (Yin, 2014).

3.8.3 Stage 3: Health care professionals

Themes emerging from analysis of data from the pilot and multiple case stages informed further interviews with other HCPs (Figure 8). This third stage of data collection illuminated the case study and provided further crystallization during the data analysis process. These key professionals were purposefully selected as members of the wider multidisciplinary team. Initially the intention was to include a physiotherapist, speech and language therapist, MS nurse specialist, and rehabilitation assistant. Unfortunately, a speech and language therapist could not be recruited due to a period of long term sick leave at the point of participant recruitment. A pragmatic decision was made in conjunction with the local research collaborator

Figure 8. Data Collection Stage 3: Health Care Professionals



to approach the service manager as a participant. The service manager had a clinical experience as a physiotherapist and agreed to participate taking the perspective of the service manager. Semi-structured interviews based on the same topics and questions as the previous

interviews were administered in this third stage to the service manager, a physiotherapist, a MS nurse specialist, and a rehabilitation assistant. The intention of this round of interviews was to obtain the perspectives of these other HCPs on occupational therapy interventions for people with MS within IADL. All these HCPs were joint workers and colleagues closely associated with the occupational therapists who meet to discuss cases and at times made joint visits to the people with MS.

3.9 Data analysis

This study focused on experiences and perceptions of occupational therapy intervention from different views within the therapeutic relationship and the direct measurement of occupational performance in IADL. This multiple case study combined the use of a quantitative objective measure of function with the subjective perspectives of the person with MS, the carer, the occupational therapist, and other healthcare stakeholders. The data analysis methods required to be robust yet pragmatic and flexible enough to bring together coherently the mixed methods design.

The raw data required filtering, reducing, and refining to provide the answers to the research question and meet the objectives of the study. To achieve this a framework approach of analysis was used based on pragmatism and realism (Ormston et al., 2014). This used an analytic hierarchy to firstly organise and manage data then build descriptive and explanatory accounts using an iterative process to arrive at interpretation through abstraction (Spencer et al., 2014; Gale et al., 2013). The advantages of the framework approach include a systematic and comprehensive coverage of the various data sources with the analysis remaining grounded in and built upon the data. The approach also keeps the researcher in close contact with the original data. The framework approach also facilitates searches and cross-cases comparisons by themes. The use of a matrix to chart and summarize data facilitates the systematic analysis of large data sets. The framework approach is transparent and provides an audit trail of decisions during the data analysis process.

Thematic analysis was used to systematically identify meaning patterns and interpretations in the data (Robson & McCartan, 2016; Spencer, Ritchie, Ormston, et al., 2014). The transcripts of the audio recordings were coded pragmatically using inductive and deductive processes of thematic analysis (Boyatzis 1998). This allows the development of a robust and reliable coding to produce themes. The researcher created categories, termed nodes in NVivo, grouped into a tiered hierarchy of sub-themes and themes with the objective of identifying core concepts and discovering answers to the research question. Themes are recurrent and characteristic features within the data relating to the perception and experiences of the impact of occupational therapy interventions for the people with MS within IADL (King & Horrocks,

2010). A metaphorical crystallisation process was undertaken where the many facets of the data are reflected on by the researcher through the writing of annotations and memos to make analytical abstractions (Denzin & Lincoln, 2008).

3.9.1 AMPS data analysis

As a mixed methods research design was used careful combination of the quantitative data into the overall analysis was required. The AMPS provided a key attribute value for each case by benchmarking the occupational performance in IADL for each person with MS (Bazeley & Jackson, 2013). Following the administration of AMPS the raw observational scores were statistically processed by software to give a report detailing linear scores for motor and process ability (Fisher & Jones, 2010). This is compared to normal values of competence in IADL task performance indicating the potential need for assistance with cut-off criteria where a person is likely to encounter problem in task performance. This quantitative data measure generated objective and valid descriptive statistics that informed the overall analysis of the multiple case study. Within the framework approach to analysis motor and process skills were also identified as a theme during the development of the analytical framework.

3.9.2 Data management software

The early stages of the data analysis involved organisation and management of the qualitative data. The large volumes of diverse data collected from participants, particularly from the interviews, require a systematic, rigorous, and transparent approach to management and analysis. A decision was made early in the research project to utilize information technology systems to facilitate data management and analysis. *NVivo* is a computer assisted qualitative data analysis software (CAQDAS) package that provided the tools to organise and manage the data (Bazeley & Jackson, 2013). It allowed for the creation of a database to store and manipulation the text documents such as interview transcripts and field notes. Functions within NVivo also permit writing of annotations and reflexive memos inked to the data, keeping of a journal to map the development of the analysis, coding, and the interrogation of data to build conceptual and theoretical knowledge within framework matrices. NVivo also is structured to create cases as the unit of analysis and allows data to be coded to more than one category so connections and relationships can be identified (Bazeley & Jackson, 2013). The NVivo software is updated and improved from time to time with versions 10, 11 and 12 used during the data analysis phase of the research.

In general CAQDAS has the benefits of reducing time required to manage data, and increase the consistency and rigour of data analysis (Spencer, Ritchie, Ormston, et al., 2014). The software, however, cannot make analytical decisions. The researcher has to use analytical

skills such as defining codes and establishing linkages that permits the building of explanations that high quality and insightful analysis requires (Bazeley & Jackson, 2013). CAQDAS has therefore, to be considered as providing a set of tools in the data analysis process (Flick, 2014).

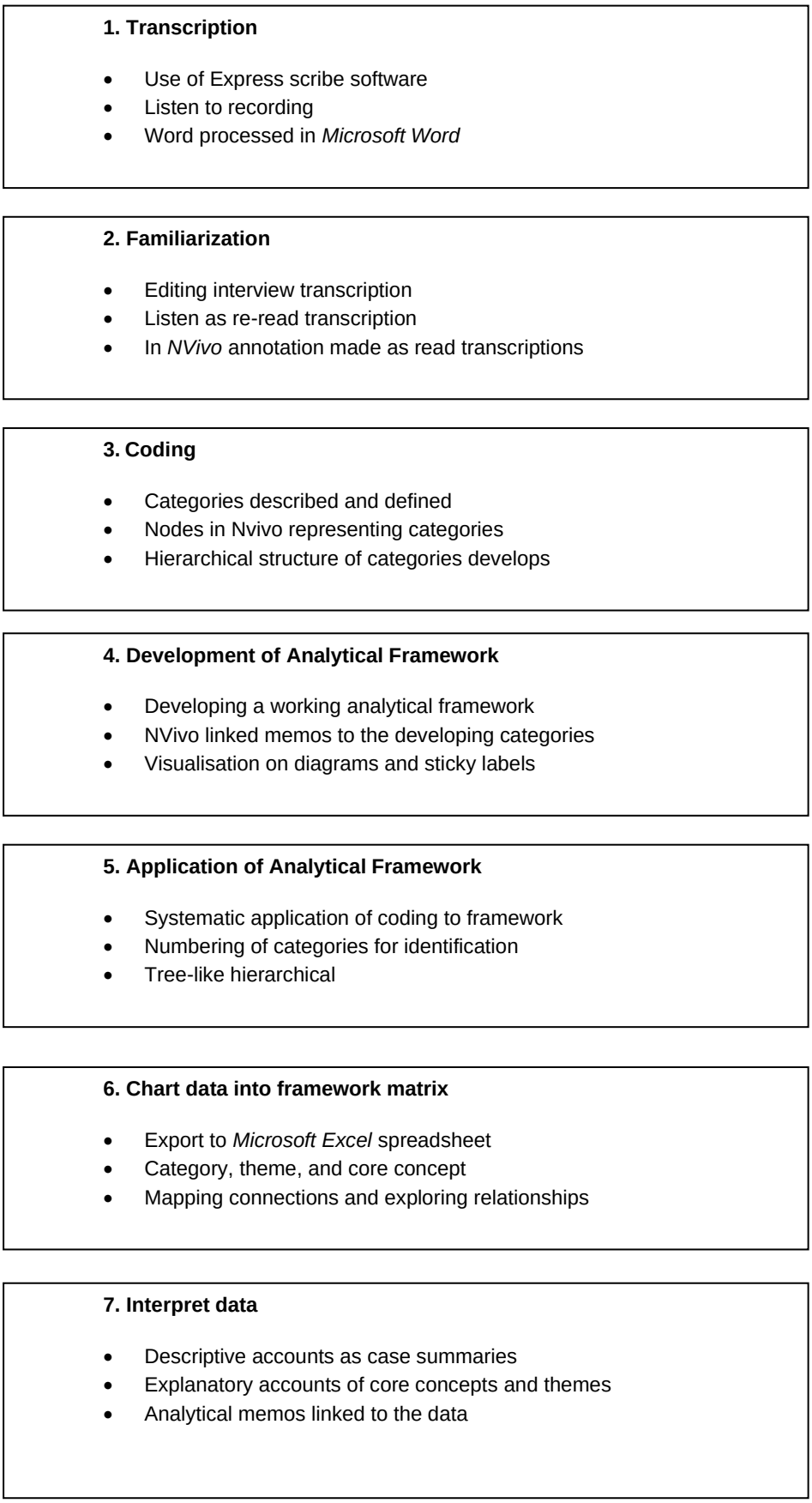
3.9.3 Data analysis process

In Figure 9 the seven stage procedure that guided the framework approach to analysis is illustrated. This provided a systematic and flexible approach to the data analysis (Gale et al., 2013). This produced a structured and summarised output of the data. The first stage involved production of verbatim transcriptions of the nineteen interview recordings. The purpose of transcription is to produce an accurate version of what is said in speech during the interviews (King & Horrocks, 2010). The transcript is, however, an interpretation of what was said and the interactions within the interview (Bazeley & Jackson, 2013). The *Express Scribe Pro version (5.78)* transcription software was used to listen to the recordings on headphones and transcribe the data. The text was then word processed in *Microsoft Word* to produce a transcript in a suitable format to import to NVivo. The transcription process allowed the researcher to become immersed in the data and was completed for all nineteen interviews (Gale et al., 2013). This was an intensive process and costly in terms of time. The objectives of the transcription stage was to capture the content of the interviews and to avoid becoming swamped by the transcription process (King & Horrocks, 2010).

Names of participants and other people associated with the cases were converted to pseudonyms during the transcription process to ensure confidentiality. The pseudonyms for participants were selected by the researcher from the Office for National Statistics lists of most common names by year (Office for National Statistics, 2014). The participant's approximate year of birth was used to identify a pseudonym from the 10 yearly lists of most popular boy's and girl's names.

The next stage of analysis involved familiarisation with the interviews (Gale et al., 2013). This began during the transcription process by re-listening to the audio recordings to check the accuracy of the text, re-reading, and editing the Word documents prior to importing to NVivo. Once the transcripts were added to NVivo familiarisation with the data continued. Careful and critical reading led to the addition of highlighted annotation to the transcripts. The benefit of using the two software systems; Express scribe and NVivo, was that the audio recordings

Figure 9. Data Analysis Process – Framework Approach (Gale et al., 2013)



could be listened to whilst simultaneously reading the transcripts. Figure 10 illustrates the process with a screenshot taken from NVivo. The transcript data is shown centrally with annotation at the base of the figure.

The third stage involved creating codes to label the transcripts and assign data to categories. NVivo uses the term node for a category. This process was iterative and ongoing as the framework analysis developed from the pilot case interviews. A pragmatic approach to creating codes to give descriptive and conceptual labels to the data was adopted using inductive and deductive reasoning. Open coding by close inspection of relevant content from differing perspectives to categorise the data was used at this stage (Robson & McCartan, 2016). This was combined with a priori identified coding categories such as those influenced by the Occupational Therapy Practice Framework and the interview themes identified from the literature review such as fatigue management and assistive technology (AOTA, 2014). A member of the research supervision team was involved in coding at this stage to provide different perspectives and confirm the process to enhance the robustness of the analysis (Gale et al., 2013). This constituted one of the quality measures employed during the research process. It was at this point that the metaphorical crystallisation process began to develop and grow from the solution of data to produce the crystals that became the categories, themes, and core concepts of the many faceted framework analysis (Sandelowski, 1995).

The fourth stage of developing a working analytical framework took place once the transcripts of the person with MS, their carer, and the occupational therapist had been coded (Gale et al., 2013). The construction of the analytical framework continued as an iterative process and was facilitated by the writing of a dated analytical journal and memos linked in NVivo to the coding categories (Bazeley & Jackson, 2013). Numerous categories were created and described at this stage and subsequently expanded, merged, or discarded as the analysis proceeded. NVivo was also able to display the frequency of coding occurrence in the number of documents (files) and references. Visualisation of the framework analysis was important. This was achieved by a diagrammatic display in iterative versions on A3 paper. Sticky labels were also used in the early versions as a flexible method to display ideas and concepts. Figure 11 shows an NVivo screen shot example of an interview extract with coding displayed (right) and analytical framework (left).

Case summaries are suggested as a step towards the end of the data management process to distil the essence of the data. Summarising data based on each person with MS as cases was an ongoing developmental process and proceeded in parallel with the framework analysis

Figure 10. NVivo Screen Shot: Transcription and Annotation Example

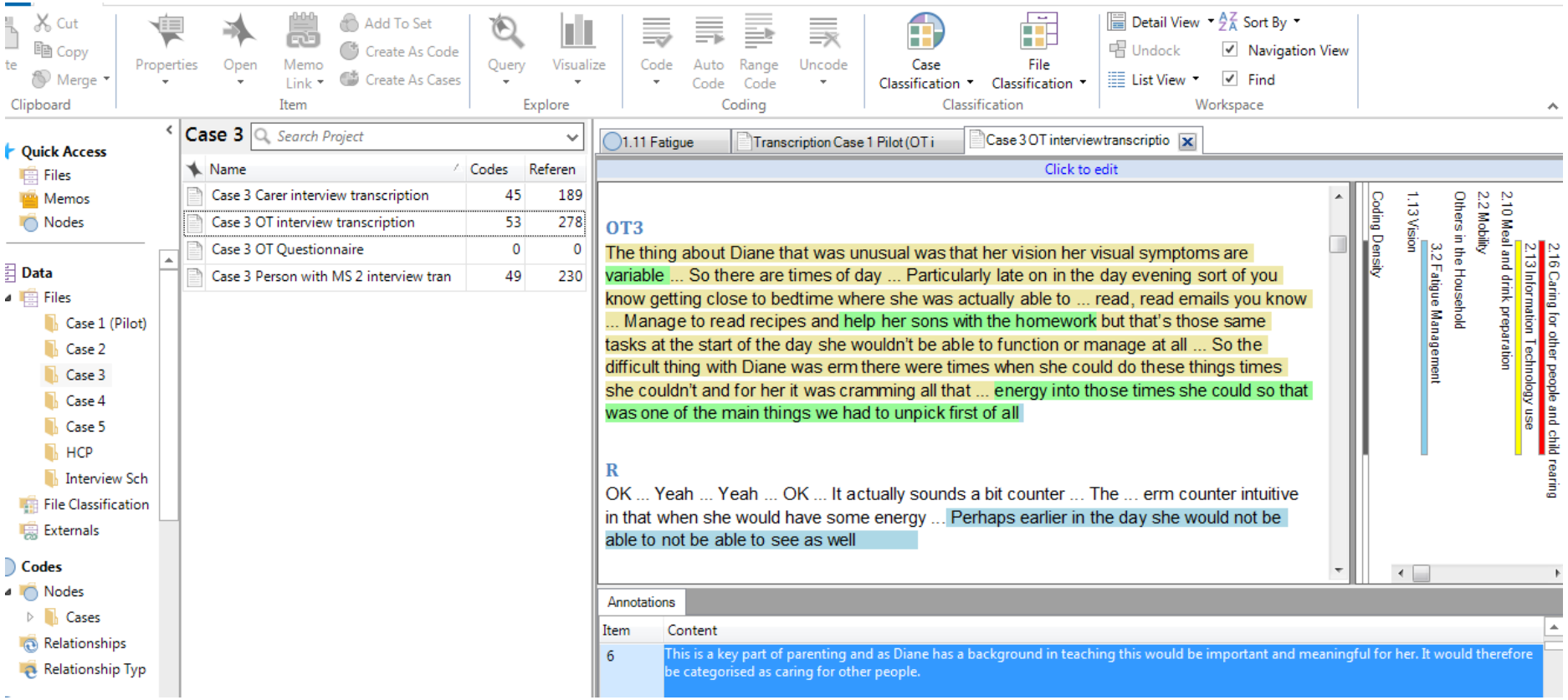
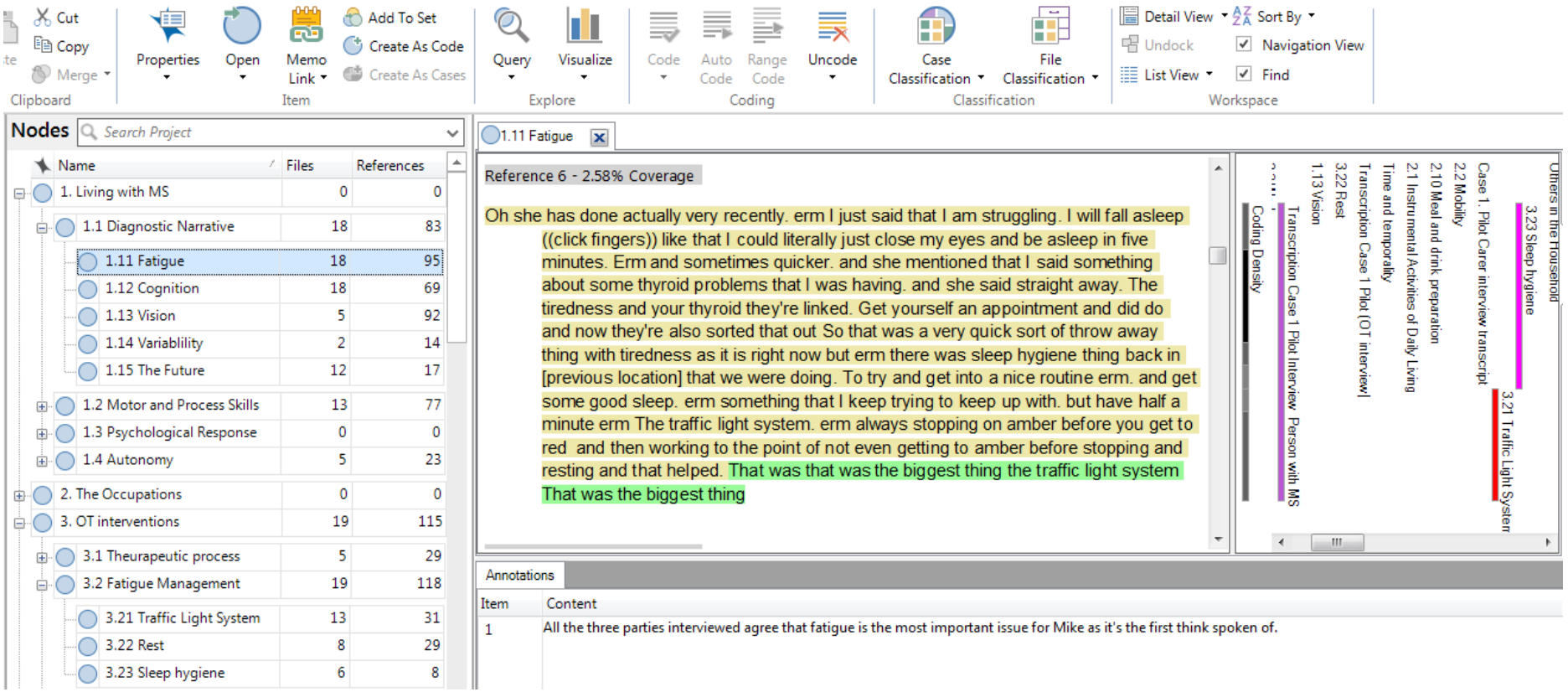


Figure 11. NVivo Screen Shot: Coding Strips, Density and Hierarchy



design culminated in the detailed case summaries reported in the following chapter (see section 4.1).

The next stage consisted of application of the analytical framework to the remaining data sources. The data for the remaining four cases was systematically indexed to coding categories. The process of framework analysis refinement continued as data extracts were reviewed and this fed back into consideration of the structure of categories and themes (Spencer et al., 2014). The categories within the hierarchy were numbered for identification. Towards the end of the application of the analytical framework a thematic chart was created in a *Microsoft Excel* spreadsheet to summarize the data and organise the descriptive accounts (see Table 8) (Gale et al., 2013). Although such matrices can be formed within NVivo the researcher found exporting summaries and examples of coding to the spreadsheet enhanced the analytical process in preparation for interpretation. Data examples were abstracted and charted to the categories and themes within the framework matrix. At this stage, the mapping of connections and exploration of relationships was recorded as linkages in the spreadsheet.

The final stage of the framework analysis involved interpretation of the data (Gale et al., 2013). This worked from the abstracted data in the framework matrix to build descriptive and explanatory accounts for each person with MS (Spencer et al., 2014). This used strategies and techniques that considered theoretical propositions, exploration of plausible rival explanations, pattern matching, and cross-case synthesis (Yin, 2014). There was also a search for patterns by comparing and contrasting the data provided by the various participants, people with MS, carers, occupational therapists, and other healthcare stakeholders. The iterative analysis process drew together the units of analysis within the context of the case study to compare the real world findings with theoretical and conceptual constructs (Thomas, 2011). An example of data abstraction and interpretation for Case 1 taken from the summary framework matrix is presented in Table 9. This matrix contained the explanatory accounts for the research findings. Research quality was insured by further meetings with a member of the supervision team to discuss, justify, and verify decision making in the identification of themes and core concepts and construction of the analytical framework.

The advantages of using the framework approach for data analysis were that it provided a systematic method of comprehensively interrogating a large volume of data. The process is transparent, allows comparisons and searches between cases yet remains grounded in the data (Spencer et al., 2014). The use of NVivo also facilitated the framework approach. Descriptive and explanatory accounts for each case are presented in the following chapter (see section 4.1). The core concepts to emerge from the framework analysis are presented in section 4.3.

Table 8. Framework Analysis Thematic Chart

Core concept Theme	Sources	Refs	Description	Interview data example	Memos	Comments Notes Annotations	Interpretation What is this about? Core concept and linkage
Core concept: **The Person Living with MS**			The experiences the individuals have in their daily lives of the impact of MS on their occupational performance in IADL.			Theme identified in conjunction with supervision team and is concerned with what it is like for the person living with MS.	Understanding the impact of MS on the person's occupational performance ability and autonomy.
Theme: **Diagnostic Narrative**	18	75	Participants showing through explanation their understanding of the process of knowing they have the condition of Multiple Sclerosis and its impact on their occupational performance 10/05/2016. It is the story the person with MS constructs about the process.	**Case 2 Person with MS:** 1987 I had that was I had five attacks in one year ... and I haven't really had anything you know proper attack tack since then but it has left me with all my left side very weak and the very last attack I had was in my foot...and I can't raise that now so I drag it. So my mobility is is poor and to compound that erm five years ago I broke my hip... **Case 2 OT:** The diagnosis the impact and accepting that ... this is how it would be and we got we got her counselling	30/03/2017 This node is associated with the processes the person with MS goes through in coming to terms and accommodating the implication of the diagnosis of MS. This narrative is their account and storey of how they found out their diagnosis and the psychological process they have been through to adapt to the symptoms and how it impacts on their IADL and OP. 03/06/2017 Just had a thought that may be good to change the title of this node to condition narrative because it's not just about the diagnosis but also the story of how the condition and the signs and symptoms progress subsequently.	The different participants in the case speak about the condition in differing ways. For the person with MS and the carer it is clearly what they try to relate to and make sense of what is happening and how it fits with occupational performance in IADL. For the occupational therapist it is much more linked to professional reasoning and working out how best to intervene. They need to understand how the person and carer are experiencing living with MS.	This is an important node as it is coded from 18 of the interviews and has 75 references. For the OT it informs professional reasoning and this could be related to the conditional reasoning of (Mattling & Fleming, 1994). There is a clear link to the professional reasoning node. The OT's professional reasoning should be informed by the person with MS and to some degree also the carer's understanding of the condition through their diagnostic narrative. **Linkage:** 1.32 Anxiety 2.10 Meal preparation 2.16 Child rearing 2.11 Health management and maintenance 3.12 Professional reasoning 3.2 Fatigue management

Table 8. Framework Analysis Thematic Chart (continued)

Theme Category	Sources	References	Description	Interview/ data example	Memos	Comments Notes Annotations	Interpretation What is this about? Core Concept and Linkage
Category: **Fatigue**	18	95	The physical and processing limitation of lack of energy that is a major characteristic and symptom of Multiple Sclerosis. Fatigue impacts on endurance and sustained effort within an IADL task.	**Case 1 Person with MS:** "I will fall asleep ((click fingers)) like that I could literally just close my eyes and be asleep in five minutes." "...mental fatigue with me is as big as physical fatigue ... **Case 1 OT:** "because the early stages were taken up with looking at the fatigue...and I do have a tendency to look at that and not look at [pause] immediately at cognition or function because if you get the fatigue sorted everything starts to sort itself out. "... as an individual OT and as a team how we work is the fatigue is always dealt with first... when it's predominant and robbing of everything the OT goes in and does that and that whole programme of finding balance..." **Case 2 Carer;** "the fatigue was the biggest problem then...so Colette may get in from school and she'd be asleep...or things like just reading her a bedtime story..."		Fatigue is the most important of the symptoms that is part of living with MS. Impairment in ability to use energy robs the person of Occupational Performance in IADL. The occupational therapists recognise and realise how significant this is and prioritise their intervention towards managing fatigue.	Fatigue is the most important of the symptoms that is part of living with MS. Impairment in ability to use energy robs the person of Occupational Performance in IADL. The OTs recognise and realise how significant this is and prioritise their intervention towards managing fatigue. **Linkage:** 1.21 Calibrates 1.3 Psychological responses

Table 9. Framework Matrix Summary Spreadsheet

Core concept	1. Living with MS Understanding the impact of MS on the persons occupational performance ability and autonomy	2: The Occupations Individual meaning and value of activities	3: OT Interventions Steering towards adaptation, promoting occupational balance and match of occupational demand and occupational performance ability	4: Inter-relationships Utilizing significant people around the person with MS to enhance occupational performance
Themes	1.1. Diagnostic Narrative 1.2. Motor and Process Skills 1.3. Psychological response 1.4. Autonomy	2.1. Instrumental ADL 2.2. Mobility 2.3. Work 2.4. ADL 2.5. Leisure and special events	3.1. Therapeutic process 3.2. Fatigue management 3.3. Environmental interventions 3.4. Psychological interventions 3.5. Therapeutic relationship	4.1. Psychosocial relationships 4.2. Multidisciplinary team
Case 1 Michael	• Fatigue - mental and physical • Upper limb weakness • Mobility and stairs • AMPS	• Driving • Motor sport • Art/artist • Mobility • Care for wife • Care of pets	• Re-housing: occupational therapist facilitated navigation of social housing system to achieve forever home concept • Driving: Occupational therapist navigating services to enable continuity of driving with automatic car and review of driving licence • Fatigue management: Traffic light system	• Carer relationship of mutual support and partnership • Community social interactions on bus, negative experiences

3.10 Research quality

This section will discuss the issues and measures that were applied during the research process to ensure the quality and trustworthiness of the research findings. In qualitative research many forms of research quality are described. A consensus on the use of terminology for quality measures has not been achieved. Some authors reject the use of terms such as validity and reliability, as they are derived from the quantitative research paradigm. They argue these terms are inappropriate due to the differences in the epistemologies underlying quantitative and qualitative research methodologies (Lewis, Ritchie, Ormston, & Morrell, 2014). However, attempts have been made to operationalize concepts of validity and reliability for qualitative research (Robson & McCartan, 2016). Justification for the research quality will be structured around a critical view of the issues of research validity, reliability, rigour, and the generalizability of the findings. Key issues of the credibility and trustworthiness of the research will be discussed. The research quality in this mixed methods design is primarily viewed from a qualitative perspective but also considers AMPS as the quantitative element of the research. The process of reflexivity on behalf of the researcher is presented through critical reflexions of the research process. The influences on the researcher in relation to potential bias are presented in the discussion of reflexivity.

The validity of the research rests on the extent to which the research findings accurately represent the phenomenon under investigation (Seale, 2012). Three types of validity have been applied to qualitative research; measurement validity where measures secure the intended concepts, internal validity where evidence in the study support statement asserted, and external validity concerned with generalising to wider populations and settings (Lewis et al., 2014). Two forms of validation of qualitative research are commonly applied; respondent validation and triangulation (Silverman, 2011). The use of respondent validation by checking interpretation and meaning of data with participants was rejected for this research as causing an additional burden of time for participants. Triangulation or crystallisation, which reflects the complexity of the real world, (see section 3.4.3) strengthens the constructs analysed in the research process (Sandelowski, 1995). The different data sources aim to confirm and improve clarity of the findings. Criticism of triangulation has been made on the grounds of the difficulty of combining the data to produce an overall truth (Silverman, 2011). Care must be taken to use a single model such as the framework approach to analyse the data.

In examining the experiences and perceptions of occupational therapy interventions in IADL by people with MS, the research phenomenon has been considered from multiple perspectives. The first quality measure involved in the crystallisation process consisted of the differing methods of data collection utilized in the mixed methods element of the study. The

AMPS is a valid and reliable quantitative measure of occupational performance in IADL (see section 3.7.1). This was complemented by the semi-structure interviews, a questionnaire, and field notes. Other sources of data consist of an ongoing reflexive journal, annotations on data, and the linked memos made during the framework approach to data analysis. These multiple sources of information collected by these methods avoid the dangers of biases associated with a single methodological approach. The second quality measure consisted in the research design involving the perspectives of the different participant groups in the person with MS, the occupational therapist, the carer, and the HCPs within the case unit of analysis. This was particularly important where the person with MS may have issues with cognitive functions. The people with MS and carers were interviewed in their home settings which represented an ecologically relevant location to discuss the research phenomenon. The research site of a community-based team also ensured that the professional participants were drawn from a relevant and real world practice context adding to validity of the data collected. This ensured the integrity and relevance of the findings with occupational therapy practice. The third quality measure involved the use of the supervision team to critically check and verify the data analysis process. In the absence of co-researchers to discuss and challenge interpretations this acted as an audit of decisions within the framework approach to analysis. Finally, the use of the theoretical lens of person-centred care during data analysis, also strengthened the validity of the study.

The concept of rigour in qualitative research is concerned with the research process being transparent, conducted in a trustworthy manner, and producing credible findings (Finlay, 2006). This can be show through the transparency of the research process. The participant recruitment process (see section 3.6 and Figure 5) involved the use of gatekeepers in the form of the research and development department at the research site and their representative in the CNT. This procedure of using the external check of the gatekeeper ensured the research participants were drawn from an appropriate sample of the available people with MS. The transparency of the research design was ensured through use of the framework approach to data analysis and the use of CAQDAS in the form of NVivo software to manage data. The merits of the framework approach are detailed previously (see section 3.9.3.) This provided a systematic and structured analysis method to interrogate data to develop and justify descriptive and explanatory accounts. This approach involved transparent stages (see Figure 9), remained grounded in the data and supported analysis of multiple data sources (Spencer et al., 2014). In combination with NVivo as a data management tool this enabled the research journal, annotations, and memos to be linked to the data and easily searched. The use of NVivo and the framework analysis thematic chart (Table 8) and framework matrix summary spreadsheet (Table 9) facilitated critical scrutiny from the research supervision team.

Reliability in qualitative research is concerned with the coding of the data to the same category on different occasions or by differing observers (Lewis et al., 2014). Several procedural checks were taken to ensure the consistency and reliability of the findings during the research process. The use of audio-recording and verbatim transcription of all interviews gave an accurate representation of interview data (see section 3.9.3). The management of large volumes of data was facilitated by using NVivo software. The consistency of coding and the analytical framework was checked and critically challenged by the supervision team. The measures to demonstrate transparency also provided evidence of auditability during the participant recruitment process. A research site folder, containing the recruitment documents and research protocol was provided. This was accessible to the HRA and research and development department at the research site if requested.

In terms of the case study design of the research characteristics of an exemplary case study have been identified (Yin, 2014). These consist of the case study being significant, complete, taking into consideration alternative perspectives, and being engagingly composed. The extensive data collected from the five people with MS aimed towards completeness and being significant for the research phenomenon. The alternative perspectives are provided not only by the different perspectives of the people with MS, the carers, the occupational therapists, and the HCPs, but also the theoretical lens of person-centred care. The purpose of the case summaries in section 4.1 was to engage the reader by present each case unit of analysis in a realistic, vivid, and evocative manner (Rubin and Rubin, 2012). This gives the cases cohesion, context, and integrity whilst enabling an accessibility through the case narratives.

The importance of developing reflexivity as a skill for a practitioner-researcher undertaking a doctoral study has been emphasised (Lee, 2009; Finlay, 1998). Reflexivity involves critical reflection that is interrogative and analytical of the assumptions underlying practice and research (Lee, 2009). This is a familiar process as reflective practice is a key element in continuing professional development for occupational therapists (Alsop, 2002). A journal of reflective writing on the research process has been maintained throughout the doctoral process. Re-reading and analysis of this journal provides the basis for detailing the development process of the study. As an example of the use of the reflexive journal an extract follows, relating to the design, data collection process, and validity of interview data:

Friday 29th April 2016

> One issue of methodology I am interested in is the motivation of what somebody chooses to tell me. In particular the activities or occupations people tell me about. Are these the first things that come to mind, the recent things or are they considered over

> the three visits I have made to the people with MS. Do people talk about what they think is important and valued. I did try to design the questions to draw this out. There is a great skill in encouraging the interview participants to talk about the research topic without becoming side-tracked or distracted. I think this was achieved and rich relevant data was collected. I can see this now as the data is analysed.

This demonstrates the reflexivity process involved during the analytical process.

It is important to consider the relationship between the researcher and participants in qualitative research (Ormston et al., 2014). An acknowledgement of biases associated with the researcher that impact on the findings should be made. Reflecting on my position as an occupational therapy practitioner and a researcher identified a paradox in expertise. Professionally as a full-time clinical specialist occupational therapist practicing in a large tertiary hospital in an acute neurological rehabilitation setting, I had gained considerable practice experience. At the time of data collection, I had 24 years post graduate experience in clinical practice. This involved expert practice, research, audit, and teaching elements to my work role. Much of this time my clinical work had included people with MS. However, my clinical experience contrasted with the stage of being a novice researcher during the research process. On encountering the research site and data collection, my clinical experience enables me to speak with professional colleagues and in particular the occupational therapists as a peer. There were, however, tensions such as when discussing the separation of IADL (an element of the research phenomenon) from other occupations and activities. My own out-patient practice context differs greatly from the community context of the CNT.

It was useful to consider an ethnographic view of the degree to which I was an insider and an outsider in relation to the research (Robson & McCartan, 2016). As an experienced occupational therapist in neurological practice I brought clinical and professional knowledge of MS as a medical condition and rehabilitation for people with MS. From this perspective I could be viewed as a professional insider and professional peer to the CNT members. When considering the research setting of a community based team I was an outsider as I have not practiced in this context. My insights to community based practice in occupational therapy was limited to the interface between hospital and colleagues in community services. Despite being conveniently situated the research site was completely new to my experience. The occupational therapists were not known to me through my professional network. As a male occupational therapist in a predominantly female profession my gender also is a factor affecting my view of the research and involving biases. I had not met the individual members of the CNT before. It must also be acknowledged that my true insight into the experiences of the people with MS and caring for a person with MS is limited to a professional viewpoint.

The impact of my unique experience, characteristic, attributes, knowledge, and skills must also be acknowledged during the data analysis process. This contributes to my own perspective as a researcher in relation to the research phenomenon. During the framework analysis measures were taken to ensure reliability. Meetings took place with the supervision team to critically scrutinise and ensure the quality of the findings of the framework analysis.

Generalization from the findings of this research to other populations of people with MS and service settings is the final measure of quality to be consider. This is important for occupational therapy as a practice-based profession. Approaches to generalization in qualitative research are distinct from statistical generalization made between sample and universal population inferred in quantitative research (Yin, 2014). Two contexts for generalization in qualitative research have been proposed; empirical generalization and theoretical generalization (Lewis et al., 2014). Empirical generalization is concerned with the application of findings other populations, settings, and contexts. The term transferability of the research findings to other populations and settings beyond the sample is useful as this avoids confusion with statistical generalization. Transferability of findings depends on the congruence between the research context and the context of wider services. Theoretical generalization is grounded in the general application of theoretical statements, propositions and principles derived from the research findings.

Claims for transferability of the research findings from the five people with MS and the interventions provided by the occupational therapists in the CNT rest on the quality measures of validity, rigour, and reliability discussed above. The quality measures act as safeguards by using multiple viewpoints and the crystallization process to produce findings, adopting an ecologically valid context for the research in a community based service, acknowledging biases through the process of reflexivity, and using the framework approach to analysis in conjunction with NVivo software to manage a large data set. The rigorous research process is able to demonstrate how assertions and propositions were derived and justify the credibility and trustworthiness of the research findings.

3.11 Summary

This chapter has presented methodology, research design and methods of the study. The background service context of the community neurology team was briefly introduced. The joint philosophical influences of pragmatism and critical realism on the development of the research design and theoretical lens of person-centred care identified. The methods applied during the data collection and analysis stages have also been describe and justified. Several possible

alternative research methodologies drawn from quantitative and qualitative traditions were considered and justification given for their rejection. The methodology chosen consisted of a rigorous multiple case study aimed at exploring the experiences and perceptions of occupational therapy interventions for people with MS within IADL in the real world context of the home and wider community.

The methods applied during the data collection and analysis stages have also been describe and justified in this chapter. The process of gaining ethical approval and access to the research site has been explained and ethical issues associated with the research discussed. The practical application of the recruitment process employed in sampling the five people with MS has been demonstrated. Justification for the use of multiple data collection methods of AMPS, semi-structured interviews, field notes, and a questionnaire, within the case study unit of analysis has been given. Data collection took place over three stages. A pilot stage tested the data collection process. This was followed by a multiple case stage of four people with MS and a third stage of interviews with HCPs. The data analysis process involved NVivo software to manage large volumes of data from the varied data sources and methods. A framework approach to analysis systematically identified descriptive and explanatory explanations to produce four core concepts containing themes. The final section of the chapter discussed the measures taken to ensure the quality of the research process. The following chapter will present the research findings that emerged from the data through case summaries of the five people with MS, the findings of the framework analysis and the practice model that emerged as a synthesis of the findings.

Chapter Four

Findings

4. Introduction

The previous chapters of this thesis have set out the background context to research of occupational therapy interventions within IADL for people with MS, critically reviewed the relevant research studies and demonstrated the methodological influences and methods employed in this multiple case study incorporating mixed methods. This chapter presents the research findings of this exploration into the experiences and perceptions of occupational therapy interventions for people with MS within IADL. The chapter is structured with the aims of meeting the research objectives detailed in Chapter Two: Section 2.5 and answering the research question:

> *How do occupational therapy interventions contribute to the ability of people with MS to perform IADL?*

The five people with MS who form the case study units of analysis of the research are introduced through case summaries detailing their social and occupational background, impact of MS on IADL occupations and how occupational therapy interventions influence IADL performance. The AMPS benchmark measurement of ability in IADL is represented for each case and integrated into the findings. The findings of the overall framework analysis will be present detailing the four core concepts identified of the Person Living with MS, the Occupations, Occupational Therapy Interventions for people with MS and Inter-relationships. The linkages between the core concepts and themes are illustrated in table form. Finally, the MS-PcOT practice model is presented as a synthesis of the research findings to guiding occupational therapy practice for people with MS.

4.1 Case summaries

In framework analysis case summaries are used as a step towards the end of the data management process and subsequently in the development of descriptive and explanatory accounts (Spencer et al., 2014). The case summaries presented in this section were integral to the development of the framework analysis and were iteratively produced in parallel during the analysis process. The case summaries aim to portray the lives and experiences of the people with MS. The case summaries also give narratives to the reporting of the multiple case study based around the person with MS as the unit of analysis. The case summaries illustrate

not only the issues people with MS encounter in participating in IADL in rich, vivid, and nuanced detail, but also the experiences and perceptions of the occupational therapy interventions (Rubin & Rubin, 2012).

The contents of these case summaries were developed as part of the process of charting into the framework matrix as explanatory accounts. The case summaries include descriptions of the social and family background of the people with MS, their medical details, the impact of MS on occupational performance, IADLs they participate in, and the occupational therapy interventions they received. The structure of the summaries was also mapped from the core concept of the framework analysis. The case summaries aim to give a thorough and vivid description and explanation of how occupational therapy interventions support the people with MS in their IADL in their personal contexts. These narratives aim to present the contrasting and common experiences of the people with MS and their responses to disruptions in occupational performance in IADL. The role that occupational therapy interventions play in counter acting these disruptions is also explained.

Appendix 7 provides a guide to the pseudonyms used in each case. All the names of the people with MS, their carers, family, and health care professionals were anonymised for reasons of confidentiality to protect the identity of participants. Throughout this chapter a convention for the identification of quotes related to interview source data is case number, participant, and line in data source from the NVivo software e.g. Case 1 Person with MS: 608. Charts were generated for each case to provide an overview of the important topics raised in data sources (Bazeley & Jackson, 2013).

4.1.1 Five people with MS

Table 10 gives background biographical and attribute information on each of the five people with MS who participated in the research. The ages of the people with MS ranged from 36 – 53 years and represents early to mid-adulthood (Cronin & Mandich, 2004). Three of the cases had relapsing remitting type MS and two had secondary progressive MS. The time period since diagnosis ranging from one year to 14 years. The episodes of occupational therapy interventions ranged from one ongoing episode to over six episodes for two of the people. Three of the people had university degree level education and two secondary school level. Only Paul was working in paid employment as an engineer in the dust extraction systems industry. The work and professional background of the other cases was Michael (Case 1) artist, Lisa (Case 2) teacher and antiques dealer, Diane (Case 3) IT professional in the financial sector and Caroline (Case 5) IT professional in the insurance sector.

Table 10. Case Details and Attributes

Pseudonym	Age	MS	OT Interventions	Education	Previous/current work
Case 1 Michael	36	SPMS 2010	4 episodes (OT)	Secondary school	Artist/Motor sport
Case 2 Lisa	53	RRMS 2002	6-10 episodes (full notes not available)	Art History degree	Teacher, antiques dealer
Case 3 Diane	51	RRMS 2014	One ongoing episode	Maths degree	IT professional (solutions architect), banking sector, Previous maths teacher
Case 4 Paul	46	RRMS 2008	4 episodes (OT)	Secondary school	Engineer - dust extraction systems
Case 5 Caroline	38	SPMS 2001	6-10 episodes (full notes not available)	University degree	IT professional - insurance sector

Table 11 shows the duration of each interview and total number of coding references made for each interview. This provides an overview of the important topics and issues expressed in each data source for the cases (Bazeley & Jackson, 2013). For Michael, Lisa, and Diane, the first three cases the interviews for the person with MS and the occupational therapist lasted for approximately an hour. The coding reference totals for Michael were (675), Lisa (671) and Diane (704). The interviews with the carers in these three cases were shorter except for Diane. The interview durations for Paul and Caroline were generally shorter in duration except for the occupational therapist interview for Caroline. The coding reference totals for Paul (309) and Caroline (274) were also much smaller in volume than the other cases. This reflected the shorter duration of the interviews, the interview questions associated with IADL being of less relevance to their lifestyles and the individual's level of occupational performance. Paul was

Table 11. Interview Duration and Coding Reference Totals

Case	Person with MS	Occupational Therapist	Carer	Total
1. Michael	226 56 minutes	283 59 minutes	166 43 minutes	675
2. Lisa	231 55 minutes	288 69 minutes	152 39 minutes	671
3. Diane	231 65 minutes	280 49 minutes	193 57 minutes	704
4. Paul	133 33 minutes	100 34 minutes	76 26 minutes	309
5. Caroline	81 38 minutes	102 61 minutes	91 46 minutes	274

notable the most able in performance of IADL and Caroline the least able due to the impact of MS. The following case summaries will highlight that Paul lifestyle is more geared towards work and leisure occupations than IADL.

4.1.2 Case 1 Michael

Michael is a 36-year-old married man who lives with his wife Jennifer. He is an artist who uses an upstairs room as a studio in their semi-detached house. Michael displays his own pictures in the living room. He has a strong interest in motor sport and in particular Formula One racing. During his interview Michael was articulate and contributed thoughtful opinions and perceptions of the impact of MS on his ability to perform IADL and his occupational therapy interventions. At times in the interview Michael expressed strong personal views with a degree of humour.

Michael had recently launched his own business when he was diagnosed with MS in 2010. Subsequently he developed the secondary progressive MS with a spinal presentation of the condition. MS impacts on Michael's occupational performance in three main ways 1) fatigue and tiredness 2) reduced mobility and ability to negotiate stairs 3) Upper limb weakness and difficulty calibrating grasp pressure resulting in difficulty handling objects during tasks. Michael had a period of low mood which affected his motivation to engage in occupations. The CNT has made five episodes of multi-disciplinary intervention with occupational therapy featuring prominently.

Fatigue was a key problem for Michael:

> I will fall asleep ((click fingers)) like that I could literally just close my eyes and be asleep in five minutes. (Case 1 Person with MS: 608)

He also distinguishes types of fatigue:

> ... mental fatigue with me is as big as physical fatigue ... (Case 1 Person with MS: 732)

Michael and Jennifer moved to a new house from their previous home in a cottage in another part of the district. This was necessitated by Michael's increasing difficulty negotiating stairs. Their current house has a stair lift installed which Michael uses to access the upstairs rooms.

Michael and Jennifer manage their IADL as a partnership. Driving continues to be an important occupation for Michael. He found a period when he was unable to drive, and they relied on public transport, particularly difficult and challenging. Following an assessment at the regional driving and mobility centre however, Michael was able to resume driving with an automatic car and the limitation of a review period for his driving licence. Shopping outings are made by them both to a large supermarket in the town centre but are limited by Michael's fatigue.

Jennifer has her own medical issues which involve appointments with HCPs. Michael drives Jennifer to these appointments and has his own role as a carer for her. Jennifer has also had interventions by the CNT which has included fatigue management.

Caring for two pet cats is an important IADL for both Michael and Jennifer. Michael chose feeding a cat as one of the AMPS tasks. He also likes to cook but finds some tasks unsafe and too dangerous to attempt. This is due to his motor skills deficits which make lifting, grasping, and handling knives, pans, and other utensils difficult. Michael chose to make coffee as his second AMPS task. The AMPS measure of ADL motor ability showed Michael to have moderate to marked clumsiness and increased physical effort or fatigue during the assessment tasks. His ADL Process measure indicated a questionable to mild inefficiency and disorganization. Table 12 gives details of the AMPS findings for Michael and further discussion is made in Section 4.2.

Starting the occupational therapy Interventions with Michael was a challenge. Karen, the occupational therapist, had to help Michael overcome the period of low mood that made it difficult for him to engage in any occupations including IADL. At this stage Michael was experiencing a grief process as he realised the impairment associated with MS were having a significant impact on his occupational performance ability. Michael was counselled and encouraged to engage in his artwork and creativity. This in turn permitted a key series of interventions aimed at helping Michael to manage his fatigue. The four stage program devised by Karen consisted of 1) listen to your body to identify how MS affect the person 2) a week of diary recording of activities and fatigue levels using a fuel tank metaphor which allows the occupational therapist to identify a personalised traffic light system of assessing fatigue 3) Identify life principles and the important occupations 4) Live in the moment and maintain energy levels.

The importance of the fatigue management program for Michael was identified by Karen:

> The fatigue management allowed him the space to go back to making meals, driving, caring for his wife, shopping, caring for his pets (cats), driving especially needed to drive wife to appointments ... (Case 1 OT Questionnaire: 049)

Michael confirmed the utility of the fatigue management programme:

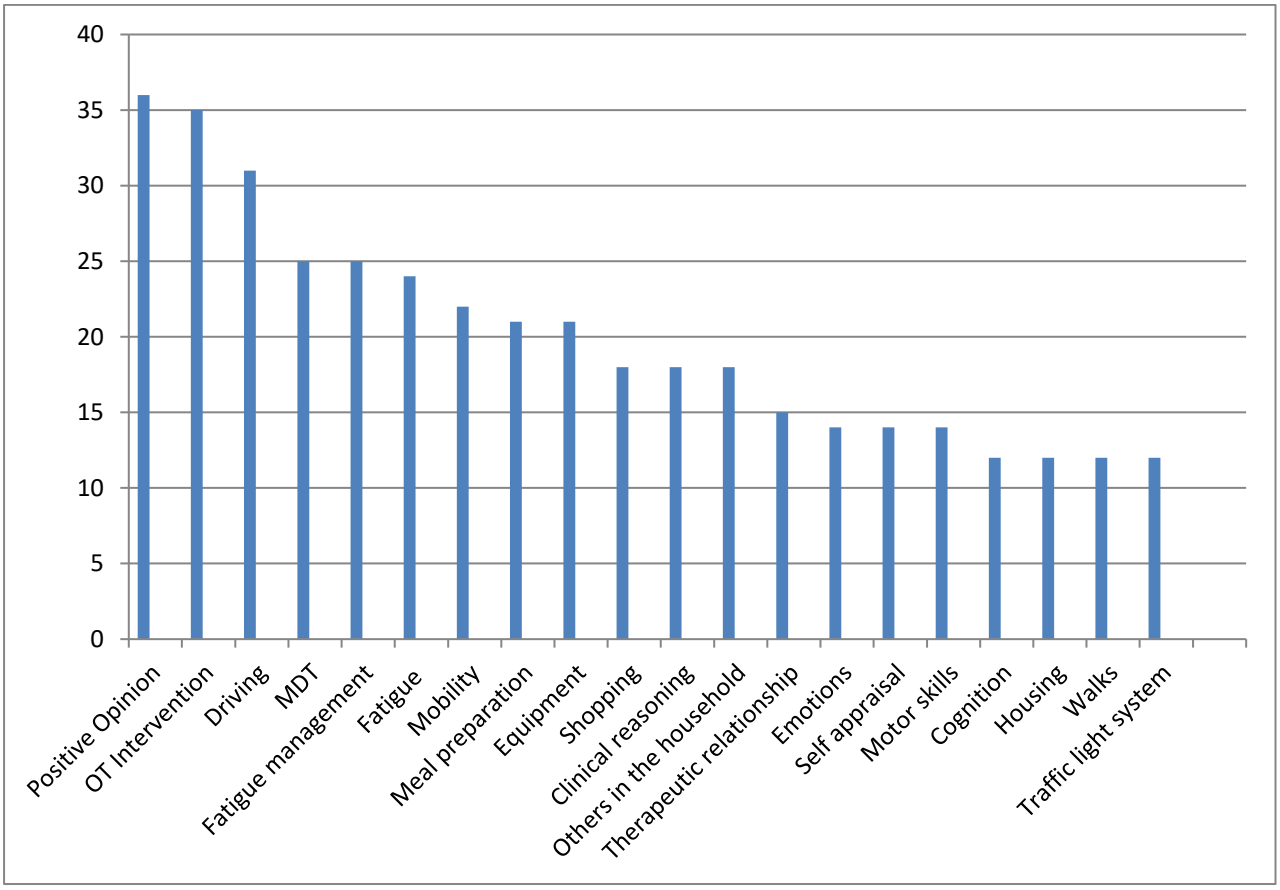
> the traffic light system we use it just every day. It's just become automatic now (Case 1: 633)

It was clear that Karen was also influential in the process of re-housing Michael and Jennifer by navigating the various services required to achieve the concept of a “forever home” for them. Installation of adaptations, such as the stair lift made the home fully accessible for

Michael. Empowering Michael to find solutions to practical problems was also part of the occupational therapy interventions. An example of this was identifying kitchen equipment through the internet and adapting recipes by the substitution of pre-prepared onions to avoid chopping tasks. Supporting Michael to continue driving again through navigating the services to provide a suitably adapted car and meet parking needs were also key interventions.

Figure 12 shows the twenty most frequently referenced categories for the coding of Michael's case. This is reflected in the case summary and representing 59% of the total coding. Occupations of driving, mobility, meal preparation, and shopping were prominent. Fatigue was the most prominent factor in living with MS with fatigue management and equipment significant occupational therapy interventions.

Figure 12. Michael (Case 1) Coding Frequency



4.1.3 Case 2 Lisa

Lisa is a 53-year-old woman married to David and has three children; two sons and a younger daughter all of whom are in full-time education at university and secondary school. Her professional background is of having worked as a teacher of English as a foreign language following graduation from university with a degree in art history. Lisa and David retain their interest in art and culture and express this through collecting antiques and the style of their home. The family enjoy regular holidays at their cottage in France. They also had been in business as antiques dealers and continue to visit antique fairs. David works as a part-time teacher. Lisa and her family moved to their current home five years ago. The Victorian period town house has been adapted to provide a ground floor apartment with bedroom and bathroom facilities to meet Lisa's needs. The children's bedrooms are situated upstairs and are not accessible to Lisa.

Lisa was diagnosed with MS in 2002 and has the relapsing-remitting form of the condition. Five years ago, she sustained a hip fracture following a fall and has experienced a gradual deterioration in her physical and cognitive ability. A right sided weakness results in Lisa experiencing difficulty with balance, mobility, and grasp. She is unable to hold a knife to cut during kitchen tasks. Lisa also experiences cognitive impairments that impact upon her processing skills. In her interview Lisa is open about her "butterfly mind" and finds the memory difficulties annoying and frustrating. This cognitive impairment was evident during the interview as Lisa experienced word finding difficulties.

Lisa chose gardening tasks for the AMPS, re-potting a small houseplant and watering plants and removing dead leaves. The AMPS measure of ADL motor ability showed Lisa to have moderate to marked clumsiness and/or increased physical effort or fatigue during ADL task performance. Her ADL process measure indicated mild to moderate inefficiency of time-space disorganisation during ADL task performance. Table 12 gives details of the AMPS findings for Lisa and further discussion is made in Section 4.2.

Lisa employs Helen as a personal assistant and carer to support her in IADL tasks such as shopping, cooking, and gardening. This is at times when David is out of the home at work. Lisa had previously been an enthusiastic and accomplished cook. David describes Lisa as:

> [a] really good cook...she used to love cooking (Case 2 Carer: 077)

She enjoyed entertaining friends as a dinner party host. She would keep a pile of cookery books on her bedside table for reference. Cooking tasks, however, became increasingly difficult as safety issues such as burns, garments catching fire and risk of falls occurred. Lisa has maintained her participation in cooking and uses her knowledge to direct Helen to carry

out cooking task to prepare family meals. Helen accompanies Lisa on extended shopping trips, assisting in preparing a shopping list, the practicalities in the shop and time management. Lisa stressed the importance of meeting people and the social aspects of shopping:

> I want to do it. I don't want to be a person that ... somebody just comes and does the shopping ... I just ... want to be as involved as I can (Case 2: 349)

When the family arrived at the home the garden consisted of mainly grass stretching for approximately 100 meters to the rear of the house. Since this time Lisa's interest in gardening has grown. The outdoor space has been transformed into a wonderful garden seen at its best in summer during the data collection. Gardening has become an occupation for Lisa to channel a new creativity. It has provided vision and purpose through the design of the garden and tasks involved in growing the plants. Raised beds and accessible paths enable Lisa to garden using equipment and with the support of Helen. House plants and seed trays are situated on windowsills inside the house. The occupation of gardening has assumed a primacy previously held by cooking. Lisa now has a pile of gardening books at the bedside. David sees the gardening as a series of activities that Lisa can participate in:

> ...there's a lot of involvement there that she can do (Case 2 Carer: 642)

Lisa has received more than six episodes of care over several years from the CNT. A continuity of occupational therapy intervention and relationship with Karen has been maintained over this period with the most recent episode taking place within a month of the data collection. Lisa has a trusting relationship with Karen and considered her to be an expert. The occupational therapy interventions go beyond this therapist client relationship and subtly involve collaborative teamwork in partnership with David and Helen. Karen describes how:

> over the years this is the subtle things we've done [pause] … as a team of her husband, me and her. (Case 2 OT: 162)

Meeting the demands of caring for the family at times has been a challenge for Lisa. When the children were younger the impact of the fatigue associated with MS was more significant. The fatigue management interventions from Karen addressed difficult situation such as oversleeping at the time of collecting her daughter from school:

> so I was able to go and get Colette from nursery ... and I didn't over sleep because the over sleeping upset me ... because I felt I was being a rubbish mother (Case 2: 749)

Provision of equipment and adaptation of the home environment forms a key series of occupational therapy interventions in conjunction with the MDT. Lisa is mobile in the home with a three-wheel folding walker with which she can walk and transport items. Lisa was given

a mobility scooter and uses this to access the garden via a ramp from the kitchen engineered by the REMAP charity organisation. Karen's careful selection of a four wheeled walker with a toolbox under the seat has been instrumental in enabling Lisa to safely engage in gardening task out of doors:

> it's really her mobility that ... is I think the ... biggest blurring symptom that really makes life hard for Lisa ... (Case 2 OT: 116)

The safety issue and concerns regarding the risk of Lisa falling were prominent and ongoing.

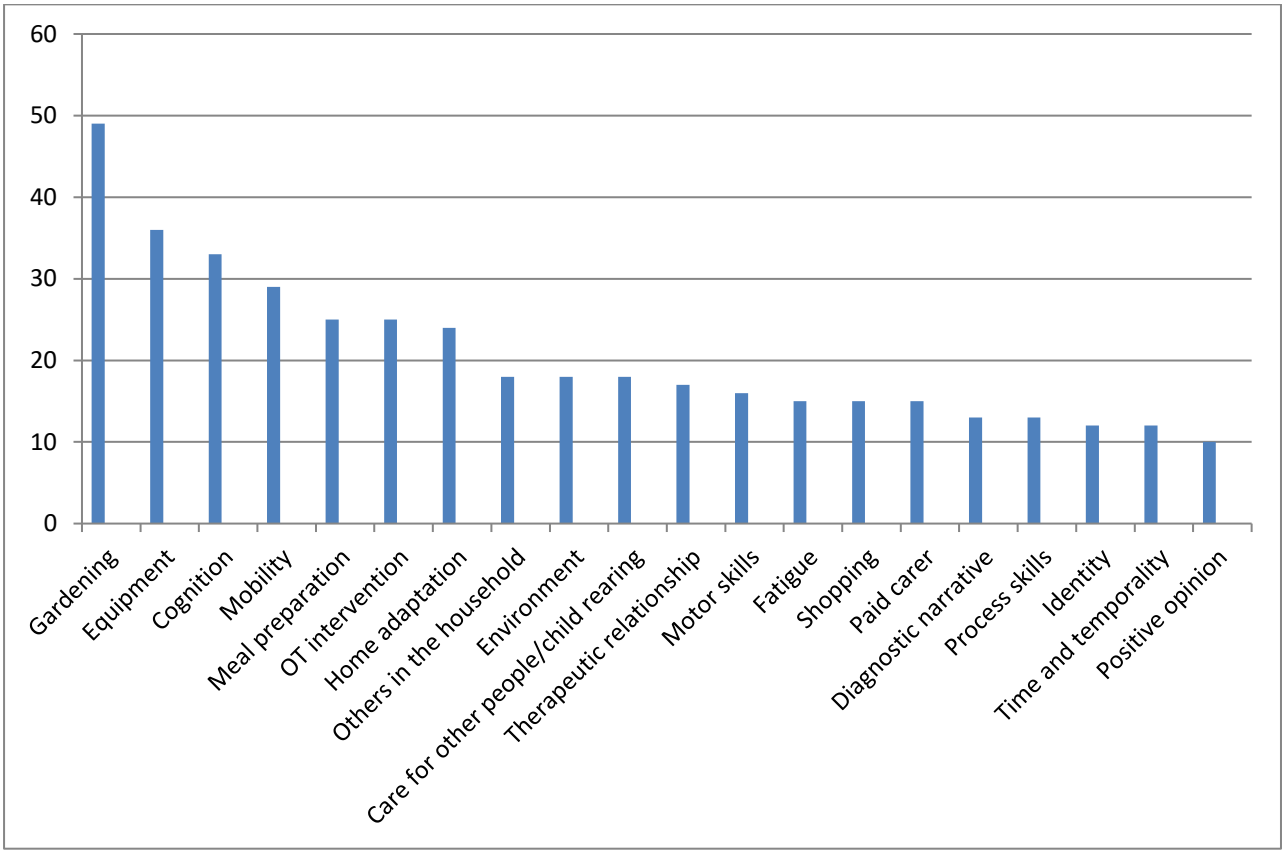
Karen employed cognitive rehabilitation strategies which included use of sticky notes as reminders and a diary to organise and schedule appointments and maintain engagement with HCPs. At one stage the hallway became excessively cluttered with antiques and this caused concern to the MDT with regards to the risk of Lisa falling. Karen suggested using this as an opportunity to create an event over a weekend where family and friends could assist to clear, sort and tidy the home:

> it was a little serendipitous moment which is what a lot of the stuff …
>
> (Case 2 OT: 659)

This was a great success with the outcome of creating a safer environment for Lisa. The occupational therapy intervention was also aimed at developing Lisa's awareness of the limitations of her cognitive function and developing her skills in instructing and directing of people and crucially Helen, her paid carer, in collaboratively engaging in shopping, cooking, and gardening tasks.

Figure 13 represents the twenty most frequently referenced categories for the coding of Lisa's case. This represents 61.5% of the total codes identified. In the interviews the occupations of, gardening, mobility, meal preparation, shopping and child rearing were most common. The categories associated with living with MS, cognition and fatigue were prominent with occupational therapy interventions of equipment and home adaptation spoken of in the interviews. Relationships with others in the household and paid carer were also important.

Figure 13. Lisa (Case 2) Coding Frequency



4.1.4 Case 3 Diane

Diane is a 51-year-old woman married to Mark and has two sons at the later stages of secondary school. They live in a semi-detached house on a suburban estate. Prior to being diagnosed with MS a year ago Diane was a fit and active person working full-time in a demanding professional job in the financial sector. After graduating with a maths degree Diane had taught prior to undertaking a successful career as a highly skilled IT designer and programmer of financial software. Her work involved a daily commute by bus and train to the regional city. Gemma the occupational therapist explains the demands of Diane's work:

> Diane's job in she worked for ... [financial institution] ... so the job was in IT she ... [was] very senior she, actually built the programmes that you would use for banking software so her level of IT skills were extremely high (Case 3 OT: 410)

The importance and significance of Diane's work was confirmed by Mark:

> ... she desperately wanted to go back to work (Case 3 Carer: 764)

Mark works as a secondary school teacher. Diane had previously enjoyed running and family outings walking in the local National Park.

Diane was diagnosed with Relapsing-Remitting MS a year ago and is the person with the most recent diagnosis of the five cases. Diane had also experienced the notable stress in the lead up to her diagnosis of the bereavement of her mother in difficult circumstances. Two features of the presentation of MS have had a significant impact on Diane's occupational performance. Optic neuritis had a severe effect on Diane's vision; she describes her blurred vision as likened to being in a steam room or looking through net curtains. She needed time to adjust to light levels, for example when entering a room, it may take 30 minutes for her vision to adjust. Uhthoff's syndrome was also identified where the person's body has difficulty regulating temperature and causing fluctuations and exacerbations of symptoms. For Diane this makes life unpredictable:

> I can never tell what I'm going to be like each day (Case 3: 374)

Fatigue was also a major limiting factor which Diane first recognised when on holiday. Mark illustrated this:

> so you can't predict ... [Diane] can go to bed have ten hours sleep and wake up and say I'm tired. (Case 3 Carer: 046)
>
> and
>
> It's [the] normal everyday activities make you fatigued. (Case 3 Carer: 567)

Problems with balance also affected her mobility. Mark describes the "double whammy" of visual and balance problems that led to Diane experiencing a lack of confidence. Her response was to be fearful and frustrated which led to a high level of anxiety. There is a great contrast between Diane's previous busy work life and current new home life where IADL has become much more significant as a group of occupations. A shift in occupational balance had been forced on Diane by the changed circumstances as Mark explained:

> She was suddenly left at home ... her world suddenly shrunk (Case 3 Carer: 201)

Naturally with Diane's professional background continuing to use information technologies was important in the home setting. She found that her vision was better later in the evening so saved emails to read and reply to at this time. There was the paradox however, of this been a time when fatigue was also more problematic. Diane's role as a parent for her sons was also affected. She found advising on homework more difficult and it necessary to teach them new skills:

> I've got fifteen and a seventeen year old ... boys ... should have trained them up sooner you know but they'll be like lifting the hover upstairs ... they're very good now they will do the bath I've taught them how to mop the kitchen floor but ... you think something so easy it's actually ... (Case 3 Person with MS: 340).

In the kitchen Diane had to adjust as a response to safety issues such as breaking glasses, cuts from knives, and burns from the cooker. She had to learn to recognise her own limits in IADL. Diane describes how she responded to this:

> I probably learned to make adjustments (Case 3: 428)

Finding a good time to carrying out a task was important so Diane could optimise her vision and minimise her fatigue. Diane chose to make vegetable soup and iron a shirt for the AMPS tasks. Following the first AMPS task Diane demonstrated the cooling jacket she uses to manage the impact of Uhthoff's syndrome on her body temperature. Table 12 gives details of the AMPS findings for Diane and further discussion is made in Section 4.2. The AMPS measure of ADL motor ability demonstrated mild to moderate clumsiness and or increased physical effort or fatigue during ADL task performance. The ADL process measure for Diane indicated questionable to mild inefficiency and disorganisation. This outcome clearly demonstrated and confirmed the impact of her visual impairment on her process skills. However, Diane's attitude to IADL remained constructive:

> it's just important to feel I'm contributing (Case 3: 408)

Mobility was important to Diane. She valued the independence of driving and would go jogging prior to MS. As she was unable to drive, Diane became reliant on others for her community mobility in the form of lifts and being accompanied when going out. Together with the high level of anxiety the impact on her independence and autonomy was significant. Going into the town centre to shop using the bus had become a challenge Diane was unable to be confident about. She also would struggle to see the digits when making a card transaction when shopping.

The course of occupational therapy intervention had been ongoing since Diane was referred. Over the period of a year Diane had the continuity of Gemma as the occupational therapist. Gemma identified that an important element of her intervention had been listening to Diane and counselling her in the emotions and coming to terms with her changed occupational circumstances:

> I was the first professional to sit down and spend a period of time allowing Diane to express how she felt (Case 3 OT: 240)

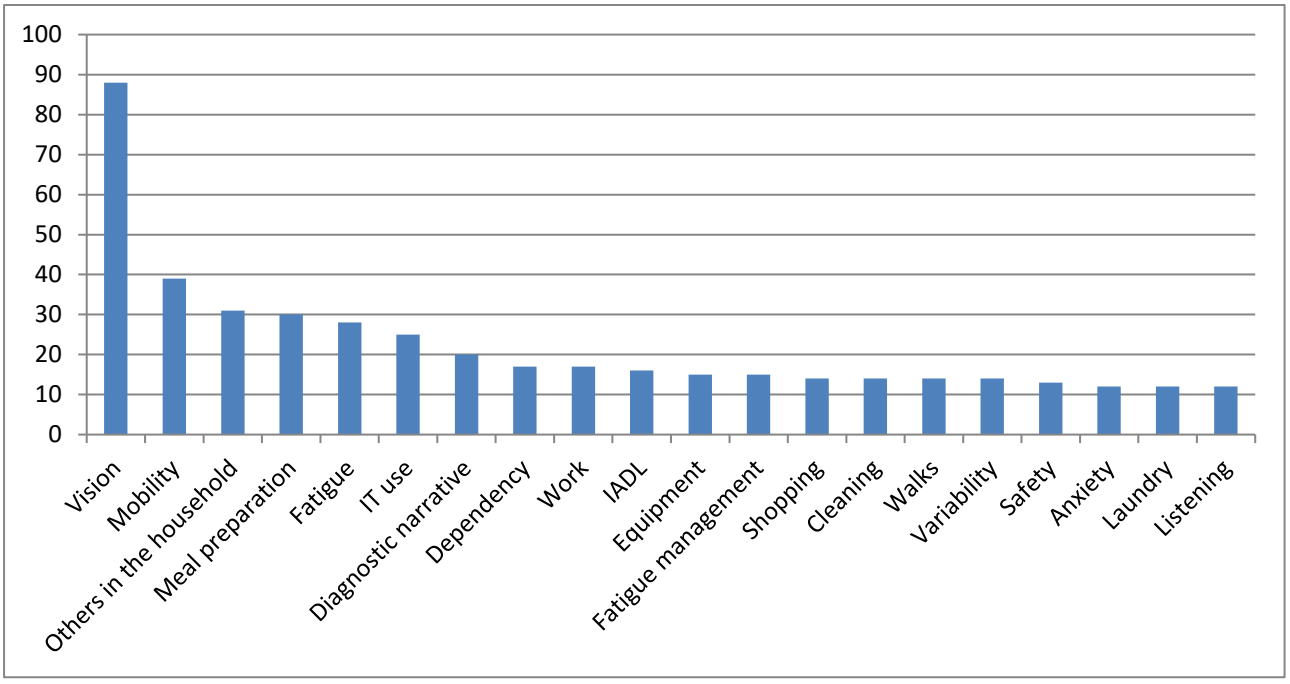
To mitigate the effects of Uhthoff's syndrome the CNT had suggested Diane try a cooling jacket which contained compartments for ice blocks. Gemma was instrumental in referring, navigating, and liaising with the local and regional network of visual impairment services. Indeed, Diane worked with the visual impairment officer to program apps and accessible functions for her mobile phone and laptop computer. Diane found the magnification software

on her mobile phone most useful. Gemma arranged some conventional high visibility markings for example on the cooker controls. The occupational therapist also encouraged Diane with the support of Mark to find their own solutions to the problems they encountered in IADL:

> ... adaptations are ongoing we just sort of come up with them from what people have said what we have read and you have to adapt it to suit your own sort of life style (Case 3 Carer: 914)

Figure 14 represents the coding frequency for the whole case for Diane. The 20 most frequent coding categories represent 63.4% of the 704 codes identified. Vision represents by far the most frequently coded category and was clearly the most problematic aspect for Diane of living with MS although fatigue and anxiety were also important factors. The occupations of value to Diane were her mobility, IT use, her previous work, and meal preparation. Fatigue management and occupational therapy interventions connected to equipment were also notable.

Figure 14. Diane (Case 3) Coding Frequency



4.1.5 Case 4 Paul

Paul is a 46-year-old man who is engaged to Nicola. He works as an engineer in a factory for a company that fabricates dust extraction systems. They live in a modern house on a steep hillside. Paul is an enthusiastic sportsman having played football and cricket at a high standard. He continues his sporting interest through a coaching role for the local junior

cricketers. He also enjoys visiting the social club in the village with Nicola and maintains his network of friendships with the lads from the football team. Nicola works in the tourism industry. Before meeting Nicola, Paul had a period of lived alone which he found much harder.

In 2008 Paul was diagnosed with MS and currently has the relapsing-remitting form of the condition. He realised his walking was affected during a weekend away with friends walking in a national park. At the time of the interviews and data collection it had been 18 months since he had experienced a relapse. The most important symptom of MS for Paul is fatigue. Paul is a quiet person and self-deprecating with Karen describing:

> his context is [pause] an incredible anxious person ... so because he's quite private and doesn't show a lot of himself (Case 4 OT: 185)

He was initially anxious and low in confidence when the CNT became involved in his care. To some extent Paul's symptoms are hidden as the Physiotherapist explains:

> he's got quite a few silent symptoms actually he's got more problems with restless legs at night and fatigue whereas actually when you see him he's quite good. (Physiotherapist: 124)

Although IADL do not form the most important area of occupations there are still IADL occupations that Paul engages in. Paul chose to make a sandwich and vacuumed the living room with a lightweight vacuum cleaner as the AMPS tasks. When Paul arrives home from work he will make a sandwich for himself as Nicola sometimes comes home later. Nicola ensures the kitchen is well organised and this facilitates Paul's occupational performance in this environment. The outcome of the AMPS for motor ability showed mild to moderate clumsiness and/or increased physical effort or fatigue was observed during the two tasks. The ADL Process measure for Paul indicated questionable inefficiency and disorganization of time and space during ADL task performance. Table 12 gives details of the AMPS findings for Paul and further discussion is made in Section 4.2.

Paul also completes other IADL tasks such as cleaning the bathroom as Nicola has an allergic reaction to cleaning products. It can be seen that IADL roles are shared as a partnership in the household. In the garden Paul cuts the lawn and undertakes DIY projects such as constructing a fence with his brother who is also an engineer. Nicola supports Paul when doing IADL at home and has insight into his abilities:

> I know what he can do and [... you know] I fill the gaps (Case 4 Carer: 199)

At times Nicola also feels she provides a safety net for Paul though for example making sure kitchen cupboards remain tidy and the organisation of house and car keys. Paul drives to his work in the local town.

Karen the occupational therapist in the CNT has been involved in four episodes of intervention with Paul. These have been primarily to enable him to continue working in a full-time capacity which has been paramount for Paul. The focus of interventions has been directed to the delivery of the fatigue management program in the context of work:

> I treated him in the workplace ... work was it for him (Case 4 OT: 226)

The other major consideration for Paul has been addressing the impact of his anxiety and low level of confidence. IADLs have been facilitated through the fatigue management program providing a balance of occupations and contribute the energy for occupational performance when Paul is not at work.

To progress the fatigue management program Karen had to negotiate through an initial barrier:

> [it] took us quite [a] number of weeks really for him to start to be honest about how he felt (Case 4 OT: 474)

Paul indicating that he struggled previously to acknowledge the impact of his MS:

> [I] Stuck my head in the sand (Case 4: 357)

Building a trusting therapeutic relationship with Paul has been prolonged and ongoing element of Karen's intervention:

> he's [only] really let anyone through the door ... in the last eighteen months (Case 4 OT: 084)

Progression with the fatigue management programme for Paul was also relatively slow. Karen needed to allow Paul to go at his own pace. In the past Paul had become fatigued due to the overtime he would work:

> you've got to be mindful of work life balance ... cause I don't do overtime now. Cause of obviously my fatigue ... Well if I'm going to do something like the garden I've got to set things in place for make sure you've had rested and you've got enough energy levels to do the task cause if you haven't got the energy levels to do the task it's pointless doing it (Case 3 Person with MS:203)

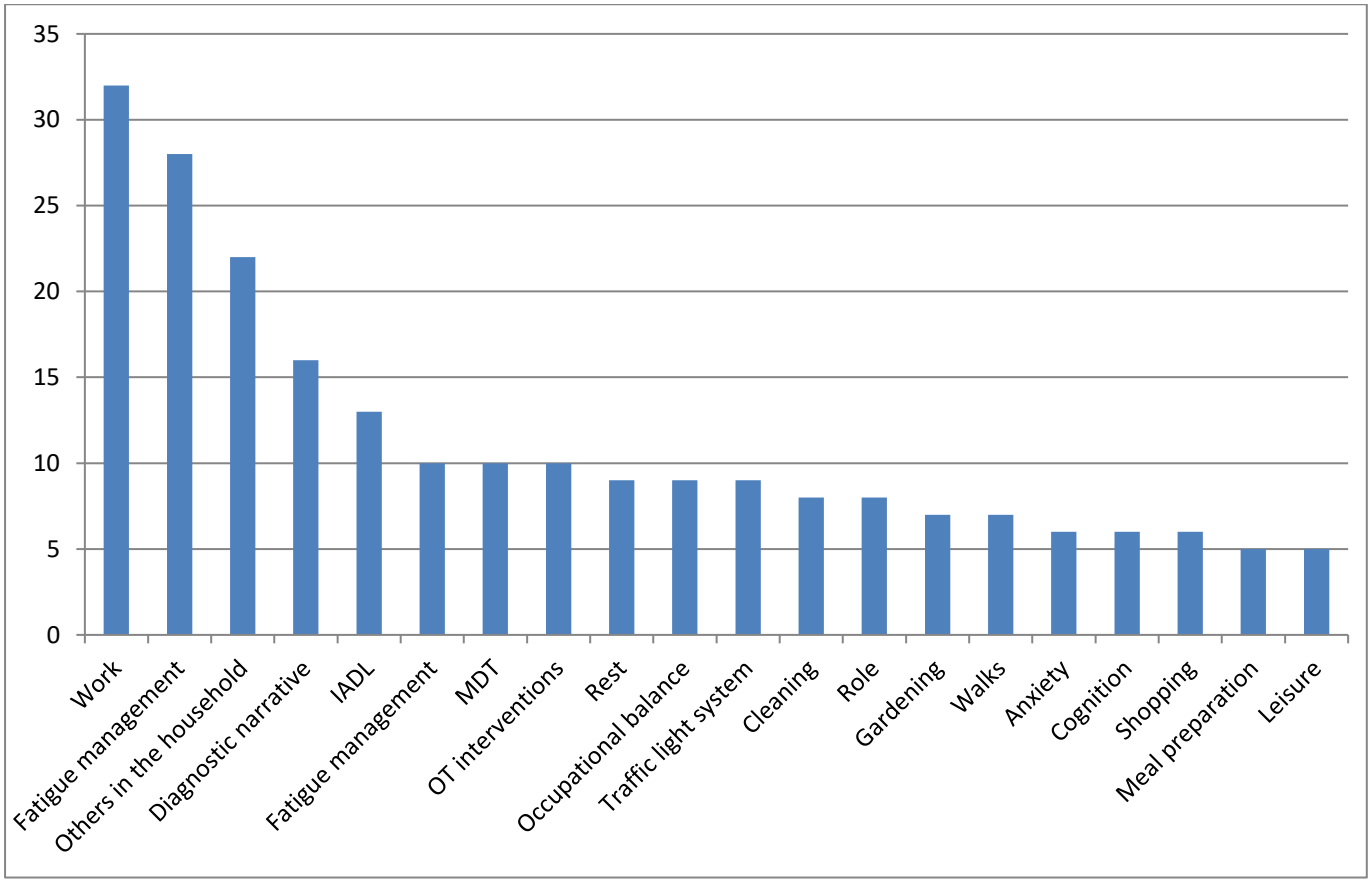
The fatigue management programme had helped him to decline offers of overtime and to pre-emptively take annual leave if he was tired in order to rest. At home Paul can pace his performance in IADL by taking rest period and not overexerting himself. Paul is much more open about how MS impacts on his occupations and Nicola plays here role in monitoring the situation:

> He can't hide anything from me anymore (Case 4 Carer: 488) and we know his limits (Case 4 Carer: 500)

Although occupations such as work and sport are more important and valued by Paul he does have a supporting role with Nicola in IADL. The occupational therapy interventions have not been primarily directed towards IADLs. However, the strategies gained from the fatigue management programme have been greatly beneficial in enabling a balance of participation in work, leisure and IADL.

Figure 15 represents the coding frequency for the whole case for Paul. The 20 most frequent coding categories represent 73.1% of the 309 codes identified. Work and occupational therapy interventions related to fatigue management with the support of Nicola (others in the household) are the most important coding categories.

Figure 15. Paul (Case 4) Coding Frequency



4.1.6 Case 5 Caroline

Caroline is a 38 year old woman who lives with her husband James and two children who attend infant and junior school. The family are supported by Caroline's retired parents who live in the neighbourhood having relocated from another part of the country in 2008. Caroline completed a university degree and worked as an IT professional for a law firm. In 2006 she

moved to the insurance industry and worked as a highly skilled planning and forecast analyst. Until retiring a year ago Caroline had continued to work full-time from her home supported by the CNT, the occupational therapist and electronic assistive technology. The family attend a local church in the town and enjoy going on holiday and camping trips. Caroline has an adventurous side to her character and has participated in sailing and paragliding. James describes Caroline as:

> "...a bit of an adrenalin junkie really and ... she loves doing anything that ... is really at the limit of her ability." (Case 5 Carer: 096)

Caroline was diagnosed with MS in 2001 when she was 24 years of age and currently has secondary progressive form of the condition. In 2010 following the birth of her son and a relapse in MS, her progressive muscle weakness resulted in the need to use a wheelchair for mobility. She noticed a tremor in 2011 and the impact of ataxia has progressively caused significant impairment of her motor function over the last four years. In the weeks preceding the data collection Caroline had returned home from a hospital admission lasting three months. During the time she was away from home the opportunity was taken to make major adaptations to the semi-detached property. A through-floor lift and tracking hoist were installed, and the bathroom environment adapted to Caroline's needs. A comprehensive care package was also commissioned with carers visiting frequently to provide assistance with ADL and relieve the carer strain from James:

> The first time in two or three years I was working nights. I was doing everything through the day and then I was working at nights until three O'clock in the morning erm five nights a week because it was the only time of day that I could work. (Case 5 Carer: 520)

> ... now that Caroline's getting the care ... There's no pressure (Case 5 Carer: 481)

> I've had to learn to realise that I can't do it so I've got to accept help (Case 5 Person with MS: 220)

During the research recruitment process, it was difficult to identify AMPS tasks that Caroline could chose and engage with. This was due to the impact of the tremor on her occupational performance. Just two tasks were possible washing and drying hands and folding a basket of laundry. The outcome of the AMPS for following these two tasks for motor ability showed a level where moderate to marked clumsiness and or increased physical effort or fatigue during ADL task performance was observed. For process skills the measure for Caroline indicated moderate inefficiency and or time-space disorganization during ADL task performance. Table 12 gives details of the AMPS findings for Caroline and further discussion is made in Section 4.2.

Caroline and James had previously lived at another house in the town on a steep hillside. At the stage where Caroline had relapsing-remitting MS she had a busy lifestyle working full-time and undertaking IADL such as cooking, laundry, and gardening. However, difficulties with access to and within the house necessitated a move to their current home. As the impact of MS became more significant on Caroline's occupational performance James with the support of Caroline's parents has taken on more IADL tasks:

> ...beyond 2004 maybe five I had to take over doing all cooking ...
> (Case 5 Carer: 427)

Maintaining Caroline's mobility in the home and community has been important. She uses an electric powered wheelchair and has a wheelchair accessible vehicle with ramped access. At the time of data collection Caroline was no longer able to use a computer keyboard or mouse due to the ataxia of her head and upper limbs. She was, however, still able to handle a phone handset in both hands although answering a call was easier than making a call:

> Handling the phone is very difficult because she's got the ataxia and she's got the ataxia of her head and her hands. (Physiotherapist: 139)

With two young children parenting and child rearing occupations are significant for Caroline. Karen the occupational therapist identifies Caroline having a:

> ...very strong role as ... the mum. (Case 5 OT: 031)

Caroline's involvement with caring for the children and parenting occupations were paramount as an IADL.

The CNT have been involved with providing rehabilitation for Caroline for a considerable length of time. There have been more than six episode of occupational therapy intervention with Karen first meeting Caroline about ten years prior to the data collection in 2015. Initially the fatigue management programme helped with the overwhelming tiredness that Caroline experienced:

> ... we started with fatigue again as we always do ... (Case 5 OT: 053)

Caroline acknowledges the importance of fatigue management provided by the occupational therapist:

> she's taught me to be able to recognise the triggers (Case 5 Person with MS: 429)

Throughout the occupational therapy interventions adaptation of the home environment has played a key role in supporting Caroline to engaging in IADL. In the previous house handrails facilitated mobility inside and outside to the garden. This enabled her to hang laundry to dry

and do gardening activities. The timing of referral by Karen to occupational therapy colleagues for the most recent major adaptations was crucial whilst Caroline was in hospital. James acknowledged the speed that the work was completed:

> ... that was amazing in that was all done in four months. (Case 5 Carer: 364)

A key consideration of the adaptation scheme was to allow access for Caroline to the bedrooms so she can maintain contact with the children and her role as a mother and involvement in child rearing tasks.

> ... a particular issue there was around Caroline's role as a parent and being … able to access the upstairs the bedrooms (Case 5 OT: 150)

The disruption of these adaptations to the home was evident by the cluttered and disorganised living environment during the data collection period. The next stage of the adaptation scheme involved the creation of a low maintenance garden with a patio area where Caroline can continue gardening by keeping plants in pots.

Karen targeted the occupational therapy interventions in more subtle ways. A chance discussion with Caroline about the choice of a new handbag style was instrumental in facilitating occupational performance. Having a shoulder strap enabled Caroline to handle personal items without holding or dropping the handbag. The CNT as a multi-disciplinary team were concerned that support from a comprehensive care package was necessary for the family. The approach for Karen was also to enable Caroline to have more autonomy through advocacy and then for this to give more opportunity for making decision about IADLs. The major adaptations to the home environment together with the care package were seen to offer a new start for the family after reaching a crisis point. Karen could see the impact on both Caroline and James:

> ... so beautifully ... how having carers in had just really transformed both their lives ... (Case 5 OT: 537)

At times there had been tensions concerning the complexity of the social situation, housing decisions and Caroline's engagement with occupational therapy interventions such as fatigue management. Despite this the continuity of the therapeutic relationship and key role played by Karen as a valued and trusted professional is reflected by Caroline:

> she's a good person to just go to ... speak to if I need knowledge about something or need help with something cause if she doesn't know it she'll know who to speak to. (Case 5 Person with MS: 269)

The position of IADL for Caroline has however, been secondary in comparison to continuing with full-time work, leisure through holidays and more recently the practicalities of ADL, as

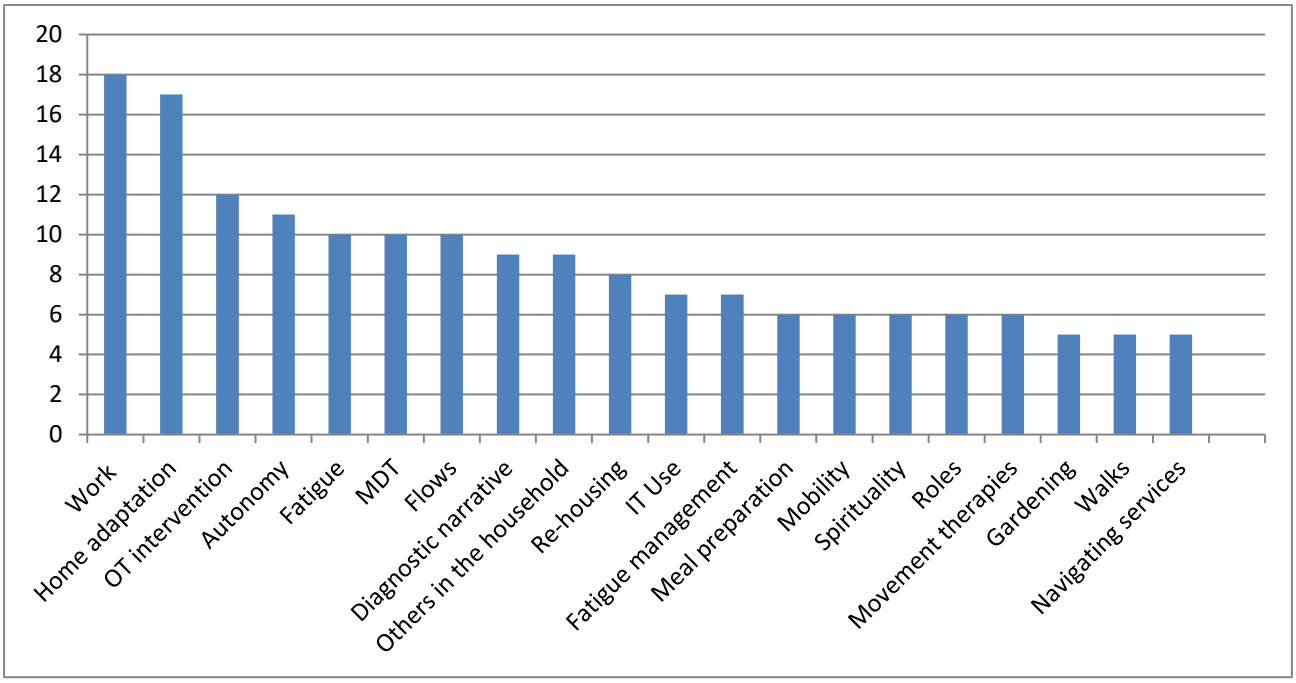
motor skills had been affected by ataxia and weakness. The physiotherapist sums up this current situation:

> ... so this lady's priority was how can I get to the toilet how can I have a wash how can I get in and out of bed and the instrumental things have to be done by somebody else (Physiotherapist: 330)

For Caroline work and leisure had previously been important until the current phase where ADL had become the priority. Despite this occupational therapy interventions have been directed towards maintaining participation in Caroline's role as a parent and in future gardening.

Figure 16 represents the coding frequency for the whole case for Caroline. The 20 most frequent coding categories represent 63.3% of the 264 codes identified. Work had remained the most important occupation for Caroline with the diagnostic narrative, fatigue, and autonomy notable factors in living with MS. The environmental interventions related to the recent adaptation of the home were also most frequently coded.

Figure 16. Caroline (Case 5) coding frequency



4.2 AMPS Findings

The AMPS was administered as the first data collection source for all five people with MS. Each person performed two relevant tasks of their choice. The researcher observed these tasks and scored the performance quality in 16 motor and 20 process skills. This standardised measure provided a benchmark of occupational performance in IADL. This forms the quantitative element of the mixed methods design and provided descriptive statistics. A fuller description and explanation of the methods used for the AMPS can be found in chapter three sections 3.7.1 and 3.9.1. Table 12 shows the overall motor and process skills ability in IADL for the five people with MS at the time of data collection. It gives the two attributes of motor skills and process skills for each case in equal interval measuring units (logits). A greater number in logits represents higher performance ability. These are important attributes as they show the range of ability between the five people with MS and enables comparisons to be made between the cases on grounds of motor and process skills ability in occupational performance. The AMPS also compares performance against healthy age-matched peers indicated in Table 12 by the *Percentile Rank*. A lower percentile indicates a person with lower ranked abilities. The overall quality of performance is assigned to a category compared to people with the same ability for each skill. A description of the overall quality of the performance is also illustrated. The AMPS attributes have been included in the framework analysis as they contributed to explanatory accounts in the development of themes and core concepts. A Motor and Process Skills theme was also included in *The Person Living with MS* core concept (see section 4.3.1). The AMPS findings for each case are presented here starting firstly with Paul.

Paul (Case 4) was the most able of the people with MS in both motor skills (1.2 logits) and process skills (1.2 logits) ability. He chose to do a vacuuming task in the living room and make a sandwich. Although Paul had the highest score of the five cases in motor skills ability this was ranked in the less than one percentile when compared with well peers. Indeed, all five cases scored in the first percentile in terms of their motor skills. When compared to people with the same ability the overall quality of Paul's performance in motor skills is categorised as having mild to moderate clumsiness and/or increased physical effort or fatigue. In terms of process skills his score was the highest of the five cases. This was at the 15.8 percentile rank with overall performance quality categorised as having questionable inefficiency/time-space disorganisation. It may appear surprising that Paul is still able to work as an engineer particularly with such low motor skill ability. An explanation may lie in the occupational therapy intervention which had concentrated on supporting Paul in the workplace and maintaining an

Table 12. Assessment of Motor and Process Skills Scores by Case

Case	Tasks chosen	ADL ability measure (in logits)		Percentile rank	Overall quality of performance compared to people with same ability	Overall quality of performance description
1. Michael	1. Feeding a cat moist cat food and water 2. Hot instant beverage – one person	Motor	0.3	<1	Moderate to marked clumsiness and /or increased physical effort or fatigue	A man living with his partner with significant motor skills deficits which impact on his performance in IADLs.
		Process	0.9	3.5	Questionable to mild time-space inefficiency/disorganisation	
2. Lisa	1. Re-potting a small houseplant 2. Watering plants and removing dead leaves	Motor	0.1	<1	Moderate to marked clumsiness and/or increased physical effort or fatigue	This lady became much more tired on this second task. She has difficulty with her mobility.
		Process	0.4	<1	Mild to moderate inefficiency/time-space disorganisation	
3. Diane	1. Vegetable soup, vegetables sautéed – one to four persons 2. Ironing a shirt – setting up the ironing board	Motor	1.0	<1	Mild to moderate clumsiness and /or increased physical effort or fatigue	Vision is a significant impairment for this lady along with fatigue.
		Process	0.8	2.3	Questionable to mild inefficiency/time-space disorganisation	

Table 12. Assessment of Motor and Process Skills scores by case (continued)

Case	Tasks chosen	ADL ability measure (in logits)		Percentile rank	Overall quality of performance compared to people with same ability	Overall quality of performance description
4. Paul	1. Vacuuming, moving lightweight furniture 2. Pre-sliced meat sandwich with vegetable(s) – one person	Motor	1.2	<1	Mild to moderate clumsiness and/or increased physical effort or fatigue	
		Process	1.2	15.8	Questionable inefficiency/time-space disorganisation	
5. Caroline	1. Washing and drying hands 2. Folding a basket of laundry	Motor	-0.2	<1	Moderate to marked clumsiness and/or increased physical effort or fatigue	
		Process	0.0	<1	Moderate inefficiency/time-space disorganisation	

occupational balance. The provision of lifting equipment, the fatigue management programme and careful liaison with a long-standing employer may account for Paul remaining in work through an ongoing process of occupational adaptation.

Diane (Case 3) chose to make vegetable soup and iron a shirt as her AMPS tasks. Her abilities in motor skills (1.0 logits) and process skills (0.8 logits) were categorised to the same overall quality of performance as Paul. In motor skills this was categorised as having mild to moderate clumsiness and/or increased physical effort of fatigue. In process skills Diane's ability was ranked at the 2.3 percentile compared to well peers and categorised as having questionable to mild inefficiency/time space disorganization. The impact of the visual impairment that Diane experienced clearly was important in accounting for the deficit in process skill ability and the overall quality of performance. Having recently ended working due to the impact of visual impairment on process skills Diane was undergoing a process of adjustment to being based at home and IADL occupations becoming more prominent in her life.

Michael (Case 1) chose to feed a cat and make instant coffee as his AMPS tasks. His motor skills ability (0.3) and process skills ability (0.9) represented a relative strength in process skills in comparison with motor skills. His motor skills abilities were categorised to moderate to marked clumsiness and/or increased physical effort. This is clearly reflected in the interviews by Michael speaking about the difficulties he has holding task items such as a knife to chop food (see section 5.1.2). Michael's process skills ability in comparison to well peers was ranked at the 3.5 percentile and categorised to questionable to mild inefficiency/time space disorganization as Paul and Diane were. Occupational therapy strategies had been aimed to develop compensatory strategies such as finding kitchen equipment on the internet to overcome motor skills deficits for Michael.

Lisa (Case 2) chose to re-pot a small houseplant and water plants and remove dead leaves for the AMPS. Her motor skills ability (0.1 logits) and process skills ability (0.4) were weaker than Paul, Diane, and Michael. Lisa's motor skills were categorised like Michael as having moderate to marked clumsiness and/or increased physical effort or fatigue. This reflects the right side weakness and difficulty with balance, mobility, and grasp. During the second gardening task it was evident that fatigue was affecting Lisa's occupational performance. Her process skills were in the less than one percentile rank when compared with well peers and categorised as mild to moderate inefficiency/time-space disorganisation. Other data sources in the interviews confirmed the difficulties Lisa had with cognitive function of memory and attention, which she described as her "butterfly brain".

Caroline was the least able of the five cases in both motor (-0.2 logits) and process skills (0.0 logits). She chose to fold a basket of laundry and wash and dry hands although it was difficult

to identify relevant tasks with an appropriate challenge. Caroline, like Lisa, was in the less than one percentile for both motor skills and process skills when compared to well peers. Her motor skills ability was categorised as having moderate to marked clumsiness and/or increased physical effort or fatigue. This reflected the severe impact of the tremor on Caroline's occupational performance. Her process skills ability was categorised as having moderate inefficiency/time-space disorganisation. Other data sources did not identify the degree of deficit in Caroline's process skills shown in the AMPS scores.

The range of occupational performance ability in IADL of the five people with MS is represented by the motor and process skills as benchmarks. The overall impact of MS as a condition can be appreciated by the low percentile rank for each motor and process skill when compared to a healthy population. During the data collection process, the importance for the researcher in negotiating and then observing the IADL tasks was confirmed. This also contributed to the relationship with each of the five people with MS and informed the interviews that followed. This quantitative data provided valuable attributes to complement and develop the descriptive and explanatory accounts during the qualitative analysis. The next section will present the themes and core concepts that emerged from the framework analysis

4.3 The framework analysis

The synthesis and analysis of the entire data from the multiple sources was identified as the final research objective. The research question, how do occupational therapy interventions contribute to the ability of people with MS to perform IADL, remained displayed and prominent throughout the framework analysis process. The framework analysis employed led to the systematic identification of four core concepts consisting of themes in an iterative process as explained in chapter 3 (section 3.9.3), and summarised in Figure 9 and further illustrated in Figures 10 and 11 (Ormston et al., 2014). This section presents the four core concepts identified in the framework analysis: The Person Living with MS, The Occupations, Occupational Therapy Interventions for People with MS, and Inter-relationships. Table 13 presents the associated themes that make up these core concepts.

The findings of the framework analysis are based on the descriptive and explanatory accounts developed during the analysis process. The content the accounts has been extracted from the spreadsheets that formed the thematic chart (see Table 8) and framework matrix (see Table 9). These spreadsheets contained the key quotes from the data sources, descriptions of themes and categories, memos, annotations, and linkages that were all considered to produce interpretations. Verbatim quotes from the data are included in this section to support the assertions made and the identification of the core concepts that have emerged.

Table 13. Research findings core concepts and associate themes

Core Concept	Associated themes
1. **The Person Living with MS**	1.1 Diagnostic Narrative 1.2 Motor and Process Skills 1.3 Psychological Responses 1.4 Autonomy
2. **The Occupations**	2.1 Instrumental Activities of Daily Living 2.2 Mobility 2.3 Work 2.4 Activities of Daily Living 2.5 Leisure and Special Events
3. **Occupational Therapy Interventions for People with MS**	3.1 Therapeutic Process 3.2 Fatigue Management 3.3 Environmental Interventions 3.4 Psychological Interventions 3.5 Therapeutic Relationship
4. **Inter-relationships**	4.1 Psychosocial Relationships 4.2 Multidisciplinary Team

The identification of linkages and relationships was made again as an iterative process during the data interpretation stages and mapped into the thematic chart as the summarized data was interrogated. The coding process in NVivo allows coding of interview passages to multiple data categories to be made. This coding was reviewed with the data extracted to the thematic chart. Links between the themes and categories are presented in tables for each core concept with major links in bold.

4.3.1 The Person Living with MS

The core concept of *The Person Living with MS* emphasises the centrality of the person with MS to the research. The experiences the individuals have in their daily lives of the impact of MS on their performance in IADL are reflected in this core concept. The core concept of The

Person Living with MS is concerned with the narrative the person develops that accounts for the condition, their skills, and the input of autonomy within IADL. The theme was identified from categories relating directly to the Person with MS. This is an interpretation of what daily life is like for the five people with MS in the cases. Figure 17 illustrates the core concept of The Person Living with MS which emerged from the collection of themes during the analytical process.

The *Diagnostic Narrative* theme is based on the impacts of the major signs and symptoms of the condition such as fatigue, vision and cognition when doing these occupations. In each case there was a theme of needing to explain and express the story of the Person's MS. This was described as a diagnostic narrative during the data management process. The participants demonstrated, through explanation in the interviews, their understanding of the process of knowing and coming to terms with the condition of MS. This was in the context of the impact on their occupational performance and ability to participate in IADL. The diagnostic narrative is associated with the difficult processes the Person with MS goes through in understanding and accommodating the implications of the diagnosis. For the Person with MS and the carer it is how they attempt to relate to and make sense of what is happening and how this fits with their daily lives. This narrative is their story and account of how they found out their diagnosis, the psychological process they have been through to adapt to the symptoms and how these impacts on engaging in IADL. For the five people with MS specifically most relevant five categories were fatigue, cognition, vision, variability, and the future.

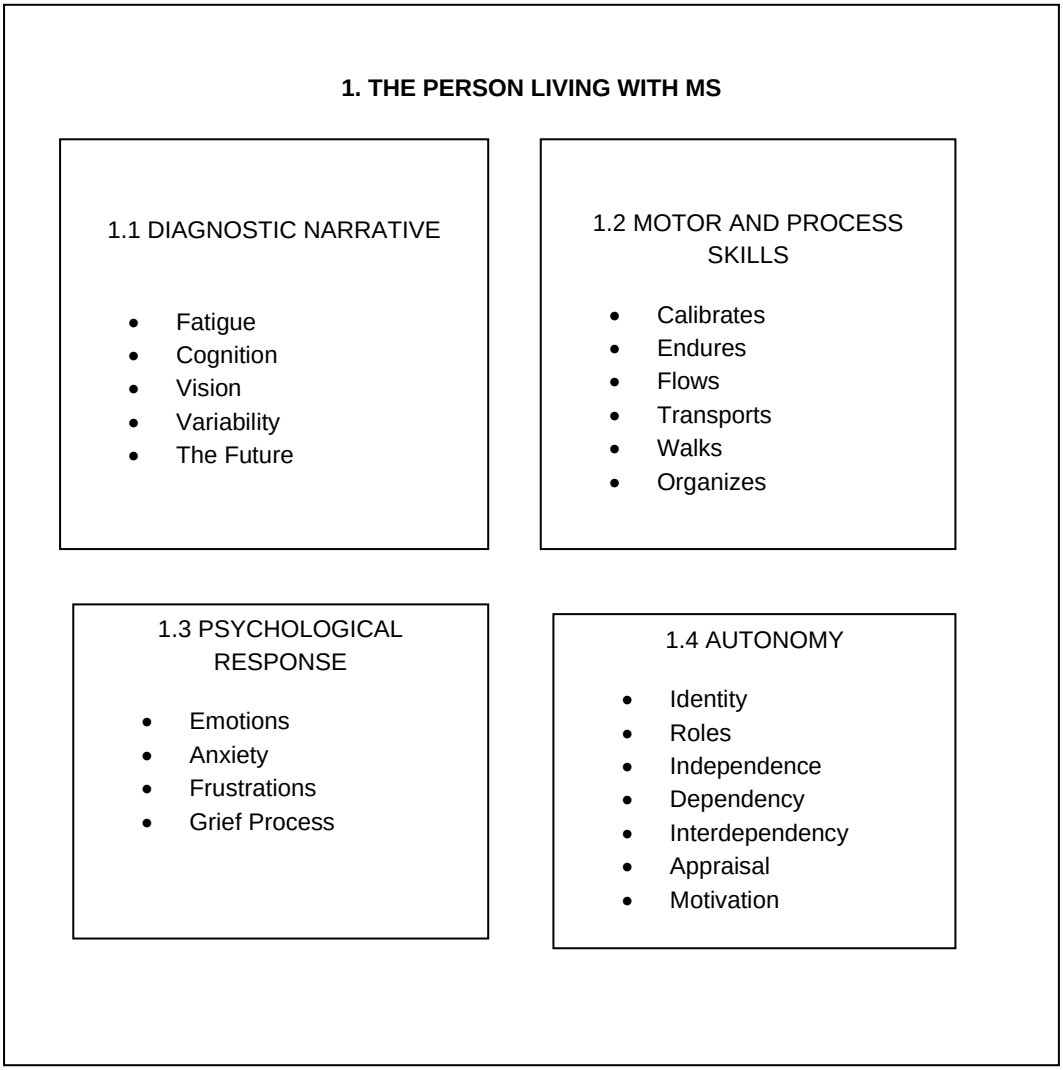
Fatigue was frequently coded in the data and relates to the physical and processing limitation caused by the lack of energy as a result of MS. It is a characteristic and significant symptom of MS and referenced on 95 occasions in 18 of the source interviews. The impact of fatigue is to decrease endurance and limit the ability to sustaining effort within an IADL task. Fatigue is the most important of the symptoms that is part of living with MS. Impairment in ability to use energy robs the person of occupational performance ability in IADL. This is illustrated by Mark as he explains how Diane (Case 3) and he came to realise the impact of fatigue in everyday activities:

> I don't think we realised the full extent of the fatigue thing ... you ... think fatigue it's after you've done a prolonged period of activity not just some normal everyday activity that makes you fatigue ... I don't think either of us were aware ... we just assumed oh well if you do a bit some hard work you'll feel more fatigued than a normal person ... When actually it isn't. Its normal everyday activities make you fatigued. (Case 3 Carer: 562)

From the perspective of the occupational therapist the diagnostic narrative informs professional reasoning as part of the therapeutic process and this is reflected in a clear link

between these two categories (see Table 11). The occupational therapist needs to understand how the person and carer are experiencing living with MS and its impact on occupational performance. The occupational therapists recognize and realise how significant this is and prioritise their intervention towards managing fatigue as a starting point.

Figure 17: Core Concept 1: The Person Living with MS



Cognition was identified as the information process and thinking skills that includes attention and memory systems. For all participants impairments to cognition is an important symptom that is linked to anxiety with coding of 69 references in 18 of the source interviews related to cognition. The vision category is concerned with the ability of the person with MS's to process and understand visual information. This was particularly relevant for Diane (Case 3) for whom

it formed the most significant symptom to come to terms with. Gemma the occupational therapist identified that for Diane visual loss was linked to anxiety:

> [the] main problems that we identified within the first couple of sessions were fatigue, her vision her visual problems but also anxiety (Case 3 OT: 201)

The *Variability* of the impact of symptoms on occupational performance can vary on a day to day or even an hour to hour basis. This means there can be a fluctuation and lack of consistency in the occupational performance ability in IADL. This was illustrated again by Diane (Case 3) where Uhthoff's syndrome resulted in variations in vision and levels of fatigue. Diane's vision was changing as she entered a different environment. This was reflected in Diane's decreased process skills (0.8 logits) in her AMPS score. Variability is a key factor for people with MS because it makes it difficult to predict and therefore plan ahead. Variability makes daily life very difficult, choosing and planning which occupations to engage in becomes complex. Gemma the occupational therapist explains how variability affects Diane (Case 3):

> The thing about Diane that was unusual was that ... her visual symptoms are variable ... so there are times of day ... particularly late on in the day evening ... getting close to bedtime where she was actually able to ... read emails ... manage to read recipes and help her sons with the homework but ... those same tasks at the start of the day she wouldn't be able to function or manage at all ... (Case 3 OT: 066)

The Future was identified as a category concerning how the person with MS and the other participants in each case view the future concerning IADL ability and participation. The occupational therapist and the MDT have the challenge of mediating the future for the person with MS and developing an optimistic understanding of their occupations based on hope.

Motor and process skills are the goal-directed actions that contribute to the performance ability in IADL for the person with MS (Fisher & Jones, 2010). It was possible to recognise and code the interview data to general motor skills and process skills as well as the specific IADL skills. Motor skills concerned with moving the self (person) and objects were most prominent, Walks, Transports, Flows and Calibrates. Michael (Case 1) described the difficulty he had gauging the pressure of his grasp when washing up glasses:

> fiddly things like say ... maybe washing something delicate up. I don't do. ... and that's because I can't gauge pressure and I've done it before and I've been washing up ... some very old thin glass thought I've been holding it lightly and delicately but I must have had so much pressure that I broke it, little cuts and what not so yeah fine things [pause] I try to steer clear of really (Case 1 Person with MS: 544).

This interview section was coded to *Calibrates* which is concerned with the regulation and grading of force speed and extent of movements as an interaction occurs with a task object

(Fisher & Jones, 2014). The link was also made during coding to the safety issue involved here. For Michael (Case 1) this was also reflected in the AMPS scores being lower for motor skill (0.3 logits). The example of *Flows* was particularly relevant for Caroline (Case 5). In AMPS Flows specifically refers to smooth and fluid movements of the arm and wrist as an interaction occurs with task objects (Fisher & Jones, 2014). The ataxia and tremor Caroline experienced impacted severely on her performance and was coded to Flows. The occupational therapy intervention where selection of a bag for Caroline was discussed, was coded to *Transports*; the carrying of objects from one place to another while walking or moving in a wheelchair (Fisher & Jones, 2014). Sustaining performance was also identified as the *Endures* skill. Only one process skill *Organizes* space and objects, however, was identified as a specific category during the framework analysis process. The motor and process skills theme of the framework analysis draws the mixed methods into the overall analysis along with the measurement of occupational performance in IADL provided by the AMPS scores (see section 4.2 and Table 12).

The components of the *Psychological Response* theme are concerned with the psychological impact of MS upon the individual in relation to IADL. This theme acknowledges that MS has a profound psychological impact on people. This theme is closely linked to the diagnostic narrative. Emotional responses such as anger and frustration were expressed and describe in the interviews. Michael experienced a time of frustration that Karen, his occupational therapist, recalled:

> we still years on talk about it because he sees that as a signpost of where he is emotionally ... when he stopped ranting at the telly he said I think I've moved on. I think I'm in a better place. (Case 1 OT: 247)

Linkage to the occupational therapy interventions was identified as the occupational therapists clearly responded to the emotions of the people with MS by managing their emotions and incorporating them into the interventions. This was particularly significant at times when a crisis was encountered requiring a crisis management response from the occupational therapist. Anxiety is another distressing emotional state identified as a category where worry and distress were interfering and limiting participation in IADL. An example of this was Diane's anxiety over community mobility both through walking outside and attempting to catch the bus into the town. The occupational therapist's response to the level of anxiety identified for Diane and Mark her husband was to intervene through targeted anxiety management. The link to this intervention is shown in the coding. The expression of grief and loss in relation of performance ability and engagement in occupations was a category was also a psychological response to MS. There is an acknowledgement and recognition by the occupational therapist that the person with MS was preceding through a grieving process for their loss of occupations.

The *Autonomy* theme is concerned with the self-determination, ability to make decisions and degree of control the person with MS has with regards to their occupational performance and choice of occupations. The features of living with MS impacts upon the person's autonomy and are also concerned with their identity. The characteristics that contribute to who the person considers themselves to be lie at the core of their identity in relation to the occupations they engage in. This may be influenced by factors of culture and spirituality. This was strongly expressed by Lisa (Case 2) indicating she did not just want to be someone with MS:

> I want to be Lisa I don't want to be ... someone with MS (Case 2 Person with MS: 429)

The roles assumed by the people with MS were also identified as a category related to the collection of IADL occupations participated in and the person's autonomy. This was linked to relationships with others in the household.

Another group of framework category identified as being associated with autonomy is the spectrum of independence, dependence on other people and interdependency with other people. Independence was described as the ability of the person with MS to complete IADL alone and under their own agency. Conversely dependency was described as a category where the person with MS was reliant on another person to perform IADL. Interdependency was described as where the person with MS and others such as the carer, others in the household or paid carers interacting and cooperating to achieve IADL performance. Lisa provides a good example of how dependency, independence and interdependency interact as she is guided and supported to engage in occupations, such as gardening, by her family, the occupational therapist and paid carer whilst safety is maintained.

Autonomy is strongly linked to the psychosocial relationships theme as all five cases were supported in IADL to varying degrees by their carers, family and friends or paid carers. The autonomy of decisions regarding IADL can be facilitated and enabled or constrained by the attitudes of others. The tension between these factors was evident for Caroline (Case 5), the occupational therapist and wider MDT who identified this area as a priority for intervention through facilitation and commissioning of a care package. This was particularly highlighted in the concern for the carer strain that James had experienced.

It was possible to identify appraisal as a framework category. This was described as where the person with MS is making a judgement of their ability, problems with and deficits in IADL. This involves a reflexive process of weighing up factors that contribute to occupational performance. Some examples of external appraisal by carers, the occupational therapist or other HCPs were evident but mainly appraisal consisted of a process internal to the person

with MS. Motivation was also a category that is seen as intrinsic to the person with MS and associated with autonomy and linked to the occupations theme. The motivation to engage is linked to the value, meaning, and importance attached to each IADL.

The complexities of the linkages between the themes of the Person living with MS and other categories are illustrated in Table 14.

Table 14 Linkages for Core Concept 1: The Person Living with MS

Theme	1. Living with MS (internal to theme)	2. The Occupations	3. OT Interventions	4. Inter-relationships
1.1 Diagnostic Narrative	**1.3 Anxiety**	2.10 Meal preparation 2.16 Child rearing 2.101 Health management and maintenance	3.12 Professional reasoning 3.1 Fatigue management	4. Psychosocial relationships 4.2 MDT
1.2 Motor and Process Skills	1.11Fatigue	**2.2 Mobility** 2.15 Safety	3.18 Movement therapies 3.21 Equipment	4.2 MDT
1.3 Psychological Response	1.1 Diagnostic narrative 1.11 Fatigue		3.15 Crisis management	4.5 Therapeutic relationship
1.4 Autonomy	1.13 Vision 1.1 Diagnostic narrative	2.101 Health management and maintenance **2.15 Safety** 2.1 IADL 2.2 Mobility 2.19 Financial management	**3.0 OT interventions** 3.12 Professional reasoning 3.4 Therapeutic relationship	**4.1 Others in the household** 4.2 MDT 4.5 Therapeutic relationship

4.3.2 The Occupations

The second core concept identified from the framework analysis was termed *The Occupations* and is illustrated in Figure 18. The core concept of this theme is concerned with the group of activities to which the five people with MS attach meaning, value and purpose. These are the occupations that the participants spoke about in the interviews and chose to participate in during the AMPS. They are also the occupations that the people with MS either want or are obliged to engage and perform in their daily lives. For the occupational therapists this is vital to the understanding the nature of the person with MS and in turn designing interventions. Karen the occupational therapist summaries these occupations as

> What lights you up and makes you tick (Case 1 OT: 252)

In some of the cases IADL were occupations that fulfilled this description and contributed to the person's core identity. For Michael (Case 1) this was driving and Lisa (Case 2) it was gardening.

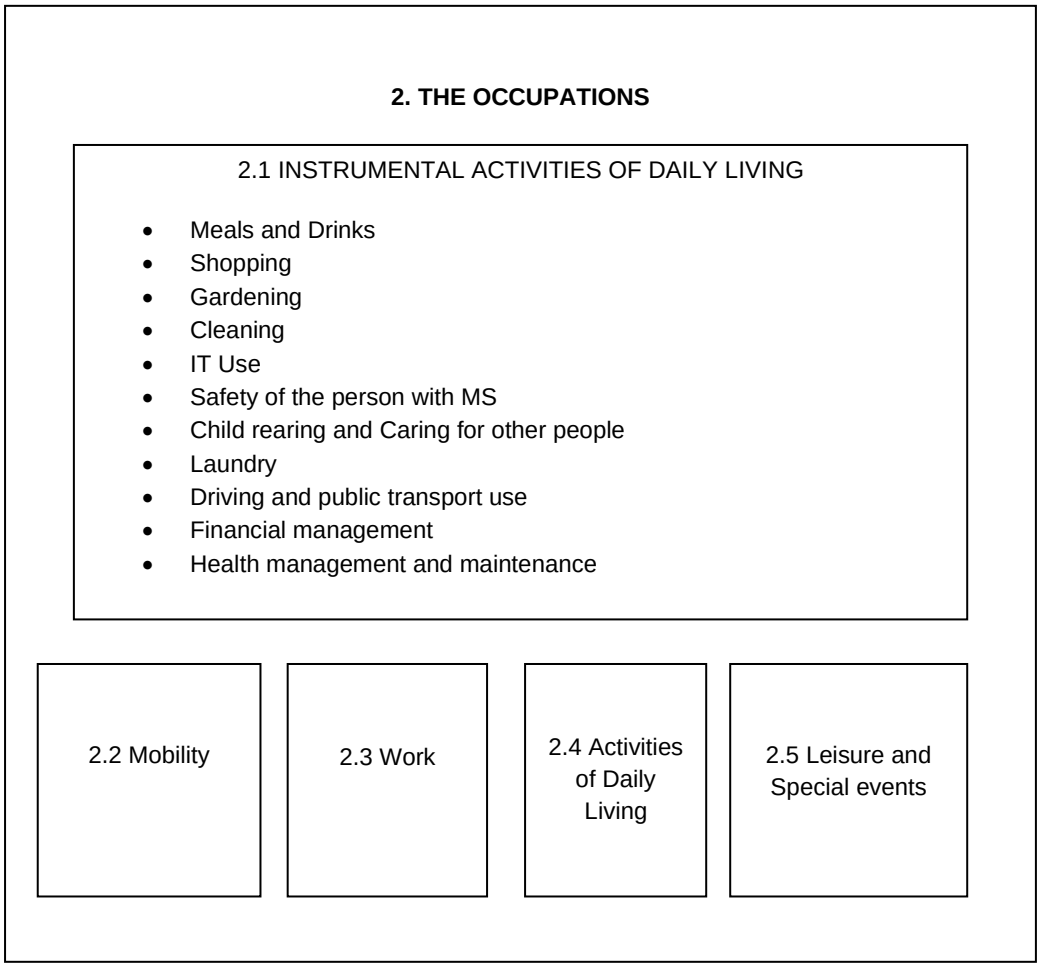
To some extent this core concept was set out a priori from the Occupational Therapy Practice Framework and in particular with IADL as forming part of the core data collected from the interview questions. Conceptually IADL form a group of activities that bound and focus the research area. They are complex occupations based at home mainly but also involve engagement with physical and social environments in the community. Four other groups of occupations; Mobility, Work, ADL and Leisure and special events emerged during the data analysis process as also being significant in the lives of the five people with MS. Karen the occupational therapist, however, pointed out the difficulty in attempting to separate out IADL from other occupations:

> ... actually everything counts ... and it all interlocks because you can't go shopping unless you can get dressed ... (Case 2 OT: 036)

This was borne out in the data analysis as these other categories of occupations were identified for the five people with MS.

The theme of *Instrumental Activities of Daily Living* formed a core focus of the research. Meal and drink preparation tasks were prominent as occupations in the data. These included food preparation tasks, cooking and serving of a meal together with drink preparation tasks. Three of the people with MS, Michael (Case 1), Diane (Case 3) and Paul (Case 4) chose meal or drink tasks for their AMPS. For Michael and Lisa cooking had formed important occupations in the past but the impact of MS had limited their participation and resulted in adaptations to continue engagement in this group of occupations. This can be explained by the AMPS scores.

Figure 18. Core Concept 2: The Occupations



Michael's motor skills ability (0.3 logits) had a moderate to marked impact on occupational performance in IADL. Lisa had moderate deficits in both motor skills (0.1 logits) and process skills (0.4) logits. Lisa now participated in cooking through directing Helen, her paid carer, due to safety concerns. For Michael cooking a full meal was too much of a demand on his cognitive and processing skills. Karen his occupational therapist had suggested substituting pre-prepared chopped onions as a solution to the difficulty of handling a knife and chopping:

> ... started looking together on the internet at all the different chopping devices you can get for very little money ... but it was only when I went to another client who was a similar age who [was] cooking who went "Oh I just buy frozen chopped up onions" and "oh right"... Bingo it doesn't look ugly it doesn't cost anymore than buying the onion (Case 1 OT: 1012)

Shopping was another coding category of significance for the people with MS. Shopping tasks included purchasing goods in shops, packing such as placing items into bags for transportation and accessing shopping services by phone or the internet for home delivery. Michael greatly

valued shopping trips with Jenny but had to balance and manage the fatigue involved. Lisa stressed the social contact she gained when shopping with Helen. Diane attempted to overcome the barriers caused by her visual impairment when buying clothing with a payment card. The link to the IADL category of financial management can be seen here. Diane's visual impairment made it hard to keep tract of budgeting. As shopping was in each example carried out in the community it was linked to driving and public transport use and relationships with others in the household.

Gardening was considered an IADL as a contribution to the maintenance of the home environment mainly externally but also inside the home in the form of houseplants. Gardening was defined as the planting, growing, and maintenance of plants. Conceptually this fits within the IADL group of occupations but could also be viewed to have a leisure component. This category of activities was particularly important for Lisa (Case 2) who had developed a passion for gardening supported by her family, paid carer, and Karen the occupational therapist. The equipment and adaptations to Lisa's home guided by Karen also supported Lisa's participation in gardening. Lisa chose gardening tasks for the AMPS.

Cleaning involved the maintenance of the physical environment and task items they may use. Cleaning includes tasks such as vacuuming, washing, wiping, and mopping surfaces throughout the home environment to remove the build-up of dirt and dust. These tasks are necessary to maintain a home and can be seen as chores or a service that may be delegated to a paid cleaner. Another view may be that these tasks are more esteemed if a person is house proud. For Paul (Case 4) cleaning tasks were an important contribution he could make to the household as Nicola was limited due to allergies. He chose a vacuuming task for AMPS. Diane (Case 3) spoke of how cleaning tasks caused her fatigue and that she had begun to teacher her children to take on more of these tasks around the home to both assist her and develop their own life skills.

Laundry related tasks involving gathering and preparing garments and bedding for washing, using a washer to launder the items, and drying them by hanging or using a tumble dryer. The items are also pressed with an iron and restored to a storage place. Laundry tasks were chosen by two of the people with MS for the AMPS. Diane completed an ironing task and Caroline folding laundry as this was the only appropriate IADL task she was able to attempt.

Information technology use has become pervasive in domestic daily life and this was borne out in the framework analysis. The use of IT devices for communication through email and completing IADL such as online banking in the home environment was particularly important and significant for Diane (Case 3). This was a key occupation also related to her work. Diane's visual impairment, however, constituted a major barrier to engaging in IT use:

> sometimes it’s there on the text but it's very faint ... It's as if it's washed out. and then ten O'clock at night I think when it's dark outside I've got no light the bedside light alright. It's as clear as anything and I'm thinking how can I look at that [pause] I've got absolutely no problem (Case 3 Person with MS: 719)

Michael also described the difficulty he encountered using a keyboard to type due to his motor skills deficits.

The category of Safety of the Person with MS involved coding references from all five cases with safety issues and concerns expressed in four of the cases. This was defined as the prevention of physical, psychological, or financial harm to the person with MS when engaged in IADL. The *Occupational Therapy Practice Framework* refers to safety and emergency maintenance as an IADL and this influenced the identification of this category during the coding process. Issues of safety constituted a clear and important category. Safety issues were concerns for all five of the people with MS. Michael (Case 1), Lisa (Case 2) had experiences minor injuries such as cuts and burns in the kitchen environment:

> chopping up of stuff; meat, vegetables Jennifer tends to do … erm and that's [pause] from a safety point of view but also that I just make a complete mess doing it too. (Case 1 Person with MS: 562).

Diane’s visual impairment had impacted on food hygiene as she did not notice and respond when food was out of date. She described a process of learning her own limitations. Paul’s carer Nicola was concerned about safety and preventing problems when Paul used an electrically powered lawn mower. A significant intervention by Karen with Lisa had mitigated the risk of falling on the cellar stairs. Safety was also linked to crisis management by the occupational therapist.

Several less frequently coded categories of IADL are also illustrative of the variety of IADL the five people with MS engage with. Caring for other people and child rearing was a combined category that developed as the framework analysis proceeded. Child rearing which involved occupations related to parenting and was significant for all three female cases as mothers. Michael also had a caring role for Jennifer his wife for example taking her to health care appointments by car.

Driving and public transport use was identified as an IADL category. For Michael (Case 1) driving was an essential occupation that held great value as can be seen from his case summary in section 5.1.2. The period of having to use public transport resulted in difficult and unwanted social interactions. The barriers for Case 3 Diane in using the bus with a visual impairment resulted in her being limited and dependent on others to engage in community based IADL such as shopping in the town centre. The inter-relationship between these

occupations is apparent here. A final category of IADL that was made prominent by the occupational therapists and HCPs was health management and maintenance. This was relevant for Lisa (Case 2) in regard to being able to make and attend hospital appointments. Occupational therapy interventions through cognitive rehabilitation were partly aimed towards enabling her to continue engaging with healthcare services and not miss appointments.

As a theme *Mobility* was classified as an occupation separate from IADL and ADL. It was frequently coded being referenced on 107 occasions in all 19 interviews. The category was described as relating to personal mobility through the environment and is obviously fundamentally linked and integral to occupational performance in IADL. There was a strong link also demonstrated with assistive technology and equipment such as a walking stick, walking frame, wheelchair, or mobility scooter. Mobility is important because occupational therapy interventions were targeted towards mobility and in turn this enabled engagement in IADL for example when going shopping or getting round the house or garden. Karen describes the occupational therapy interventions of selecting a walker, with a storage box under the seat for gardening tools. This was to facilitate Lisa to mobilise outdoors and engage in gardening occupations:

> “she was finding the gardening really difficult ... and had a three wheeled walker but couldn't sit down with that ... she also had a motorised scooter couldn't ... sit down with that ... So we've gone for something in the middle ... and gone for a four wheeled [walker] with a seat...” (Case 2 OT: 127)

Mobility was also linked to safety of the person with MS in the avoidance of falls and can be seen as a key consideration in this occupational therapy intervention.

Work was categorised as occupations that are associated and linked to productivity that may involve making objects or services. These may or may not involve payment. This theme involves occupations where the person is committed to organisations and other people. When a cross case comparison is made work can be seen as particularly important for Paul (Case 4) who was still in paid employment. The occupational therapy interventions for Paul had focused on work, fatigue management, and achieving a balance between occupations. Paul acknowledged the dangers of work becoming too important:

> ... there’s no point having work, working all hours god sends, and then not having no lifestyle at home (Case 4 Person with MS: 198)

There was a strong link with fatigue management as an occupational therapy intervention and this allowed an occupational balance to be maintained so he had the energy to engage in IADL such as cleaning, meal preparation and cutting the lawn. He had learned to manage fatigue related to work and balance IADL with leisure occupations. For the other four cases

work remained an influence. Diane (Case 3) had reflected on the previous year where she had been going through a difficult transitional process in ending work. For Caroline (Case 5) work had been prioritised above other occupational areas until a point where ADL had become the imperative. At a previous stage Caroline was supported by the occupational therapy interventions to balance work and IADL in the home through fatigue management. Michael's (Case 1) work as an artist in motor sport was utilised by the occupational therapist to re-engage his interest through painting after a period of low mood. Only Lisa (Case 2) did not express the importance of her previous work as a teacher but was still involved in the antiques business to some extent.

ADL are the occupations that people with MS perform to maintain themselves. The definition is in line with the Occupational Therapy Practice Framework, activities orientated to taking care of one's own body, enable basic survival and well-being. ADL were particularly relevant for Caroline (Case 5) where the most recent occupational therapy interventions had involved the adaptation of the home to provide facilities for ADL. For Caroline in particular the importance of ADL such as washing, dressing, and feeding and the occupational therapy interventions directed to supporting these occupations is crucial as shown in the case summary (see section 5.1.6). Despite being steered away from discussing ADL and other groups of occupations by the research design, ADL and in particular work were discussed and identified as categories.

Some occupations of importance and meaning for the cases were categorised as relating to *Leisure and special events*. Paul (Case 4) placed much on maintaining his social relationship through sporting activities such as football and cricket. He clearly found these recreational activities enjoyable. An interesting example for Case 2 (Lisa) was being hostess for dinner parties where the preparation was clearly IADL, but the socialising with family and friends differed from the day to day being exceptional, special, and memorable. As an occupational therapy intervention supporting Lisa's deficits in process skills (0.4 logits) was significant. Proposing a weekend where friends could help to sort and tidy the home was also a novel occupational therapy intervention but crucial to ensuring a safer environment:

> I remember that day ... they were different after ... I said call me in when you're done. I won't come until it's done cause there's no point doing anything else till this is de-cluttered ... there was no point going on because the clutter was stopping her it was affected by quite a lot of external factors really (Case 2 OT: 721)

Caroline (Case 5) participated in tall-ships and paragliding expeditions which were occupations coded to this category. These leisure and special events occupations were

Table 15. Linkages for Core Concept 2: The Occupations

Sub-Theme/ Category	1. Living with MS	2. The Occupations	3. OT interventions	4. Inter-relationships
2.1 Instrumental ADL	**1.11 Fatigue** **1.12 Cognition** 1.42 Roles	**2.1 Safety** 2.2 Work 2.19 Driving and public transport use	3.21 Equipment 3.22 Home adaptation 3.24 Assistive technology 3.16 Navigating services 3.15 **Crisis management**	4.5 Directing IADL **4.1 Others in the Household**
2.2 Mobility	1.26 Walks	2.16 Safety	3.21 Equipment 3.33 Re-housing	4.1 Other in the Household
2.3 Work	1.11 Fatigue		3.0 OT Interventions 3.1 Fatigue management	

infrequently coded in the interviews. This may be due to lack of occupational balance with other areas.

The linkages between The Occupations core concept and the other themes in the framework analysis are illustrated in Table 15.

4.3.3 Occupational therapy interventions for people with MS

The third core concept identified in the framework analysis was *Occupational Therapy Interventions for People with MS* and was concerned with the varied range of collective techniques, specialist and generic knowledge and skills that the occupational therapists utilize in their professional reasoning and practice. These interventions are illustrated in Figure 19 and steer the person with MS towards adaptation in their occupational performance in IADL through promoting occupational balance and the matching of performance ability to occupational demand. These were classified into five themes: therapeutic process, fatigue management, environmental interventions, psychological interventions, and therapeutic relationship.

The *Therapeutic Process* theme involved generic occupational therapy interventions. These consisted of assessment of people with MS, goal setting, problem solving and professional reasoning with the latter being a key category in this theme. Approaches to interventions in the form of coaching and education and implementation of movement therapies were also identified as categories. Professional reasoning was described as the process of appraisal of patient related information that contributes to decisions made by the occupational therapist in devising and enacting occupational therapy interventions. The following quote from Karen in relation to Michael's (Case 1) intervention illustrates aspects of professional reasoning:

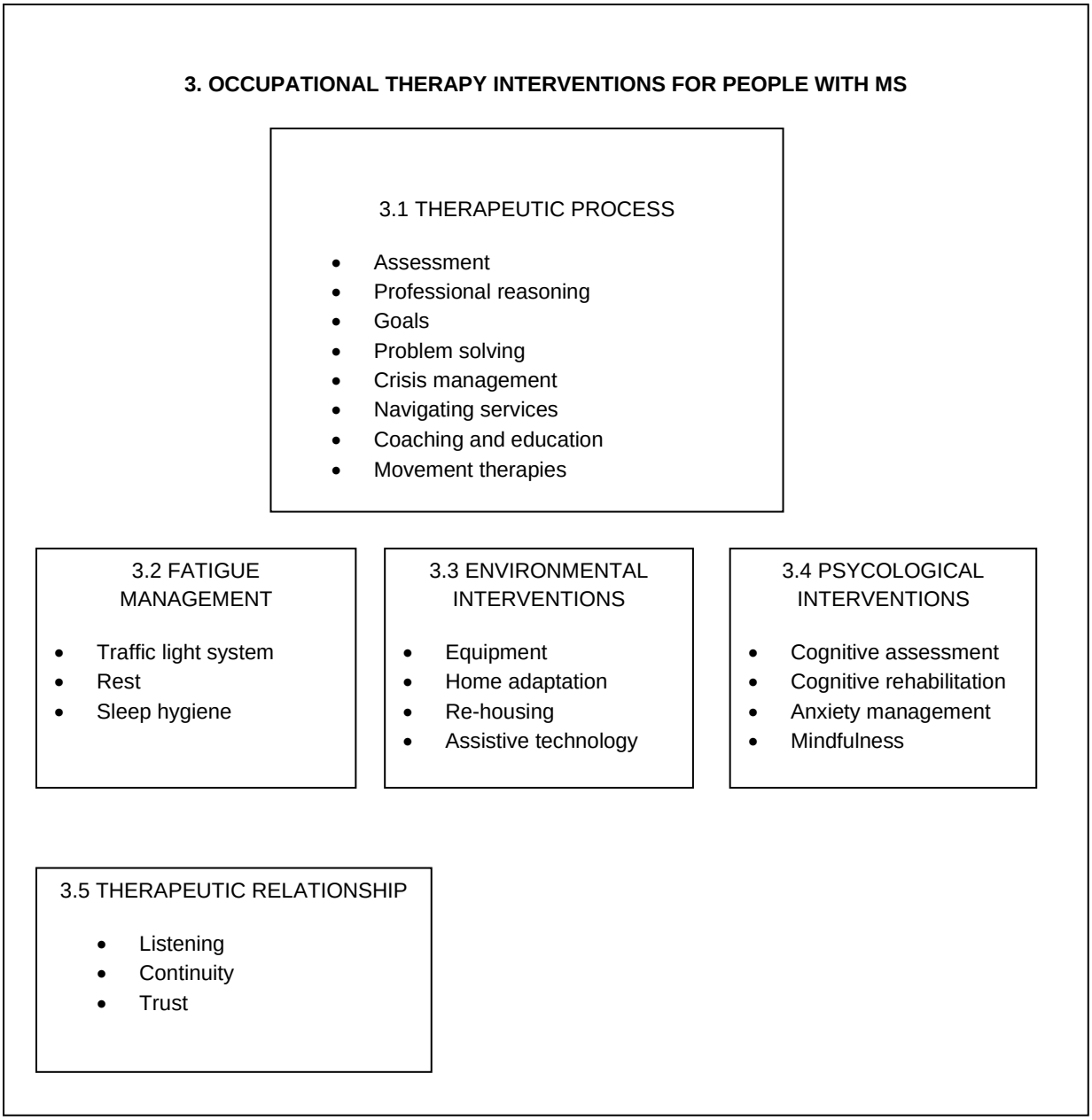
> and so what we found was that physios were going in and ... trying to do exercises but ... they could neither take in what they were saying or find the energy or time to do it. Whereas if you had looked at life balance and using your energy and refilling when you need to then ... once that's done you can add those things in. (Case 1 OT: 157)

Some of the occupational therapy interventions were categorised as constituting crisis management. This was linked to issues of safety and was identified as an intervention the occupational therapist makes in response to a serious situation that occurs for the person with MS in performing IADL. An example was how Karen the occupational therapist responded in the situation when Lisa (Case 2) was experiencing difficulty with childcare whist making a scheduled visit. Lisa explains:

> she was actually there when the children were driving me mad once and I ... kind of [pause] I think on that occasion I probably did lose it a bit ... and she was there to say

now she was brilliant now this is not you we are going to sort this out and ... she ... helped me in that way so ... psychologically and ... she's helped me in a lot of ways and I think that it's important to have someone you know OT ... (Case 2 Person with MS: 910)

Figure 19. Core Concept 3: Occupational Therapy Interventions for People with MS



Here the occupational therapist was able to counsel the person with MS, respond to the immediate situation by ensuring the children's needs were met and identify the impact of the underlying issue of Karen's cognitive impairment.

The contribution of the occupational therapist in *Navigating Services* for the person with MS is also noteworthy. Negotiating the various services necessary to achieve the person's goals is complex and needs direction from the occupational therapist and wider MDT. This may involve referral to other agencies for relevant assessment and interventions. A role of advocacy is assumed as the occupational therapist acts as an intermediary conveying the needs and specific requirements of the person with MS to the other agencies. Knowledge of the service provision available is also crucial in dealing with the bureaucratic processes in a timely manner. This is illustrated by how the occupational therapist supported Michael (Case 1) in continuing to drive through sign posing to the regional driving assessment centre and the motorbility scheme:

> we sold his manual car and we were without a car for a while ... it was Karen who [pause] spoke about getting a motorbility car ... and ... basically said that it can be done you can still drive ... I'm sure it was her who said about the motorbility. (Case 1 Carer: 511)

Fatigue management had a strong profile as an occupational therapy intervention, was well integrated with other interventions and recognised as a starting point of intervention by the whole CNT. The process aimed to enable the person with MS to manage their fatigue level and allow a balanced engagement in occupations. Fatigue management involved the collaboration of the carers and was coded for all five cases. The occupational therapists working in the CNT had developed a structured program of fatigue management that involved four stages. These were named after key terms and phrases used by the team:

1) "Tune in and listen to your body" referred to an initial stage where the person with MS is encouraged to attend to the physical symptoms related to fatigue.

2) "Get out of red". The person with MS is asked to keep a seven day journal of activity and grade their energy levels. The occupational therapist then carries out a complex analysis of the journal findings to draw up a traffic light system. The person with MS is then encouraged to avoid reaching the red level where fatigue becomes detrimental. Considerations of rest and sleep hygiene were also made with the aim of restoration to a position where task performance could be resumed. The traffic light system constituted the element of fatigue management that formed a significant and memorable metaphor for the people with MS and the carers. It was remembered and spoken about by the people with MS in their interviews and seems to have been internalised and become automatic for some. Michael (Case 1) illustrates this:

> Red, amber, green ... that was one of the best things was that because I didn't realise but I didn't know ... [pause] going too far ... The traffic light system ... always stopping on amber before you get to red ... (Case 1 Person with MS: 422)

3) “Life principles” relates to the stage of fatigue management where the occupational therapist supports the person with MS to identify what is fundamentally important and valued to them. This may involve occupations, roles, and relationships.

4) “Live in the moment” The final stage incorporated ideas and concepts derived from mindfulness and living in the moment.

The occupational therapists placed emphasis on the psychosocial aspects of fatigue management as well as cognitive and emotional factors. The fatigue management programmes proceeded at differing paces and to differing effect for each person with MS. For Paul (Case 4) Karen, the occupational therapist, felt the process was slow to work through. The engagement with the program by the person with MS was crucial and for Caroline (Case 5) questionable. The MDT recognised that fatigue management could be a lengthy process but recognise that it was essential before other intervention could take place. The fatigue management programme involved commitment to potentially significant lifestyle changes for the people with MS. Fatigue management links to the occupational therapist being aware and understanding of the diagnostic narrative for the person with MS. This provides a key explanation of how this occupational therapy intervention contributes to the ability of people with MS to perform IADL.

Environmental Interventions made by the occupational therapists were primarily aimed at facilitating IADL through manipulation of the environment with equipment provision or adaptation to the physical environment. Occupational therapy interventions that facilitated re-housing were key in enabling Michael (Case 1) to remain safe and continue driving. This included the concept of a forever home where suitable adaptation could be made in the future for the person’s changing needs. Provision of, and advice on, items of equipment ranged from kitchen equipment to support Michael with cooking to the careful choice of a walker for Lisa (Case 2) to use when gardening. Assistive technology was utilised particularly by Diane (Case 3) in her use of apps on her mobile phone such as a magnifier to compensate for visual impairment.

The adaptation of the home environment by the installation of a substantial piece of equipment was illustrated by the through floor lift installed for Caroline (Case 5) and the ramped access to the garden for Lisa (Case 2). Karen the occupational therapist explained how she involved the REMAP organisation to engineer a solution and facilitating Lisa to access the garden by mobility scooter:

> ... intervention that I did last year was all about accessing the garden ... I think we still have a job as an OT to ... really ... use our creativity and problem solving to talk about the concept they are looking for (Case 2 OT: 176)

Psychological Interventions as a theme consisted of a group of intervention categories that aim to address psychological issues related to symptoms of MS that impacted on the performance in IADL of the person with MS. Anxiety management and mindfulness interventions were particularly significant for Diane (Case 3) as she contended with her visual impairment. Cognitive assessment and rehabilitation interventions are illustrated in how Karen is able to analyse the cognitive function difficulties experienced by Lisa (Case 2):

> The problem that she would describe is ... terrible memory ... but actually err the building blocks right at the bottom and she's got really poor auditory attention ... and therefore poor information processing skills. (Case 2 OT: 406)

The *Therapeutic relationship* formed a part of both the core concept of Occupational Therapy Interventions for People with MS and the fourth core concept of *Inter-relationships.* The elements in the therapeutic relationship are qualities of listening, trust, and continuity of the occupational therapist. These all contributed to the development of a therapeutic partnership between each person with MS and the occupational therapist.

In summarising the core concept of Occupational Therapy Interventions for People with MS the themes of therapeutic process, fatigue management, environmental interventions and psychological interventions combine to provide a multi-faceted set of tools to address the issues of the clients as they engage in IADL and adapt to the unpredictability of the impact of the condition. The linkages to other themes are presented in Table 16. These interventions provide individualised and personalised solutions to problems built on a carefully constructed and ongoing therapeutic relationship. Fundamental changes in lifestyle may be implied in these interventions such as the fatigue management programme and the psychological interventions. Self-management to empower the person with MS and their carers is also an aim of the occupational therapy interventions.

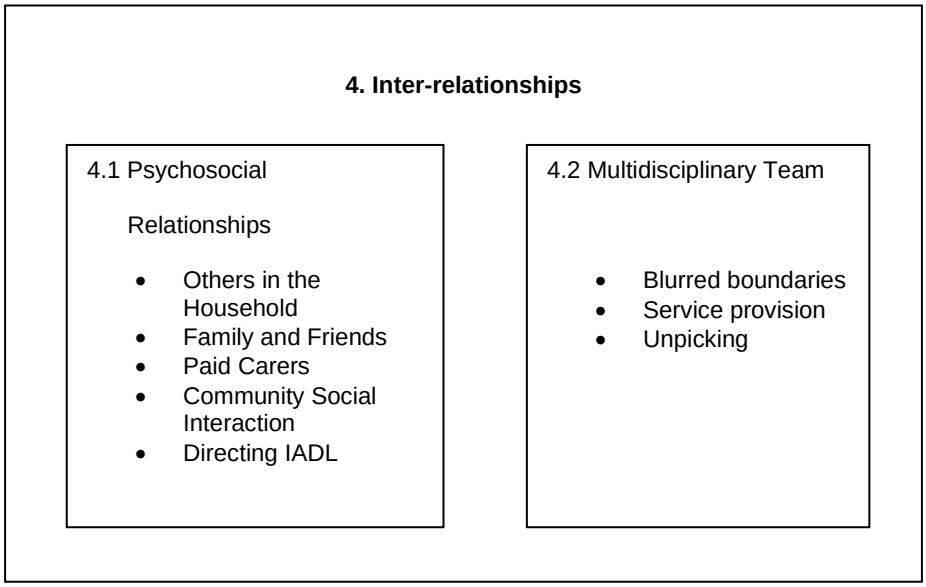
Table 16. Linkages for Core Concept 3: Occupational Therapy Interventions for People with MS

Theme	1. Living with MS	2. The Occupations	3. OT Interventions	4. Inter-relationships
3.1 Therapeutic Process	1.1 Diagnostic narrative 1.2 Motor and Process Skills 1.3 Psychological Responses	2.13 IT Use		4.2 MDT
3.2 Fatigue management	1.11 Fatigue 1.32 Anxiety		3.43 Anxiety Management	4.2 MDT
3.3 Environmental Interventions		**2.15 Safety of the Person with MS** 2.16 Care for other people		4.1 Others in the Household 4.2 MDT
3.4 Psychological Interventions	1.1 Diagnostic Narrative 1.3 Psychological Responses			

4.3.4 Inter-relationships

The fourth core concept identified in the framework approach to analysis was concerned with Inter-relationships with other significant people around the person with MS. Figure 20 illustrates the two themes of Psychosocial Relationships and the Multidisciplinary Team that made up the Inter-relationships core concept. This group of significant people for each case supported and enhanced occupational performance in IADL. The core concept was described as being concerned with how the person with MS interacts with the people around them and in the wider social environment in relation to IADL and the occupational therapy intervention.

Figure 20. Core Concept 4: Inter-relationships



The Inter-relationships with Others in the Household, which included all five carers, was the most important category. Diane (Case 3) illustrates this through describing the inter-relationship she has with Mark her husband and carer when it comes to meal preparation in the kitchen:

> "it's just important to feel I'm contributing ... I don't want to put on Mark all the time it's hard enough you know for him but ... it is important to do stuff I used to like cooking and baking ... yeah cooking try and share it [we] both do" (Case 3 Person with MS: 204)

There is a clear interdependency with Mark, but Diane is concerned that a previous balance has been disrupted and she needs more support.

Directing IADL is a category that was particularly important for Lisa (Case 2). Helen a paid carer played a key role in supporting Lisa's participation in IADL and acted as a personal assistant employed to carry out care tasks including IADL. The Directing IADL category was coded where the person with MS was involved in directing carers or other people to do IADL. This was supported by the psychological interventions that Karen the occupational therapist made with Lisa as explained in the following quote:

> ... although she no longer cooks being able to instruct her personal carer to do it and she gets her personal carer doing so many beautiful creative ... like elderflower wine which she can't do herself ... she says she knows the recipe in her head and ... I've caught them before now you know boiling ... elderflowers up ... and doing it together ... so a lot of the work I've done is teaching Lisa how to give instructions to people and how to get the best out of them because her cognition hasn't always shown that ... (Case 2 OT: 300)

These interventions had been significant in maintaining Lisa's occupational engagement, autonomy, and sense of self-identity. A continuation of participation in occupations such as cooking, gardening, and shopping had been achieved through her directing her paid carer to do tasks but with Lisa retaining some control and influence over the occupations. This has allowed Lisa to continue to be engaged in the meal preparation through directing the shopping and cooking. There must, however, be some negotiation between Lisa and Helen as Lisa's attention, memory, and process skills (AMPS: 0.4 logits) at times may make this problematic. As Caroline (Case 5) was at the early stages of having a complex package of care eventually this category could contribute to her continuing engagement and participation in IADL such as gardening and parenting occupations.

Other categories contributing to the Psychosocial Relationships theme were Family and Friends who have a significant relationship with the Person with MS and do not live in the same household. The communication and interactions with other people such as encountered when shopping was also a category identified as Community Social Interactions. Michael (Case 1) found that interactions could be problematic and form a barrier to his community mobility on the bus. The difficulties that Michael encountered when interacting with other passengers when using public transport contrasts with Lisa's (Case 2) experiences when out shopping:

> it's quite nice to get out and about. I've met people in the supermarket I've started talking to we swapped numbers [laugh] ... and things like that you know so it's ... a sort of ... social thing as well for me (Case 2 Person with MS: 367)

The attitudes of other people in the social environment of the community are important in hampering or facilitating IADL.

The Multidisciplinary Team formed the second theme of the Inter-relationships core concept. Within this theme the categories of blurred boundaries between occupational therapy and the other professions was identified. Where disciplines had common interventions an arrangement of practice cross-over based on the underlying skills competency was in place. This was also concerned with professional roles and how they are shared and interact in an inter-disciplinary manner. Unpicking was a term the MDT used for analysing and appraising assessments and clinical information to produce a clear picture of a situation for a person with MS. This was linked to professional reasoning. The final category was concerned with Service Provision including occupational therapy by the CNT. Table 15 shows the linkages identified between the Inter-relationships core concept and other themes.

The theme of the therapeutic relationship between the Person with MS and the occupational therapists sits within both the core concept of Occupational Therapy Interventions for the Person with MS and Inter-relationships core concept as part of the Multidisciplinary team.

Table 17. Linkages for Core Concept 4: Inter-relationships

Theme	1. Living with MS	2. The Occupations	3. OT Interventions	4. Inter-Relationships
4.1Psychosocial Relationships	1.4 Autonomy	2.2 Mobility	3.4 Psychological interventions	
			3.5 Therapeutic Relationships	
4.2 MDT			3.12 Professional Reasoning	

4.4 MS person-centred occupational therapy (MS-PcOT) practice model

In this section a pragmatic synthesis of the research findings is presented in the form of a new model of occupational therapy practice for people with MS. The final research objective was to synthesise and analyse the data to produce evidence-based guidance for occupational therapy intervention. A practice model consists of explanations of a body of knowledge that aims to generate and test theory of professional issues (Kielhofner, 2002). A model of practice is a simplification of the complex reality of occupational therapy practice that seeks to facilitate strategies, tools, and techniques in therapeutic practice (Nelson & Jepson-Thomas, 2003). It gives insight into the nature and workings of the phenomena. An iterative process was undertaken considering the links and relationships between the themes and core concepts of the framework analysis to produce the components and interactions of the model. The influence of person-centred care as the theoretical lens informed this development. Comparisons with the ICF and other occupational therapy practice models were also considered.

The ICF was created by the WHO to provide a standard for measuring and describing health conditions, disability, and functioning at the body, person, and societal levels (WHO, 2001). This classification system was introduced in section 1.3.3 in relation to the core sets of categories for people with MS that have been identified (see Table 1). Disability and functioning are seen as resulting from the interaction of health conditions and contextual factors (see Figure 1). This demonstrates the impact of MS on body structures, body functions, activities, and participation. The ICF provides a potential structure to base a practice model upon. Table 18 represents the outcome of a comparison of the research core concepts and themes with ICF identified with the ICF browser (WHO, 2017). Some of the components of the model map directly to ICF domains. Although the occupational therapy practice framework to identify and define IADL in the research, an advantage of using the ICF is the universality of terminology. The ICF can facilitate communication with a wider audience of health care professional groups in the MDT. Consistent use of terms is important as can be seen in the discussion of IADL definitions (see section 1.4). Therefore, for clarity some ICF terminology has been adopted in this practice model.

The Occupations core concept can be clearly mapped to the *Activities and participation* domain in the ICF. Each theme can be represented by a more detailed domain: IADL by *Domestic life* and ADL by *Self-care*. By using these terms in the model, the confusion in terminology of ADL and IADL can be avoided. Themes of mobility, work, and leisure and special events are directly represented by ICF domains. The Psychosocial and MDT Inter-relationships can be mapped to *Support and relationships*. The physical and social

Table 18. Components of the MS Person-centred Occupational Therapy (MS-PcOT) Practice Model Mapped to ICF

Research findings	ICF Domain	Comment/ theoretical influence/ application in model
Person Living with MS	**Personal factors** Not classified in ICF	Person-centred care
Diagnostic narrative		Emerged from framework analysis
Psychological Responses		Emerged from framework analysis
Autonomy		Emerged from framework analysis
Skills	Body functions (b)	Linked to the impact of MS on the body functions of the person. ICF not categorize for skills specifically Performance skills in OT Practice Framework
The Occupations	**Activities and participation (d)**	**The Occupations**
IADL	Domestic life (d6)	IADL in domestic life
Mobility	Mobility (d4)	Mobility
ADL	Self-care (d5)	Self-care
Work	Work and employment (d840-859)	Work
Leisure and special events	Recreation and leisure (d920)	Leisure and special events
OT interventions for people with MS	**Health services, systems and policy (e580)**	Treating health problems, providing medical rehabilitation and promoting health lifestyles
Therapeutic process	Not represented	Therapeutic process
Fatigue management	Not represented	Fatigue management
Environmental interventions	Products and technology (e1)	Environmental interventions
Psychological interventions	Not represented	Psychological interventions

Table 18. Components of the MS Person-centred Occupational Therapy (MS-PcOT) Practice Model Mapped to ICF (continued)

Research findings	ICF Domain	Comment/ theoretical influence/ application in model
Inter-relationships	**Support and relationships (e3)**	**Relationships** that support the person with MS. The degree of support is influenced by the attitudes of these individuals
Psychosocial	Immediate family (e310) Personal care providers and personal assistants (e340) Friends (e320)	Psychosocial relationships
Therapeutic relationship	Health professionals (e355)	*Therapeutic partnership* of occupational therapist to empower the person living with MS. Person-centred care
MDT	Health professionals (e355)	Professional relationships
Environment	Environmental factors (e)	
Physical	Natural environment and human-made changes to environment (e2)	Physical environment
Social	Support and relationships (e3)	Social environment an overview of the support and relationships e3 Attitudes can facilitate or act as barriers to participation in the Occupations

environment maps to *Environmental factors* of *Natural environment and human-made changes to the environment* and *Support and relationships*.

The ICF does not, however, give a complete structure to the research findings. Mapping the Person Living with MS and occupational therapy interventions themes to the ICF is more problematic. The Person living with MS is most closely related to the *personal factor* domain. The ICF includes personal factors that influence how disability is experienced by the person. These factors include age, gender, behaviour, social background, education, profession, and character (WHO, 2001). Personal factors, however, are not classified in the ICF due to wide variation in societies and cultures and insufficient definition of their scope (WHO, 2001). The

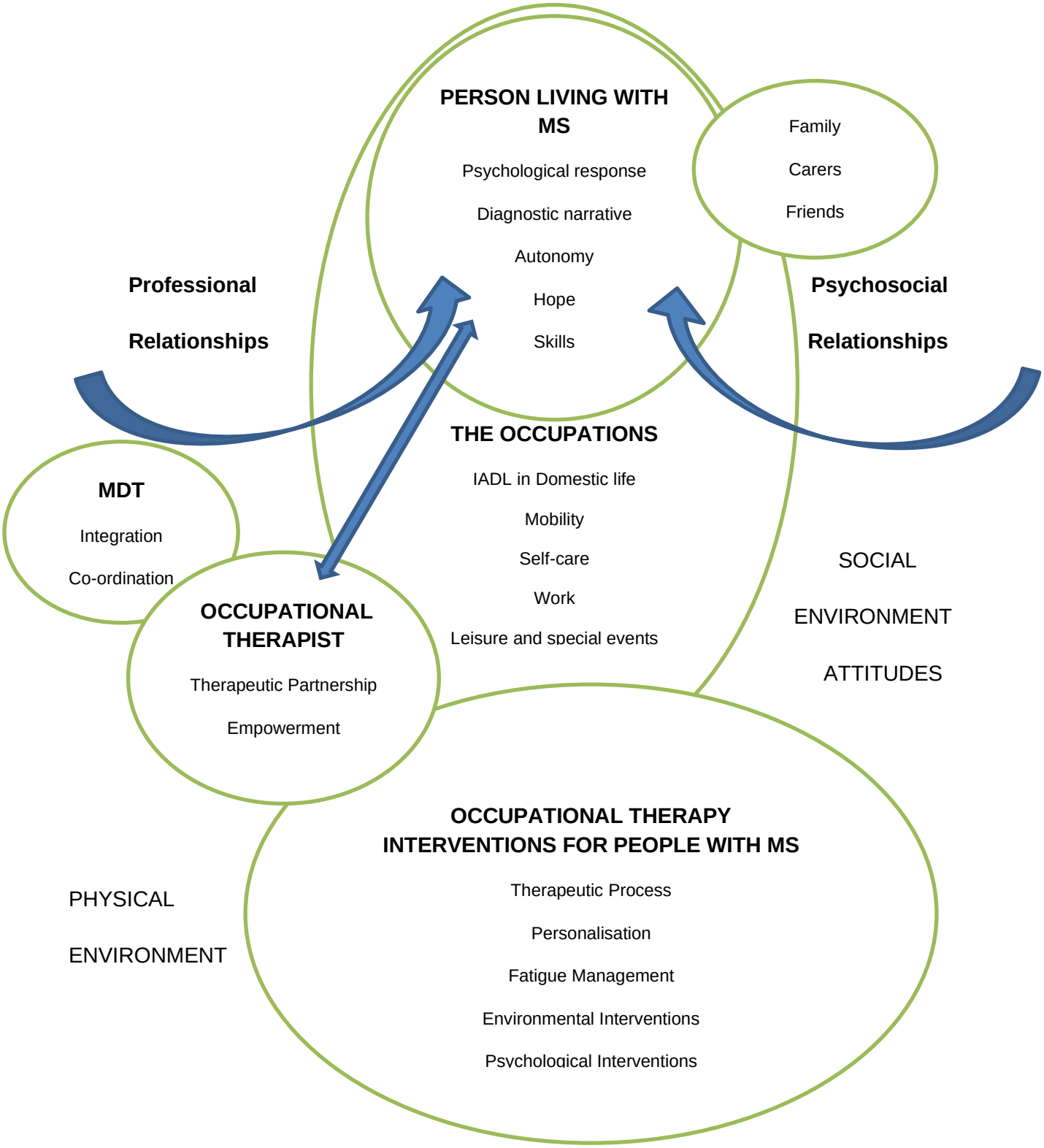
compatibility of the ICF with client-centred occupational therapy practice has been identified in professional guidance (COT, 2004). However, since the publication of the ICF the influence and development of person-centred care in healthcare and rehabilitation has grown. In this research The Person Living with MS concept gives the details and analysis of the personal factors of the five people with MS that contributed to the development of the new model and expands on the ICF. The research themes of diagnostic narrative, psychological responses, and autonomy cannot easily be mapped the ICF. The motor and process skills theme is linked to the impact of MS on *Body functions.* Skills are not, however, specifically classified in the ICF.

The core concept of Occupational therapy interventions for people with MS also cannot be fully mapped to the ICF. The *Health services, systems, and policy (e580)* domain is concerned with treating health problems and providing medical rehabilitation. The environmental interventions theme can be mapped to the *Products and technology* domain. The other component themes of therapeutic process, fatigue management, and psychological interventions, however, are not represented by the ICF.

The ICF can be seen to compliment some of the underlying structure and terminology used in the model. The findings are only partially compatible with ICF therefore a new model of practice, also taking elements of person-centred care into account, is proposed. Client-centred occupational therapy practice has contributed respect, empowerment, personalisation, a therapeutic partnership, and hope to the theoretical lens of person-centred care (Sumsion, 2000; Sumsion & Law, 2006). The model goes beyond the scope of the ICF by identifying the personal factors associated with the core concept of the Person living with MS and detailing the occupational therapy interventions for people with MS.

The MS person-centred occupational therapy practice model (MS-PcOT) is presented in Figure 21. This holistic practice model comprehensively guides practice of occupational therapy for people with MS. The components and interactions of this new model are consistent with the research findings and theoretical lens of person-centred care. The Person living with MS and the occupations they engage in are the concepts at the core of the model. The person with MS expresses the perceptions of the impact of the variable clinical features of MS, such as fatigue and cognitive changes, through the diagnostic narrative. This narrative is important in the early period following diagnosis and develops over time as the person makes sense of the impact of MS on occupational performance and lifestyle at the life stage reached. Psychological responses such as anxiety, anger, grief, and emotions also contribute to the impact of the MS on occupational performance. Hope is an important concept for the person

Figure 21. MS Person-centred OT (MS-PcOT) Practice Model



with MS and the people around them. This is linked to the person having an optimistic perception of the future as the diagnostic narrative develops

Relationships with other significant people in the close social environment are important in the model. The Person living with MS is not alone. They are supported in their occupations by family, carers, and friends. These psychosocial relationships are linked to the autonomy of the person with MS which relates to personal factors of identity, roles, and motivation and the degree of independence, interdependency, and dependence experienced by the person with MS. The attitudes of people in the social environment can enable or limit engagement and performance of occupations. The psychosocial relationships are also part of the wider social environmental context of occupational performance. It is through the person's motor and process skills that goal-directed actions are performed. These skills enable the person with MS to engage and participate in occupations.

Surrounding the Person living with MS are the occupations the person chooses or is obliged to engage in. IADL in domestic life are complex occupations of daily life based at home and the in the community such as meal preparation, cleaning, IT use, shopping, and gardening. IADL are an important group of occupations for people with MS. Other important groups of occupations for people with MS are mobility through the domestic and community environments, work, self-care, and leisure and special events that enrich life. These groups of occupations are interlinked with complex personal choses and responsibilities influencing an individual's lifestyle. Participation in occupations is maintained by the interdependent support of other significant people and can be sustained by the person with MS directing other people to assist or perform IADL and other occupations.

The occupational therapist establishes a therapeutic partnership with the person with MS that enables personalised interventions to be implemented. The partnership involves a process of empowerment that enables the person with MS to engage and participate in the occupations they choose or need to do. The occupational therapist aims to encourage a balance between groups of occupations. By listening to and respecting the diagnostic narrative of the person with MS an understanding of their experiences and perceptions develops, and the occupational therapist builds the therapeutic partnership. The occupational therapist aims to empower and instil hope for the person with MS and their significant other people. Continued engagement and participation in occupations results through the therapeutic partnership and occupational therapy interventions within the MDT context.

Occupational therapy practice for people with MS is set within a problem solving and goal setting therapeutic process. This is integrated and co-ordinated within an MDT practice context. The professional relationships of the MDT with the person with MS are also important

in enabling or limiting engagement, participation, and performance of occupations. The therapeutic process includes crisis management when safety is threatened by serious situations. Safety, to prevent harm when engaging in occupations, is also a key consideration for the person with MS, significant other people, the occupational therapist, and the MDT within the model. The therapeutic process also involves navigating services to advocate for and access support for continuing occupations or finding alternatives.

Occupational therapy interventions are personalised by considering and respecting the occupations of meaning and value to the person with MS. The interventions may be categorised into three groups. A structured programme of fatigue management enables the person with MS to deal with the debilitating symptoms of fatigue that often occur. Fatigue management can be personalised by awareness and understanding the diagnostic narrative. Environmental interventions consist of assistive technology provision and adaptation of the physical environment usually in the home. Identifying and providing equipment to enable occupational performance or involve facilitation of rehousing. The physical environment such as topography, architecture and the urban environment surrounding the person with MS is a context for occupational performance. Psychological interventions set out to address the psychological issues associated with MS. These interventions use cognitive rehabilitation and anxiety management to address the impact of MS on occupational performance. Fatigue management should be integrated with cognitive rehabilitation interventions.

This model of occupational therapy practice has developed from a synthesis of the core concepts and themes identified in the research findings. Guidance for occupational therapy practice is provided using the therapeutic partnerships to identify the holistic needs of people with MS in their engagement and performance of occupations and use the appropriate and personalised interventions available. The model is based on the principles of person-centred care and is compatible with the ICF.

4.5 Summary

Chapter Five has presented the findings of the data analysis. The case summaries have been used to describe and explain in detail the experiences and perceptions of the occupational therapy interventions on the meaningful and purposeful occupations of the five people with MS in their daily lives. The framework analysis of the data resulted in the identification of the four core concepts of living with MS, the occupations, occupational therapy interventions for people with MS and Inter-relationships. The AMPS measurements of ability in occupational performance within IADL added valuable attributes to provide explanatory accounts within the framework analysis. The complex links between the core concepts and their associated themes have also been presented. The data analysis has culminated in a synthesis to produce

the new and contemporary MS Person-centred Occupational Therapy (MS-PcOT) Practice Model. The following chapter will discuss, the findings considering previous research, the strengths of the study and contribution to occupational therapy practice, the degree to which the research question has been answered, objectives met and the limitations of the research.

Chapter Five

Discussion

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5. Introduction

In Chapter Five the findings are considered, compared, and contrasted with reference to the wider literature and policy background. A summary is presented of the original contribution this study makes to knowledge of occupational therapy practice for people with MS. Initially, this research set out to explore how occupational therapy interventions contribute to the ability of people with MS to perform IADL. The research findings presented are the five case summary accounts and the core concepts and themes that emerged from the framework analysis. The key findings of the research are represented by the themes that make up the four core concepts of: The Person Living with MS, The Occupations, Occupational Therapy Interventions for People with MS, and Inter-relationships (see Table 13). A new and contemporary person-centred model (MS-PcOT) of occupational therapy practice for people with MS has been constructed, following a synthesis of these core concepts and their themes. The originality and strengths of these new findings are identified within the contexts of previous research, policy, the theoretical lens of person-centred care and models of occupational therapy practice. The novelty of this multiple case study research methodology and methods employed are also justified. Finally, the outcome of the research question and the objectives are examined, and limitations of the study discussed.

5.1 The Person Living with MS

Discussion of the findings begins with the core concept of *The Person Living with MS*. This core concept relates to experiences, which are reflected in the individual narrative and stories the people with MS construct about the impact of MS on their daily lives and occupational performance in IADL. The four associated themes of: diagnostic narrative, motor and process skills, psychological responses and autonomy make up this core concept. All these themes are intrinsic to the person with MS. This core concept is an interpretation of experiences and perceptions of each of the five cases. The Person Living with MS confirms the person-centred nature of the research findings and represents an important and insightful contribution to occupational therapy practice.

The literature reviewed focused on occupational therapy interventions for people with MS related to ADL and IADL. The studies reviewed are predominantly quantitative in research design and do not consider the experiences and perceptions of people with MS. The literature

review themes of in-patient rehabilitation, assistive technology, cognitive rehabilitation, and professionally guided self-care identified (see Table 6), are not directly related to this core concept as the studies do not consider the experiences or perceptions of people with MS. The service user perspective identified in the literature review would initially appear to be of relevance to the Person Living with MS core concept (Finlayson et al., 2008). This work, however, is more concerned with identifying which people with MS engage with occupational therapy services than the perceptions and experiences of people with MS in relation to occupational performance in IADL. Finlayson et al. (2008) focuses on the service provision level and does not consider the details and complexities expressed in the Person Living with MS core concept.

One study does consider the perceptions of people with MS through selecting their own therapy goals (Asano et al., 2015). People with MS set goals about IADL but this does not go beyond indicating the crucial importance of IADL. Details are not provided of which IADL are engaged with or the perceptions of the participants. Employing quantitative methods does not therefore consider the perceptions and experiences expressed in the core concept of The Person Living with MS. The concern of previous quantitative has been the clinical effectiveness of occupational therapy interventions. For this core concept the reviewed literature provides an unsatisfactory explanation of the findings and this represents a gap in knowledge.

The qualitative research concerning the lived experience of people with MS and person-centred occupational therapy practice models offer some structure to discussion of the Person with Living MS core concept. The diagnostic narrative theme within the Person with MS core concept when compared with the Person Environment Occupational Performance (PEOP) practice model, confirms the concern with a personal narrative and the individual stories suggested by this occupational therapy practice model (Baum, Christiansen & Bass, 2015). In PEOP the narrative is concerned with past, current, and future perceptions and meanings. This is close to the contents of the diagnostic narrative which also includes the future as a concern of the five people with MS. These narratives influence the individual's unique occupational choices, interests, and goals. The PEOP is also concerned with motivation to perform occupation. Motivation was included in the autonomy theme in the Person Living with MS core concept and linked to the occupations. The identification of the diagnostic narrative confirms the importance for the occupational therapist of understanding the client's viewpoint and their issues through the personal story as the starting point of the therapeutic process and therapeutic partnership. This is reflected by the linkages identified in the framework analysis between the Person Living with MS and Occupational Therapy Interventions (see Table 11). Narrative reasoning has previously been identified as a feature of professional reasoning in

occupational therapy (Mattling & Fleming, 1994). Occupational formulation is a recently proposed and relevant concept concerning the process of making sense of a person's circumstances (Brooks & Parkinson, 2018). This occupational based concept recommends taking a narrative approach into account by incorporating a client's subjective perspective into occupational therapy practice. Occupational formation locates occupation at the centre of a clinical reasoning process. It involves a three part structure of occupational influences, occupational presentation, and occupational focus within the occupational therapy process to inform practice.

The time dimension within the diagnostic narrative is reflected by *The Future* category. Another qualitative research paper referred to an occupational perspective of IADL in considering the use of everyday technology (Stern & Goverover, 2018). One of the themes identified in this research relates to seeing the present and future self and shifting occupational identities. This was certainly reflected for Lisa (Case 2) as she moved from an occupational identity of being a cook to a gardener. For Caroline (Case 5) the occupational therapy interventions involving adaptation of the home were designed to enable her to participate in parenting and gardening occupations in the future.

Some of the introductory and background discussion of Chapter One is relevant to the core concept of the Person Living with MS, despite not being identified in the literature review. The lived experience of MS fatigue is central to the diagnostic narrative, the expression of the impact of the condition on participating in occupations. This confirms other qualitative research on MS fatigue where understanding the impact of fatigue on daily life informs occupartional therapy interventions (Turpin et al., 2018). The disruption to the person's life in the first year after a diagnosis of MS, as identified in Finlay's (2003) phenomenological study, is a significant factor. The research findings presented in this thesis confirm, and expand on, this disruption offering insight for occupational therapy practice. It is at this time that the diagnostic narrative forms and develops. Finlay's (2003) qualitative research is particularly pertinent to Diane (Case 3) who had the most recent experience of coming to terms with the diagnosis of MS. She was still in the process of constructing a narrative of her experiences and transition in work and domestic life. The impact of MS is reflected in this and relates to occupational performance for the person with MS in IADL. The Psychological Response identified were emotions, anxiety, frustrations, and grief concerned with the psychological impact of MS on occupational performance in IADL. The Diagnostic Narrative was strongly linked with the Psychological Response theme and represents important new knowledge for occupational therapy practice. The new model advocates that the occupational therapist should build optimistic perception of the future to counter these early negative psychological responses and develop realistic hope in occupational performance for people with MS.

Inclusion of a Motor and Process Skills theme as a dimension of the Person Living with MS in the framework analysis reflects the intrinsic capabilities of occupational performance in IADL. Skills are central to occupational performance in the Model of Human Occupation (MOHO) practice model (Kielhofner, 2008). Motor and process skills were identified as integral attributes of the person with MS that could be measured with AMPS. Skills are universal goal directed actions that a person needs for occupational performance in IADL (Fisher & Jones, 2010). MS has a profound impact on a person's ability in both motor and process skills (Doble et al., 1994; Mǻnsson & Lexell, 2004). This was reflected in the links between the diagnostic narrative and Motor and Process Skills themes (see Table 11). When the process skills were analysed, they were found to be much less prominent than the motor skills (see Section 4.3.1 and Figure 17). This is despite cognition presenting as a prominent category within the diagnostic narrative theme with linkage to the psychological interventions within the Occupational Therapy Interventions for People with MS core concept.

The autonomy of the individual to make decisions and retain agency and control over occupational performance in IADL, formed a theme within the core concept of the Person living with MS. Autonomy has been identified as a key human need, alongside health, with major variables of understanding, cultural expectation, ability to form options and opportunities that enable activities (Wilcock & Hocking, 2015). A distinction has also been made between decisional autonomy and executional autonomy which is the ability to act on decisions (McPherson, Gibson, & Leplege, 2015). Autonomy involves a social relations process which is clearly confirmed in the research findings through the links between the autonomy and the Inter-relationships core concept (see Table 11). The challenge to decisional autonomy presented by cognitive impairment is contained within the Person with MS core concept with the internal linkage between autonomy and cognition (McPherson et al., 2015). Concerns about safety during occupational performance in IADL also challenges the person's autonomy but can be overcome by drawing on relationships with others to continue participation by directing IADL. The importance of social and cultural norms has been stressed in the value societies place on autonomy and its relationship to independence and interdependency with others (Reed, 2015). Other relevant theory concerning the diagnostic narrative and the autonomy themes is the work of Archer, (2003) on social structures, an individual's agency, and the internal conversation. The appraisal of IADL performance links into the diagnostic narrative as the person with MS through their own internal conversation or self-appraisal.

The core concept of the Person Living with MS is central to the MS-PcOT model and an important starting point for the occupational therapist to understand the values, aspirations, and viewpoint of their client. The therapeutic relationship theme links the occupational therapist in a partnership that respects the experiences and perceptions of the person with

MS through this understanding of the Person Living with MS core concept. The design of effective occupational therapy interventions can follow through listening and respecting the experiences and perceptions of the person living with MS. The details of the contents of this core concept is a notable new finding in relation to occupational practice for people with MS.

Research into the experiences of people with MS is in line with the drive for person-centred care in UK health policy. The NHS long-term plan identifies a need to shift services towards more person-centred care (NHS England, 2019). There is a need to base healthcare provision and professional practice on qualitative evidence that respects the meaningful occupations of the person. By identifying how the occupational therapist can use the diagnostic narrative by listening and analysing the perceptions and experiences of the people with MS and building a therapeutic partnership, the research contributes towards achieving person-centred care.

5.2 Occupations of people with MS

The Occupations core concept contained the five themes of: Instrumental Activities of Daily Living, Mobility, Work, Activities of Daily Living and Leisure and Special Events. The Occupations core concept is about both the variety and range of occupations undertaken by the five people with MS. The links and interplay between IADL and other groups of occupations is emphasized. This section compares and discusses the findings with the occupations featured in the literature review. The influence of life stage theory and gender are also considered.

The Occupations core concept is concerned with the meaningful and purposeful occupations that the five people with MS engage and participate in during their daily lives. The IADL theme alone reflects the depth and detail of the data and contains eleven categories of activities. The occupational therapist needs to understand the demands of these key occupations at this stage of life to design interventions. The activities to which the people with MS attached value and meaning are related to individual roles and occupational identity; the occupations they want and need to engage in their daily lives. The multiple links between these identified daily occupations concurs with the work of Månsson-Lexell, Iwarsson, & Lexell, (2006) who conclude on the complexities of daily occupations for people with MS. These occupations, however, are not only complex but also unique in their individuality for each person with MS. The complexity of interactions involved in IADL and the demand on occupational performance are also referred to in the definition of IADL in the Occupational Therapy Practice Framework (AOTA, 2014) (see section 1.4, p. 40). To support these occupations respect of this individuality is required so that personalised occupational therapy interventions can be built.

Meal and drink preparation were prominent IADL occupations in the data for the five people with MS. Continuing participation in cooking was important for Michael (Case 1) and Lisa (Case 2) despite limitations due to MS. Meal or drink preparation tasks were selected for AMPS by Michael, Diane (Case 3) and Paul (Case 4). Only one of the studies previously reviewed involved meal preparation tasks. Preparing breakfast foods and financial management were used as everyday functional tasks to examine the utility of a self-generation strategy to improve performance in a quantitative study (Goverover et al., 2008). This category has otherwise been overlooked as activities in previous intervention studies.

Previous research on IADL and occupational performance by people with MS in occupations including cooking, money management and IT use was introduced in Section 1.4. When these predominantly quantitative designed studies are compared with the research findings the complexity and in-depth nature of the occupations can be seen. The ability to prepare a cooked breakfast was used as an outcome measure in a study of the impact of cognitive function on occupational performance (Goverover et al., 2015). Cooking is described as a universal and culturally accepted representation of activity and participation. It does not however, consider the form and meaning of cooking to the individual participants or involve an intervention to improve function. The findings presented in the IADL theme of the Occupations core concept identify meal and drinks preparation as important occupations for four of the five people with MS. Occupational therapy interventions and support from family and carers also enable participation in cooking to continue.

The value of shopping for the people with MS and the interconnection of IADL occupations was demonstrated in the research findings. Links between shopping and financial management, IT use, driving and public transport use were demonstrated. The support of other people to facilitate participation in shopping occupations also emerged in the data. In the reviewed research one study used on-line shopping tasks in assessing everyday functioning (Goverover and DeLuca, 2018). This was justified as relevant to contemporary lifestyles and technology use and avoiding the biases of kitchen-based performance assessments. Despite the potential value of assessing IADL performance through this approach the shopping occupations for the five people with MS were physical acts. Both Michael and Lisa expressed preference for visiting the supermarket over internet shopping in their interview data.

Money management has also been used as a complex and cognitively demanding IADL to identify the impact of cognitive function impairment for people with MS (Goverover et al., 2016). The findings of Goverover et al. (2016) confirmed a correlation between cognitive impairment and self-reported problems with money management. Financial management was

identified as a more minor category of IADL in the Occupations core concept. However, money management had important links with IT use for Dianne (Case 3) through the difficulty she encountered making a charge card payment or using online banking services. The importance of IT use is confirmed by qualitative research regarding everyday technology use by three men (Stern & Goverover, 2018). The importance of connections with other people was identified as a belonging theme (Wilcock & Hocking, 2015). This was reflected in the research findings associated with email and internet use. Dianne's visual impairment formed a barrier to email communication with former colleague and friends. This compounded her sense of isolation at home.

The importance of the IADL theme within the Occupations core concept strongly concurs with the conclusions drawn by Asano et al (2015) when analysing goals set by people with MS following a teleconference delivered fatigue management programme. Indeed, the IADL goal categories were dominant accounting for 58% of the goals set by people with MS. The Occupations core concept builds on this finding to give details of the individual IADL categories and their relationship to other groups of occupation for the five people with MS.

The Safety of the Person with MS in IADL was a noteworthy theme within the Occupations core concept. The Occupational Therapy Practice Framework describes this with reference to knowledge and occupational performance to maintain safety and prevent the threat to health and safety (AOTA, 2014). This was a crucial consideration for the occupational therapist during the design of occupational therapy interventions. Details of how people experience safety issues when participating in IADL and the link to crisis management is an informative finding of the research. Issues of safety were not considered by the studies in the literature review.

It is of interest to consider how the IADL occupations the five people with MS were related to other groups of occupations. One of the occupational therapists expressed a difficulty in separating IADL occupations from other occupations when reflecting on professional reasoning. IADL were viewed as interlinked with other occupations. This holistic occupational perspective was borne out as four other prominent groups of interlinked occupations, Mobility, Work, ADL, and Leisure and special events, emerged during data analysis.

Functional mobility is classified as an ADL occupation in the Occupational Therapy Practice Framework (AOTA, 2014). In the research findings Mobility was justified as a separate theme within the Occupations core concept due to its importance to the people with MS and prominent frequency of coding reference. Mobility in the wider sense also links to the skills of the person with MS, through the Motor and Process Skills theme (Walks), and community mobility, through Driving and Public transport use in the IADL theme. The later of these was

important for Michael and Diane who had both encountered considerable barriers in their community mobility resulting in frustrations and anxiety. Comprehensive review of the individual needs of the person with MS should include assessment of driving and access to transport (NICE, 2014).

The literature reviewed on assistive technology included two studies related to community mobility (Akinwuntan et al., 2014; Gillen, 2002) (see section 2.2.2). A case report considered the provision of an electrically powered wheelchair system to a person with MS (Gillen, 2002). The argument for the importance of community mobility is presented through the goals of visiting friends and participating in the life of the neighbouring community. Improving driving related skills was the objective of the study using a driving simulator (Akinwuntan et al., 2014). Despite the limitation and bias to well performing drivers of this study, the focus on improving driving performance is welcome. Driving comprises a major area of transportation and studies of fitness to drive have received research attention (Van der Feen et al., 2019). For people with MS such as Michael (Case 1), the value of continuing to drive safely is an important part of their identity.

Problems with mobility have also been found to account for 20% of occupations perceived to be difficult and therefore form a major concern for people with MS (Månsson-Lexell et al., 2006). This indicates the importance of functional mobility, in the form of how the person with MS moves through space in the domestic or community environment. The prominence in the research findings of the Mobility theme as a concern of the person with MS confirms that this theme in the Occupations core concept, should be of high importance to the occupational therapy intervention and reflect personalised needs. Wider transport policy should aim to overcome the barriers encountered by people with MS in the community and reflect this concern.

In the literature review ADL outcomes represented the most frequently considered group of occupations. The two studies of in-patient rehabilitation were concerned with ADL occupations (Lexell, et al., 2014; Maitra et al., 2010). Both studies into the effect of cooling suits used ADL outcomes (Flensner and Lindencrona, 1999; Özkan et al., 2017). The study of a guided self-care programme was also based on ADL occupations (O'Hara, 2002). Although ADL emerged as a theme within the Occupations core concept this was primarily as a concern for Caroline as her level of occupational performance did not permit engagement in IADL. For the other four people with MS the importance of IADL occupations far out-weighed ADL. The focus of research into occupational therapy interventions has previously centred on ADL. A more holistic view of the fuller range of occupations people with MS engage in is reflected in the

research findings. A shift from concerns with ADL towards the complexities of IADL is a major finding of this research.

Other IADL occupations of key importance to the five people with MS are not reported in the reviewed literature. Details and insight into participation in gardening, cleaning, laundry, child rearing and parenting, caring for other people and pets, health management and maintenance are presented in the findings and constitute unique new knowledge. The case summaries give vivid narratives of the valued and importance of these occupations for the five people with MS. IADL also link to other themes in the Occupations such as balance with work and leisure.

As the onset of MS occurred in early to mid-life for the five cases it is useful to consider life stage theory when discussing The Occupations core concept. The life stage the person with MS has reached when onset and diagnosis of MS occurs provides an illustrative explanation of the subsequently pattern of occupations in IADL and other groups of occupations for the individual cases. The participants were aged between 24 and 50 years at diagnosis of MS which represents the early to mid-adulthood life stage. At this time of life it would be expected that occupations associated with work, leisure, parenting and care giving are undertaken and prominent in people's lives (Matuska & Barrett, 2015). Early adulthood is also a time when intimate relationships develop and family life begins (Erickson, 1994). Work occupations become increasingly important during early and mid-adulthood, with career choices being made and work role development take place (Shaw & Cronin, 2005). In early and mid-adulthood skills are developed and competency gained in IADL such as home management, care giving to children and potentially one's own parents as they age. Maintaining an occupational balance with time for leisure as well as work and IADL demands such as maintaining the home and care responsibilities can be challenging at this stage of life.

The Occupations core concept identified the reality of the occupations engaged in by the five people with MS. The disruptive impact of MS on occupational performance and patterns of occupational engagement at this adult stage of life is reflected in only Paul (Case 4) maintaining a paid work role. The disruption to autonomy results in difficult and unwelcome work choices being made. This was particularly poignant for Diane (Case 3) who had to contend with ending a successful career and being forced by circumstance to engage in IADL occupations mainly based at home. For Caroline (Case 5) work had remained paramount until the impact of MS on her occupational performance, in the form of ataxia, had become so severe that ADL occupations had overtaken as the current precedence leaving little engagement in IADL occupations. For Lisa (Case 2) IADL occupations, in the form of gardening, had provided new and supported opportunities. Leisure occupations, however, did not feature greatly with implications for occupational balance.

The difference between the meaningful occupations of the male and female participants is noticeable in this study. The reviewed literature, however, does not consider or discuss occupations by gender. The three female cases are all mothers: Lisa (Case 2) and Diane (Case 3) with older children at secondary school and Caroline with younger children. The onset of MS occurred for Caroline in early adulthood and resulted in disruption to parenting and the balance of work and IADL occupations. The occupational therapy intervention took this into account by enabling Caroline to continue engaging in parenting occupations and family life. Living with a parent with MS can have an emotional impact on children's lives. The children can assume additional roles and responsibilities which lead to the restriction in participation in developmentally appropriate occupations (Turpin, Leech, & Hackenberg, 2008). In the case summaries both Lisa (Case 2) (see section 4.1.3) and Diane (Case 3) (see section 4.1.4) refer to the impact of living with MS on their role as a parent and this change in their children's lives. The response of the occupational therapist was to take these issues into account by considering the impact not just on the person with MS, but also the whole family unit.

The two male participants engaged in IADL occupations. The relationship, however, between IADL and other prominent groups of occupations in their lives contrasted. The occupational identity of Michael (Case 1) was strongly associated with his role as a driver. This was based on his previous work in motor sport and linked to an on-going interest in motor sport as a leisure occupation. Driving as an IADL was also valued by Michael as part of his role of caring for his partner. This was integral to his daily life. Paul spoke of the importance of maintaining a balance between occupations, so his work was not dominant to the detriment of his home life. Maintaining participation in sport as a cricket coach and through socialisation at the local community sports club were highly valued and meaningful leisure occupations for Paul. Although occupational therapy interventions in the form of fatigue management were not directly targeted at IADL occupations, the outcome of promoting an occupational balance between work and home life enabled him to engage in IADL such as cleaning and gardening.

Having discussed the findings of the Occupations core concept the next section will show how the occupational therapy interventions contributed to the ability of the people with MS to continue performing IADL.

5.3 Occupational therapy interventions for people with MS

The third core concept of *Occupational therapy intervention for people with MS* reflects the wide range of knowledge, skills and techniques employed by the occupational therapists. The themes comprised of three groups of interventions fatigue management, environmental interventions, and psychological interventions. The therapeutic process guided these

interventions. The therapeutic relationship sat within this core concept but was also connected to the psychosocial relationships core concept of the MDT.

The Therapeutic Process theme and the therapeutic relationship can both be seen as part of professional reasoning which are the thought processes the occupational therapist uses as they engage with the client (Unsworth & Baker, 2016). These processes involved generic interventions such as assessment, problem solving and goal setting but also identified other key areas of importance in navigating services and crisis management (see Figure 19). When viewed through the theoretical lens of person-centred care in the MS-PcOT model, the therapeutic relationship develops into a therapeutic partnership between the person with MS and the occupational therapist which respects and considers the diagnostic narrative.

Fatigue management was clearly a central intervention for occupational therapy and the wider MDT in the CNT and forms a core theme of occupational therapy intervention in the MS-PcOT model. Previous research into fatigue management has predominantly used quantitative methods and is recognised as being a clinically effective intervention (see sections 1.5 and 2.2.5). The research findings build on this evidence base by interpreting qualitative data with an illustrative example of how fatigue management strategies are implemented. The people with MS, carers and occupational therapists express their perceptions of the value of fatigue management interventions in the findings. The research confirms and adds to the importance of fatigue management identified in the previous quantitative studies. The real world practice context of the CNT endorses the role and value of fatigue management. This was led by occupational therapy and often considered to be a starting point for wider multidisciplinary interventions. The fatigue management programme consisted of a well-structured series of interventions, was integrated into the MDT approach, and used with all five cases at some point (see section 4.3.3).

The research findings offer a detailed description of the four stages deployment of a fatigue management programme. A structured yet flexible approach to fatigue management for the individual is also important. This personalisation was demonstrated for Paul (Case 4). A face-to-face and personalised fatigue management programme was applied by the occupational therapists in the CNT. This contrasted with the remote tele-conference programme used in the Asano et al. (2015) study. The research confirms the key role that fatigue management plays as an occupational therapy intervention and provides details of real world practice with feedback quotes from people with MS. The findings give insight into the strategies that work in the real world of occupational therapy practice and stress the timeliness of the intervention. This thereby adds qualitative detail from the viewpoints of the person with MS and the occupational therapists. The research findings confirm the conclusions drawn by (Asano et al.,

2015) that occupational therapist should focus fatigue management strategies on IADL. Fatigue management therefore should have an occupational base.

Fatigue management is not a simple and straight forward process. The necessary behavioural and lifestyle changes account for fatigue management being perceived as difficult to implement (Bogdan et al., 2017). The occupational therapist stressed the importance of the psycho-social elements of fatigue management. Particular attention was paid to the role of family, friends, and carers in supporting the person with MS to continue engagement and performance in occupations. The profound changes demanded by the fatigue management process used by the occupational therapists was targeted at empowering the person with MS to self-manage their fatigue.

An original aspect of this qualitative designed research lies in seeking the Person with MS perspective and the occupational therapist's perspective on a fatigue management programme. The findings give depth and detail to the stages and process of fatigue management during real world implementation. Previous research has demonstrated the effectiveness of fatigue management (Thompson et al., 2018). Studies have not, however, built from this to detail how fatigue management programmes can contribute to improving occupational performance in IADL and other occupations. The current guidance to occupational therapists on fatigue management and IADL for people with MS is based on expert opinion and not research evidence (Harrison, 2007).

The environmental interventions theme was concerned with facilitating occupational performance in IADL through manipulating the environment by physical adaption and the provision of equipment. Previous research concerning the role of assistive technology has considered PDA's as cognitive rehabilitation tools (Gentry, 2008), provision of an electrically powered wheelchair (Gillen, 2002), a driving simulator (Akinwuntan et al., 2014) and cooling suits (Flensner & Lindencrona, 1999; Özkan, et al., 2017) (see section 2.2.2).

When comparing the use of IT devices studied by Gentry (2008) with the research findings the five participants did not use such IT devices within their cognitive rehabilitation programmes. The daily use of IT devices, however, was particularly important to Diane (Case 3). The occupational therapy intervention was more important in navigating services to enable Diane to use her own computer coding skills and mobile phone apps to develop personalised solutions to mitigate the impact of visual impairment. Despite Caroline (Case 5) using an electrically powered wheelchair, the research data did not identify a role of occupational therapy with this mobility theme. A more detailed description of the involvement of occupational therapy in equipment provision is provided by the examples of the selection of a

walker and the ramped access adaptation to that facilitate gardening occupations for Lisa (Case 2) (see section 4.3.2 and 4.3.3).

Driving simulation has potential value in contributing to the valid and accurate identification of driving abilities for people with MS (Akinwuntan et al., 2014). Safe driving is a complex task involving many demands on cognitive skills (Samuelsson, Tropp, Lundqvist, & Wressle, 2019). Occupational therapists employed at driving assessment centres are involved in decision making for fitness to drive. The use of a driving simulator, such as researched by Akinwuntan et al. (2014), could be beneficial if they are shown to improve validity and reliability of driving ability assessment. This would be suitable for Michael (Case 1) as driving was such a contribution to his occupational identity. The occupational therapist in the CNT supported him in navigating the driving assessment process and took his parking needs into account during the re-housing process.

Evidence for the effectiveness of wearing a cooling-suit and the impact on occupational performance in ADL has been presented in two studies (Flensner & Lindencrona, 1999; Özkan, et al., 2017). Diane (Case 3) wore a cooling vest when participating in the AMPS. She was unsure about the effectiveness of wearing the vest on her abilities in IADL but subjectively found the cooling effect from the vest helpful. Knowledge of the evidence base for cooling-suits could have informed discussion within the therapeutic partnership with the occupational therapist, however, further research is required to establish the effectiveness of cooling-suits in IADL occupations.

The literature search did not identify papers associated with home adaptation or rehousing for people with MS and how this relates to IADL occupational performance. This is despite the physical environmental context being a key and integral component in occupational performance considered in occupational therapy practice models such as the Canadian Model of Occupational Performance and Engagement (CMOP-E), the Model of Human Occupation (MOHO) and the PEOP model (Baum, Christiansen, & Bass, 2015; Kielhofner, 2002; Townsend & Polatajko, 2007). The research findings therefore contribute illustrative descriptions and explanations of environmental interventions to facilitate IADL from the perspectives of the person with MS and the occupational therapist. Environmental interventions can also be related to the wider contextual category of the physical environment around the person with MS in the MS-PcOT model.

The Psychological Interventions employed by the occupational therapists included cognitive assessment and rehabilitation. These are incorporated in the new model as would be expected from the recommendations of the review of by Yu & Mathiowetz (2014b) and the cognitive

rehabilitation theme in the literature review (see Section 2.2.3). The effectiveness of self-generation to improve processing skills through using the person's own words and personal references in IADL is informative (Goverover, et al., 2008). This cognitive rehabilitation technique would be beneficial within the context of fatigue management. Integrating self-generation into a fatigue management programme would enable the person with MS to develop their own personalised descriptions of experiences of fatigue and a self-management programme. The Goverover et al. (2008) study also provides evidence of an effective person-centred approach. Assessment of IADL function is a component of the MS-PcOT model. The use of on-line shopping tasks in the *Actual reality* assessment is relevant to many contemporary lives and accessible to occupational therapists (Goverover and DeLuca, 2018). The relevance of this approach of assessment for the five participants, however, was limited due to motor and process skills impairment and preferences for physical shopping.

The research findings go beyond the use of cognitive rehabilitation but also highlighted the importance of anxiety management and mindfulness. The research adds detail to the participants' view on psychological interventions for example in how the occupational therapist supported Lisa (Case 2) with her cognitive difficulties (see sections 5.1.3 and 5.3.3). An area of potential useful future research is investigation of the links between not only the impacts of cognitive rehabilitation on cognitive functioning, but also its association with process skills and occupational performance in IADL. This is particularly important if the impact of cognitive dysfunction on occupational performance is underestimated. A key feature of the new model is the integration of the valued and meaningful occupations of people with MS and occupational therapy interventions. A cognitive occupational-based intervention programme (COB-MS) has attempted such a holistic approach (Reilly & Hynes, 2018). This is the only previous research to integrate occupations with an intervention programme.

For the occupational therapist the research findings indicate a key of intervention is an understanding of how the clinical features of MS impact on the person's skills, competencies and ability to engage in the occupations they choose in the real world of their daily lives. This is an important finding for occupational therapy practice. This section has discussed the repertoire of occupational therapy interventions revealed by the research. They represent major research findings that have implications for occupational therapy practice.

5.4 MS-PcOT: A new model of occupational therapy practice

The innovative MS-PcOT practice model has been constructed as a synthesis of the core concepts: The Person Living with MS, the Occupations, Occupational therapy interventions for people with MS, and Inter-relationships (see section 4.4). The model encompasses the research findings and contributes evidence-based guidance to occupational therapy practice

for people with MS. The model is uniquely centred on the Person living with MS and their occupations. A holistic and personalised view of the occupations and the interventions used by occupational therapy is incorporated within the model. This model contributes to integrated and co-ordinated care by the MDT in the community practice context. This context is aligned with the drive and commitment for community based services. MDT working is embedded in the model through the professional relationships of the MDT and the therapeutic partnership of the occupational therapist. The model is also compatible with the ICF and facilitates communication with other professions. This collaborative working between the HCPs and patients is aligned with the fundamental shift called for in the NHS plan (NHS England, 2019). The model also explicitly highlights to other disciplines the concern of occupational therapy for the meaningful occupations of the person with MS and the range of interventions available.

When compared to three other influential occupational therapy practice models, The *Canadian Model of Occupational Performance and Engagement* (CMOP-E), The *Model of Human Occupation* (MOHO), and *Person Environment Occupational Performance* (PEOP) the MS-PcOT model has shared concern with broad elements of the person, environment, and occupation. In contrast, The CMOP-E has a focus on occupational performance and engagement in a social environmental context (Townend & Polatajko, 2007). In the CMOP-E the person's occupational performance is centred on affective, physical, cognitive, and spiritual components. Human occupation involves interactions between the person and the environment using different categories of self-care, productivity, and leisure, in contrast to the MS-PcOT model and does not identify mobility and IADL as categories (Baum, Bass & Christiansen, 2015). The MS-PcOT model goes beyond CMOP-E to detail the importance of IADL occupations in domestic life, psychosocial relationships, MDT relationships, and the therapeutic partnership with the occupational therapist and the intervention they utilise.

MOHO is an open systems model to guide occupational therapy practice which labels concepts of human occupation into person, environment, and occupation (Kielhofner, 2008). The person component of MOHO is concerned with the person's participation in occupations which is sustained by volition, habituation, and performance capacity (Baum, Bass & Christiansen, 2015; Forsyth & Kielhofner, 2003). Volition or motivation to perform and engage in daily occupation is central to MOHO and concerned with personal causation, values, and interests. Habituation involves routines, habit, and roles that the person assumes and form patterns of daily occupation. A concept in MOHO regarding the physical environment is that occupations are performed with objects in spaces (Baum, Bass & Christiansen, 2015). Occupational performance in MOHO is concerned with doing and completing daily occupational tasks through purposeful actions or skills. The concept of skills as purposeful

actions that contribute to, and are embedded in, occupational performance is important for the research project undertaken here. In contrast MS-PcOT model the Person living with MS core concept includes skills as a theme and motivation in the autonomy theme. In both models the physical and social environment provides facilitation to support the person's occupational performance in daily life but also can act as a constraint.

The PEOP is a practice model which aims to enable everyday living for individuals, groups, and communities (Baum, Bass & Christiansen, 2015). Focusing on occupational performance PEOP recognises the interaction of the person, environment, and occupation through doing meaningful activities. The model consists of four parts, the narrative, person factors, occupational factors, and environmental factors which contribute to occupational performance. The PEOP is a model that attempts to make a link between biomedical and sociocultural models and is relevant for health and social care practice settings. The MS-PcOT practice model shares similar elements to the PEOP in the use of narrative reasoning and consideration of personal factors.

Unlike the CMOP-E, MOHO and PEOP, which are generic models, the MS-PcOT practice model is based on research findings specific to people with MS. The new model includes the occupational therapist as an agent and details interventions within the model with particularly applicable in the context of a community-based MDT services. Emphasis is placed on relationships between the person with MS and family and carers, the MDT, and the therapeutic partnership with the occupational therapist in supporting occupations. Despite sharing elements of these other models, the MS-PcOT has a unique concern with the occupations in lifestyles of people with MS and operationalising occupational therapy interventions to support ongoing engagement and participation through person-centred care. The novel features of the MS-PcOT model also include the diagnostic narrative of the person living with MS from which the occupational therapist gains knowledge and respect for the experiences and perception of the person with MS in their occupations. The importance for the occupational therapist to build realistic hope with the person with MS and their families and carers is included in the model.

5.5 Originality and strengths of the research

The original contribution to knowledge made by this research rests on the interpretation of the new findings and the novelty of the methods employed. Many original findings have been discovered during this explorative study of occupational therapy interventions for people with MS. Table 19 summarises these new findings and novel methods. The strengths of the

Table 19. Summary of New Findings and Novel Methods

New findings	Novel methods
1. **The Person living with MS** core concept represents the person's understanding of the impact of MS on occupational performance ability and autonomy in IADL and other occupations. The psychological responses experienced and impact on skills ability are expressed in the diagnostic narrative constructed by the person. The concept is concerned with the perception of their meaningful occupations and occupational performance. 2. **The Occupation** core concept concerns the complex and varied nature of IADL in domestic life and the links to other occupations such as self-care, mobility, work, and leisure. The emphasis on IADL in domestic life represents shift from self-care occupations. IADL are particularly important occupations in the early and mid-adulthood life stages when diagnosis of MS occurs. The research is based on the meaningful occupations of five people with MS. 3. **Occupational therapy interventions** are multi-faceted and personalised to the needs of the person with MS. Interventions are grouped into fatigue management, environmental interventions, and psychological interventions. A detailed process of fatigue management was revealed. Environmental interventions include assistive technology, domestic environment adaptation and re-housing. Psychological interventions not only include cognitive rehabilitation but also anxiety management and mindfulness. 4. **Relationships** are important in supporting people with MS to continue engagement and participation in occupations. This includes close people in the social environment, the therapeutic partnership with the occupational therapist and other professional relationships with the MDT. On-going participation in occupations can be supported by directing others. 5. **MS-PcOT Practice model** is a synthesis of the findings that guides person-centred occupational therapy to meet the needs of people with MS in their engagement and performance of occupations. Through developing a therapeutic partnership, that listens and respect the diagnostic narrative, personalised interventions can be used in collaboration with other people in the close social environment and the MDT.	1. **Multiple case study** design methodology person-centred and from perspectives of five cases, Person with MS, carer, occupational therapists and HCPs. This methodology unique in occupational therapy research. 2. **Qualitative** research predominantly in this area detailed, rich, in depth data and interpretation. Contrasting with previous studies using quantitative methods. 3. **Mixed methods** using AMPS as a quantitative benchmark of occupational performance ability in IADL. Inclusion of AMPS data as complement to qualitative methods within case study design. 4. **CAQDAS** NVivo used in data management and development of a framework analysis. The findings are based on a transparent, systematic, and thorough analysis of a large volume of qualitative data together with AMPS, a quantitative measure of occupational performance in IADL. 5. **Real world context** of occupational therapy practice in a multi-disciplinary community based neurology team.

research lie in the use of a multiple case study design employing mixed methods to demonstrate a holistic, person-centred and occupation based perspective on occupational therapy interventions. The research also reveals the importance of relationships between the person with MS and close people in the social environment as well as professional relationships with the occupational therapist and MDT in enabling and supporting occupations. The analysis of the findings culminated in the construction of the new MS-PcOT practice model.

The novel research findings consisted of:

a) The Person Living with MS core concept which is concerned with the intrinsic themes of psychological responses, autonomy, and skills. The impact of MS on these themes and the person's occupations was expressed through the diagnostic narrative. The occupational therapist listens to the diagnostic narrative in the process of developing a therapeutic partnership with the person with MS. Wider quantitative research does not consider or concentrate on the stories of the person with MS and relate this to the implementation process of occupational therapy interventions.

The research is person-centred, being based on data from the perspective of the person with MS and their experiences of IADL and other occupations. Five people with MS were studied by exploring the purposeful and valued occupations in their daily lives and the occupational therapy interventions they received. As the unit of analysis was based on each case, the research is focused on each person with MS which contributes to the core concept of the Person Living with MS. The research has a strong current of hearing and interpreting the voices of the people with MS and their carers. The carers' view on occupational therapy interventions was also included and contributed a valuable perspective to the Person living with MS in a wider sense than the individual. This is integral to the MS-PcOT practice model through the psychosocial relationship theme. The case summaries present deep descriptions from the rich data collected on the experiences in domestic life of the five people with MS. This is also consistent with the theoretical lens of person-centred care. Previous research has not approached occupational therapy practice for people with MS from such a person-centred perspective.

b) The Occupations people with MS engage and participate in are complex, interlinked, and personal to the individual's lifestyle. The complexity of the meaningful occupation of the five people with MS, is demonstrated in the rich description of the case summaries which analysed and interpreted data from the people with MS, carers, occupational

therapists, and other HCPs. The research and MS-PcOT practice model are based on these occupations. The case summaries also contain details of participation in occupations such as meal preparation, shopping, gardening, and driving. IADL are a demanding and crucial group of occupations for people with MS particularly at the early and mid-adulthood stage of life when the condition is usually diagnosed. The importance of mobility, both in the domestic and community environments was emphasised in the findings along with safety of the person with MS in IADL. The focus of the research on IADL is relevant and contrasts with previous studies where ADL outcomes have featured.

c) The Occupational therapy interventions are multi-faceted in nature, personalised to the person with MS and can be grouped into fatigue management, environmental and psychological interventions. These interventions are a response to the complex needs of people with MS. The analysis brings together all the components of intervention in fatigue management, environmental interventions and psychological interventions, and their application in the MS-PcOT practice model. Previous research has concentrated on individual interventions whereas this research was able to illuminate the fuller details of occupational therapy interventions for people with MS. The research also highlights the role of occupational therapy in supporting people with MS to continue participating in occupations such as IADL and to provide a balance with other groups of occupations. Concerns for safety and crisis management within the occupational therapy process themes that have not emerged in previous studies. A detailed perspective of fatigue management by the people with MS and the occupational therapists is presented. Previous research involving assistive technology has not reflected the environmental interventions identified in the research. Re-housing, home adaptation and provision of assistive equipment were key interventions for the five people with MS and were detailed in the case summaries. Such environmental interventions have not previously been described or studied. The findings related to the Psychological interventions go beyond cognitive rehabilitation but also include the novel findings of anxiety management and mindfulness interventions.

d) Relationships between the person with MS and significant others in the close social environment, the MDT and crucially the occupational therapist through the therapeutic partnership, are important in enabling and supporting the continued engagement and participation in occupations. On-going participation in occupation can continue through directing others. This core concept has not been considered in previous research.

e) The contemporary MS-PcOT practice model has been developed from the core concept of the framework analysis as a synthesis of the findings. The model draws together the core concepts to guide person-centred occupational therapy practice to meet the needs of people with MS in their engagement and performance of occupations. Through developing a therapeutic partnership, that listens and respect the diagnostic narrative, personalised interventions can be used in collaboration with other people in the close social environment and the MDT.

The methodological approach combined novel methods in a detailed exploration of the meaningful and purposeful occupations of five people with MS. No other study has attempted to employ such methods to examine the occupational therapy interventions received by people with MS. In comparison with previous studies the methods are new for the following reasons:

a) Qualitative methods of semi-structured interviews were predominately used to collect data. The advantages of qualitative methods enabled in-depth illustrations and explanations of the experiences and perceptions of the people with MS through the rich narratives presented in the case summaries. In contrast previous research has used quantitative methods. These have not presented personal narratives in the form of case summaries or considered occupational therapy interventions in-depth. The research reviewed in Chapter Two contributes knowledge to the effectiveness of elements of occupational therapy interventions but do not have a holistic overview of the interventions available to an occupational therapist. Neither has the wider research conducted by other disciplines used qualitative research designs. The studies reviewed in chapter two were almost entirely quantitative in design. The exception was a study of the effects of wearing a cooling suit on self-care abilities which included thematic analysis of open-ended interviews (Flensner & Lindencrona, 1999).

b) The multiple case study design of five people with MS used a unit of analysis centred on the person with MS. Previous occupational therapy research has used case study design but not extensively (Salminen, et al., 2006). A multiple case study research design has not been used before to research occupational therapy interventions for people with MS.

c) The multiple perspectives of the person with MS, the carer, the occupational therapist, and HCPs in the MDT have not previously been combined and incorporated in a framework analysed. Previous research has not included carer or HCP perspectives.

d) The mixed methods research design incorporates a quantitative element by using the AMPS to provide a benchmark of ability in IADL. The AMPS has been used in research with people with MS to measure IADL ability but not as part of a mixed methods design in combination with qualitative methods (Doble, et al., 1994; Månsson & Lexell, 2004).

e) Data analysis used of CAQDAS through NVivo enhanced the quality of the framework analysis to provide a consistent, systematic, and comprehensive analysis that was rigorously produced.

f) The research has been conducted into occupational therapy practice in the real world context of a multi-disciplinary community based neurology team who work with people with MS in their homes, workplaces, and communities. This is highly relevant to the policy drive of the NHS long-term plan which commits resources to providing integrated community based services (NHS England, 2019).

The findings and discussion demonstrate that this research contributes new academic knowledge to the understanding of the lives of people with MS and occupational therapy practice. This study has also taken a pragmatic and critical realist consideration of occupational therapy in the real world context of community based practice in a multidisciplinary team. The study has been careful to consider the voices of participants, and in particular the people with MS, to provide an occupational perspective of the five individuals. These voices have been heard through the qualitative data that has been collected and analysed. The case study design also places the cases as the unit of analysis and is therefore centred on each person with MS. The theoretical lens adopted for the research takes a person-centred care perspective on occupational therapy interventions with an exploration of the purposeful and meaningful occupations in the lives of the five people with MS. Previous research has not related the person living with MS to their occupations and occupational therapy interventions.

5.6 Research question and objectives

The research question that the project set out to explore and answer consisted of:

How do occupational therapy interventions contribute to the ability of people with Multiple Sclerosis to perform IADL?

Answers to the research question lie in the occupational therapy practices identified in the core concept of Occupational Therapy Interventions for People with MS. These interventions

are carefully designed and help the person with MS to adapt their participation in IADL to their occupational performance capacity. The therapeutic partnership that develops between the occupational therapist and the person with MS enables the interventions to support participation in IADL and other occupations. The interventions consist of the identified themes of therapeutic process, fatigue management, environmental interventions, psychological interventions, and therapeutic relationship. Occupational therapy interventions take place within a multi-disciplinary team context and are co-ordinated and integral with the wider interventions to support the person with MS.

When appraising the six research objectives (Section 2.5) some objectives have been more fully accomplished whereas others have only been partially met. The first research objective consisted of measuring occupational performance in IADL during occupational therapy intervention. This objective was met through the administration of the AMPS to measure the ability of each person with MS to perform IADL. This provided a benchmark attribute of occupational performance in IADL for each case and added towards the explanatory accounts in the framework analysis. The first objective was successfully met and contributed to the research quality by providing crystallization of methods and data analysis. The AMPS quantified motor and process skills in IADL ability. This provided two of the multiple data sources in answering the research question in this mixed methods research design.

The next series of four objectives were all concerned with the experiences and perceptions of the occupational therapy interventions from the perspectives of: a) the person with MS b) the carer c) the occupational therapist d) heath care professionals. The perspective and viewpoints of the people with MS are represented in the case summaries (see section 4.1). The five case summaries were written with prominent consideration of the research question and this second objective. The case summaries and inclusion of verbatim quotes give in-depth and rich accounts of the perspective of the people with MS. It was decided during the analysis process to use NVivo to combine the perspectives of all the participants associated with each case rather than the perspectives of the group of participants. This was justified to maintain the integrity of the case as the unit of analysis. The experiences and perspectives of the person with MS and the occupational therapists are favoured in the reporting of the case summaries and the framework analysis. These two perspectives are closest to the phenomenon of research as both the person with MS and the occupational therapist directly experience the occupational therapy interventions. This was reflected in larger data sets than for the carer and HCP participants who formed a more distant viewpoint. Comparisons of the differing viewpoints enabled harmonies and tensions between the participant perspectives to emerge during the data analysis process.

Research objective three was similar to the second and identified the experiences and perceptions of occupational therapy interventions from the perspective of the carer. This was a more distant view than the Person with MS and the occupational therapist as they did not experience the intervention directly. The shorter duration of the carer interviews (see Table 9) compared with the Person with MS and the occupational therapist reflects this distance. The carers did, however, contribute valuable data in the form of key quotations and contributed to the crystallization process during the framework analysis.

The fourth objective was to identify the experiences and perceptions of occupational therapy interventions from the perspective of the occupational therapist. This was a rich source of data and gave details of the interventions. The occupational therapists had much to say and contributed in particular to the occupational therapy interventions core concept. The interviews with the occupational therapist provided not only a large volume of data in the number of coding references (see table 9), but also insightful quotes that were used in the case summaries and to illustrate the framework analysis.

The fifth objective set was to identify the experiences and perceptions of occupational therapy interventions from the perspective of other significant health care professionals such as the physiotherapist, MS specialist nurse and speech and language therapist. Meeting this objective was less satisfactory for several reasons which will be discussed further, as a limitation to the research (see section 5.6). This perspective contributed to the MDT theme of the Inter-relationships core concept of the framework analysis. Inter professional insight was provided from this viewpoint. The HCPs perspective was considered the most distant and general viewpoint. At times, the HCPs were not able to comment on the specific experiences of the people with MS as they may not have been clinically involved with some of the individuals due to the research design. A more general overview perspective was therefore provided. The HCPs were less directly involved with the occupational therapy interventions than the other participant groups. The data collected from the HCPs was less relevant to the research question which was reflected in fewer coding references (see table 9).

The sixth and final research objective was to synthesise and analyse the data to produce evidence-based guidance for occupational therapy intervention. This is the key objective to contribute new knowledge to occupational therapy practice. The objective was met through the framework analysis which provided an analysis and synthesis of the overall data collected. Based on these findings the new MS Person-centred Occupational Therapy Practice Model has been developed (see section 5.5). Considering the research process and recommendations the final objective was considered to have been met. The implications and

recommendations for occupational therapy practice are presented in following chapter (see section 6.2.).

In retrospect after reviewing the objectives, the research question would be adjusted and re-phrased to a revised question of not just how but also *why* occupational therapy interventions contribute to the ability of people with MS to perform IADL. This would produce more explanation as well as description of the research phenomenon.

5.7 Limitations of the research

The limitations of the research were identified during the research process through ongoing reflection and critical examination which was recorded in a reflexive journal. These limitations were related to the research design and context causing just two occupational therapists to contribute data, the exclusion of people with MS living alone from the research, the time burden incurred by the large volume of data generated for analysis by the qualitative methodology and the utility of the HCP stage of data collection.

An unforeseen limitation of the multiple case study research design and the real world circumstances at the research site, resulted in a lack of control in the recruitment of professional participants. These were also influenced by the real world circumstances and constraints of the structure of the health services at the research site. Two areas of data collection that will be examined with regards to limitations are the occupational therapists' and the Health Care Professionals' contribution. As the recruitment of the five people with MS was of a primary concern this resulted in identification of the occupational therapist participants as a following-on (see section 3.8.3). To maintain the case unit of analysis the occupational therapist to be interviewed had to have provided occupational therapy interventions to that person with MS. In the real world setting of the research site this resulted in two occupational therapists contributing data with Karen providing interviews for four of the five people with MS. It is therefore acknowledged that most of the occupational therapy viewpoint is dependent on a single source and may not reflect the full range of occupational therapy interventions. As only five people with MS met the inclusion criteria it was not possible to include people with MS treated by other occupational therapists. Despite the danger of not representing occupational therapy practice this was fortunate for the quality of the research as this single source was able to provide detailed descriptions and explanations of the intervention processes from a highly experienced, skilled, and expert perspective. The series of four interview with this occupational therapist also resulted in a strong relationship being built between the researcher and participant. This relationship contributed to an accumulation of in-depth and insightful data from a dynamic and innovate occupational therapist. This element

of the research resulted in the study having features of an exemplar case study of good practice (Yin, 2014). It can also be considered as having an element of a scientific view of the singular within the case study (Simons, 2009).

The participation of two occupational therapists had an implication for the data collected by the questionnaire (see section 3.7.4). As four of the questionnaire responses came from the same occupational therapist duplication occurred and limited the utility of the data. The real world experiences of the curtailment of the research access period (as explained in section 3.7) also resulted in the questionnaire not been used as a longitudinal and reflexive data collection tool as was intended.

The final stage of data collection involved recruitment of other HCPs. Again, this stage was limited by the research design and real world circumstances at the research site. The data was gathered from a physiotherapist, a MS specialist nurse, a rehabilitation assistant, and the service manager who had a professional background as a physiotherapist. A speech and language therapist, however, was not available to provide a wider range in the HCPs perspective due to sickness. A medical perspective on the research would have been useful as neurologists and general practitioners are important potential source of referrals to occupational therapy. The composition of MDTs varies between services. At the original research site, where recruitment was not possible, a consultant in rehabilitation medicine and a clinical psychologist were members of the CNT.

Integrated into the research design was the recruitment of people with MS supported by a primary carer (see Figure 5) to provide a carer perspective. These criteria resulted in the exclusion of people with MS without a carer who were living on their own in the community. This limitation became apparent during the recruitment process in discussion with the site collaborator. Some people with MS were not recruited, despite being identified as otherwise suitable to participate, as they could not satisfy this criterion. The experiences of occupational therapy interventions in IADL for people with MS living alone is therefore an area this research was not able to study.

The volume of data generated by the data collection strategy had time consequences for the analysis process and can also be seen as a limitation of the research. The selection of a research design that included multiple cases and multiple data points, contributed to this limitation. The danger here, in a predominantly qualitative research project, is of data overload and over complexity of analysis (Robson & McCartan, 2016). Despite selecting NVivo as a powerful toolbox, the process of data management and analysis using the framework approach (see Figure 9) was lengthy and complex (Bazeley & Jackson, 2013). The decision to transcribe the interview script was time consuming but allowed emersion in the interview

data. A careful balance had to be found between collecting enough relevant data to answer the research question, not being over ambitious in the research objectives for the resources available and the ethics of collecting data unnecessarily and burdening participants. Gaining mastery over a complex software tool such as NVivo presented its own challenges.

Reflection on the data collection methods produced a limitation to the validity and reliability of some of the data collected. One of the outcomes of using interviews was the reliance on the memory and interpretation of events by the participant (King & Horrocks, 2010). The interview data did not always refer to contemporary events as sometimes the occupational therapy intervention had begun and continued over a period of many years. Despite this cautionary criticism, on balance semi-structured interviews were accepted as a valid research method. The danger of reliance on one data source was moderated by the multiple viewpoints and the crystallization process during data analysis.

The HCP stage of the data collection represented a more distant viewpoint as discussed in the previous section. The ability of the HCPs to comment on the research phenomenon and each individual case resulted in data being provided in more general terms. Despite some quotes from HCPs being included in the case summaries, a limited amount of data was coded during the framework process. The ability to contribute to each case as the unit of analysis was in turn also limited. This did, however, give insights into a valuable perspective on the role of occupational therapy interventions within the MDT and the position of the Multi-Disciplinary Team within the Inter-relationships core concept.

In retrospect an argument could be made for simplifying the data collection and reducing the volume of data. This may have been achieved by reducing the number of cases, by leaving out the questionnaire, or even not including the HCP stage. All these however, would have compromised the range and variety of the finding and impacted on the quality of the research. A more detailed examination of the relationships and mapped linkages could have been included to produce an interpretation of the processes involved in the research findings. The final section summarises the discussion.

5.8 Summary

In Chapter Five the research findings have been discussed with reference to previous research and policy. The original and unique contribution the research makes to occupational therapy practice knowledge is synthesised in the MS-PcOT practice model. The research represents new findings of the experiences and perceptions of people living with MS and how they express the impact of the condition on their occupations through the diagnostic narrative. The new model at its core is person-centred and takes the social environment of the person

into account both of which are novel in comparison to previous research. The meaningful occupations of the people with MS have been shown the complex and interlinked nature of the occupations. A new holistic view of the occupations and the interventions available to occupational therapist is demonstrated in the findings and incorporated into MS-PcOT model. The therapeutic partnership and professional relationships with the person with MS are aligned with the health and care policy agenda of person-centred services involving collaborative and integrated professional working that are community based.

The methodology of a multiple case study design employing predominantly qualitative methods has not previously been used in occupational therapy research with people with MS. This novel and unique approach has produced in-depth case summaries and an analysis centred on the person with MS that incorporates multiple perspectives. The limitations of the research rest on issues of research design and pragmatic factors throughout the research process.

The final chapter will conclude the thesis by presenting the key findings of the research. The implications of the findings for occupational therapy practice and policy will be discussed and recommendations for future directions in research suggested. A strategy for dissemination of the findings will be proposed and final conclusions drawn on the research.

Chapter Six

Research implications, recommendations, and conclusion

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6. Introduction

Chapter Six concludes the thesis by summarising the key findings that resulted from this multiple case study research and then discussing the implications of the findings. The key findings are highlighted relating to the experiences of people living with MS in IADL and other occupations, the occupational therapy interventions, and important relationships. A synthesis of these findings has been made in the design of the MS-PcOT, a new holistic practice model. The consequences of the findings for enhancing service provision, occupational therapy practice, policy and education are then discussed. Recommendations are also made for the future direction of research in occupational therapy practice for people with MS. A strategy for dissemination of the research findings is proposed and a conclusion on this explorative research into the complexity of occupational therapy interventions for people with MS draws the thesis to a close.

6.1 Key findings

The findings of the research are presented in detail in Chapter Five and further discussed in Chapter Six. The outcomes of the research can be summarised into key findings which aim to represent new insights made during the research process (Jones & Hocking, 2015). Previous quantitative designed research into occupational therapy interventions has not captured the experiences and perceptions of the people with MS in relation to meaningful occupations. The research findings are based on the investigation of the occupations of five people with MS and the occupational therapy interventions they received. The findings have been synthesised into the new MS-PcOT model with the aim of guiding occupational therapists to meet the ongoing needs of people with MS to continue participation in occupations (see section 4.4).

The core concept of the Person Living with MS is a key finding which represents the person's understanding of the impact the progressive neurological condition on their occupational performance ability and autonomy in IADL and other occupations. The psychological responses experienced and impact on skills ability are expressed in the diagnostic narrative constructed by the person. This represents the perception of their meaningful occupations and occupational performance. The research demonstrated the links between this core concept and the professional reasoning of the occupational therapists as they devise and present interventions to people with MS. A starting point for the therapeutic process is understanding

and respecting the person's views of their occupational performance issues through their diagnostic narrative and the formation of a therapeutic partnership to build realistic hope for the future.

The identification and confirmation of the importance of IADL in domestic life within the Occupations core concept for people with MS forms another key finding. Balancing IADL occupations with other roles such as parenting and work, is particularly demanding at the early and mid-adulthood stage of life when diagnosis of MS often occurs. The Occupations also demonstrates the complexity and linkage of IADL with other groups of occupations such as work, self-care, and leisure. The importance of functional mobility for the five people with MS, with linkages to motor skills and community mobility, were key findings related to the Occupations core concept. Occupational therapists should be mindful of mobility as a core concern for people with MS in their intervention planning. The safety of the person with MS in IADL was also a key finding taken into consideration by the occupational therapists when constructing interventions. The Occupations core concept was based on the rich individual meaning and value the people with MS ascribed to the occupations they participate in. The focus on IADL in domestic life represents a shift in emphasis from self-care in occupational therapy practice.

The Occupational Therapy interventions for people with MS core concept reveals the range of knowledge, skills and techniques used by the occupational therapists. The research confirms the central role of fatigue management programmes and illustrates how these are implemented in a community practice setting. Environmental and psychological interventions were two other identified themes that contributed to supporting occupational performance in IADL for the five people with MS. The therapeutic process and relationship were also part of the professional reasoning employed by the occupational therapists. A key element in professional reasoning is an understanding of the diagnostic narrative of the person with MS and their experience and perception of the impact of MS on the person's skills, competencies and ability to engage in the occupations they choose in the real world of their daily lives.

Occupational therapy interventions take place within the social environmental context of the person with MS. The psychosocial relationships with carers, family, friends, and the MDT also support ongoing occupational performance, engagement, and participation in individualised and chosen occupations. This becomes particularly important as the impact of MS on the person's autonomy develops. The research described and analysed how the occupational therapists utilise significant people around the person with MS in a collaboration to enhance occupational performance.

The synthesis of these components to construct the MS-PcOT practice model represents a final key finding. The objective of this new model is to provide guidance to person-centred occupational therapy interventions in the real world context of multi-disciplinary community practice. The aim is to enhance occupational performance for people with MS in their valued occupations. This is accomplished through interventions in partnership with the occupational therapist.

The research findings mirror the current research agenda in occupational therapy (RCOT, 2020). Person-centred practice and the daily occupations of people with MS are integral to the findings along within the social context of families, carers, and the MDT. Ten priorities for occupational therapy research in the UK have been identified. These priorities include how occupational therapy makes a difference and impact on everyday lives, ensuring person-centred practice is central to the work of occupational therapist, working more effectively with families and carers, and effective working with other professionals to improve outcomes. These priorities have been addressed in this research. The research also supports the identification of participation and access to daily activities as priorities of research identified in NICE clinical guideline 186 for the management of MS (see section 1.6) (NICE, 2014). The findings are a contribution to be taken into consideration when the guideline is revised.

6.2 Enhancing occupational therapy practice and service provision

The novel contribution made by this thesis to occupational therapy practice knowledge relates to professional reasoning concerning people with MS. Application of the MS-PcOT by occupational therapists will enhance the quality of service provision for people with MS by providing an innovative framework to comprehensively guide holistic and person-centred occupational therapy practice. The MS-PcOT model is a tool to assist practitioners to gather and organise information to make a unique professional contribution to knowledge, skills, and society by supporting the occupational performance of people with MS (Baum, Bass, & Christiansen, 2015). The study reported in this thesis indicates a process and strategy of fatigue management, environmental interventions, and psychological interventions to support people with MS in performance of IADL in domestic life and other occupations. Other key elements in interventions are safety and crisis management. The importance of the occupational therapist understanding the diagnostic narrative of the person with MS and incorporating this into professional reasoning when planning and designing personalised interventions is recommended. The MS-PcOT practice model promotes narrative reasoning where the occupational therapist listens to the diagnostic narrative and develops a respectful therapeutic partnership to build personalised interventions to support occupational performance and participation. The occupational therapist empowers people with MS through

the therapeutic partnership to engage and participate in occupations. The study contributes to the understanding of the contemporary experiences and perceptions of people with MS and how they construct their lives in relation to the occupations they need, want and expect to do.

The life stage of the person with MS and the occupational demand of IADL is also an important consideration for occupational therapy services. Occupational therapy interventions should be personalised and considering the demands of the person with MS at their life stage. A challenge to occupational therapy practice is the temporal nature of intervention to match the priorities and demands of the life stage and stage of MS progression as the impacts on occupational performance is variable. This is ongoing from diagnosis of MS until a palliative stage. The MS-PcOT model supports continued occupational performance, engagement, and participation to encouraging realistic hope for the future. This includes participation through directing others such as family or carers to complete tasks during occupational performance.

The findings will enhance current practice of occupational therapy by encouraging services provided for people with MS to be integrated and coordinated with wider MDT care. The role of occupational therapy in navigating the resources of the MDT and other services to support people with MS in occupations is integral to wider health and social services for people with MS. This includes navigating services to support occupations. Wider use of the MS-PcOT practice model in organisations will also have the benefit of increasing the profile and understanding of occupational therapy in interprofessional, commissioners, education, and research contexts.

Current practice of occupational therapy for people with MS is based on a limited and fragmented research evidence base as discussed in chapter two. This does not consider all areas of occupation or interventions and under plays the central role of IADL in domestic life. The MS-PcOT model has a wider and holistic view of the occupations of people with MS. Application of the model moves the focus away from self-care occupations towards IADL in domestic life and other occupations. In using the MS-PcOT model occupational therapy service provision will benefit people with MS and their families by supporting collaborative, integrated, and coordinated practice with other professionals in the MDT. The research aligns occupational therapy practice and services with the key policy directives of the NHS long term plan of providing person-centred, coordinated, and integrated community based care (NHS England, 2019). For the occupational therapy profession this research contributes the MS-PcOT practice model to the construction of the evidence base for professional reasoning and person-centred interventions.

Review and revision of the RCOT guidance should take the research findings relating to fatigue management and IADL into account (Harrison, 2007). As MS is the most prevalent of

the progressive neurological conditions, including the study of occupational therapy interventions for people with MS during the undergraduate curriculum occurs as preparation for clinical practice on graduation. The MS-PcOT and case summaries are useful teaching resources to contribute to the undergraduate curriculum. This research provides evidence for occupationally relevant interventions for people with MS.

Applicability of the assertions and propositions associated with the core concepts beyond the particular context of the research site, rest on transferability to other practice settings where occupational therapy services operate (Finlay, 2006). These research findings are highly relevant to community based occupational therapy services providing interventions for people with MS. The transferability is based on the validity, reliability, and rigour of the research process. Despite the MS-PcOT practice model and core concepts specifically relating to people with MS, it could provide a basis and be adapted for occupational therapy practice for people with other long term neurological conditions such as traumatic brain injury, MND, spinal cord injury and stroke. Living with these conditions has different characteristics and impacts on occupational performance. These would generate different diagnostic narratives and have occupational therapy interventions specific to the condition. The next step to developing occupational therapy practice theory using the MS-PcOT would be to research the application and adaption of the model for other conditions.

6.3 Further Research

The research has made an original contribution to occupational therapy practice using a multiple case study incorporating mixed methods to centre the findings of the study on the meaningful and purposeful occupations of five people with MS. As the research process proceeded several areas for further research were identified which are presented in this section. The following recommendations are therefore made to advance this work for the future:

1. As the research confirms the importance of IADL for people with MS, consideration of engagement and participation in specific IADL occupations such as meal preparation, shopping, driving, and gardening would yield valuable knowledge to base occupational therapy interventions. This would involve the use of measures of occupational performance in these specific occupations.
2. Investigation of the links and relationships between cognition within the diagnostic narrative, process skills and the influence of cognitive rehabilitation on occupational performance in IADL would inform occupational therapy practice. This would also develop previous research into cognitive function and occupational performance in cooking and money management for people with MS (Goverover et al., 2015;

Goverover, et al., 2016). A systematic review of previous studies would appraise previous research.

3. The position and timing of occupational therapy interventions alongside interventions made by other professionals within the MDT relationship would inform practice.
4. During the participant recruitment process, it was noted that some potential participants were not included as they lived alone and did not meet the criteria of having a primary carer. Investigating the interventions that could support this group of people with MS in IADL occupations in relation to safety issues would be of great value.
5. The role of the physical environment in facilitating occupational performance in IADL constitutes another research priority for people with MS. This includes the identified environmental interventions in all forms of assistive technology: equipment provision, electronic assistive devices, home adaptation and rehousing policies.
6. The MS-PcOT practice model could be used as a framework for research into occupational therapy interventions for people with other long term neurological conditions.

6.4 Dissemination strategy

It is an ethical and professional duty to disseminate research findings of to appropriate audiences (Lee, 2009). The dissemination of research findings has been ongoing since the early stages of the research process. Three conferences presentations to audiences of follow professionals have been made:

- Paper presentation to College of Occupational Therapists, Glasgow, 14 June 2012 *Maintaining activities of daily living in Multiple Sclerosis: A literature review* (Walshaw & Kirshbaum, 2012).
- Poster presentation to University of Huddersfield Post Graduate Research Festival, 17 April 2015 *Occupational therapy interventions for people with Multiple Sclerosis within instrumental activities of daily living.*
- Poster to Leeds Teaching Hospitals NHS Trust AHP, Mid-wifery and Nursing Conference, 07 June 2017 *Exploring occupational therapy interventions for people with Multiple Sclerosis and instrumental activities of daily living*

The research findings and methodologies employed have wider interest as a contribution to academic knowledge. The use of a multiple case study design incorporating mixed methods would be of interest to a wider audience beyond neurological practice in occupational therapy. The potential audience for future dissemination of the findings are situated not only in the professional community of occupational therapy practice, but also in the academic community

of other rehabilitation professionals. The targeting of abstracts submission on the research findings to publications including the British Journal of Occupational Therapy and other international occupational therapy journals is part of the dissemination strategy. A presentation to the World Federation of Occupational Therapists conference (Paris, 2022) would ensure dissemination to an international audience. Targeting of a conference presentation to the MS Trust in the UK will also disseminate the findings to an audience including people with MS, carers, and a wide range of professionals.

6.5 Conclusion

In concluding this thesis, the research has explored the meaningful and purposeful occupations in the lives of five people with MS. This progressive neurological condition has a profound and unpredictable impact on occupational performance from onset which often occurs in early or mid-adulthood. At this stage of life IADL constitute a complex and demanding group of occupations contributing to occupational identity and based in the environmental contexts of the home and wider community. The novel use of a multiple case study methodology with mixed methods to explore the occupations of five people with MS has collected rich and in-depth data from not only the person with MS but also carers, occupational therapists, and other HCPs. A process of crystallization, using a framework approach in data analysis, drew together descriptive and explanatory explanations to derive core concepts.

The research findings are original and reveal the experiences and perceptions of people living with MS, their occupations and occupational therapy interventions. The repertoire of interventions at the disposal of occupational therapy practitioners in a community-based rehabilitation team has also been identified. Occupational therapy interventions consisting of fatigue management, environmental interventions and psychological interventions have a multi-faceted role in supporting people with MS in their physical and social environmental contexts. The importance of relationships of significant people in the social environment and the therapeutic partnership have been emphasised. The findings have been synthesised in the construction of the contemporary MS-PcOT model, a person-centred, occupation based and holistic guide for occupational therapy practice. As a professional group, occupational therapists can offer a wide range of personalised and complex interventions to enable people with MS to engage and participate in their own meaningful occupations. This is an important and integral contribution to person-centred care and maintaining the health and well-being of people with MS.

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Appendix 1. Instrumental Activities of daily Living (AOTA, 2014)

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADL)—Activities to support daily life within the home and community that often require more complex interactions than those used in ADLs. These activities are orientated towards interacting with the environment and are often complex and generally optional in nature.

Category	Description
Care of others (including selecting and supervising caregivers)	Arranging, supervising, or providing care for others
Care of pets	Arranging, supervising, or providing care for pets and service animals
Child rearing	Providing care and supervision to support the developmental needs of a child
Communication management	Sending, receiving, and interpreting information using a variety of systems and equipment, including writing tools, telephones (cell phones or smartphones), keyboards, audio-visual recorders, computers or tablets, communication boards, call lights, emergency systems, Braille writers, telecommunication devices for deaf people, augmentative communication systems, systems, and personal digital assistants
Driving and community mobility	Planning and moving around in the community and using public or private transportation, such as driving, walking, bicycling, or accessing and riding in buses, taxi cabs, or other transportation systems
Financial management	Using fiscal resources, including alternate methods of financial transaction, and planning and using finances with long-term and short-term goals

Appendix 1. Instrumental Activities of Daily Living (AOTA, 2014) (continued)

Category	Description
Health management and maintenance Addition to 3rd edition (2014)	Developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreased health risk behaviours, and medication routines
Meal preparation and clean-up	Planning, preparing, and serving well-balanced, nutritious meals and cleaning up food and utensils after meals
Religious and spiritual activities and expression Addition to 3rd edition (2014)	Participating in religion, "an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent" (Moreira-Almeida & Koenig, 2006, p. 844), and engaging in activities that allow a sense of connectedness to something larger than oneself or that are especially meaningful, such as taking time out to play with a child, engaging in activities in nature, and helping others in need (Spencer, Davidson, & White, 1997)
Safety and emergency maintenance	Knowing and performing preventive procedures to maintain a safe environment; recognizing sudden, unexpected hazardous situations; and initiating emergency action to reduce the threat to health and safety; examples include ensuring safety when entering and exiting the home, identifying emergency contact numbers, and replacing items such as batteries in smoke alarms and light bulbs
Shopping	Preparing shopping lists (grocery and other); selecting, purchasing, and transporting items; selecting method of payment; and completing money transactions; included are Internet shopping and related use of electronic devices such as computers, cell phones, and tablets

Appendix 2. Participant identification sheet

Participant Identification Stage 1

Complete for people referred (or ongoing) to the Community Neurological Rehabilitation Team who have a diagnosis of MS to determine their eligibility to participate in the study.

		Yes	No
1. Diagnosis:	Does the person have MS?	□	□
2. Age:	Is the person aged between 18 and 70 years?	□	□
3. Language:	Is the person able to use English to read information and complete an interview?	□	□
4. Capacity:	Does the person have the mental capacity to give informed consent to interventions?	□	□
5. Location:	Does the person live at home?	□	□

If YES for all questions, then kindly record their name below.

Name:

Date:

Participant Identification Stage 2

Please complete for people with MS during the initial assessment by the Community Neurological Rehabilitation Team.

			Yes	No
1.	**OT:**	Will OT be part of the intervention program?	□	□
2.	**IADL:**	Does the person undertake instrumental activities of daily living as part of their routine? IADL includes everyday activities such as; cooking, cleaning, doing laundry, caring for children and pets, looking after the home, shopping and community mobility.	□	□
3.	**Carer:**	Does the person have a primary carer as opposed to a care team?	□	□
4.	**Fatigue:**	Does the person experience severe fatigue that prevents participation in IADL?	□	□
5.	**Psychology:**	Is the person fragile in terms of mood or emotion?	□	□

If the answers to questions 1-3 are yes and 4-5 no, please read the following statement:

Script

"You and your carer are invited to participate in a research project. The research is concerned with how your occupational therapist works with you to continue doing everyday activities. Here are information sheets for yourself and your carer which give more details of the research project. If you wish to take part please contact Chris Walshaw, the researcher. His details are on the information sheet. Thank you."

Name of potential participant: Date:

Please pass ALL completed sheets to...

Appendix 3. Information sheet (Person with MS) version 3.0 (22.01.15)

Exploring occupational therapy interventions

for people with Multiple Sclerosis

within instrumental activities of daily living

INFORMATION SHEET

As a Clinical Specialist Occupational Therapist at Leeds Teaching Hospitals Trust I have developed an interest in how occupational therapists help people with Multiple Sclerosis. My doctoral studies at the University of Huddersfield give me the opportunity to investigate this in a research project.

You are being invited to take part in this study of occupational therapy and everyday activities. Before you decide to take part it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you wish discuss it with others. Do not hesitate to ask if there is anything that is not clear or if you would like more information.

What is the study about?

The purpose of the study is to explore how your occupational therapist helps you to continue doing activities. I am particularly interested in how you do everyday activities such as; cooking, shopping, cleaning, doing the laundry, looking after your home and caring for children and pets. It is important to know what the occupational therapist does and how well it works.

The study will listen to your opinions on the effect of occupational therapy on your ability to continue doing these activities. The study also wants to know about the perceptions of your main carer, the occupational therapist and other health care professionals associated with the team.

Why have I been approached?

You have been asked to participate in this study because you are receiving treatment from an occupational therapist in the community neurology team.

Do I have to take part?

Taking part in this research is entirely voluntary and you are free to change your mind at any point. If you do decide to take part you will be asked to sign a consent form. You will be free

to withdraw at any time without giving a reason. It is acceptable to withdraw if you feel uncomfortable about any aspect of the research. If you decide to withdraw it will not affect the standard of care you receive. If you withdraw from the research we will use the information collected up to your withdrawal.

What will I need to do?

If you agree to take part in the research you will contribute to the study in two ways;

1) An assessment will be made which involves you being observed doing two familiar activities. This Assessment of Motor and Process Skills (AMPS) is used by occupational therapists to measure your ability to do activities of daily living. The assesment will take place in your own home and lasts about 45 minutes.

2) A seperate interview with the researcher will take place on another day. This will last between 45 minutes and an hour. You will be asked questions about what the occupational therapist does and what you think about it. What you say in the interview will be recorded. The interview will take place in a quiet and private setting either at you home or elsewhere if you choose. This is your chance to have your voice heard.

Your involvement is in parallel with that of your main carer and other health care professionals who will also be interviewed as part of the research study.

Will my identity be disclosed?

All information gathered within the assessment and interview will be kept confidential. Your identity will be protected by the use of a pseudonym or coded number. No written information that could lead to your identification will be included in any report. There may be exceptional circumstances, such as the protection from harm of individuals involved in the research, where the researcher passes information to other professionals for legal reasons. Your GP and Consultant in Neurology will be informed that you are taking part in the research.

What will happen to the information?

All information collected from you during this research will be kept confidential and secure. Identifying material, such as names, will be removed in order to ensure your anonymity. The research will be written up as a doctoral thesis and may be published in a journal. Should this happen it may be necessary to use your words in the presentation of the findings. The consent form includes your permission for this. The research will help to inform the development of occupational therapy for people with MS.

Who can I contact for further information?

If you require any further information or have a concern about any aspect of the research, please contact the researcher who will do his best to answer your questions:

Chris Walshaw (Researcher)

Clinical Specialist Occupational Therapist

Lower Ground Floor

Chancellor wing

St James's University Hospital

Leeds LS9 7TF

Telephone: 0113 2064702

Mobile: …

Email: u1076796@hud.ac.uk

If you remain unhappy and wish to complain formally, you can do this by contacting either of the research supervisors or the Patient Advice and Complaints Service at … NHS Trust.

Research supervisors

Joanne Garside

Senior Lecturer (Acute Care)

University of Huddersfield

Queensgate

Huddersfield HD1 3DH

Telephone: 01484 473567

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Mrs Janice Jones

Senior Lecturer (Occupational Therapy)

University of Huddersfield

Queensgate

Huddersfield HD1 3DH

Telephone: 01484 473350

Email: j.jones@hud.ac.uk

Thank you for taking the time to read this information sheet.

Appendix 4. Consent form - Person with MS Version 3.0 (22.01.15)

CONSENT FORM

Exploring occupational therapy interventions

for people with Multiple Sclerosis

within instrumental activities of daily living

It is important that you read, understand and sign the consent form Person with MS Version 3.0 (22.01.15). Your contribution to this research is entirely voluntary and you are not obliged in any way to participate. If you require any further details please contact Chris Walshaw, your researcher (details on information sheet).

If you are satisfied that you understand the information and are happy to take part in this project please put a tick in the box opposite to each statement

I have been fully informed of the nature and aims of this research contained in information sheet version 3.0 (22.01.15)

I consent to taking part in this research. □

I understand that I have the right to withdraw from the research at any time without giving any reason. However, if I do withdraw any data that I have contributed will be included in the analysis phase of the research.

□

give permission for my words to be quoted (by use of pseudonym). □

I give permission to be informed of paper publications as a result of the research. □

I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield. □

I understand that no person other than the researcher and research supervisors will have access to the information provided. □

I consent for my main carer and other health care professionals to be involved in the study. □

Appendix 4. Consent form - Person with MS Version 3.0 (22.01.15) continued

I understand that my identity will be protected by the use of pseudonym or coded number and that no written information that could lead to my being identified will be included in any report.

□

I understand that my GP and Consultant in Neurology will be informed that I will be participating in the research.

□

I understand that this research will not involve me receiving any additional treatment or therapy.

□

I understand that data collected during the study may be looked at by individuals from regulatory authorities or from … NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.

□

Please sign and print your name in the box below.

Signature of Participant:	Signature of Researcher:
Print:	Print:
Date:	Date:

The participant will retain one copy and the researcher will retain a second copy.

Appendix 5. Interview guide (Person with MS)

1. Introduction **Time start:**

The purpose of the study is to explore how your occupational therapist helps you to continue doing activities. I am particularly interested in your opinions on how the occupational therapist has affected your ability to do these everyday occupations.

Some of these activities you may do at home such as;

- making meals and drinks
- doing the laundry and cleaning
- looking after your home
- caring for children, other people or pets
- organising your own care
- using communication devices such as the phone and the internet
- responding in an emergency and safety procedures
- doing financial management

Some activities you may do when away from home such as;

- shopping
- getting out and about or your community mobility and driving

I'm not interested in activities you do to care for yourself such; as getting washed and dressed. Neither am I interested in work or leisure activities.

Questions

1. **MS Journey and impact on occupational performance in IADL**

   Main question:

   - **Tell me how your MS affects how you do these activities?**

   Follow-up questions

   - What was your function like in these activities a year ago?
   - How have you been able to do these tasks over the last year?
   - How did you do these activities in the past?
   - How does this contrast with now?
   - How well do you do these activities now?
   - Has this affected how much help you need from others?
   - Which activities do you want to continue doing?
   - How do you see the future?

Probe

- That's interesting can you tell me more?
- Go on ...
- Can you give me an example?
- Use body language and gestures to encourage continuation of conversation

2. Meaning of IADL to the person with MS

Main question

- **What do these activities mean to you?**

Follow-up questions

- How important are these activities to you?

Probe

- That's interesting can you tell me more?
- Go on ...
- Can you give me an example?
- Use body language and gestures to encourage continuation of conversation

3. Occupational therapy intervention

Occupation based intervention, doing the activities, top-down. Time spent doing these tasks or assessing them. Assessing how you do these tasks

Main question:

- **Tell me what you did with the OT?**

Follow-up questions.

- Tell me about the last time you saw the OT.
- What happened?
- What did they do?
- Have you changed how you do these activities?
- Did you change which activities you do?
- What did the OT do with regards to this?
- Have you had OT before?
- Did the OT spend time assessing how you did these activities?
- How meaningful to you were the activities the OT did with you?
- Was this purposeful to you?
- What would you suggest would be a better way to help you?

4. **Motor skills**

Main question:

- ‘**Tell me about your movements and strength before OT ... and after OT**.’

Follow-up questions:

- Tell me how this has affected how you do these activities.
- How well did this work for you?
- How did they do this?

5. **Fatigue management**

Main question:

- **‘Tell me about your tiredness and fatigue before OT ... and after OT.’**

Follow-up questions;

- What did the OT do with regards to your tiredness?
- Did the OT help you to overcome tiredness related to doing IADL
- How did this work for you?
- What did this involve?

6. **Assistive technology**

Main question:

- **Do you use equipment to do these activities?**

Follow-up questions.

- Tell me more about the equipment.
- What equipment did the OT use with you?
- Was any electronic equipment used?
- Did they use equipment or a technology to help you with these activities?
- What about a wheelchair?

7. **Process skills**

   Main question:

   - **Does your thinking, memory or vision affect how you do these activities?**

   Follow-up questions.

   - What did the OT do with regards to this?
   - Was any technology used?

8. **Other interventions** (orthotics fitting, contrast baths, sensory integration, sensory - vision)

   Main question:

   - **Was there anything else the OT did with these activities that you would like to tell me about?**

   Follow-up question.

   - Did the OT make a splint?
   - Tell me about the splint

At 45 minutes give a time check and ask if the person is tiring or would like to continue.

At 60 minutes draw the interview to a close.

Thanks

Thank you for taking part in the research by speaking with me about occupational therapy.

Appendix 6. OT questionnaire

1. Introduction

This brief questionnaire follows up the interview you completed as part of the research project. It aims to collect your reflections and opinions on the occupational therapy intervention you completed. The questionnaire will further explore how your occupational therapy practice affected the occupational performance in instrumental activities of daily living of the people with Multiple Sclerosis. Please give examples to illustrate your reflections.

Questions

1. What clinical effects did the OT interventions make to the person with MS?
2. How well did the person with MS engage with the OT interventions?
3. How did OT intervention contribute to the person with MS coping with a decline in occupational performance?
4. Were activities regained through OT intervention?
5. Were activity patterns adjusted to meet occupational performance?
6. Did the person with MS adapt to changing abilities in IADL?
7. How was this facilitated?
8. What OT concepts, theory or models did you base your interventions on?
9. What would you do differently on reflection?
10. What guidance would you suggest to other OTs?
11. Do you have any further comments?

Thank you for completing this questionnaire as part of the research project.

Appendix 7 Guide to names used in case summaries

Case	Person with MS	Carer	OT	Others
Case 1	Michael	Jennifer	Karen	
Case 2	Lisa	David	Karen	Helen (Paid carer)
Case 3	Diane	Mark	Gemma	
Case 4	Paul	Nicola	Karen	
Case 5	Caroline	James	Karen	