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DOCTOR OF PHILOSOPHY

Investigating the Physical and Psychological Impact of Assistive Technology Use (and its Influences) Among People Living with Multiple Sclerosis

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School of Psychology

Bangor University

Investigating the Physical and Psychological Impact of Assistive Technology Use (and its Influences) Among People Living with Multiple Sclerosis

Luke Squires

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Bangor University

September 2018

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For Joan and Molly

∞

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∞

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Summary

Multiple Sclerosis (MS) is the most common neurological condition among young adults (aged 18-39) with approximately 100,000 people with MS (PwMS) in the UK. To counter the physical and psychological effects of living with this incurable condition, PwMS obtain assistive technology (AT) devices. These devices range from basic walking aids to complex electronic equipment, and are designed to help improve physical and psychological function. Guided by the Common Sense Model of Illness, the aim of this thesis was: (a) to establish the nature of AT use among PwMS, (b) to identify determinants of AT use, physical and psychological outcomes of MS (c) and to explore the relationship between these variables as part of self-management in MS. In order to address these objectives, a systematic review was first conducted, which identified a range of devices being utilised by PwMS with mixed effects. However many of the reviewed studies lacked theoretical insight. Determinants of AT use, and the effects of use on physical and psychological outcomes, were then explored in a qualitative focus group study. PwMS, carers and occupational therapists identified personal (e.g. illness perceptions, acceptance, optimism), device (e.g. ease of use), and external factors (e.g. AT service, social support) that may influence the uptake and continued use of AT, as well as the potential impact of using such devices (e.g. independence vs. stigma). Finally, the determinants of AT use, physical and psychological outcomes of MS were then investigated as part of a longitudinal study. PwMS were assessed at baseline and at three, six and twelve months. Physical impact of MS (baseline, 3 month), perceived illness effect (baseline, 6 month) and the psychological impact of MS (3 and 6 month) were found to be significant predictors of the physical impact of MS at 12-months. Optimism t each time point predicted 12-month psychological impact of MS. There were no significant effects of AT use on key physical or psychological variables in this study however the number of AT devices used was significantly associated with physical impact. Likelihood of AT use was increased if unemployed, or in receipt of a carer or MS medication. The findings of the presented studies have implications for future research, policy and practice around AT use and its role in self-management and self-regulation in illness.

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Chapter 1

General Introduction

Introduction

Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic and degenerative autoimmune condition whereby the immune system attacks the central nervous system. The immune system mistakes the myelin sheath – a protective layer that surrounds nerve fibres – for a foreign body and attacks it. Damage to the myelin, and sometimes the underlying nerves, leaves scars known as lesions and disrupts the messages travelling along the nerve fibres. This causes a breakdown of neural communication between the brain and the rest of the body.

Although it can develop at any age, MS is the most common neurological condition among young adults (aged 18-39) with an estimated 2.3 million people worldwide living with this incurable condition (Browne et al., 2014). In the UK, there are approximately 100,000 people living with MS, with 5000 people newly diagnosed each year, which is roughly equivalent to 100 people per week (Mackenzie, Morant, Bloomfield, MacDonald & O'Riordan., 2014). Diagnosis usually occurs between 20-40 years of age for example, 50% of diagnoses occur before the 30th birthday and 75% are made before the age of 40 (Kalb, 2012). There are three times as many women with MS than men and it is most common among Caucasian-Europeans (Browne, et al., 2014; Mackenzie, et al., 2014).

Approximately 85% of people with MS (PwMS) are diagnosed with 'relapse-remitting' MS (RRMS) whereby people have symptom attacks that can last days, weeks or possibly months before completely getting better – this is known as remission. Some relapses however result in permanent damage to the myelin or nerves, in which case symptoms do not improve. Many people with RRMS will then progress to 'secondary

progressive' MS (SPMS), which is usually diagnosed once symptoms have persisted and deteriorated over a period of at least six months, regardless of any relapses (MS Society UK, 2016a). The remaining 15% of people with MS (PwMS) are diagnosed with 'primary progressive' MS (PPMS) where they face a steady progression of symptoms over time with no remission. There is no known cause or cure for MS with treatment currently in the form of disease-modifying treatment (DMTs) – limited to those with RRMS only – and symptom management (Gajofatto & Benedetti, 2015).

Physical Impact of MS

MS has a significant physical, emotional and social impact upon those living with the condition with various challenges throughout the MS experience: from symptom development, gaining a clinical diagnosis, accessing and receiving the necessary care and support to meet MS needs as well as processing the impact of MS thereafter (Edmonds, Vivat, Burman, Silber & Higginson, 2007; MS Society UK, 2015; Solari, 2014; Solari et al., 2007; Wollin, Yates & Kristjanson, 2006).

The symptoms of MS can be intrusive and disabling, for example: loss of balance and limb function, bowel and bladder incontinence, emotional changes, fatigue, hypersensitivity to heat, numbness, pain, sexual dysfunction, spasticity, stiffness, tremor, and problems with speech, swallowing and vision (Goodkin, 1992; Holper et al., 2010). Such symptoms occur at the body structure level, including neurological, and thus also impact the metacognitive function of PwMS including executive functioning, memory, processing speed and visual perception (Guimarães & José Sá, 2012). In addition to these impairments, any activity limitations (e.g. bathing, dressing, walking) and restrictions in social participation (e.g. employment, shopping) all determine the level of disability PwMS may experience (World

Health Organisation [WHO], 2001). According to the International Classification of Functioning, Disability and Health (ICF; WHO, 2001), disability can also be influenced by environmental/contextual (e.g. private versus public space) and personal factors (e.g. optimism). The original classification for disability (ICIDH, 1980) was limited in that it did not fully consider the influences of environmental and personal factors. It was also originally proposed as a 'process' model where stages would follow each other resulting in a final 'functional disability outcome. The newer version proposes processes that interact with each other and can be bidirectional – offering 'building blocks' for researchers and clinicians to study (Imrie, 2004). Thus, psychological constructs involved in this process have since been incorporated and researched (Johnston & Dixon, 2014) For example, perceived control is consistently seen as a predictor of physical function and activity limitations in people with long-term conditions (Johnston & Dixon, 2014; Martin Ginis et al., 2012; Motl, Snook, McAuley, Scott & Douglass, 2006).

High rates of disability are reported by PwMS, for example around 75-80% of PwMS experience problems with their mobility within the first 10-15 years of diagnosis, with the loss of walking reported as one of the most significant factors in their sense of disability - perhaps due to the consequent decrease in physical function and social participation (Heesen, Poettgen & Rudiger, 2008). A large US study (Marrie et al., 2017) found that 60% of PwMS (n=7463) reported upper limb impairment and that higher levels of self-reported disability correlated moderately with worse physical functioning scores (e.g. managing daily activities).

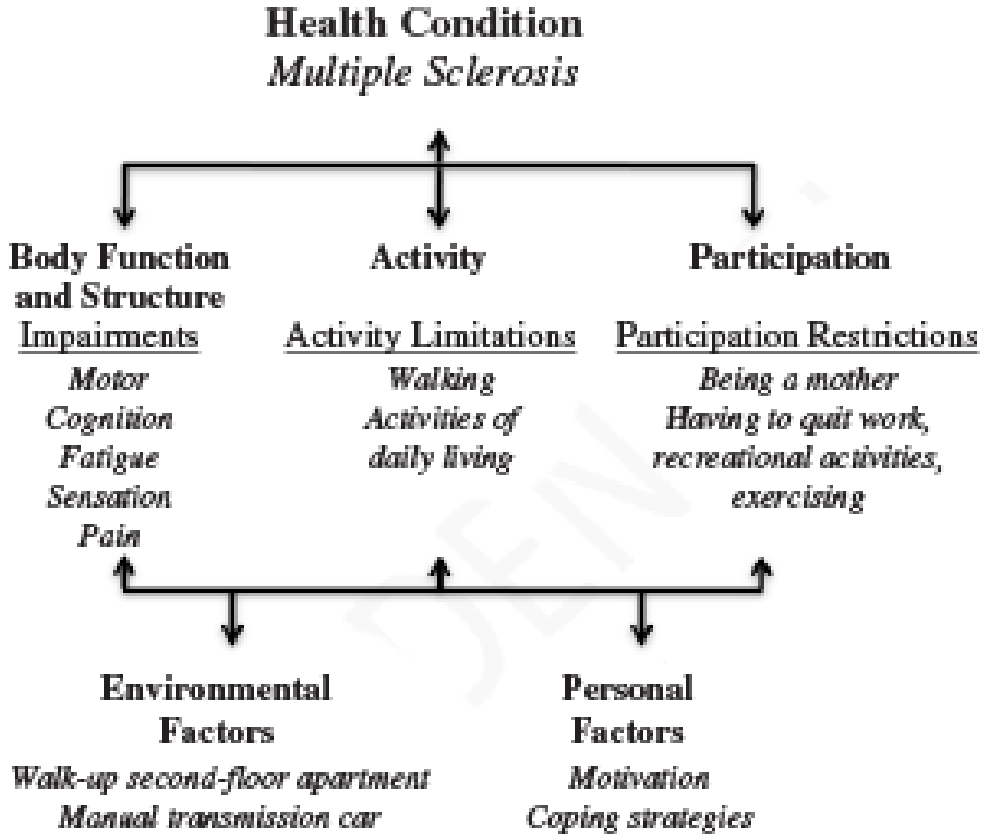

Figure 1.1: Example of MS experience according to the ICF model, adapted from WHO (2001).

Psychological Impact of MS

In addition to the physical impact of this condition, higher rates of anxiety and depression or lower general and health-related quality of life outcomes have been reported in those with MS as compared to the general population (Jones et al., 2012; Klevan et al., 2014; Mikula et al., 2016) and even when matched by age (Siegert & Abernethy, 2005). Quality of life (QoL) is defined as an individual's evaluation of their position in life (including goals, standards and expectations) in relation to their cultural context (WHOQOL, 1998). QoL is assessed across multiple domains including physical and psychological health, level of independence, quality of social relationships and surrounding environment, and personal,

religious and spiritual beliefs (WHOQOL, 1998; Skevington, Lotfy, O'Connell & WHOQOL Group, 2004). QoL has been found to be influenced my many factors including demographics (e.g. age), psychosocial factors (e.g. mood, social context), and health conditions (e.g. symptoms, treatment). QoL is often reported as low in PwMS (Morales-Gonzalez, Benito-Leon, Rivera-Navarro, Mitchell & The GEDMA Study Group, 2004; Nortvedt, Riise, Myhr & Nyland, 1999) and lower than the general population when matched by age and socioeconomic status (McCabe & McKern, 2002) and in comparison to people with other chronic and neurological conditions (Sprangers et al., 2000; McCabe, Stokes & McDonald, 2009; Riazi et al., 2003). Mood and quality of life are related also, as shown for example by Hayter and colleagues (Hayter, Salkovskis, Silber & Morris, 2016) who found that those with high anxiety reported lower QoL compared to those with low anxiety and a healthy control group, when controlling for level of disability. Those with higher levels of anxiety were also likely to have an impaired perception of their cognition and fatigue despite normal scores (i.e. high anxiety may distort symptom perception in MS).

Due to the unpredictable nature of the condition (i.e. cycles of relapses and remissions, progressive) PwMS face uncertainty surrounding their future and it has been suggested in a qualitative study that this contributes to a 'sense of loss' (i.e. lower self-confidence, career changes, question their competency; Bogenschutz, Inge, Rumrill, Hinterlong & Seward, 2016). Such feelings likely contribute to reported depression for example Siegert and Abernethy's (2005) review reported that an estimated 40-50% of PwMS will experience depression in their lifetime and similarly, 30-40% of PwMS experience anxiety, particularly after diagnosis. Alternatively, it may be emotional processes (i.e. anxiety and depression) leading to a 'sense of loss' and lower self-confidence – highlighting

an issue around directionality of different illness processes. It should also be noted that during notable events (i.e. diagnosis, adjustment to new symptoms) some low affect may be understandable and not all PwMS will reach 'caseness' of anxiety or depression.

Also, such negative psychological outcomes are not inevitable. However, positive outcomes have also been reported by PwMS, for example, feelings of personal growth and increased life appreciation (Bowen, MacLehose & Beaumont, 2011; Pakenham, 2007a; 2007b; Pakenham & Cox, 2009) particularly following acceptance of MS (Pakenham & Fleming, 2011) (see Chapters 3-5 for a fuller discussion on acceptance of MS).

Social Impact of MS

A worldwide review of literature from 2002-2010 concluded that 59% of PwMS were unemployed (26 papers, n=32,507: Schiavolin et al., 2013) with similar findings reported in the US despite many being graduates (Roessler, Rumrill, Li & Leslie, 2015). A recent UK survey conducted by the All-Party Parliament Group for MS found that a quarter of 1511 PwMS (24%) reported that their employer had treated them badly as a result of their condition (MS Society UK, 2016c) and a fifth of their colleagues (20%) had done the same. It was also reported that 80% of PwMS retired within 15 years of their initial diagnosis however this may be a biased sample due to its affiliation with the MS Society UK and the potential for PwMS to retire within 15 years of their diagnosis due to their age.

Carers of MS

The psychosocial consequences of MS as described above can also extend beyond the PwMS to family members, many of whom take on additional caring roles (Dennison, Moss-Morris, & Chalder, 2009; Pakenham, 2007). Friends or family members who provide

unpaid care for those with physical, psychological, or developmental needs are generally referred to as an 'informal carer' (Revenson et al., 2016). There are over 6.5 million UK informal carers helping to support the complex and multiple needs of people with disability, of which care can vary from completing personal, domestic or financial tasks for their loved one to specialised care such as transferring or changing dressings (Office for National Statistics [ONS], 2016).

Seventy-one per cent of PwMS receive care from a friend or family member (MS Society, 2013), which places inevitable demands on the carer in proportion to the time devoted to caring, the carer's health status, age and other commitments (Hirst, 2005; Forbes, While & Mathes, 2007; Iles, 2003). MS carers are likely to be young or middle-aged adults, with children at home, at an early stage of their career, and thus a loved one's diagnosis of MS can be very disruptive, requiring many adjustments to family life (O'Brien, 1993; Hughes, Locock & Ziebland, 2013). A review conducted by Corry and While (2009) concluded that caring for PwMS can negatively affect carer wellbeing due to the high level of activities undertaken and perceived burden. Psychological needs of carers have been noted as a particular area of concern (Benbow & Koopman, 2003) as PwMS and carers of MS report higher anxiety, depression and health-related QoL compared to the healthy population when matched by age and gender (e.g. Schipper, Clinch, & Olweny, 1996). This is perhaps due to the constant challenges that carers face due to the unpredictability of MS i.e. new relapses/symptoms and progressive forms of MS present new 'losses' (Wollin et al., 2006). While some of the reviewed studies were limited (e.g. descriptive, methodologically flawed), there was consistency across nations.

A more recent study found that carers of people with secondary progressive MS (n=78) reported significantly lower health-related QoL compared to the norm especially within the physical and emotional wellbeing domains (Giordano et al., 2016). They identified 68% of carers with anxiety and 44% with depression according to the Hospital Anxiety and Depression Scale (HADS). High carer anxiety, low economic status and living with partner were significant predictors of high caregiver burden.

Looking at UK carers of PwMS specifically, there were only two studies identified in the review based in the UK - Chipchase and Lincoln (2001) focused on the memory of PwMS, as they identified it as a factor in determining carer strain. The other UK study (Kersten et al. 2000) focused on the unmet needs of carers of MS (see Chapter 3 for more carer findings). They identified that finances, services and information were key areas that needed improvement for carers of PwMS. The limited UK research on carers highlights the need for further carer involvement in MS research. In addition, the two above carer studies focused solely on carer outcomes neglecting the interaction or potential of carer factors affecting the outcomes of PwMS.

As with PwMS, anxiety and depression among carers is not inevitable and the impact of caring is dependent on individual differences in personal outlook, expectations and coping responses (Morrison, 1999; Pakenham, 2005). Potentially positive aspects can be gained from receiving and providing care, as found in other conditions (i.e. the PwMS receives practical help and emotional support, and carers may learn new skills and benefit from feeling useful; Schmitz & Westphal, 2015).

However, in spite of possible gains of caregiving, McCabe and McKern (2002) have reported lower relationship satisfaction in those with MS compared to healthy controls;

however a later study suggested that in some cases the MS experience can strengthen relationships (McCabe, 2004). Low relationship quality has however been found to be associated with poor physical and mental health in MS and other conditions (McPheters & Sandberg, 2010). For example, an online survey of 115 PwMS conducted by Wright and Kiropoulos (2017) found that a better relationship quality (i.e. an emotional and physical relationship with effective communication, problem solving, support, and satisfaction; Prager, 1995 as cited by Wright & Kiropoulos, 2017) was significantly associated with higher illness acceptance and a greater self-concept (i.e. own perception of identity, adjustment, social skills and status, self-fulfilment, physicality and morality: Fitts & Warren, 1996). In addition, it has been suggested that an individual's perception of their, or their loved one's situation may relate to illness outcomes, including acceptance, and in this thesis the perceptions of MS are a key focus. To address perceptions therefore we turn to self-management and the self-regulation theory of illness.

Illness Self-Management

While there is no universal definition of illness self-management, it generally reflects an active patient-centred approach to managing general health and lifestyle, illness, associated symptoms and treatments, including the decisions taken around these rather than relying passively on management or intervention by medical or healthcare professionals (Lorig & Holman, 2003; Bishop, Frain & Tschopp, 2008). Effective self-management (in terms of achieving desired outcomes such as improved QoL, or simply living with a chronic condition in a way that is acceptable) will involve the employment of cognitive, behavioural and emotional strategies. Lorig and Holman (2003) proposed several processes of self-management: problem-solving, decision-making, utilising resources,

improving self-efficacy, taking action, and partnering with healthcare providers. Self-management is likely influenced by outcome expectancies and individual goals and as such relates to Bandura's (2001) social cognition theory where self-efficacy is a central construct required to attain goals. Self-management and the coping responses employed are shaped by personal experiences and by observing others. For example, Schulman-Green et al. (2012) conducted a metasynthesis of self-management processes in chronic illness (N=101 studies) and found that people become 'experts' of their condition by managing their symptoms and addressing the specific health needs that come with it. The successes in achieving symptom control (e.g. managing their medication) leads to increased confidence and adherence and continued use of their new skills, which holds likely benefits for their QoL.

The belief and confidence in one's abilities and available resources to complete a given task or goal attainment is termed as one's level of self-efficacy. Self-management training typically focuses on acquiring new skills in managing health conditions and developing the confidence in continued use of these skills – giving patients a sense of control over their condition (Lorig, 1996). Such programmes often present modest improvements in long-term conditions in domains of disability, fatigue, distress and QoL however there is little self-management research in multiple sclerosis (Bishop et al., 2008). While self-efficacy beliefs are often key predictors of health behaviours and behaviour change (e.g. Morrison et al., 2015; Eccles et al., 2012), they are found to interact with other cognitions relating to one's illness.

Self-Regulation and Illness Perceptions

Leventhal et al.'s (1980; 1992; 2003; see Figure 1.2) Common Sense Model of Self-

Regulation of illness (CSM) was developed to better understand the processes involved in the uptake and maintenance of illness management. Leventhal proposed that dynamic interactions exist between biopsychosocial variables, cognitions regarding the illness, health behaviours and health outcomes (physical and psychological). Unlike other health belief models, the CSM consists of perceptual and behavioural constructs in that past experiences of illness form memories of somatic sensations, functional impairments and the required treatment so when faced with similar illness experiences in the future, these memories produce illness representations (Leventhal, Phillips & Burns, 2016). These illness representations (IRs) are formed in relation to the perceived identity of the disease, timeline, cause, consequences and control/cure; all of which overtime have been seen to shape coping behaviours and outcomes (Hagger & Orbell, 2003; Leventhal, Phillips & Burns, 2016). The success or failures of these coping behaviours are then evaluated (self-regulated) to shape future responses i.e. as to whether to continue to use or replace their coping mechanisms with a different strategy.

In this way, one's cognitions, emotions and coping responses combine with the use of available resources (e.g. healthcare service, social support) to contribute to illness management (see also Chapters 4-5 for a full examination of these constructs). It has been proposed that this not only provides a framework for predicting illness management but also helps identify specific targets for intervention at the personal, family or social level (Leventhal, Phillips & Burns, 2016). However it has been consistently highlighted that many patients discontinue healthy self-management behaviours, particularly with regards to treatment adherence (e.g. Holmes, Hughes & Morrison, 2014). Therefore it is important to identify individual differences in mental representations of their illness experiences and

symptoms.

The dynamic process of illness representations, illness management and self-regulatory feedback is particularly important in a chronic illness such as MS where by its very nature Is unpredictable - symptoms can progress overtime slowly or rapidly, or can come and go without warning. Due to this, people with MS are having to constantly re-adjust to their condition, forming a new 'norm' as well as new illness perceptions, and potentially different coping responses.

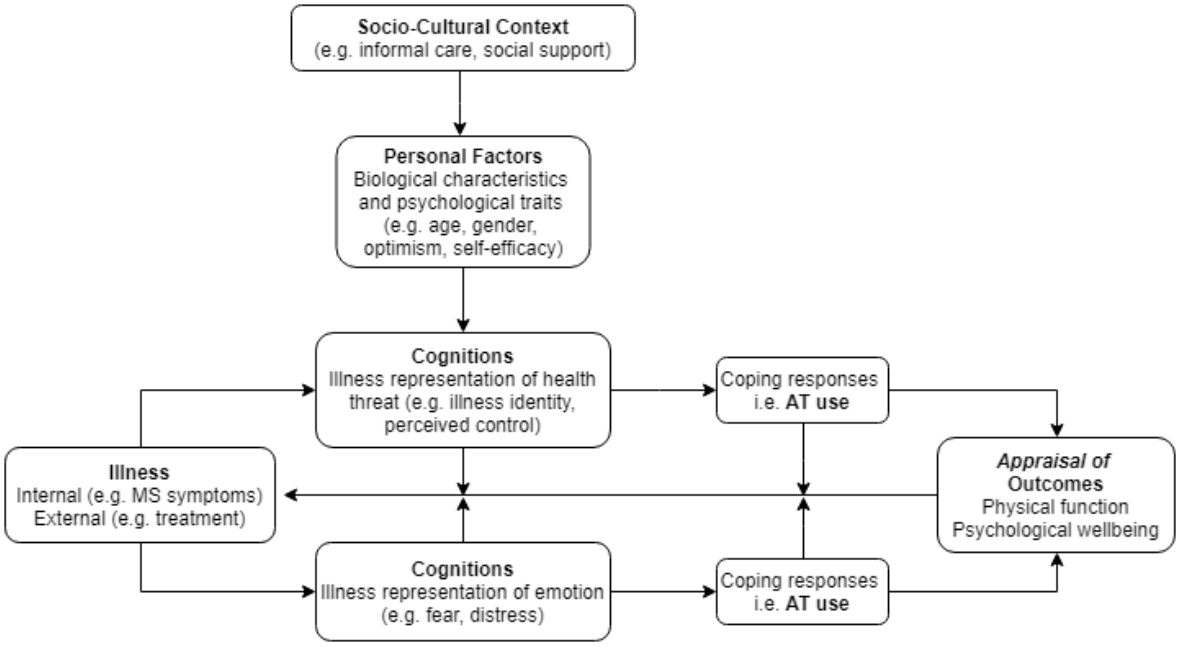

Figure 2.2: Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness, adapted for MS experiences.

In spite of their obvious relevance there have been a limited number of studies of patients' illness perceptions of MS. In these, PwMS have demonstrated strong illness identity, low illness coherence, and perceptions of a chronic condition with severe consequences and low personal control (Jopson & Moss-Morris, 2003). In this study, these

illness representations were significantly associated with anxiety and depression. Negative illness perceptions, emotions, and cognitions (e.g. catastrophizing, ruminating) have been found to be significantly associated with poor psychological outcomes in PwMS, for example anxiety, depression, distress, and health-related QoL (Dennison et al., 2010a; Jopson & Moss- Morris, 2003; Osborne, Jensen, Ehde, Hanely, & Draft, 2007; Spain, Tubridy, Kilpatrick, Adams & Holmes, 2007; Skerrett & Moss-Morris, 2006). However these studies were cross-sectional in design making it difficult to infer the direction of these relationships and thus require further study in how these interact overtime.

In terms of positive factors, two recent studies point to the importance of illness acceptance. High levels of acceptance were significantly associated with positive QoL and better physical functioning among a Belgian sample of PwMS (van Damme, de Waegeneer & Debruyne, 2016), and an online questionnaire study (*n*=329 PwMS) found that high acceptance was significantly associated with high levels of self-concept, while low acceptance was significantly associated with low self-concept and higher levels of anxiety and depression (Ward & Kiropoulos, 2017).

Similar findings emerged from a recent study looking at anger, anxiety, depression, and life satisfaction among PwMS and their carers (Bassi et al., 2016). Positive perceptions (i.e. fewer symptoms, better coherence) were associated with better levels of wellbeing among PwMS but not carers, however wellbeing was in turn positively associated with highly perceived personal and treatment control in both PwMS and carers (Bassi et al., 2016). Such findings support the premise that illness perceptions influence the long-term outcomes of chronic conditions, including adherence to treatment (Jessop & Rutter, 2003).

Self-regulatory feedback is crucial in developing effective coping interventions for illness management particularly in conditions such as MS. For example, PwMS (*n*=381) were

unlikely to adopt problem-focussed coping strategies (i.e. seeking support), instead, they were likely to adopt detached coping strategies (e.g. trying to forget about it) and exhibit poor adjustment to MS (i.e. confusion, depression; McCabe, 2004).

Coping strategies may help determine 'successful adjustment' to MS, defined as when a critical illness event creates less distress and less impact on life than before (Moss-Morris, 2013). However, given the unpredictable progressive and relapsing nature of MS, adjustment can also be considered as when one accommodates the potential and actual, change (i.e. acceptance; Stuifbergen, Becker, Blozis & Beal, 2008). Pakenham and Fleming (2011) found that higher levels of acceptance predict lower levels of distress and more positive adjustments to MS (e.g. positive affect, health status and life satisfaction). Furthermore coping strategies and social support were linked to acceptance of MS (Pakenham, 2006). In contrast, poor adjustment to MS, and poor acceptance of MS, were associated with high levels of stress, more symptoms, increased perception of severe consequences, cyclical illness and uncertainty (Dennison, Moss-Morris, Silber, Galea & Chalder, 2010a; Dennison, Yardley, Devereux & Moss-Morris, 2010b). However, both studies acknowledged the need for further longitudinal study so potential causal relationships could be determined.

In an attempt to synthesise findings from a large number of studies (N=45) employing the self-regulation model, Hagger and Orbell (2003) conducted a meta-analysis on illness perceptions, coping behaviours and outcomes. The analysis revealed that high personal control beliefs were consistently positively associated with problem-focused coping behaviour, adaptive outcomes such as psychological wellbeing, social functioning and negatively associated with distress. They also found that holding beliefs of a strong

illness identity/experience, chronic condition with severe consequences were associated with avoidant coping behaviours, and negatively associated with psychological wellbeing, physical and social function. The uptake and use of AT could be considered to be a problem-focused coping response to the need for illness management (as is medication adherence) and guided by the CSM, the success or failure of its use in achieving physical or psychological function would determine the continued use of the device (i.e. self-regulation).

Despite empirical support for these self-regulatory illness process theories in explaining health-related outcomes including illness self-management, little is known as to how individual perceptions relate to the acceptance, use of and adherence to assistive technology - devices designed to improve self-management.

Assistive Technology

A Quality Requirement of the former National Service Framework for long-term conditions (NSF; DoH, 2005) stated that people are *'to receive timely, appropriate assistive equipment and adaptations to accommodation to support them to live independently, help with their care, maintain their health, and improve quality of life'*. In previous years, it was estimated that 4 million people with a physical disability used AT (Audit Commission, 2004) with a growing trend of AT displacing personal care (Anderson & Wiener, 2015; Freedman, Agree, Martin & Cornman, 2006). More recently, it was estimated that 57% of 18-64 year olds are likely to benefit from using AT (British Assistive Technology Association [BATA], 2013) especially the 11+ million people living with limiting long-term illness, impairment or disability in the UK (DWP, 2017).

People with disabilities, including MS, are provided AT devices to counter their functional impairments, activity limitations and restrictions in social participation (i.e. to

deal with illness-related 'problems', hence it is considered as a means of problem-focussed coping in this thesis). These devices range from basic walking aids to advanced electronic equipment, and aim to support people with their complex and numerous needs e.g. bathing, communication, eating, memory, mobility, toileting etc. Despite these aims, people with disabilities report many problems accessing AT including inadequate funding, inadequate information regarding AT, insufficient training and lengthy waiting lists (Cowan & Turner-Smith, 1999). When acquired, there is evidence of physical, psychological and economic benefits of AT, including enhanced independence, quality of life, social inclusion and reduced costs of care (e.g. Hammel, Lai & Heller, 2002; Hoenig, Taylor Jr. & Sloan, 2004; Squires, Rush, Hopkinson & Morrison, 2013; Steel & Gray, 2009). However, as we have previously shown, the use and impact of AT varies within and between individuals, and across the time course of the illness (Squires et al., 2013).

Ravneberg (2012) stated that AT is traditionally considered a 'double-edged sword' as it offers independence and normality but can also be a marker of dependence and stigma (e.g. Parette & Scherer, 2004). Furthermore, there have been some reports of depression in users of AT (Johnson, Bamer, Yorkston & Amtmann, 2009; Okoro, Strine, Balluz, Crews & Mokdad, 2010) and while the impact of AT on carers is often overlooked, there is some suggestion that losing their care role or aspects of it may create distress (Boerner, Schulz & Horowitz, 2004). Whilst Boerner did not study AT *per se*, their findings could suggest that a 'role loss' may follow on from AT fulfilling tasks that carers would have previously performed. A review (Mortenson et al., 2012) on the impact of AT on carers found that while carers report frustration and worry relating to AT provision, devices reduced the physical demands placed on them. This was supported in the author's own more recent

work (Squires et al., 2013).

The majority of research on the use and impact of assistive devices tends to focus on older adults and persons with disabilities such as spinal cord injury, stroke, brain injury, and amputations (Scherer, Jutai, Fuhrer, Demers & DeRuyter, 2007; Squires, et al., 2013; Wessels, Dijcks, Soede, Gelderblom, de Witte, 2003), which leaves unanswered questions surrounding the use and implications of AT use among people with MS.

Assistive Technology in MS

While there is no official health and social care register of MS-AT provision or usage, a large American study (n=1063) identified that the most common AT devices used among PwMS were for mobility and walking, shortly followed by electronic memory aids and home adaptations (Johnson et al., 2009). They also identified many other AT devices PwMS use including aids for bathing, cooking and eating etc. These findings were supported in a recent study (Marrie et al., 2017) where the most common AT devices used were mobility aids and grab bars. They also found that on average PwMS own 3.4 AT devices and display a high interest in advanced technology to communication, such as smart pens.

While technology continues to advance, Blake and Bodine (2002) recommended that basic devices should still be considered when evaluating the impact of AT. For example, non-glare paper has been found to reduce visual fatigue and so very basic AT can make a clinical impact on one's activity and participation in similar light to complex electronic devices. Marrie et al. (2017) reported that 56% of PwMS use an AT device to aid upper limb function and identified that the likelihood of using an AT device was significantly increased by older age, female gender, greater disability, high levels of fatigue, cognitive or sensory impairment, and spasticity.

In a comparative review of Functional Electrical Stimulation (FES) and orthotics, it was suggested that FES would offer greater functional benefit to PwMS. However, either device would benefit if matched appropriately to their need (Wening, Ford & Jouett, 2013). The limited research into AT leaves unanswered questions regarding the psychological impact of using AT devices.

Another review (Souza et al., 2010) of mobility aids among PwMS identified physical and psychological outcomes of using mobility devices, concluding that independence and better quality of life were the main benefits of such devices. They also acknowledged the 'double-edged sword' whereby mobility AT was also perceived as a symbol of disability which could be detrimental to PwMS. One limitation of this review however was that the included studies consisted of mixed populations of those with neurological conditions including MS.

MS-AT-related research typically focuses on mobility devices, which is unsurprising as up to 50% of PwMS will use a mobility device at some point following diagnosis (Pittock et al., 2004). However the mobility focus leaves unanswered questions regarding the use and impact of other AT devices such as cognitive, communication, and domestic aids, which vary in important aspects such as visibility and cost etc.

Despite AT devices being commonly used among PwMS, the MS: Enough (2016b), MS Postcode Lottery (2013) and FES (2009) campaigns suggested that there is still not enough being done to gain access to devices and in turn, maximise the potential gains to be had from AT use. For example in Wales, PwMS were found to wait over 18 months for an electric wheelchair despite progressive illness; however Merseyside Primary Care Trusts provided them in less than 18 weeks (MS Society UK, 2017). Access to AT appears to be a

worldwide problem. One American study looking at working-age PwMS (n=500) found that although 57% of participants recognized a need for an AT device 28% had not received a device (Bingham and Beatty, 2003). This study however included other neurological conditions in addition to MS such as cerebral palsy and spinal cord injury. A Canadian study identified significant predictors of the need for AT in PwMS (n=250), which were: younger age, female gender, mobility limitations, in employment, low income and having a carer (Turpin, Janzen, Warren & Warren, 2011). Furthermore, PwMS wanted more involvement with occupational therapy (OT) services to improve the continued and successful use of AT devices (Preston, Haslam & Lamont, 2012). This suggests that AT equipment currently provided is not meeting the needs of PwMS, for whatever reason, and may be having a detrimental impact on those affected by MS given that avoiding AT use can result in more fatigue, limited function and embarrassment due to lay perceptions of 'appearing drunk' due to their instability (Dennison et al., 2010b).

Abandonment

It is well documented that up to 60% of AT devices are abandoned or misused within the first year of acquisition (Phillips & Zhao, 1993; Verza, Lopes Carvalho, Battaglia & Ucceli, 2006; Wessels et al., 2003). This suggests that current equipment is neither meeting user needs (Gottberg et al., 2008) nor assisting illness self-regulation. Reasons for AT abandonment have been explored extensively in general disabilities, not specifically MS (Verza et al., 2006), and relate to a lack of access, lack of information or support regarding AT, changes in physical function, poor device performance, lack of motivation, or low social support (Prior, 2011; Scherer, 2002). For example, a large Canadian study (n=906) – a country with a similar publicly funded healthcare system to the UK – found that PwMS with

more symptoms, limitations, and greater involvement with OT services were found to be associated with AT use. This is supported by the suggestion that shared decision-making between PwMS and AT providers is likely to lead to choosing the correct device and to continued use (Johnston, Currie, Drynan, Stainton & Jongbloed, 2014). The former Canadian study found that those PwMS in employment were less likely to use AT devices suggesting a lack of need however in the US, health insurance is often provided through employment and as such PwMS are likely to access AT services through these avenues (Finlayson, Guglielmello & Liefer, 2001).

The Human Activity Assistive Technology (HAAT) model (Cook & Hussey, 1995) is commonly used by AT practitioners (OTs, physiotherapists) to assess the need and provision of AT devices. According to self-regulation illness models (e.g. Leventhal, 1980), it is believed that in order for AT to help PwMS achieve their functional goals then practitioners must consider the personal (e.g. characteristics, symptoms) and contextual factors (e.g. social support, employment) relating to that person and their desired outcome. For example, a person displaying higher levels of optimism is more likely to capitalise on the benefits of AT than a person with low optimism (Scherer et al., 2007). Consistent with illness process models, the external influences on AT include family involvement, financial wellbeing, healthcare service, and social support (Johnston et al. 2014; MS Society, 2013; Scherer et al., 2007; Verza et al., 2006; Wessels et al., 2003). In addition to these potential resources, users' perceptions of the device in terms of the design, interface and ease of use are important (Squires et al., 2013). However the HAAT model does not consider the potential emotional consequences of using AT devices, nor does it extend to their continued use, which is particularly important in a relapsing and progressive condition such as MS.

Surprisingly, there have been few studies investigating the psychological processes of AT acceptance, yet we know that poor acceptance of MS is related to higher perceived stress, uncertainty, more symptoms, a lack of personal control and perceived severe consequences (Dennison et al., 2009). In addition, better adjustment and problem-focused coping related to better outcomes for people living with chronic health conditions. This thesis aims to investigate the physical and psychological impact of AT devices on PwMS, while investigating the relationship between illness perceptions on the use and impact of AT. Reasons for AT abandonment will also be explored (see Chapter 3). Finally, this thesis aims to extend on the understanding of illness perceptions on the physical and psychological outcomes of living with MS.

Summary

Multiple Sclerosis has a significant physical, psychological and social impact on those living with the condition. Symptoms can affect mobility and functional independence, continence and self-care challenges, memory and communication, amongst other things, thus it is not perhaps unexpected that people with MS also report higher rates of anxiety and depression, and lower levels of quality of life. Negative outcomes of MS are not inevitable however with reports of positive growth and life appreciation, particularly after acceptance of MS has been attained. People with MS can obtain assistive technologies to help counter their functional limitations and as such offer a means of problem-focused coping. From a theoretical perceptive, namely the Common Sense Model of Illness, people self-manage their condition in response to current illness experiences and perceptions, and the successes or failures of previous coping responses. Illness perceptions (physical and emotional) are shaped by illness experiences but can also be informed by external factors such as social

support. Cognitions, emotions and coping responses combine with one's available resources to contribute to illness management. The role of AT in illness management has yet to be explored despite mixed evidence of positive and negative outcomes from using AT. Of this research, little investigates the impact of AT among people with MS. It also lacks psychological insight as to what role AT has in self-management and illness self-regulation processes. Therefore there is a need for a systematic literature review of the physical and psychological impact of AT use on people with MS, and scope to explore the factors influencing uptake and continued use of AT devices, within the context of furthering understanding of the physical and psychological outcomes of living with MS. The aim of this thesis is therefore to address these questions via a mixed methods approach: (a) to explore the nature of AT use among people with MS (b) to determine the impact of AT on those affected by MS (c) and to investigate the influences of AT use, and the physical and psychological outcomes of MS.

Aim of the thesis

Chapter 2

This chapter will present a systematic review to initially explore the nature of AT use among people with MS. In line with the Common Sense (self-regulation) Model of Illness (CSM), it will explicitly examine the physical and psychological outcomes of using AT devices (as a coping behaviour) on people with MS. The findings of this systematic review provided justification for the need to further explore the use of AT among people with MS. It also highlighted the lack of explanatory theories of how people with MS come to use AT devices, and what determines the outcome of such device use.

Chapter 3

This chapter explores the lived experiences of people living with MS, carers and occupational therapists and their individual perspectives on the physical and psychological processes involved in relation to AT use. Guided by the CSM, this chapter aimed to identify potential determinants of AT use (as a coping behaviour), and the physical and psychological outcomes of its use. It will also explore the physical and psychological impact of living with MS.

Chapters 4 and 5

Informed by the review of findings regarding AT use, theoretical underpinnings derived from the CSM and the qualitative findings reported in chapter 3, the subsequent chapters present findings from a longitudinal questionnaire study in relation to AT use and the physical and psychological impact of MS. Chapter 4 presents the cross-sectional, baseline findings and examines the correlates of previously identified biopsychosocial factors that may influence AT use. Chapter 5 presents the longitudinal findings and identifies the biopsychosocial predictors of physical and psychological outcomes of MS including the influence of AT as a coping behaviour.

Chapter 6

The final chapter will summarise and critically discuss the findings presented in the thesis and its implications for policy, practice and future research. It will also address the study limitations.

Chapter 2

The Physical and Psychological Impact of Assistive Technology Use among People with Multiple Sclerosis: Systematic Review with Meta-Analysis

The material presented in this chapter has been prepared as a paper for submission to Health Psychology Review.

Abstract

This study aimed to review the physical and psychological outcomes of assistive technology (AT) use among people living with MS. We searched MEDLINE via PubMed, PsycINFO, CINAHL, Cochrane and Web of Science using the key terms multiple sclerosis, assistive technology and physical and psychological outcomes. Twenty-six articles were retrieved for review and addressed a range of AT, of which three were suitable for meta-analysis concerning the use of TENS (Transcutaneous Electrical Nerve Stimulation). No significant effects of TENS were found on various physical and psychosocial outcomes including pain (SMD = -0.43; 95% CI [-1.40, 0.54]), physical (SMD = 0.49; 95% CI [-0.47, 1.45]) and mental (SMD = 0.61; 95% CI [-0.36, 1.59]) health. Although few studies investigated cooling garments and cognitive aids these reported significant improvements in physical and psychological wellbeing, as did mobility devices (i.e. wheelchairs, orthoses, FES). Other under-researched devices presented mixed findings (e.g. catheters) and therefore require further study. Key limitations to data synthesis across AT devices were differences in methods and outcome measures utilised. More robust research designs and standardised measures would benefit our understanding of the factors associated with AT use/non-use and the consequent functional and psychosocial outcomes.

Introduction

An estimated 100,000 people in the UK currently live with multiple sclerosis (MS Society, 2016a), which can cause intrusive and disabling functional changes affecting mobility, attention, memory, thermoregulation, urinary and sexual function (Goodkin, 1992; Holper et al., 2010). Consequently, people with MS (PwMS) report activity limitations and social restrictions particularly with work (Holper et al., 2010), high rates of anxiety and depression, low general and health-related quality of life outcomes (Jones et al., 2012; Mikula et al., 2016), and subsequent disability (Heesen et al., 2008).

Drawing on Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of illness, it is believed that PwMS coping behaviours are shaped by the successes and failures of their past coping responses. To counter such disability, PwMS obtain assistive technology (AT) devices in response to the physical limitations they face. Therefore, it is important to monitor the effects of these devices to maximise outcomes for PwMS but also to encourage positive self-management among PwMS. AT devices are commonly provided by health and social services (e.g. occupational therapists) or purchased privately. They can range from basic walking aids to advanced electronic equipment, and can aid people with their complex and numerous needs e.g. bathing, communication, eating, memory, mobility, toileting. They are primarily designed to 'improve independence, help with care, maintain health and improve quality of life (QoL)'. Despite these aims, and a growing trend of AT use (Anderson & Wiener, 2015), no current register of MS-AT use exists. A previous review (Souza et al. 2010) identified some physical and psychological benefits of using mobility devices however this included mixed populations of those with neurological conditions including MS. Also, the full extent of how other, non-mobility devices (e.g. memory and

toileting aids) impact one's psychological wellbeing remains unknown.

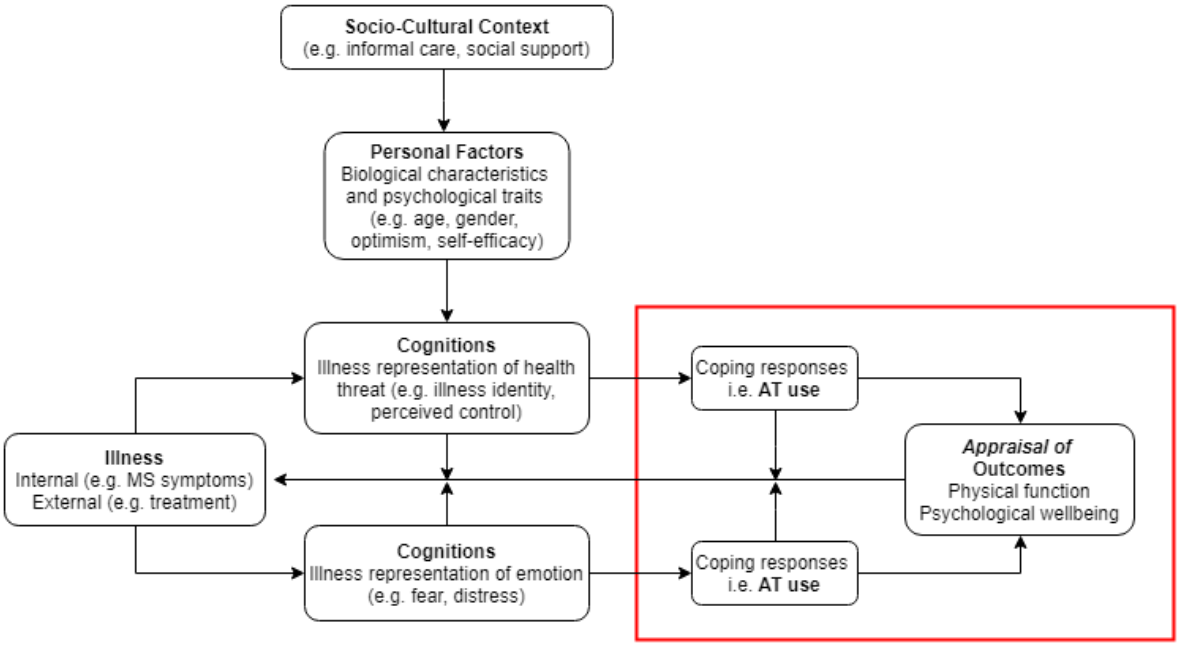

Figure 2.1: Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness. Chapter 2 to focus on AT use and outcomes of use.

The main objective of this review was to examine the evidence regarding AT use and its physical *and* psychological consequences among PwMS (see Figure 2.1). Therefore the research questions were:

- What AT devices are currently used by PwMS?
- What are the physical and psychological outcomes of using such devices?

Method

Protocol Registration

The review protocol (ID=CRD42014013529) was registered at PROSPERO International Prospective Register of Systematic Reviews on 17/09/2014.

Search Strategy

Study searches were conducted in PsycInfo, MEDLINE via PubMed, CINAHL, Web of Knowledge, and Cochrane library. The databases were searched from their inception and the last search was conducted May 2015. Three different electronic search strategies were used combining the key terms: 'multiple sclerosis' (population); 'assistive technology' or 'assistive devices' (intervention). The search was not restricted by study type or control group, which included placebo, usual care, other treatment and no control group (see Appendix A[1] for full search strategy). Identified articles were then screened for a physical *and* psychological outcome – 'function', 'quality of life', 'wellbeing', 'mood' etc. Manual searches of reference lists for further eligible articles were also conducted.

Inclusion and Exclusion Criteria

Given the nature of the PhD research questions relating to the physical and psychological outcomes of AT use, studies had to measure a functional *and* psychological outcome from assistive device use (for example, physical function *and* QoL or wellbeing or mood etc) to be eligible. This is also in line with the Common Sense Model of Self-Regulation of illness (1980; 1992; 2003) where illness experience involves both physical and psychological processes which interact, for example the interaction between pain and depression. Given the psychosocial facets of pain (Haythornthwaite, 2013; Osborne et al., 2007) and fatigue (Bol, Duits, Hupperts, Vlaeyen & Verhey, 2009), these were also considered as psychological outcomes. Included studies had to be written in the English language. Eligible participants were adults (+18 years) with a confirmed diagnosis of multiple sclerosis using an assistive technology. Mixed sample studies were included if the analyses separated PwMS sample from other conditions. Peer-reviewed and grey literature

were all included if they met the inclusion criteria. Studies were then excluded pre-1995.

Study Selection

In the first stage of the review process, titles and abstracts of identified articles were screened by the principal researcher (LS) according to the inclusion and exclusion criteria. In the second stage, potentially eligible articles were retrieved and full articles were reviewed for eligibility. Throughout the study selection process, progress meetings were held among co-authors where at least 10% of articles were screened together.

Data Extraction

A data extraction form was developed and piloted and the following items were extracted (Appendix A[2]):

- Study characteristics: background/rationale, aims/objectives, hypotheses, design, time points, design, study setting, recruitments strategy, control, inclusion/exclusion criteria, sample size, attrition rates, ethics, data source/measurement, bias
- Sample: age, gender, education, type of MS, previous AT use, length of AT use, AT device
- Measures: Level of AT use, function/disability, wellbeing, QoL, depression, anxiety, other
- Findings: data analysis, key findings, author-acknowledged limitations, interpretation, generalisability, credibility/integration and valuable

Two independent reviewers (LS, EM) extracted data and conducted the quality assessment of the studies. Each reviewer scored 434 items and agreed in 403 cases (92.86%). Inter-rater reliability was strong (κ=.85).

Quality Assessment

For quantitative studies, a quality assessment tool (see Appendix A[3]) was adapted based on criteria for assessing internal validity of studies (Altman, 2001; as seen in Magklara, Burton & Morrison, 2014). It comprised 18 criteria with a maximum score of 36 (scored 2=high quality, 1=low quality, 0=insufficient information). A study was considered high quality when achieving a score of 50% or more i.e. 18+. Qualitative studies were assessed using the 10-item Critical Appraisal Skills Programme (CASP) tool (2014; see Appendix A[4]) and mixed-methods studies were assessed using the Mixed-Methods Assessment Tool (MMAT: Pluye et al., 2011; see Appendix A[5]). These gave maximum scores of 20 and 26 respectively. No study was excluded based on their quality score (see Table 2.1 and/or Appendices A[3-5]) however quality was considered when drawing conclusions. PRISMA statement was completed to limit reporter bias (see Appendix A[6]).

Data Synthesis

When considering the question of the physical and psychological impact of using specific devices, meta-analyses of findings from a range of relevant studies would have been ideal in order to synthesise findings. However, due to the different (i) devices, (ii) instructions given for AT device use (i.e. 30-minute use vs. 'full-time' use), (iii) outcome measures employed, and (iv) timings of outcome assessments, a meta-analysis was only feasible for three Transcutaneous Electrical Nerve Stimulation (TENS) studies. In accordance with Field and Gillett (2010), a basic meta-analysis was conducted with a random-effects model using RevMan 5.0. For other types of AT, a narrative synthesis of results is presented (e.g. Magklara et al., 2014; Souza et al., 2010).

Results

The literature search identified 2780 articles. After electronic de-duplication, 2142 articles were screened by title, and then abstract, according to the inclusion and exclusion criteria. A total of 157 potentially eligible articles were retrieved for full review, of which, 26 met the inclusion and exclusion criteria, and were consequently included in the review (see Figure 2.2).

Study Characteristics

Of the 26 studies included, 19 investigated the impact of mobility devices: seven Functional Electrical Stimulation (FES) devices; five wheelchairs (manual or powered); four TENS devices; one hip-flexion orthosis; one which included all mobility devices; and the final study that compared FES and ankle-foot orthoses. Urinary catheters and cooling suits (i.e. garments to reduce body temperature) were investigated by three studies each, and cognitive aids were evaluated in one study. Twenty-one studies employed a purely quantitative methodology, three were purely qualitative (two interview, one focus group) and two used mixed-methods. Of the quantitative studies, 19 were longitudinal and four were cross-sectional in design. Follow-up time-points varied across all studies and ranged from 45 minutes to 6 months (see Table 2.1). Ten studies each were conducted in the US and the UK (four in Scotland, three in Northern Ireland, two in England and one all-UK). The three cooling suit studies were conducted in Sweden. Canada, France and Taiwan contributed one study each to the review.

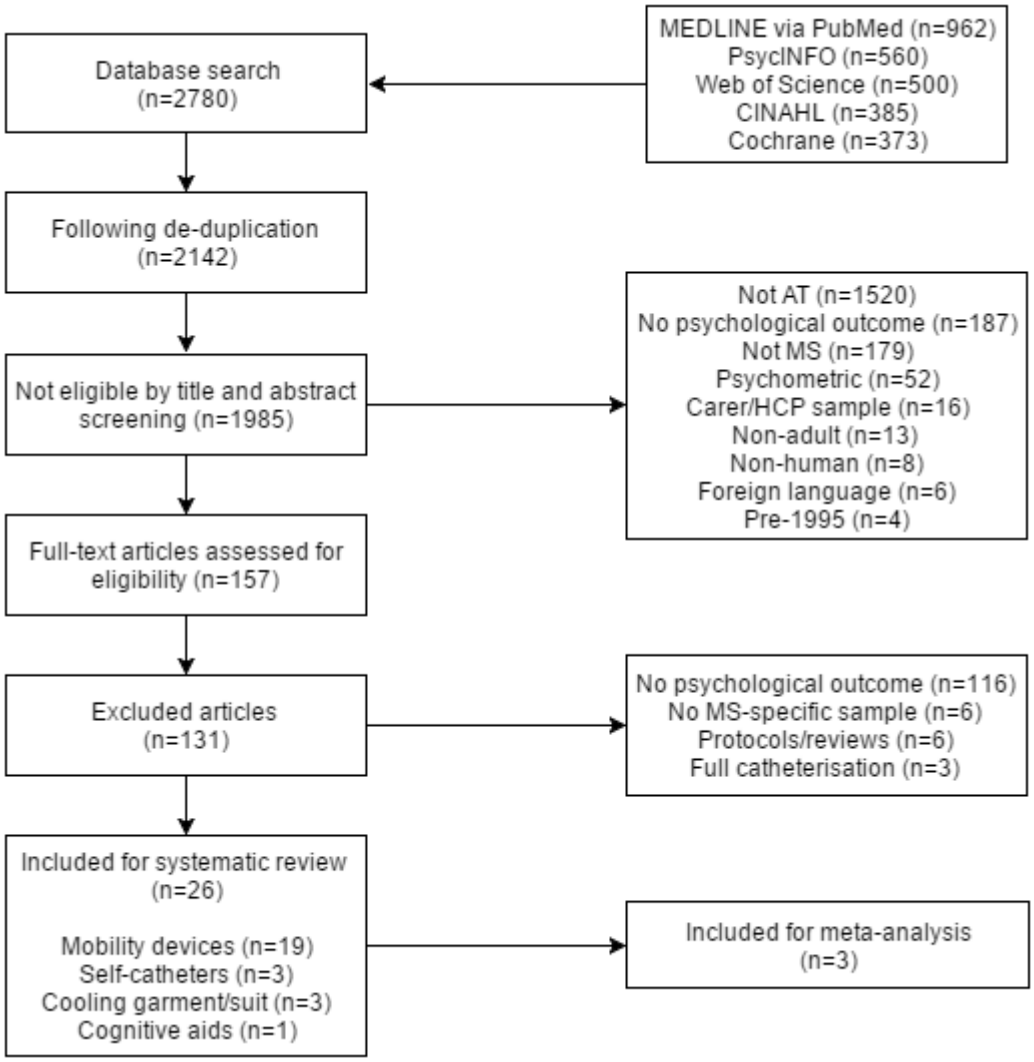

*Figure 2.3.*PRISMA flow diagram of study selection process

Nineteen studies assessed the impact of mobility devices upon the person with MS, with impact variously defined and assessed (i.e. function, QoL, pain, fatigue, satisfaction with AT). Functional outcome measures mainly consisted of objective mobility measures for example, ambulation, balance, gait, walking and wheelchair propulsion speed tests. The Multiple Sclerosis Walking Scale (MSWS-12; Hobart et al., 2003) was also used by three studies, which measured perceived walking ability i.e. patient-reported. Further functional outcome measures included the Barthel Index (Mahoney & Barthel, 1965), Canadian

Occupational Performance Measure (COPM; Law et al., 1990), Expanded Disability Status Scale (EDSS; Kurtzke, 1983), Instrumental ADL Scale (Graf, 2008), MS Self-Care ADL Scale (Gulick, 1987), Multiple Sclerosis Functional Composite (MSFC; Fischer Rudick, Cutter & Reingold, 1999), Multiple Sclerosis Impact Scale (MSIS-29; Hobart, Riazi, Lamping, Fitzpatrick & Thompson et al., 2001), Patient Determined Disease Steps (PDDS; Hohol, Orav & Weiner, 1995) and the Roland Morris Disability Questionnaire (RMDQ; Roland & Fairbank, 2000). Mobility was also recorded by an activity monitor, number of falls, and the nine-hole peg test (dexterity). Spasticity was measured using the Global Spasticity Scale (GSS; Levin & Chan, 1992), the Modified Ashworth Scale (MAS; Ansari, Naghdi, Arab & Jalaie, 2008), the Penn Spasm Scale (PSS; Penn et al., 1989) and visual analogue scales for back, leg and muscle spasm. Memory function was assessed using the Rivermead Behavioural Memory Test – Extended Version (RBMT-E; Wilson, Cockburn & Baddelay, 1991). Participation was measured using the CHART (Craig Handicap Assessment and Reporting Technique; Whiteneck et al., 1992) by two studies, with another study opting for the revised edition. Other physical outcomes assessed included oral temperature, isometric muscle strength (Biodex 3), cytokines and growth factors in cerebrospinal fluid (CSF), kinematic and time-based electromyography observations.

In terms of QoL measurement, seven studies employed the generic QoL 36-item Short Form Health Survey (SF-36; Brazier et al., 1992), which covers eight health domains including physical and social function, emotional wellbeing, fatigue, pain, general health, health change and limitations due to physical and emotional problems. However each of these studies differed in the type of AT device used or time-point assessed (see Table 2.1), thus no meta-analysis of these data was possible. This was the case for all studies except

three examining TENS devices (Al-Smadi et al., 2003; Warke, Al-Smadi, Baxter, Walsh & Lowe-Strong, 2004; Warke, Mattison, Paul & Wood, 2006). Three studies utilised a specific QoL measure, the Multiple Sclerosis Impact Scale-29, a 29-item scale with two subscales assessing the physical and psychological impact of living with MS. Subscales are added to provide a 'total impact of MS' score. Two studies used a different specific tool, the Leeds Multiple Sclerosis QoL (LMSQoL; Ford et al., 2001) measure, a 16-item wellbeing outcome measure. Two studies used the Psychosocial Impact of Assistive Devices Scale (PIADS; Jutai & Day, 2002), a 26-item scale with three subscales: competence (e.g. independence, QoL), adaptability (e.g. ability to participate, wellbeing) and self-esteem (e.g. sense of control, happiness). One study used Qualiveen (Bonniaud et al., 2004), a specific QoL measure for urinary disorders in patients with neurological conditions such as MS. Finally, one study used a 7-point Likert scale to score QoL.

Other psychological outcomes assessed included fatigue, pain and satisfaction. Fatigue was assessed in five studies, however each used different measures e.g. Fatigue Impact Scale (and modified version; Frith & Newton, 2010), Fatigue Severity Score (Krupp et al., 1989), Central Fatigue Index, General Fatigue Index and the Peripheral Fatigue Index. Pain was measured in five studies using the McGill Pain Questionnaire (Melzack, 1975) and visual analogue scales for back and leg pain (i.e. average/current/worst). Satisfaction was measured using the Quebec User Evaluation of Satisfaction with Assistive Technology (Demers, Weiss-Lambrou & Ska, 1996) and a 5-point Likert scale (see Table 2.1).

Effect of AT devices and usage on Physical and Psychological MS Outcomes

Due to the known interactions between physical and psychosocial outcomes, for example, between pain, fatigue, depression (Bol, Duits, Hupperts, Vlaeyen & Verhey, 2009; Haythornthwaite, 2013; Osborne et al., 2007), the findings are structured around AT device type rather than outcome-led.

Catheters Although bladder problems were more likely to be reported among people with longer duration of MS and greater physical impairment, there was no significant relationship between age and catheter use found in McClurg's (2009) study. Limited evidence of positive outcomes of catheter use was reported: Castel-Lacanal et al. (2013) found no significant difference in either physical or psychological QoL (as measured by SF36) at 6-month follow up of intermittent catheter use. They did however find evidence of significant reductions in overall QoL and catheter-related 'bothers' e.g. fears, limitations and negative feelings (measured by Qualiveen, a QoL measure, specific for those with urinary disorders).

Similarly, McClurg and Hagen's (2009) cross-sectional study reported that most PwMS (58%) felt 'very uncomfortable' using catheter devices, although a quarter of participants felt 'very comfortable'. In a retrospective questionnaire study of PwMS using a range of AT (i.e. not all catheter users), James, Frasure and Mahajan (2014) also identified no significant overall effect of catheters on QoL. However in the whole sample, 61% of those reporting a positive QoL were self-intermittent catheter users, and 63% of participants who reported a negative QoL were not catheter users.

Cognitive aids Gentry (2008) found that self-reported memory function was significantly improved by a memory aid delivered via a personal digital assistant, with gains maintained at 8-week follow-up. Performance dropped during the longer post-treatment period, however remained significantly higher than at initial assessment, with a similar pattern of results found for satisfaction with memory performance.

Cooling garments Flensner and Lindencrona (1999; 2001) examined the effect of cooling garments on illness symptoms and outcomes using mixed methods (multiple-case series, open interviews and diaries) whereas Nilsagård (2006) conducted a randomized cross-over trial. The latter found a significant improvement in walking ability and balance following 45-minute use of a cooling garment. Participants also reported significant subjective improvements on a range of symptoms/outcomes including spasticity, weakness, balance, gait, transfers, ability to think clearly and time to recover. Interestingly, Nilsagård, Denison and Gunnarsson (2006) found no effect on spasticity (as measured by the Ashworth scale; Ansari et al., 2008), nor on oral temperature, pain, or other objective balance/step tests. Positive findings were also apparent in the qualitative data of Flensner's study with participants reporting improved self-care ability, which varied in nature and extent, in terms of walking, mobility, transfer, toileting and sleep. Performance of daily activities and social participation also improved for some participants who reported fewer social conflicts (e.g. family arguments) and restrictions following the use of a cooling suit. Others however identified some limitations in daily activities particularly in warm environments, which were specifically attributed to the cooling suit.

Table 2.1 *Study characteristics of review articles*

Reference (Quality Score)	**Sample**	**Age/Gender**	**AT Use**	**Design (Longitudinal Follow-up)**	**Outcome(s)**	**Key Findings of AT Use and Outcome**
Flensner 1999 (19/26)	n=10	33-60 yrs (M=47); 7 females	Cooling suit (30-45 minutes, 3-4 times a day; differed for each participant)	Mixed methods: Multiple-case control design; open interviews; daily diaries	Activity (MS Self-Care ADL Scale)	Improved self-care ability and performance of activities (including social participation). Some limitations in daily activities.
Flensner 2001 (20/26)	n=8 1 RRMS, 2 RPMS, 5 CPMS	5 females (M=51yrs); 3 males (M=49 yrs)	Cooling suit (30-45 minutes, 3-4 times a day; differed for each participant)	Mixed methods: Multiple case–control design; open- interviews; semi-structured diaries	Fatigue (FIS)	Reduced fatigue for all participants (less frequent and shorter periods). Qualitative: decreased muscular strain, and positive effects on fatigue-related cognitive, social or affective problems.
Nilsagård 2006 (35/36)	n=43 22 RRMS, 13 SPMS, 8 PPMS	M=52 yrs (+-9); 30 females	Cooling garment (45 minutes, presented at -20c or 22c)	Randomized crossover study (vs. placebo) (45 minutes, crossover 1 week later)	Mobility (10TW, 30TW, standing balance test, TUG); Oral temperature (oC); Spasticity (MAS); Dexterity (Nine-hole peg test); Subjective experience of symptoms	Significant improvement in all mobility tests (all $p<.05$). Significant subjective improvement in fatigue, spasticity, weakness, balance, gait, transfers, time to recover (all $p<.001$) and ability to think clearly ($p=.034$).
Castel-Lacanal 2013 (28/36)	n = 23 T2, n=22	M=49.3 yrs (+-10.3); 15 females	Intermittent catheter (not reported)	Prospective study; (At least 6 months (M=9.3))	QoL (Qualiveen; SF36)	Significant decrease in quality of life ($p=.004$), bother with limitation ($p=.007$), fears ($p=.02$) and feelings ($p=.002$).

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
James 2014 (20/36)	n = 727	20-93 yrs (M=55.4); 77.4% females	Intermittent self-catheterisation (not reported)	Retrospective questionnaire (N/A)	Disability (PDDS); QoL (7-point Likert scale)	Non-significant effect
McClurg 2009 (19/36)	n = 66	23-76 yrs (Mdn=51); All female	Intermittent self-catheterisation (not reported)	Questionnaire study (N/A)	Study-specific questionnaire	57.8% were 'very uncomfortable' with using a catheter; 15.6% 'moderately comfortable'; 26.6% 'very comfortable'.
Gentry 2008 (29/36)	n = 20	37-73 yrs (Mdn=50); 16 females	Personal Digital Assistant (Frequency of use was determined by counting calendar events for each week of the study. Use varied across participants e.g. 27/day vs 3/week)	ABC repeated-measures design Week 12: End of Training Week 21: Post-treatment	Memory (RBMT–E); Disability (COPM, CHART–R)	Significant improvement in functional performance (3.27 to 7.09, p<.001) and satisfaction (2.72 to 7.03, p<.001).
Sutliff 2008 (30/36)	n = 21	M=52.8 yrs (+-8.8); 57% female	Hip flexion assistive orthosis ('Trained to use the device, and given a wear schedule' - not specified)	Pre- and post-intervention uncontrolled pilot study (8 & 12 weeks)	Impairment (Passive ROM, MMT, MAS, Pain); Gait Performance (T25FW; TUG; 6MWT; MCGT); Satisfaction (5-point Likert)	Significant improvement of strength (2.5 to 0.3, p<.001), pain (1.6 to -1.2, p=.004), and gait (19.5 to 2.4, p=.001). 19% of HFAO users reported low back pain as a side effect.

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
Souza 2011 (28/36)	n = 87 T2, n=24	M=51.16 (+-9.35); 60.9% female	Mobility AT (including powered wheelchairs, scooters, walkers, walking sticks) (not reported)	Longitudinal questionnaire (6 months)	Disability (EDSS); Participation (CHART); QoL (SF36); Satisfaction (QUEST)	Baseline: non-wheeled AT users reported higher QoL than wheeled AT users (p=.0234). Significant improvement in physical independence (new devices users; 55.00 to 86.33, p=.025).
Woollard 2005 (29/36)	n = 11 T2, n=6 T3, n=3	37.5-63.3 yrs, M=49.9; 9 females	Wheeled mobility (not reported)	Quasi-experimental longitudinal design (2-4 months)	Function (8MTW, 8m Timed Wheelchair Propulsion, CHART); QoL (SF36); Fatigue (Biodex 3, MFIS)	Increased muscle strength (184.7 to 124.5). Increases in SF36 related to amount of wheeled mobility use overtime.
Al-Smadi 2003 (31/36)	n = 15 T2, n=14	34–65 yrs; not specified	TENS: (1) TENS at 4 Hz, 200 µs; (2) TENS at 110 Hz, 200 µs; and (3) placebo TENS; (n = 5 all groups). To apply for 45 minutes, 3 times per week for 6 weeks.	Randomized double-blind placebo controlled pilot study (Week 6: End of treatment Week 10)	Function (RMDQ); QoL (SF36, LMSQoL); Pain (McGill, VAS for current LBP, right and left leg pain)	No significant effects. Positive trends.

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
Miller 2006 (30/36)	n = 32	30-67 years, M=47; 17 females	TENS (100 Hz, 0.3 ms) Two weeks of 60 minutes OR 8 hours daily of TENS applications	Single, blind, repeated crossover same subject design (2 weeks)	Spasticity (GSS, PSS, VAS for muscle spasm) Pain (VAS for pain)	Significant reduction in PSS (*p*=.038) & VAS (*p*=.008; longer treatment only). Non-significant reduction in GSS.
Warke 2006 (29/36)	n = 90 T2, n=81 T3, n=79 T4, n=75	21-78 yrs; 69 females	TENS (low freq = 4 Hz, 200 ms; high freq = (110 Hz, 200 ms) To apply at least twice daily, for 45 minutes, for 6 weeks, and at any painful episode	Randomized blinded, placebo-controlled design (6, 10 & 32 weeks)	Function (RMDQ, BI, RMI); QoL (MSQoL-54); Pain (McGill, VAS for average & worst LBP); Spasticity (VAS for back & leg spasm)	No significant differences between groups in pain, spasticity, disability/function, quality of life.
Warke 2004 (28/36)	n = 15 T2, n=12 T3, n=11 T4, n=10	37-71 yrs; not specified	TENS (low freq = 4 Hz, 200 ms; high freq = 110 Hz, 200 ms) To apply at least twice daily, for 45 minutes, for 6 weeks, and at any painful episode	Placebo-controlled, double-blind, randomized pilot study (6, 10 & 32 weeks)	Function (RMDQ, BI, RMI); QoL (SF36; LMSQoL); Pain (McGill, VAS for average & worst LBP); Spasticity (VAS for back & leg spasm)	Significant improvement in pain only (*p*=.01).

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
Boss 2006 (18/20)	n=7	31-72 yrs; 5 females	Power mobility (not reported)	Qualitative – Semi-structured interviews	N/A	Major impact theme: Positive, negative outcomes and adjustment (*mobility, freedom (alone, carer, outside), adjustment, destructiveness, lack of access, stigma, maintenance and safety concerns*)
Dewey 2004 (18/20)	n=23	35-71 yrs (M=55.5); 13 females	Wheelchairs: Tilt-in-space vs conventional; manual vs powered	Qualitative – In-depth interviews	N/A	Major impact themes: Comfort, pressure ulcers, sitting for prolonged periods of time, spasms, size of chair, powered chairs, transport, financial burden and fatigue
Devitt 2003 (28/36)	n = 16	41-70 yrs, M=53.4; 10 females	Wheelchairs (9 manual, 7 powered) 9='daily, most of the day', 2='daily, part of the day', 5='several days a week, part use'	Cross-sectional pilot study (N/A)	QoL (PIADS)	Positive PIADS subscale scores for competence (*m*=1.54), adaptability (*m*=1.64) and self-esteem (*m*=1.06). Powered chairs scored higher than manual chair users; 'everyday' users scored higher than 'not everyday'.
Fay 2003 (21/36)	n = 9 (& 9 healthy)	Not reported	Manual wheelchairs M=6.7 yrs previous use	Between groups design (vs. healthy controls) (N/A)	Fatigue (Kinematic and time-based EMG observations)	Decreased rate of pushrim force (i.e. fatigue; *p*=.04).

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
Bulley 2014 (19/20)	n=10	AFO: 47-59 yrs (M=54); 2 females FES: 36-58 yrs (M=47); 5 females	AFO (n=4); FES (n=6) 3 daily; 6 selected days; 1 for exercise	Qualitative – Focus groups	N/A	Both devices reduced fatigue, improved gait, reduced trips and falls, increased participation, and increased confidence. AFOs: greater balance/stability FES: increased walking distance, fitness and physical activity
Barrett 2010 (20/36)	n = 20 (& 21 stroke)	41-70 yrs, M=56; 12 females	FES – ODFS Subjects were asked to use the ODFS as much as they felt able to during this time period	Between groups design (vs. stroke) (18 weeks)	Mobility (10TW); QoL (PIADS)	Positive PIADS subscale scores for competence (*m*=0.91), adaptability (*m*=0.50) and self-esteem (*m*=0.75). No significant correlation between changes in PIADS and walking speed.
Chang 2011 (24/36)	n = 7	M= 42.9 +- 13.5yrs; 5 females	FES 8 weeks of surface FES training	Repeated measures design (8 weeks)	Fatigue (FI, CFI, PFI, MFIS)	Improved FI (*p*=.01), CFI (*p*=.02) & MFIS (*p*=.02)
Downing 2014 (31/36)	n = 19	M=51.77 +- 10.16 yrs; 10 females	FES – WalkAide 2 weeks of full-time use	Longitudinal (2 weeks)	Gait Speed (T25FW); Perceived walking ability (MSWS-12); QoL (MSIS-29)	Improved T25FW, MSWS-12, MSIS-29 (physical and total, all *p*<.001); psychological subscale (*p*=.0006)

Reference (Quality Score)	Sample	Age/Gender	AT Use	Design (Longitudinal Follow-up)	Outcome(s)	Key Findings of AT Use and Outcome
Mayer 2014 (31/36)	n = 20	35.7-67.5 yrs, M=51.7; 12 females	FES – Walk Aide 3-months of daily full-time use	Unblinded sequential case series (1 & 3 months)	Mobility (T25FW, 6MW, FAP); Perceived walking ability (MSWS-12); QoL (SF36)	Improved T25FW (*p*=0.15), MSWS-12 (*p*=.003), physical health (SF36, *p*=.032)
Ratchford 2010 (28/36)	n = 5	46-60 yrs, Mdn=50; 2 females	FES – RT300 (3 times per week for 1 hour)	Repeated measures design pilot study (3 & 6 months)	Mobility (Two Minute Walk Test, TF25W, TUG, leg strength); Function (EDSS, MSFC); QoL (SF36)	Improved 2MWT, T25FW, TUG, muscle strength, physical and mental health (SF36)
Taylor 2014 (29/36)	n = 25 T2, n=24 T3, n=21 T4-5, n=20	Group 1: M=54.6 +-8.6 yrs; 8 females Group 2: M=56.9 +-7.8 yrs; 10 females	FES – O2CHSII (12 weeks)	Randomized crossover with baseline feasibility study (6, 12, 18 & 24 weeks)	Mobility (ROGA; 10MTW); QoL (MSIS-29); No. of falls	Improved walking speed, gait and MSIS-29 Reduced falls
van der Linden 2014 (29/36)	n = 9	35-64 yrs, M=53; 7 females	FES – ODFS III or PACE (12 weeks)	Repeated measures design (6 & 12 weeks)	Mobility (10TW, 2TW, Activity monitor); Perceived walking ability (MSWS-12); Fatigue (FSS); QoL (MSIS-29)	Improved peak dorsiflexion in swing (*p*=.006), 10MWT (*p*=.006) & 2MWT (*p*=.002). Reduced perceived exertion

ADL – Activities of Daily Living; RRMS – Relapse-Remitting MS; RPMS – Relapsing Progressive MS; CPMS – Chronic Progressive MS; FIS – Fatigue Impact Scale; SPMS – Secondary Progressive MS; PPMS – Primary Progressive MS; 10TW – 10m Timed Walk; 30TW – 30m Timed Walk; TUG – Timed Up & Go Test; MAS – Modified Ashworth Scale; QoL – Quality of Life; PDDS – Patient Determined Disease Steps; RBMT-E – Extended Rivermead Behavioural Memory Test; COPM – Canadian Occupational Performance Measure; CHART-R – Revised Craig Handicap Assessment and Reporting Technique; ROM – Range of Movement; MMT – Manual Muscle Test; T25FW – Timed 25-foot Walk; 6MWT – Six-Minute Walk Test; MCGT – Mellen Center Gait Test; HFAO – Hip-flexion assistive orthosis; EDSS – Expanded Disability Status Scale; SF36 – 36-item Short Form Survey; QUEST – Quebec User Evaluation of Satisfaction with Assistive Technology; 8MTW – 8m Timed Walk; MFIS – Modified Fatigue Impact Scale; RMDQ – Roland Morris Disability Questionnaire; LMSQoL – Leeds MS Quality of Life; VAS – Visual Analogue Scale; LBP – Lower Back Pain; TENS – Transcutaneous Electrical Nerve Stimulation; FES – Functional Electrical Stimulation; GSS – Global Spasticity Scale; PSS – Penn Spasm Scale; BI – Barthel Index; RMI – Rivermead Mobility Index; MSQoL-54 – MS QoL-54 Instrument; PIADS – Psychosocial Impact of Assistive Devices Scale; EMG – Electromyography; FI – General Fatigue Index; CFI – Central Fatigue Index; PFI - Peripheral Fatigue Index; MFIS - Modified Fatigue Impact Scale (MFIS); MSWS-12 – 12-item MS Walking Scale; MSIS-29 – 29-item MS Impact Scale; 6MW – 6-Minute Walk Test; FAP – Functional Ambulation Profile; MSFC – MS Functional Composite; ROGA – Rivermead Observational Gait Analysis

In addition to the physical impact of cooling garments, both Nilsagård et al. (2006) and Flensner and Lindencrona (2001) reported significant reductions in subjective self-reported fatigue attributed to regular use of a cooling suit. Flensner's qualitative data further identified positive effects on physical, cognitive and psycho-social dimensions of daily fatigue.

Mobility devices Souza (2011) assessed participants' disability status, social participation, physical and psychological wellbeing and satisfaction longitudinally and considered all types of mobility devices, including wheeled (e.g. manual and powered wheelchairs, scooters) and non-wheeled aids (e.g. walking sticks, walkers). At baseline, non-wheeled AT users reported higher QoL and social participation than wheeled AT users hinting at a hierarchy of AT equipment and its effects on MS. Only new AT users at baseline were followed-up 6 months later (n=24), which limited the generalisability of the findings that physical independence had significantly improved.

Wheelchairs The evidence as to benefits of wheelchair use was generally positive although differences emerge between powered and manual equipment. In a cross-sectional pilot study, Devitt, Chau and Jutai (2003) found that PwMS reported positive QoL in respect to competence, adaptability and self-esteem. Powered wheelchair users scored higher on these variables than manual wheelchair users. 'Everyday' users also scored higher than occasional users. Similarly, Woollard (2005) reported increases in physical and mental QoL, which were correlated with the amount of AT use overtime. This study also reported increases in muscle strength and found no effect on fatigue when assessing the impact of wheeled mobility devices. One between-groups study (Fay, Boninger, Ambrosio & Cooper,

2003) comparing MS wheelchair users to healthy controls in wheelchairs concluded that PwMS displayed fatigue via a reduced rate in wheelchair propulsion.

Interview studies regarding the use and impact of powered mobility devices also revealed conflicting findings. PwMS reported freedom as a key benefit from using powered mobility (Boss & Finlayson, 2006) with different facets described: own freedom, carer freedom, outside freedom. However some participants struggled with the lack of powered wheelchair accessibility in the wider environment which therefore limited their social life. The destructive nature of the chair within the home environment and the financial costs of devices and home adaptations were also noted as negative social outcomes (Boss & Finlayson, 2006; Dewey, Rice-Oxley & Dean, 2004). Emotional outcomes of using powered mobility devices were also identified for example, adjustment, stigma and safety concerns (Boss & Finlayson, 2006). In addition, whilst wheelchairs (manual and powered) increased comfort for some PwMS (Dewey et al., 2004), for others there were reports of pressure ulcers. Powered wheelchair users reported more positive aspects of use than manual wheelchair users.

Orthoses Sutliff et al. (2008) investigated the impact of hip-flexion assistive orthoses in an uncontrolled intervention study and reported a significant improvement in strength and gait at 8 weeks post-treatment with orthosis. Strength, gait and pain remained significantly improved at 12 weeks with the overall mean satisfaction with orthosis at 12 weeks being 39/45. One frequently reported negative impact was low back pain (in 19% of the sample).

In Bulley et al.'s (2014) qualitative focus group study exploring different experiences of ankle-foot orthosis (AFO) and FES, participants described the positive psychosocial impact

of using orthoses, including improved confidence, and social participation, as well as observed physical improvements in their balance and fatigue.

Functional Electrical Stimulation Bulley's focus group study described above also reported similar positive outcomes to FES use but in contrast to AFO users, FES users also identified increased fitness and physical activity. While some participants reported difficulties and limitations in using FES, overall they felt the positives outweighed the negatives. In studies providing quantitative data however the most common functional outcome reported was improved walking ability (distance and/or speed), reported in all seven repeated measures studies, with one randomised crossover study (i.e. Taylor, Barrett, Mann, Wareham & Swain, 2014).

Following two weeks of full-time FES use, Downing et al. (2014) reported significant improvements in objective and self-reported walking ability and in physical and psychological QoL. Similar findings were found following 3 months of daily full-time use at 1 and 3 month follow-up (Mayer, Warring, Agrella, Rogers & Fox, 2015; Taylor et al., 2014). Additional physical benefits including reduced number of falls and perceived exertion were reported at 6 and 12 weeks (Taylor et al., 2014; van der Linden, Hooper, Cowan, Weller & Mercer, 2014). Fatigue was reported as significantly improved following 8 weeks of FES training (Chang, Hsu, Chen, Lin & Wong, 2011). When participants were asked to wear their FES devices 'as much as they felt able', Barrett and Taylor (2010) found positive QoL with regards to competence, adaptability and self-esteem however no significant correlation was found between QoL and actual walking speed. FES delivered through the use of a cycling exercise machine improved walking speed, muscle strength and physical and mental health at 3 and 6 months (Ratchford et al., 2010).

Transcutaneous Electrical Nerve Stimulation There were three randomized controlled studies of TENS devices and one repeated crossover study. In a repeated crossover study, Miller, Mattison, Paul and Wood (2006) compared the effect of 2 weeks of 1- or 8- hour daily use of TENS treatment (100Hz, 0.3ms) on pain and spasticity. Spasticity significantly reduced for PwMS according to two scales (8 hours use only) whereas there was a non-significant reduction in spasticity on the other scale. Al-Smadi et al. (2003) compared three experimental groups in a randomised double-blind placebo controlled pilot study assessing at 6 (end of treatment) and 10 weeks. The three groups included 45-minute TENS treatment at 4Hz; at 110Hz; none. Participants received treatment three days a week for six weeks. No significant effects were found in physical and mental QoL, or pain although positive trends were identified in the data. Warke et al. (2006) found no significant differences between groups randomly assigned to either 45-minute TENS treatment at 4Hz or 110Hz (administered at least twice per day, and any time a painful episode occurred) or a placebo.in terms of their pain, spasticity, self-reported disability/function and QoL. The researchers argued that meaningful clinical differences were identified. For example, the 110Hz group showed greater reductions in pain and spasticity than the 4Hz group, and QoL increased for all three groups but more so for the two TENS groups. However the *placebo* group demonstrated the greatest reduction in pain overall. Their earlier (Warke et al, 2004) study had reported a significant improvement in pain for the active treatment group.

Meta-analysis on the effects of TENS Consistency in outcome measurement in three of four studies made meta-analysis of the impact of TENS devices possible. Whilst exploratory, a meta-analysis was conducted using a random-effects model. As shown, these meta-analyses found no significant effects of TENS on the various physical and psychological outcomes addressed by the included studies (see Figures 2.3-2.4). There were no significant

effects of TENS found on pain (as measured by the MPQ), physical or mental health (both measured by the SF36) at 6 or 10 weeks (n=10 TENS vs. 8 control). Nor were there any effects of TENS on activities of daily living (as measured by the BI) or functional mobility (as measured by the RMI) at 6, 10 or 32 weeks (n=28 TENS vs. 30 control).

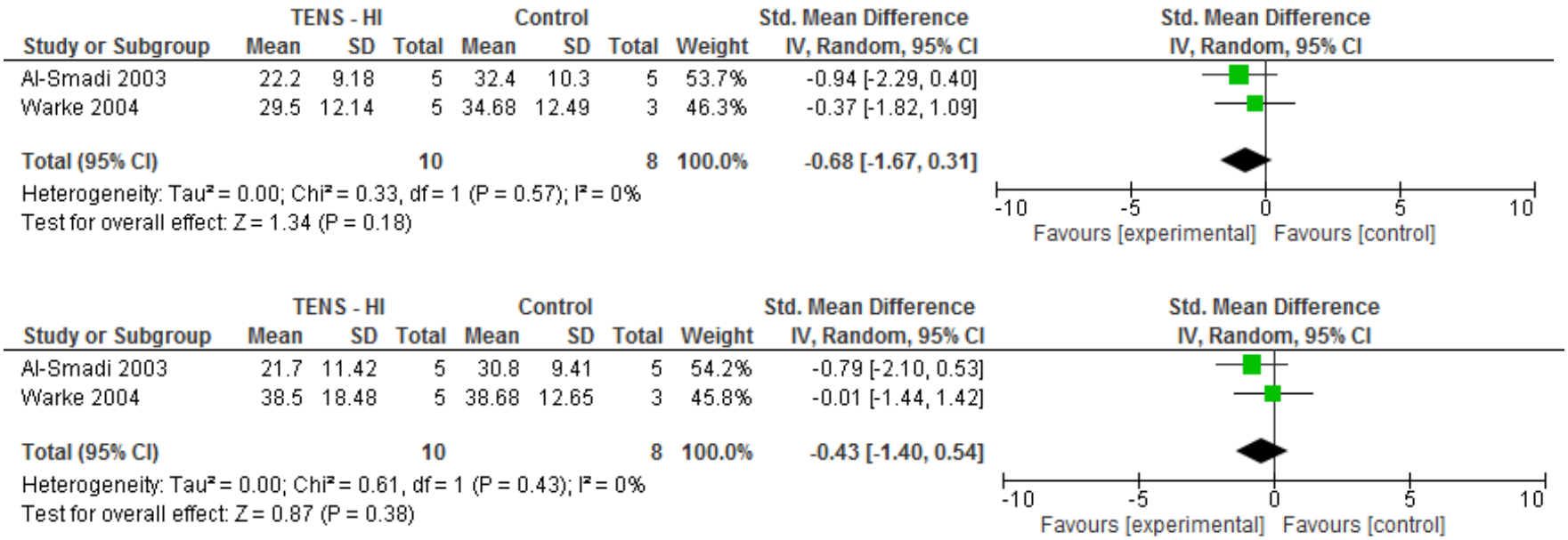

Figure 2.3a. Forest plots representing effects of TENS (high) on pain (McGill) at 6 and 10 weeks respectively.

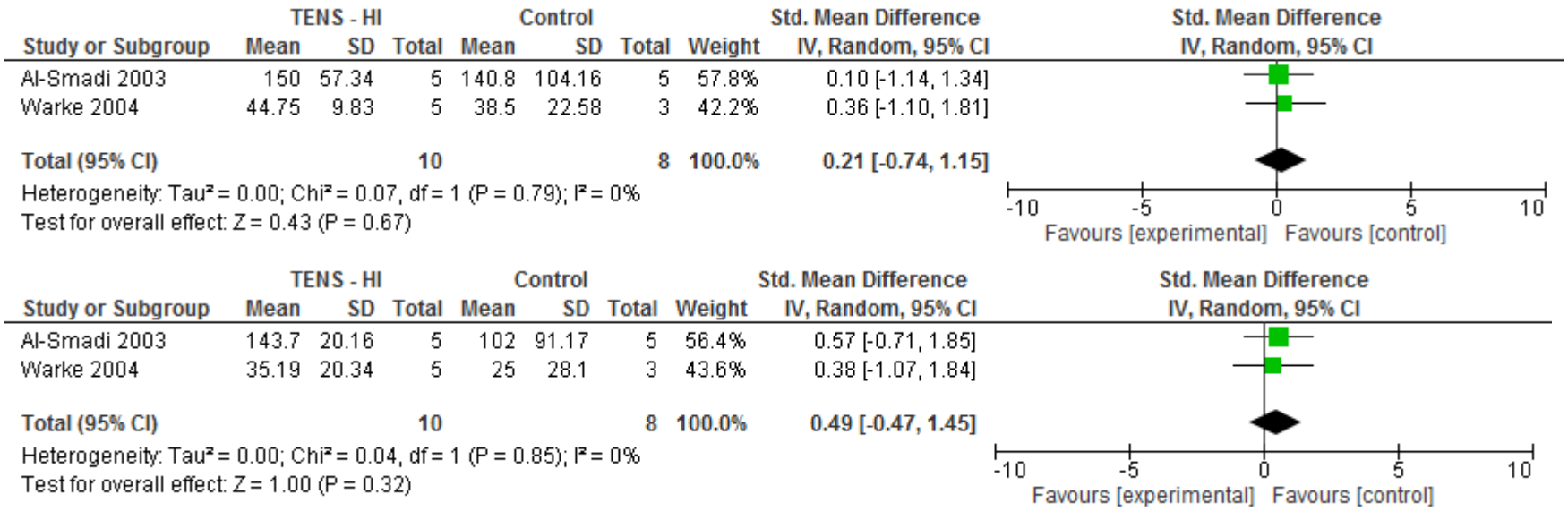

Figure 2.3b. Forest plots representing effects of TENS (high) on physical health (SF36) at 6 and 10 weeks respectively.

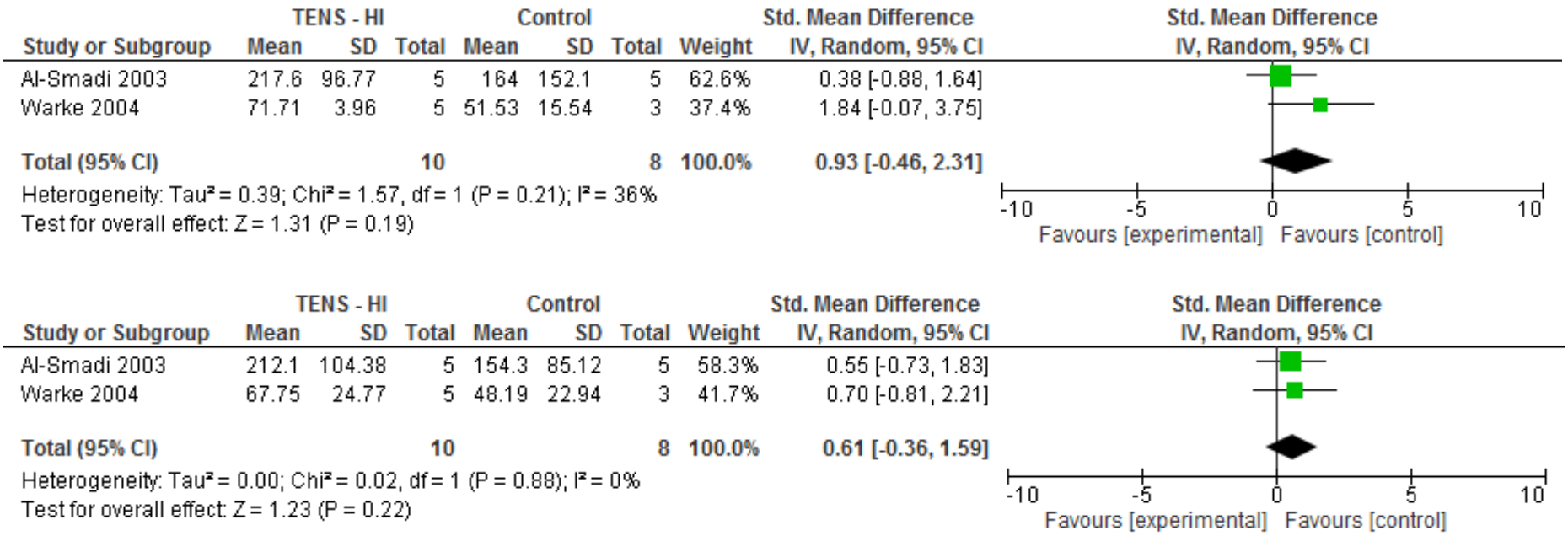

Figure 2.3c. Forest plots representing effects of TENS (high) on mental health (SF36) at 6 and 10 weeks respectively.

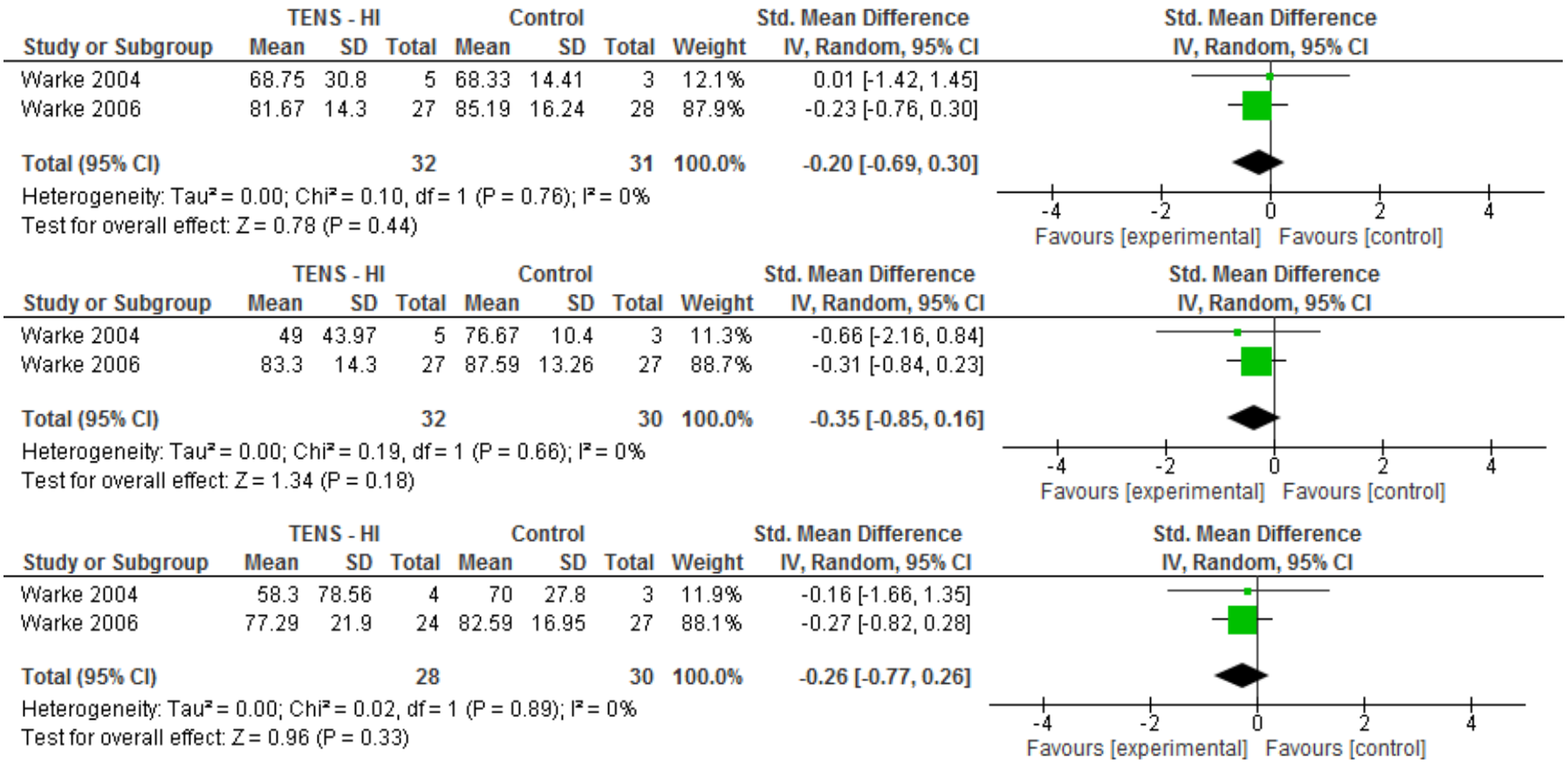

Figure 2.4a. *Forest plots representing effects of TENS (high) on activities of daily living (BI) at 6, 10 and 32 weeks respectively.*

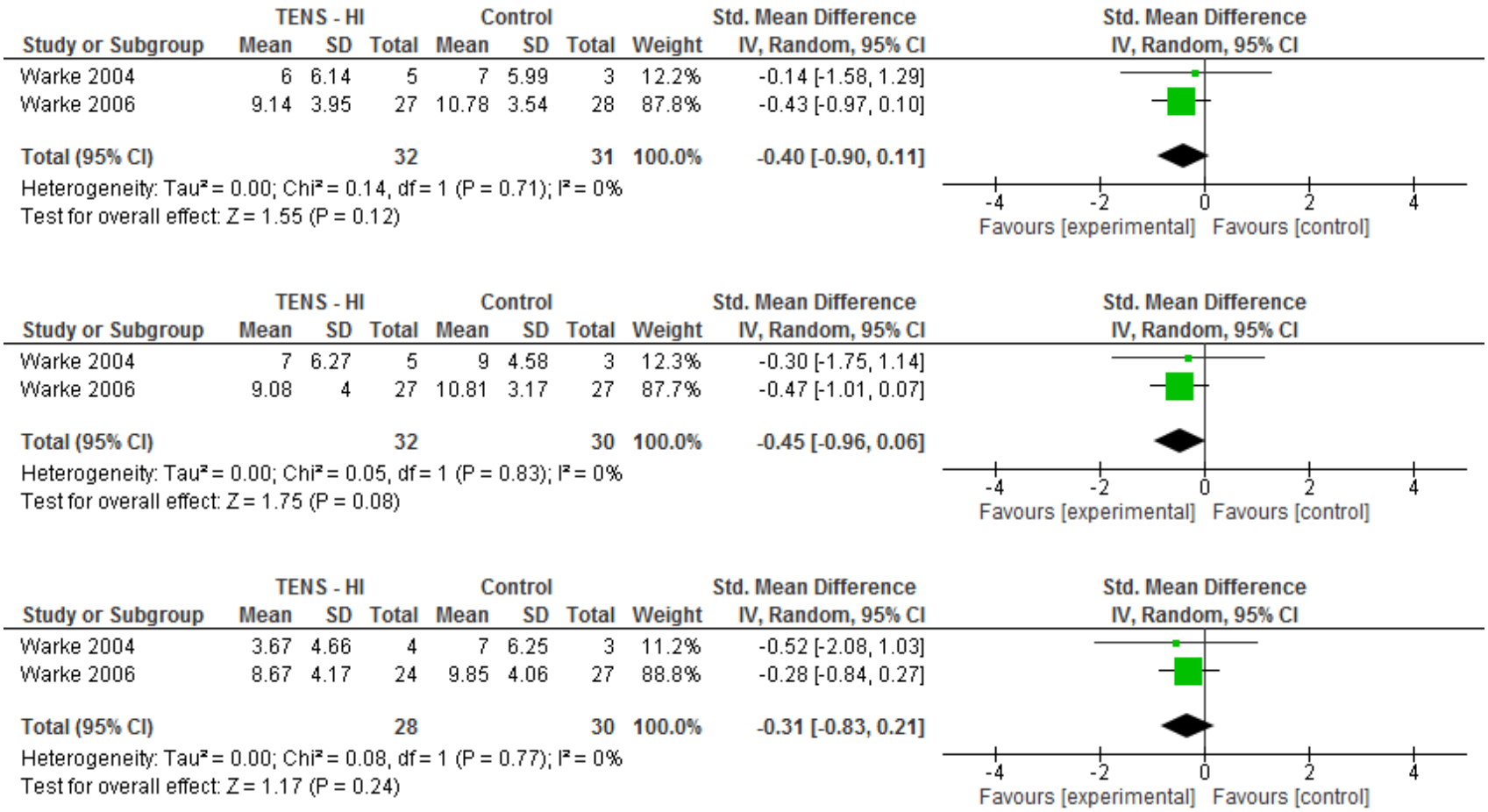

Figure 2.4b. Forest plots representing effects of TENS (high) on functional mobility (RMI) at 6, 10 and 32 weeks respectively.

Discussion

To our knowledge, this is the first systematic review to be conducted evaluating the physical and psychological impact of a range of AT devices among people living with MS. There is a growing trend towards the use of AT and therefore a clear understanding as to the effects of their use on physical and psychological outcomes was needed. Although a review specifically of mobility-related device use has been conducted (Souza et al., 2010), there was little consideration of the psychological aspect of AT use. The current review considered both physical and psychological outcomes amongst studies considering both aspects given their known interrelatedness. This review addresses the use and impact of catheters, cognitive aids, cooling garments, and mobility devices (including wheelchairs, FES, TENS, orthoses). Evidence of benefits to AT use varied by device and by outcome assessment (measures used and timing of assessments).

In terms of non-mobility AT, there was mixed evidence as to whether catheter use increased QoL but notably their use was more prominent among those with severe MS, which may have affected the potential benefits attainable (Castel-Lacanal et al., 2013; James et al., 2014; McClurg & Hagen, 2009). Only one Personal Digital Assistant (e.g. provides calendar and alarm functions as compensatory memory aids) study was identified in this review, with significantly improved cognition reported (Gentry, 2008). Kirsch et al. (2004) report other benefits amongst people with moderate-severe traumatic brain injuries where PDA reminders were effective in curbing verbosity (excessive talking). Both of these studies show promising results for integrating cognitive aids into daily lives effectively. The continuing growth in electronic device capability and use in rehabilitation programmes (i.e. computers, PDAs, smartphone/apps; as reported in Scherer, Hart, Kirsch & Schultesis, 2005)

may, in the future, increase the social acceptability of such devices and thus eliminate the stigma and embarrassment previously reported.

Whilst evidence of improvements in the physical and psychological domains of QoL were found, results varied according to device type. Use of hip-flexion orthoses benefitted strength and pain (Sutliff et al., 2008) with this substantiated in qualitative findings of increased balance, confidence, and social participation (Bulley et al., 2014). The most 'successful' mobility device appeared to be FES (i.e. a device providing electrical stimulation to nerves and weakened muscles for gait and walking) with five studies reporting a significant increase in walking ability (distance or speed) (Downing et al., 2014; Mayer et al., 2014; Ratchford et al., 2010; Taylor et al., 2014; van der Linden et al., 2014) and significant improvements in physical **and** psychological QoL in follow-up studies ranging from 2 weeks and 6 months (Barrett & Taylor, 2010; Downing et al., 2014; Mayer et al., 2014; Ratchford et al., 2010; Taylor et al., 2014). Yet the largest sample of these studies only consisted of 25 participants.

Other benefits of TENS included improved fatigue and self-esteem (Barrett & Taylor, 2010; Bulley et al., 2014; Chang et al., 2011). Across the three TENS controlled trials comparing low and high intensity TENS with placebo, no significant benefits of TENS were found for physical function or QoL (Al-Smadi et al., 2003; Warke et al., 2004; 2006).

The impact of using mobility devices extended beyond physical and psychological effects with environmental and financial consequences also reported. For example, wheelchairs can destroy home furniture and AT can be considered expensive to purchase privately (Boss & Finlayson, 2006; Dewey et al., 2004). Qualitative data also identified both

positive and negative impacts of wheelchair use (Boss & Finlayson, 2006; Dewey et al., 2004).

Greater understanding is still needed as to the variability in response to AT (e.g. perceived and received stigma, improved or reduced QoL) and how these are influenced by patient and illness characteristics. Positive patient experience is highly associated with adherence, health-promoting behaviours and better health outcomes (Doyle, Lennox & Bell, 2013), therefore it is vital that we understand how this translates to the use and impact of AT.

Limitations of Studies and Review

When reviewing the current literature on the impact of AT device use among PwMS it has become clear that the choice of outcome measurement is important. For example, Miller et al. (2006) identified a significant decrease in spasticity on only two of the three spasticity measures used in their study. Similarly, Mayer et al., (2014) only identified a significant improvement in walking ability in two of their four walking measures used. Also, there were reported differences between perceived and objective outcome measures with patients reporting better outcomes than that were measured (Barrett & Taylor, 2010). There has even been recent efforts to identify a robust measure of MS-specific physical and psychological QoL, for example the MSIS-29 (Jones et al., 2013), which is claimed to be more reliable and valid than the HADS and SF36 for people living with MS, yet the measures used within the reviewed studies varied. Only two utilised the MSIS-29. While there are pros and cons to both the use of disease-specific measures and of generic measures, greater consistency would benefit data synthesis and enable understanding in this field to move forward. There is also a great need for robust and consistent measurement of MS-specific

symptoms (e.g. fatigue, pain) as generic measures often miss these important issues, and changes therein, that are specific to neurodegenerative conditions (Page et al., 2017).

The timing and frequency of outcome assessment is also important because, as this review has shown, some devices may have longer term benefits e.g. powered wheelchairs whereas others operate more in the short term e.g. TENS perhaps as a means of responsive symptom management. Devices have different intended functions and different trajectories of potential benefits and therefore research/assessment timings need to be appropriate.

A challenge to synthesising available data in this review arises from the different device types available to PwMS. For example, there were six different FES devices provided across the studies and two studies (Bulley et al., 2014; Chang et al., 2011) that did not specify which FES devices had been used. Similarly, TENS devices across the studies were utilised at different frequencies (e.g. 4, 100, 110 and 200 Hz) making comparison difficult and disputing the clinical definition of 'high' frequency. Different instructions on how and how often to use devices was also apparent. For example, the recommended use of cooling garments varied across the different studies from '30 to 45 minutes use' to 'as much as they felt'. This meant the review was largely descriptive, and although a basic meta-analysis was conducted, the authors acknowledge that a synthesis of three studies is limited and therefore draw caution to interpretation. Additional research in the area of AT and greater homogeneity in AT use and instruction would make data synthesis and review less challenging, *however* the authors suggest that this may neither be feasible, nor in fact clinically desirable i.e. AT devices are provided or obtained to suit individuals' specific, often complex, and changing needs i.e. treatments/devices are tailored, and thus homogeneity is unlikely.

One suggestion to strengthen the evidence base however would be to include control groups so that the evidence of device effectiveness can be more robustly assessed against other forms of treatment or intervention. Most of the reviewed studies had no comparison group. However, there is a question around what comparison group is suitable when studying the physical and psychological outcomes of using AT - one study (Fay, 2003) included a control group of healthy individuals which brings questionable added value. Control group implementation can be complex and bring ethical questions (i.e. withholding a treatment in order to compare with a group receiving it) however for this condition, we would recommend comparison groups of PwMS without AT that would be offered devices on an 'intention-to-treat' basis subsequent to trial completion if the device(s) were found to be effective. More robust designs, potentially incorporating mixed-methods studies (similar to Flensner & Lindencrona, 1999; 2001) should go some way towards furthering understanding the variability found in AT use and impact (i.e. the goals of the studies reported in this thesis). Also currently the generalisability of findings with regards to the use and impact of some devices is limited, for example, we identified only one study assessing cognitive aids and three examining catheter use.

Implications

Despite the limited number of studies identified, the findings are encouraging with regards to benefits of AT for PwMS, although many devices remain under researched in terms of their psychosocial impact as opposed to functional impact. Given the unpredictable nature of MS, there are many symptoms for which AT is available, for example, to assist with attention and memory, posture/support, toileting, visual and sexual function aids, but their use and varied potential impact on multiple domains remain untested. Self-regulatory

feedback from the success (or failure) of using AT devices is crucial in developing and maintaining effective self-management for PwMS.

Similar to illness process models, future research should consider a biopsychosocial approach by studying the personal, device and contextual influences on AT use and outcome. For example, powered and manual wheelchairs serve the same physical function (i.e. increase mobility) yet disparities in QoL impact exist due to the factors alluded to in this review. These differences may arise from personal (e.g. acceptance, pain), contextual (e.g. perceived stigma/lay perceptions of wheelchair users) or device (e.g. design, ease of use) factors (Squires et al., 2013; Squires, Williams & Morrison, 2016). It would be worth considering whether device factors are also associated with the *impact* of using mobility devices. For example, TENS devices have previously been considered as less intrusive than other mobility devices which may be associated with greater willingness to use them (Souza et al., 2010; Squires et al., 2016), and thus their positive impact. By understanding the complex interrelationships between person, device and the context of AT use, it is more likely that the full potential of using AT devices in alleviating symptoms and reducing the activity limitations and social restrictions that PwMS face will be attained.

Conclusions

Overall, the impact of using assistive technology was generally positive for both physical and psychological outcomes. Given the mixed evidence, the authors recommend further research on a wider range of AT than currently and the use of more robust research designs (e.g. longitudinal, controlled trials) and measures (e.g. validated, gold-standard, disease-specific). In that way, we can develop a better understanding of the factors associated with the use and wider impact of AT devices i.e. beyond the purely functional.

Chapter 3

Matching and accepting Assistive Technology in Multiple Sclerosis: A focus group study with people with MS, carers and occupational therapists

The material presented in this chapter has been published as:

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Abstract

To explore experiences and perceptions of assistive technology, 14 people with multiple sclerosis, 5 carers and 4 occupational therapists participated in focus groups. Transcripts were analysed thematically drawing from illness self-regulation theory. Identified themes are as follows: *critical multiple sclerosis events* (developing symptoms/disability, delayed diagnosis and coping, public reaction and multiple sclerosis progression to assistive technology), *matching assistive technology for continued use* (acceptance of multiple sclerosis and assistive technology, realistic expectations, occupational therapist responsiveness, timing is crucial and carers and others) and *impact of assistive technology* (promoting or losing independence, stigma and embarrassment and redefining the carer). Acceptance and communication among those involved ensures assistive technology matches needs and maximises health and psychosocial outcomes.

Introduction

Multiple Sclerosis (MS) is the most common neurological condition among young adults although it can develop at any age and currently affects 100,000 people in the United Kingdom. Symptoms include loss of balance and limb function, fatigue, cognitive dysfunction, emotional changes, incontinence, pain, sexual dysfunction, and visual problems (Goodkin, 1992). These impairments, along with the limitations and restrictions in activity and social participation, determine the level of disability people with MS (PwMS) may experience (World Health Organisation, 2001). The challenges of living with MS (i.e. gaining a clinical diagnosis, accessing appropriate care and support, and processing the impact thereafter; Edmonds et al., 2007; MS Society UK, 2015; Solari, 2014) can also have a significant emotional impact for example high rates of anxiety and depression or low quality of life (Jones et al., 2012; Mikula et al., 2016). Positive outcomes of living with MS have also been identified such as personal growth and increased life appreciation, particularly following acceptance of MS (Pakenham & Fleming, 2011). 71% of PwMS receive informal care from friends and family (MS Society, 2013), of which care can vary from completing personal, domestic or financial tasks for their loved one to specialised care such as transferring or changing dressings. A 'carer' completes such tasks, unpaid, for a friend or family member who has physical, psychological, or developmental needs (Revenson et al., 2016). Although providing care for PwMS can negatively affect carer wellbeing (Corry & While, 2009) this is not inevitable and is dependent on personal outlook, expectations and coping responses (Pakenham, 2005).

According to Leventhal et al.'s (1980; 1992; 2003) Illness Self-Regulation model, when faced with a condition such as MS, one's perceptions of that condition influences

one's coping behaviours. The success, or failure, of these coping behaviours is then evaluated (self-regulated) to shape future responses. In this way one's cognitions, emotions and coping responses combine with the use of available resources to contribute to illness management. Such factors may help determine 'successful' adjustment to MS (Moss-Morris, 2013) i.e. critical illness events create less distress and impact on life than before. However, given the unpredictable progressive and relapsing nature of MS, adjustment is also considered when one accommodates change (i.e. acceptance; Stuifbergen, 2008). Despite empirical support for these theories in explaining health-related outcomes including illness self-management, little is known as to how individual perceptions relate to the use of assistive technology - devices designed to improve self-management.

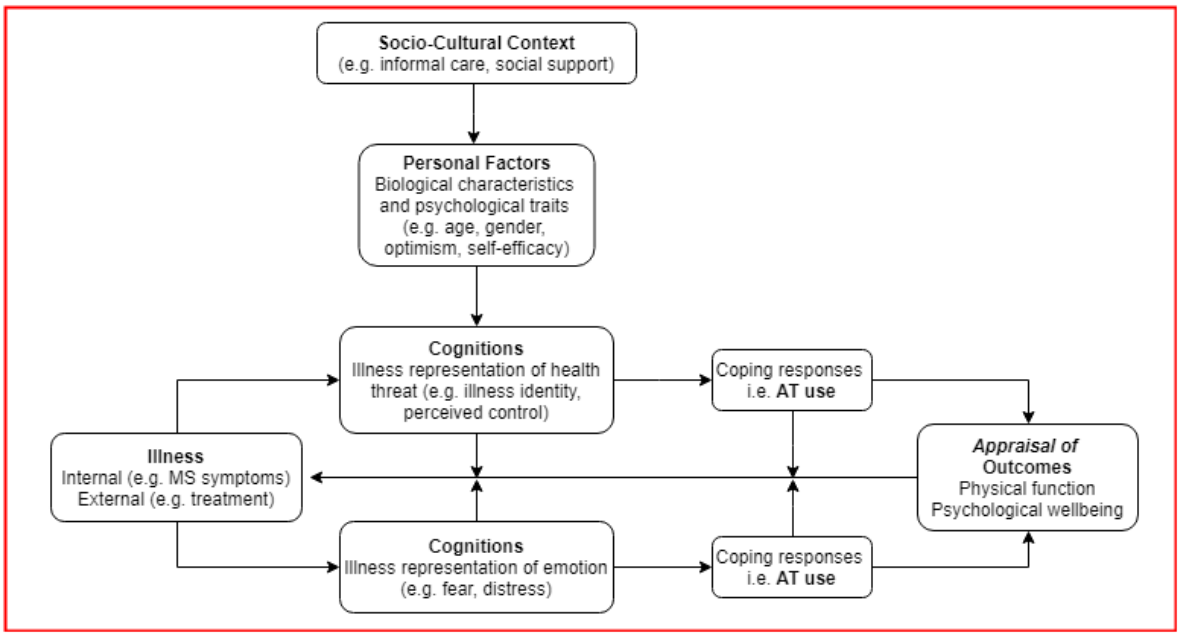

Figure 3.1: Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness. Chapter 3 to focus on influences and outcomes of AT use.

Assistive technology (AT) can potentially reduce the negative impact of MS however many devices are abandoned or misused within the first year of acquisition (Phillips & Zhao,

1993; Verza et al., 2006; Wessels et al., 2003). This suggests that available equipment is neither meeting user needs (Gottberg et al., 2008) nor assisting illness self-regulation. While there is no official health and social care register of MS-AT provision or usage, Souza et al. (2010) reviewed the impact of mobility devices specifically and concluded that independence was the main benefit of such devices although acknowledging that they were also perceived as a symbol of disability, which was detrimental. They recognised the importance of identifying the influencing factors of AT use in order to improve patient quality of life. However this review was somewhat convoluted by including studies that sampled other neurological conditions besides MS. Another American study reported that home modifications and memory aids were also common among PwMS (Johnson et al., 2009) highlighting the need to evaluate all device types – not just those that aid mobility.

General disability research suggests that successful AT use may be dependent on personal characteristics, for example, a person high in optimism may be more likely to capitalise on AT features, than a person with low optimism (Scherer et al., 2007). Similarly, AT perceptions and expectations can influence whether devices are integrated into daily life (Squires et al., 2013). In addition, and consistent with illness process models, external resource influences exist including family involvement, financial wellbeing, healthcare service, and social support (Johnston et al. 2014; MS Society, 2013; Scherer et al., 2007; Verza et al., 2006; Wessels et al., 2003). For example, matching devices to patients can be a difficult process with a long wait between needs assessment and equipment provision, and a lack of information as to which devices are most beneficial (MS Society, 2013). Practitioners (i.e. mainly occupational therapists) assess for and provide AT devices often working to the Human Activity Assistive Technology (HAAT) model (Cook & Hussey, 1995).

This model, similar to illness process models (e.g. Leventhal et al., 1980), suggests that in order for AT to help people with disabilities to achieve a task OTs must consider personal (e.g. characteristics, symptoms) and contextual (e.g. social support, finances) factors when assessing and providing AT. They also identified the different device factors that enable patients to complete activities such as the design, interface and the patient interaction with the device features. However it does not consider the emotional outcomes of using such devices and nor does it extend onto continued use of such devices, which is particularly important in MS - a relapsing and progressive condition.

When acquired **and** utilised, there is evidence of physical, psychological and economic benefits of AT, including enhanced independence, quality of life, social inclusion and reduced costs of care (e.g. Hoenig et al., 2004; Squires et al., 2013). However, the use and impact of AT varies within and between individuals, and across time (Squires et al., 2013) with reports of depression in AT users (Johnson et al., 2009; Okoro et al., 2010) and frustration and worry among carers following AT provision (Mortenson et al., 2012).

Given that few studies address AT in MS populations from a psychological perspective, an inductive qualitative approach sought to explore the experiences and perceptions of AT use in the self-management of MS symptoms held by those involved in the AT process (see Figure 3.1), from needs assessment and AT provision, through to use and support of use: PwMS, carers and occupational therapists (OTs).

Methods

Participants

Four focus group meetings were held: two with adults with MS, one with non-related

carers and one with OTs. PwMS were included if they were aged 18+ with MS and if they had previous experience of AT device use. Individuals with self-identified severe communication difficulties were excluded due to the nature of the study. Carers were defined as any person who provided support for a friend or family member living with MS who currently used AT, and OTs were eligible if they were currently working in health and social care services with PwMS.

Procedure

Ethical approval was granted from the Bangor University Research Ethics and Governance Committee (Ref: 2013-7962) before participants were recruited via existing support groups for PwMS and carers. Six local MS Society UK branch managers (North Wales and England; both rural and urban areas) were contacted and informed of the study. Three of which were willing to support the study and invited their members to take part in a focus group to discuss AT experiences at one of the regular branch meetings. This provided a familiar, open and supportive environment. One PwMS group allowed one non-participating carer to sit in on the meeting with their care-recipient. OTs were recruited through word of mouth after initially contacting the local MS Specialist OT. Prior to the meeting, participants were fully informed of the research study (see study documents: Appendix B[1]), consented to being audio-recorded and completed a short demographic questionnaire addressing their AT use. Semi-structured focus groups were used to establish and explore themes around the use of AT. A topic guide (see Appendix B[2]) was devised to help gather new knowledge about AT issues that little is known about while offering flexibility in exploring unanticipated issues. The lead researcher (LS) led all sessions with a co-facilitator (EM) acting as observer and note-taker. The lead researcher and co-facilitator were also to ensure that the focus

groups remained on topic and that all participants had the opportunity to contribute to the topics discussed. Focus groups lasted between 45-62 minutes. Participants were debriefed and offered reimbursement for participation and travel costs; £80 from participant payments was donated to the MS Society UK at their request.

Analysis

The lead author transcribed all sessions verbatim, anonymised accordingly and analysed data via experiential thematic analysis (Braun & Clarke, 2006). This allowed exploration of the experiences *and* perceptions of MS and AT use, and any influences thereon. Themes and patterns of meaning were identified across groups while focusing on individual participants' viewpoint. Following transcription and familiarization, the lead author coded the entire dataset while actively searching for themes until data saturation, which were then reviewed manually via Microsoft Word before a thematic map was developed highlighting provisional themes and the relationships between them. All authors drew on their previous qualitative research experience to then discuss, define, name and finalize themes before analytic assurance was completed. Inter-coder agreement was completed with the focus group co-facilitator due to their familiarity with the data and also their own previous qualitative research experience. Agreement was good (73%) and increased (to 93%) following further discussion.

Results

Twenty-three participants consented prior to the focus groups, however four withdrew due to illness. Fourteen PwMS (10 female, 4 male) and five non-related carers (3 female, 2 male) participated in the current study. PwMS were aged 43-74 years old

(mean=58yrs) and carers aged 66-69 years (mean=68yrs). MS was mostly progressive among participants (6 secondary progressive, 3 primary, 2 relapse-remitting, 3 unknown at time of group). In addition, four female OTs, aged 49-57 years (mean=52yrs), shared their experiences of working with PwMS, with 13-28 years of experience (mean=23yrs) which was similar to the length of time that they reported working with AT (8-27yrs; mean=19).

The most common devices used by PwMS were for mobility and the home environment: manual wheelchairs (*n*=12), grab bars and shower seats (*n*=11). Other common devices included continence aids, personal alarms (*n*=7); adapted toilets, specialised cooking equipment and walkers (*n*=6). Other mobility devices (e.g. walking sticks, scooters), computer access aids, vehicle adaptations, transfer and memory aids were also reported. The participants' demographic information are presented in Tables 3.1-3.3.

Table 3.1. *Demographic information of PwMS*

Participant (Age)	Type of MS (Yrs since diagnosis)	Perceived MS severity	Mobility device experience	Other device experience
Andrew (59)	PPMS (23)	Quite	Manual and motorised wheelchairs, crutches	Bathing, computer access, kitchen (cooking/eating), toileting aids; Environmental control system; Home adaptations
Bill (65)	SPMS (30)	Average	Manual wheelchair, crutches, orthoses	Bathing, kitchen aids; Home and vehicle adaptations
Lily (65)	RRMS (n.g.)	Average	Manual and motorized wheelchairs	Bathing, computer access, memory, toileting aids; Home adaptations
Angela (74)	SPMS (17)	Quite	Manual and motorized wheelchairs, crutches	Bathing, toileting aids; Home and vehicle adaptations
Alyssa (48)	SPMS (17)	Quite	Manual wheelchair, scooter, walker	Bathing, computer access, kitchen, memory, toileting aids; Falls detector; Home and vehicle adaptations
Grace (n.g.)	PPMS (7)	Quite	Manual wheelchair, cane, orthoses, walker	Bathing, kitchen, toileting aids; Vehicle adaptations
Hayley (45)	SPMS (12)	Average	Manual and motorized wheelchairs, cane, orthoses, scooter, walker	Bathing, memory, toileting aids; Home and vehicle adaptations
Anne (58)	RRMS (22)	Not very	Manual wheelchair, cane, orthoses, walker	Bathing, toileting aids; Home and vehicle adaptations

Participant (Age)	Type of MS (Yrs since diagnosis)	Perceived MS severity	Mobility device experience	Other device experience
Audrey (57)	PPMS (3)	Average	Manual wheelchair, cane, walker	Memory, toileting aids; Vehicle adaptations
Rose (61)	SPMS (30)	Quite	Manual wheelchair	Bathing, computer access, kitchen, medication, memory, toileting aids; Home and vehicle adaptations
Gabby (43)	SPMS (12)	Quite	Manual wheelchair, scooter	Bathing aids; Home modifications
Norah (n.g.)	Unknown (14)	Quite	Crutches, scooter	Home modifications
Eli (n.g.)	Unknown (6)	Not very	FES, walker	Communication, medication, memory, kitchen aids
Archie (63)	Unknown (26)	Quite	Motorised wheelchair	Kitchen, medication, toileting aids; Falls detector; Home and vehicle adaptations

Abbreviations: PPMS – Primary Progressive MS; SPMS – Secondary Progressive MS; RRMS – Relapse-Remitting MS; n.g. – Not given; FES – Functional electrical stimulation

Table 3.2. *Demographic information of non-related carers*

Participant (Age)	Relationship (Yrs of providing care)	Type of MS (Yrs since diagnosis)	Mobility device experience	Other device experience
Gail (69)	Spouse (11)	PPMS (11)	Manual wheelchair	Bathing, toileting aids; Home and vehicle adaptations
Dawn (66)	Spouse (10)	SPMS (18)	Manual and motorised wheelchairs, cane, orthoses, walker	Bathing, kitchen, toileting aids; Home and vehicle adaptations
Laura (n.g.)	Friend (4)	Unknown (30)	Manual and motorised wheelchairs	Bathing aids; Vehicle adaptations
Paul (69)	Spouse (20)	RRMS (20)	Manual wheelchair, crutches, scooter, walker	Bathing, computer access, kitchen, memory, toileting aids; Environmental control system; Home and vehicle adaptations
Malcolm (67)	Friend (11)	RRMS (15)	Manual and motorised wheelchairs, scooter, walker	Bathing aids; Home and vehicle adaptations

Table 3.3. *Experience and expertise of OT participants*

Participant (Age)	Years of relevant work experience	Mobility device experience	Other device experience
Lucy, MS Specialist OT (49)	AT = 27 MS = 27	Manual and motorised wheelchairs, canes, crutches, FES, scooters, walkers	Bathing, communication, computer access, kitchen, medication, memory, toileting aids; Environmental control system; Home and vehicle adaptations
Sarah, OT in AT (52)	AT = 23 MS = 13	Manual and motorised wheelchairs, orthoses	Bathing, communication, computer access, kitchen, memory, toileting aids; Environmental control system; Home and vehicle adaptations
Charlotte, Mobility and Posture Specialist OT (50)	AT = 8 MS = 28	Manual and motorised wheelchairs	Bathing, computer access, kitchen, toileting aids; Environmental control system; Home and vehicle adaptations
Cora, Social Services OT (57)	n.g.	Manual and motorised wheelchairs, scooters	Bathing, kitchen, toileting aids; Environmental control system; Home adaptations

Abbreviations: OT – Occupational therapist; FES – Functional electrical stimulation; n.g. – Not given;

Three themes were identified: Critical MS events, Matching Assistive Technology for continued use, and the Impact of AT. These present a chronological narrative from prior to, during and following use of AT.

Critical MS Events (PwMS/Carers only)

Many PwMS and carers reflected upon symptom experiences prior to receiving AT, and how they came to the position of needing such devices. This predominantly focused on developing disability, diagnosis and its implications i.e. how they saw themselves and were perceived by the general public.

Developing symptoms and disability Individual variation in MS symptoms and disability was highlighted in the different negative experiences reported.

One PwMS described his sudden symptom onset and the negative emotional consequences of this, while another described an emotional coping response to her physical limitations prior to the use of AT. Both participants showed the negative emotional response to changes in functionality and to perceptions of a) what was normal for men and b) what was normal for 'me'. It was following these responses that patients recognised a need for AT to aid their impairments.

Delayed diagnosis and coping Immediately following symptom onset, half of the PwMS sample recalled their struggle to understand what was happening and not receiving treatment or equipment to self-manage their condition. Misdiagnosis was common.

PwMS (n=5) agreed that health professional communication was crucial in helping them understand and adjust to their diagnosis. Despite a clear need for treatment and AT equipment, some PwMS felt that help was not possible until clinical diagnosis, with some

waiting between 2-14 years. One PwMS suggested that this was due to healthcare services waiting for a "*second episode*" of MS symptoms; leaving them in a state of uncertainty as to whether it would happen and if so, what form it would take. This uncertainty challenged individuals in regulating their MS as they were left wondering about their symptoms without any internal or external resources to help. Some PwMS and carers (n=7) demonstrated proactive coping (Aspinwall & Taylor, 1997; i.e. seeking MS and AT information, planning ahead to reduce negative impact) whilst others (n=4) reported emotive coping (i.e. anger, denial).

Establishing public reaction Public perceptions and reactions to PwMS were heavily discussed within groups with shared experiences of receiving *"funny looks*", feeling invisible to others and people assuming that "*they're drunk*" due to instability. Some PwMS suggested that other people might be fearful or reluctant to engage with individuals with disabilities, due to a lack of understanding, which in turn may be encouraged by the many 'invisible' symptoms of MS.

One participant highlighted how the appearance of AT helped identify disability and, when perceived in a positive manner, allowed people to develop an understanding of how technology helped people living with a disability, however this was not always the case (see Impact of AT: Stigma and Embarrassment).

MS progression to AT In sharing their expectations of illness progression, MS participants recognised a progression in AT needs, which they likened to a hierarchy, going from basic equipment to more advanced and complex electronic equipment.

Reflecting illness self-regulation, PwMS and their carers were seen to re-evaluate current symptoms and the benefits of current and available AT e.g. when walking sticks no longer supported mobility, they considered using a wheelchair. This progression then required OTs to match equipment to patients as their needs changed.

Matching Assistive Technology for continued use

By appropriately matching AT to PwMS and their needs, individuals seemed more likely to use the device. Participants identified the ideal personal, service and contextual conditions that influenced their AT acquisition and use.

Acceptance of MS and AT Accepting the need for AT was considered to be as important to the acquisition and use of AT as accepting the MS diagnosis. Participants hinted at active and passive approaches to acceptance (Stuifbergen et al., 2008), moving from initial denial to proactivity. The belief that one's MS (and need for AT) became integrated into daily life, rather than passively resigned to a hopeless situation.

All groups highlighted continued AT use as primarily determined by MS symptoms, with suggestions that fatigue, cognitive impairments, poor dexterity or vocal ability bring struggles in using AT. The progressive nature of MS left people vulnerable although symptom severity fluctuated daily. PwMS reported resisting the use of AT; resolving a conflict between accepting disability whilst maintaining independence was crucial to the continued use of AT equipment.

Table 3.4. *Illustrative quotes from PwMS, carers and occupational therapists.*

THEMES/*Subthemes*	**Quotes**
CRITICAL MS EVENTS	
Developing Symptoms and Disability	Suddenly. One day I was running, jogging like a normal guy would be and the next day I couldn't even get out of my bed…I get spasms in my legs and my back plays up…and that's more embarrassing to me because I have a bladder problem (Eli, Unknown MS)
	Then I realise I can't…I get frustrated with myself – not with anybody else – it's with myself because I think I should be able to (Grace, PPMS)
Delayed Diagnosis and Coping	"You've got a viral infection"…I saw another doctor this time…"I'm gonna send you for a brain scan"…I'm thinking, "What's going on?"…That's when they discovered I'd got MS…"What do you mean, MS?" and they tell me I've got these lesions on my brain…"Oh wow!" (Norah, Unknown MS)
	You're just left in limbo…It's not until they say, "Oh sorry Bill, you've got MS. There might be some help out there for you"…They're the bad years because you don't know what to do…Seven years before I had an actual diagnosis. I was running around, limping, had been paralysed, lost my voice, everything but no help was offered at all." (Bill, 65, SPMS)
Establishing Public Reaction	It's very difficult for them because they're fit and well and we look alright…With Rose and Archie at least you can see they're in a wheelchair but with me I'm just sitting here looking like there's nothing wrong with me so I think it's difficult then for my family to understand that there is summut wrong with me (Audrey, 57, PPMS)
MS Progression to AT	I started off one of my feet used to drag and then the other one but I ended up having a stick then two sticks and I have had crutches. I have got a wheelchair if I need to get any distance (Anne, 58, RRMS)

THEMES/*Subthemes*	Quotes
MS Progression to AT (cont.)	When I first started, she had a manual chair but then we used to transfer her on a Banana Board into the car and stuff. Obviously it's got worse so she has this electric [wheel]chair (Laura, friend of PwMS)
MATCHING ASSISTIVE TECHNOLOGY FOR CONTINUED USE	
Acceptance of MS and AT	I just thought that I can get by but you become a danger to people around you and you have to take charge but I think you can only do that when you accept that yeah, you've got MS and you've gotta deal with it properly (Alyssa, 48, SPMS) It's about acceptance - especially in MS. People tend to have this idea that if they're using equipment, they're giving in to a condition. I get that a lot. I saw a lady this morning and she said "I actually want a wheelchair because I actually know it's going to make my life better because I'm stuck in the house now" but she's come to that decision herself (Lucy, 49, MS Specialist OT) That's the trouble…we all feel too independent sometimes and don't want to be seen to be not be able to do it…and I think it depends on the character that you are that determines whether you will use this thing…It's just getting it right in your mind (Anne, 58, RRMS)
Realistic Expectations	It's trying to get them to understand their expectations [can] sometimes be quite high. It's about trying to get them to be realistic…they might have created something that's going to be like a nice pink rail to go in their pink bathroom or something. It's not going to be like that so it's about being upfront (Lucy, 49, MS Specialist OT)
OT Responsiveness	I got a trolley for my kitchen. When I first got it I thought, 'What do I need this for?' shoved it in the corner and now it's the most useful thing I've got (Grace, PPMS)

THEMES/*Subthemes*	Quotes
OT Responsiveness (cont.)	I've had very different experiences with OTs ((laughs)) Disastrous experiences. Totally unhelpful. Totally trying to force you to do something a certain way. Give up pieces of equipment you've got. Insisting that [PwMS] use the toilet and not the commode (Dawn, 66, Wife of person with PPMS)
Timing was Crucial	You refer somebody [at] that point of time for that problem but with MS being a progressive condition by the time it's assessed, the condition might have changed quite significant and actually the powered wheelchair may not be appropriate anymore (Lucy, 49, MS Specialist OT)
	OTs where we are isn't too bad if you can get them…it's difficult. Try and make an appointment, can take two or three months and by the time you get there you've really got too frustrated and bought something (Malcolm, 69, Husband of RRMS)
Carers and Others	They're not encouraging the person to become more independent…it's about their role – the carer's role that's been possibly jeopardised…I've seen that happen quite a lot (Charlotte, 50, Artificial Limb and Appliance Specialist OT)

THEMES/*Subthemes*	**Quotes**
THE IMPACT OF AT	
Promoting or Losing Independence	Ceiling track hoist means I can get to bed, I can get to toilet....Well I'd be lost without it (Archie, 63, Unknown MS)
	I use aids that make him feel not independent - like a hoist (Dawn, 66, Wife of PPMS)
Stigma and Embarrassment	I don't need those. I do. All the things [my OT] thought of, I now need (pause) it's embarrassing in a way but there we are (Archie, 63, Unknown MS)
	"She's probably brain-dead" or "She can't talk to us because she's in a wheelchair"…and they used to give the funny looks and all that and I'm thinking, "What are you looking at?" (Gabby, 43, SPMS)
Redefining The Carer	[AT] is multi-purpose. We've taken it on to help me as much as him…It's psychological…I feel more me 'cause I'm walking me…When you've been pushing a manual wheelchair for five years, just actually being able to walk straight makes you feel so much better (Dawn, 66, Wife of PPMS)

It was also suggested that personality traits linked to acceptance (e.g. openness, optimism) may influence AT use and willingness to try new equipment. Such positive attitudes may relate to an observation made by OTs that some individuals were 'natural' users of AT and 'took to it well' while others struggled to use the equipment.

Realistic expectations One obstacle that OTs faced when providing AT were the expectations of the device held by PwMS and their carers. OTs explained that they focused on the functional needs of PwMS: ultimately patient function was the goal of healthcare providers and systems, however therapists did try to tailor to PwMS and carer preferences. Therapist goals may not map directly onto their patient goals e.g. patients may be more concerned about social participation whereas therapists focus on motor function. Establishing the balance between patient-centred and professional-centred care appeared to be crucial in the patient-carer-therapist relationship.

OT responsiveness Most PwMS and carers described a positive relationship with their OTs, as they were easy to access, provided a fast service and often anticipated their future needs.

One carer however described her OTs as "*unhelpful*", which elicited agreement from another carer and both individuals expressed dissatisfaction at being sent unwanted equipment, rather than their preferred equipment.

Similarly, other carers described feeling forced to accept new devices by OTs, highlighting a difference between passive acceptance and active. This suggested that patient-carer-therapist communication regarding rehabilitation goals was vital to determine the best approach for continued AT use.

Timing was crucial In addition to waiting for a clinical diagnosis, PwMS and carers faced further delay in gaining access to AT from two months to a "*few years*", which then delayed the receipt of any functional benefits that AT could bring. Given such delays and the changing nature of MS, OTs acknowledged that AT often failed to meet patient requirements and thus went unused.

OTs acknowledged a "*trial and error*" approach when matching AT to individuals, which further highlighted the importance of timing when meeting AT needs. Like PwMS and carers, OTs also needed to continually reappraise the condition and its associated symptoms with similar reappraisals being made regarding AT. However OTs were not necessarily available or seen regularly enough to be optimally responsive.

Carers and others All groups recognised the crucial role carers play in AT uptake and use, with carer assistance essential when using some devices (e.g. hoists) however different aspects of carer involvement in AT decision-making emerged. For PwMS, a positive perception of being cared for and encouragement from loved ones influenced their decisions to access and continue using AT. Carers and OTs identified that empathy and persuasion could help in this motivational process.

Low carer acceptance of AT could influence its use by PwMS. OTs recognised that some carers were not willing to integrate AT into their homes and discouraged its use.

An OT suggested that carers feared being displaced, explaining that because the caregiving role now contributed to the carer's personal identity, that they anticipated being removed or displaced by AT. Overall it was evident that supportive social networks encouraged access to, and use of, AT.

The Impact of AT

Participants explored the different physical, social and emotional impact of devices on their day-to-day life, and therapists reflected on their perception of AT impact on their clients. Perceptions were generally shared across the following subthemes.

Promoting or Losing Independence All groups recognised increased independence was the most common benefit of AT specifically in overcoming restrictions for mobility, daily living, and continued employment.

Some considered that AT had given PwMS a "*further lease of life*" by opening up opportunities to restore 'normality' and enabling access to travel and social participation. In contrast, one carer suggested that by depending on AT devices, individuals were simply transferring their dependence from the carer to a device and losing their independence regardless.

Consistent with the WHO ICF model of disability, AT (as an external factor) is seen to moderate activity and participation by both alleviating and reinforcing disability. Following AT use, PwMS were able to appraise the outcomes of its use, which were likely to influence their decisions around AT use continuation or abandonment.

Stigma and embarrassment Two PwMS expressed embarrassment in relation to their need for AT and having to admit that they needed help. Such negative emotions seemed to arise from negative coping responses such as denial or passive acceptance, and fed into their internalised stigma (Chaudoir, Earnshaw & Andel. 2013). Other PwMS and carers discussed how AT could cause embarrassment through people looking, and thinking that they were different (i.e. anticipated stigma; Chaudoir et al. 2013).

Not everyone shared these negative experiences however two carers felt there was less stigma attached to disability following the Paralympics 2012 and members of the Armed Forces "*coming back with limbs missing*". Overall, however there was a feeling that AT could reinforce a disability by increasing visibility and that this brought negative connotations with it.

Redefining the carer (Carer/OTs Only) Some carers derived benefit from AT use by indirectly restoring their own dignity, health and wellbeing by reducing their care load. This encouraged one carer to discuss her identity as 'herself' versus the 'pusher' of a wheelchair.

In contrast, as described earlier, AT provision could be considered a negative experience if carers felt that they were being displaced (see *Matching Assistive Technology: Carers and Others*). One OT expressed concern that perceived displacement could decrease social interaction and result in social isolation, which are important illness self-regulation factors (Leventhal et al., 1980; 1992; 2003).

Discussion

Interpretation of Findings

Common themes emerged in exploring the individual experiences of those affected by and working with MS. Several critical MS events were found to precede the identification of a need for AT including disability progression and delayed clinical diagnoses. Once the need for AT emerged several personal, service, device and external influences were considered key in determining continued use of AT, which resulted in both perceived positive and negative outcomes for PwMS and carers.

Diagnosis uncertainty An MS diagnosis is a major milestone for PwMS and carers and our findings support the literature that uncertainty surrounding the process can be stressful with negative experiences such as long waiting times, feelings of frustration, and concern for the future (Edmonds et al., 2007; MS Society UK, 2015). While service developments are being made to improve this as discussed (see also Solari, 2014) there is still work to be done in order to reduce this stressful period. PwMS and carers in this study expressed a need for clear communication and information from healthcare professionals to help alleviate their distress. For participants, problem-focused coping (i.e. seeking further advice) appeared to help process the MS diagnosis, as reported previously (Dennison et al., 2010a). Following diagnosis, PwMS and carers begin to gain a better understanding of the condition, which according to self-regulation theory will also enable positive adjustment (e.g. greater acceptance) and coping responses (e.g. seeking AT to reduce impact of symptoms).

Acceptance of MS, and then AT Acceptance was a key subtheme found to influence the acquisition *and* use of AT; it also came in two parts: acceptance of MS *and* acceptance of AT. Such acceptance helps adjustment but also self-management via AT use.

Surprisingly, there has been limited research examining the psychological processes of AT acceptance, although we know from MS studies that poorer acceptance and adjustment is associated with higher perceived stress, uncertainty, more symptoms, a lack of personal control and perceived severe consequences (Dennison et al., 2009). Our findings hinted at key aspects of acceptance (e.g. high/low levels; active/passive acceptance) that relate to AT use and to PwMS and carer adjustment. Dennison found that the type of coping

strategies employed and social support received were linked to acceptance, as did the current data.

Our findings highlight the importance of considering PwMS and carer levels of acceptance. Only by establishing a patient relationship can OTs match AT appropriately to needs and identifying symptoms. It has however been suggested that acceptance 'labels' can be detrimental to a person's illness experience and may prevent healthcare members from listening to individual experiences (Telford, Kralik & Koch, 2006). For example, those labelled as non-accepting may be seen as difficult and problematic rather than asserting self-independence through their own goals. This may explain some PwMS' reported reluctance to use AT as they wish to lead a 'normal' life and remain independent without the use of such often visible devices. The visibility of these devices can make it difficult to conceal and brings along perceived stigma (e.g. anticipated or internalised; Chaudoir et al, 2013). Healthcare professionals could perhaps encourage emotional acceptance by helping recognise changes in functional limitations, and adapt behaviour for activity and social reintegration – through use of AT.

In addition to PwMS, acceptance appeared to be crucial from carers also. OTs particularly identified that carers at times can be resistant to the idea of AT due to the potential of reducing their care load, and thus their carer identity. This has important implications for clinicians to also consider the loved ones/carers when they enter into discussions of AT with those living with MS.

AT use and impact Mobility aids were the most common devices used in this UK study sample. AT acquisition was influenced by individual perceptions and coping responses, for example those avoiding acknowledgement of their MS and the limitations it brings, did

not seek or use AT devices. However those demonstrating active acceptance-coping behaviours tended to use AT equipment. For many this transition took place as their condition progressed.

Our MS-specific samples described personal, service and environmental influences on non-use of equipment, which is in line with studies of AT use among the elderly and disabled (Scherer et al., 2007; Squires, et al., 2013; Wessels et al., 2003). For PwMS and carers, it appears that acceptance, expectations, AT service, and social support (from family carers and OTs) were all important influences on AT acquisition and continued use. Our data support findings that PwMS want more choice and involvement with OT services (Preston et al. 2012) and shared decision-making is likely to lead to the 'right' device (Johnston et al., 2014) and thus the likelihood of continued AT use. These factors warrant consideration when OTs match PwMS to technology devices.

The self-regulatory reappraisal process following the use of AT may help explain the long-term use of devices i.e. if positive outcomes are reached and AT meets expectations of physical and psychological needs then PwMS are more likely to continue using them. At this point, social services and wheelchair OT services would typically close the case. However if PwMS feel that their device no longer provides benefit to them in supporting their needs, or their perceptions of that device have changed, they may discontinue use. Given the closed case, there would be no review from healthcare services which could potentially leave PwMS limited and restricted through no AT unless they self-refer. Some participants referred to "*trial and error*" implying also a more cyclical process. Perseverance in seeking a device to meet their needs is likely to be displayed by those with strong internal (optimism) or external (social support) resources. Therefore it is crucial that physical and psychological

responses to/outcomes of AT use are monitored consistently following acquisition. The current NICE guidelines (Maw, 2013) suggest an annual review with a professional who can discuss AT issues however given the rapid and unpredictable nature of MS, this may be considered too infrequent especially for those who do not self-refer due to lack of information or social support. Clinicians ideally should be required to implement longer-term follow-up of PwMS and their carers following AT provision in order to ensure that their needs continue to be met by the provided AT.

The importance of continued AT use is seen in our findings of increased independence and reports of gaining a new lease of life - for PwMS and carers too. There were suggestions that AT can validate a person's condition both positively and negatively, and some concerns that it may decrease independence by enhancing reliance on devices that limit the sense of achievement gained through completing tasks and activities independently. Carers were more open to discussing the negative impact of AT (e.g. barriers to use, embarrassment) than PwMS, with OTs further suggesting that some carers may feel that their role is displaced by devices. Further involvement with carers may help alleviate their concerns when matching devices to PwMS needs. Monitoring the use of AT in the longer-term, than current practice, would allow feedback from PwMS and their carers as to whether the devices still meet needs, and what impact it has had on their quality of life.

Strengths and Limitations

Overall the findings demonstrate good credibility, transferability (Schou et al., 2012) and rigour (Meyrick 2006). By acknowledging the authors' theoretical background, we consider the study confirmability and dependability to be trusted (Schou, Høstrup, Lyngsø, Larsen & Poulsen, 2012). However several limitations need acknowledged.

The varied length of time since diagnosis and AT provision was a likely influence on participant accounts, as is all participants being current AT users. In addition, with all behavioural research, self-selection and self-serving bias may occur. The presence of a carer in one PwMS group may have influenced responses of their partner although all groups knew each other by virtue of MS Society branches, and thus were perhaps more open and honest in sharing their experiences. A familiar, open and supportive environment was provided for participants in an attempt to empower participants. This was evident by virtue that PwMS and carers would discuss personal and sensitive experiences relating to their limitations and restrictions.

During the focus group sessions, the lead researcher and co-facilitator ensured that each participant had the opportunity to share their experiences. This meant personally managing active members to allow the more passive members to have their voice heard. This in turn increased the chances of allowing interpretation of data at both the individual and group level (Wilkinson, 1998). Whilst it is acknowledged that recruitment from wider health and social care services may have improved the sample representativeness, we sought primarily to generate hypotheses for further study. Also, conducting multiple focus groups enhances the confidence in our findings (Kidd & Parshall, 2000).

Implications

Our findings highlight a clear need for further prospective longitudinal research to explore the (passive and active) acceptance of AT, and the influences of AT use among PwMS. The findings that factors such as illness acceptance and device perceptions may contribute to the coping behavior of using AT, and thus the outcomes of MS, draws question as to whether the Common Sense Model of Self-Regulation of Illness needs broadening (see

Figure 3.2 for proposed inclusion of these variables). These require further investigation as to the role they play in coping behaviours such as AT use.

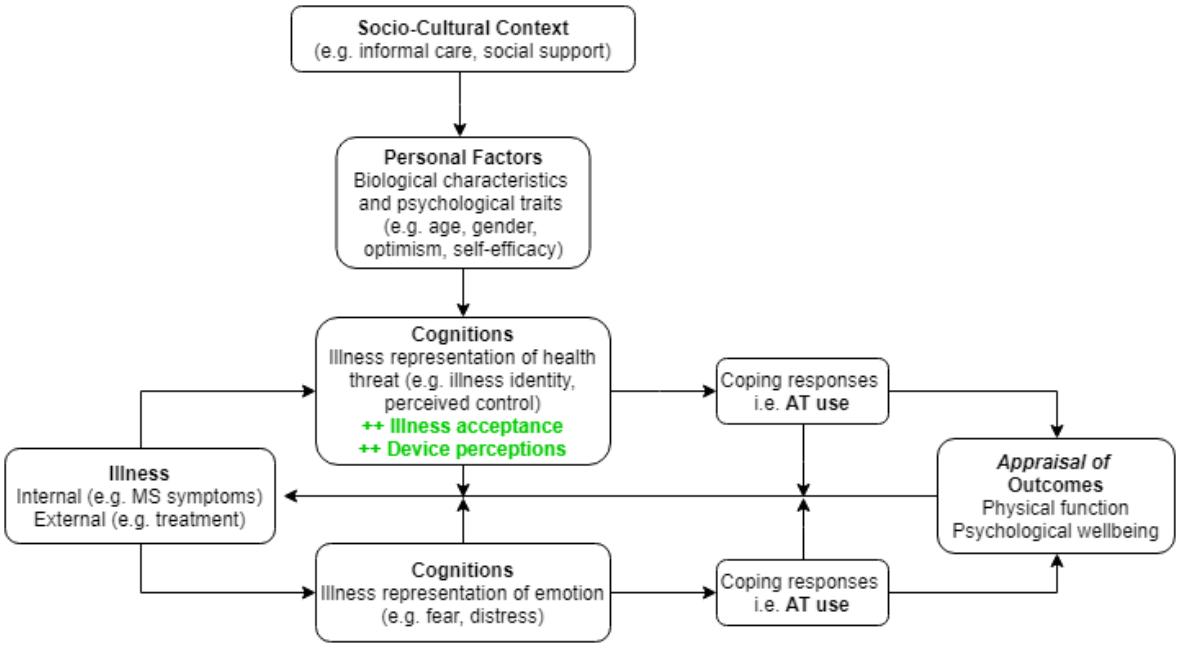

Figure 3.2: Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness with additional cognitions to consider i.e. illness acceptance, device perceptions.

Given the unpredictability of MS, acceptance is likely to be an ongoing process and may present itself at any time. OT teams should be aware of the carer influences, including their acceptance of the illness or AT, and educate carers on the benefits of AT and how their role can adapt to enhance the care they are providing to their loved ones. Other biopsychosocial influences whether personal (e.g. illness perceptions, optimism), service (e.g. communication, waiting times) and environmental (e.g. social support, public perceptions) factors would be best addressed by following individuals use of AT from delivery overtime. Longitudinal monitoring is essential to identify any changes in the impact of AT use, and to ensure needs are still being met by their AT device.

In order to maximise continued AT use and its benefit, our findings suggest that service providers should consider personal, and external influences when matching device to PwMS. The key issues that have been identified require further investigation including acceptance, optimism, social support (carer), and service delivery.

Chapter 4

What Assistive Technology is used and by whom ? – A baseline analysis of AT usage and associated factors amongst individuals living with MS

Abstract

Evidence suggests that illness perceptions and other psychosocial factors can influence individual's coping behaviours however few studies have addressed these influences in respect to the use of AT devices, specifically considered here as a coping behaviour amongst people with MS (PwMS). Studies that have addressed influences on AT use have also lacked psychological insight. Also – and in spite of the potential positive outcomes of AT devices – many devices are abandoned or misused within the first year (Wessels et al., 2003) with little understanding of what leads to AT abandonment. These questions are addressed here using baseline findings of a 3-wave longitudinal survey of the nature of AT use among PwMS. Participants were recruited via specialist MS clinics, MS Society UK branches and social media. One-hundred-and-twenty-five participants (*M*=51.89yrs, *SD*=12.96) completed a questionnaire battery, including: demographic and clinical questions, the Revised Life Orientation Test (optimism), the Duke Social Support Index, the Brief Illness Perceptions Questionnaire; the Acceptance of Chronic Health Conditions, and items regarding AT use and AT perceptions devised for this study. Contrary to key theory and evidence-led hypotheses, optimism, illness perceptions, acceptance or device perceptions were not significantly associated with AT use (following Bonferroni adjustment due to multiple comparisons). Instead, it was found that AT use was most likely among those reporting having a carer, lower relationship quality, being unemployed, and being in receipt of medical treatment. Unadjusted analysis noted trends between key psychosocial variables and AT use which are the subject of subsequent longitudinal investigation, particularly to how these relate to physical and psychological outcomes of living with MS, reported in Chapter 5.

Introduction

In the UK, it has been estimated that the annual healthcare cost *per patient* with multiple sclerosis (MS) ranges from £10,000 to £40,000 depending on the severity of illness (Kobelt et al., 2017a; 2017b; Thompson et al., 2017). With approximately 100,000 people living with MS in the UK (Mackenzie et al., 2014), it could be calculated that the annual cost of MS care is between 1-4 billion GBP per year. With no known cure, these costs are comprised of direct healthcare, disease modifying treatments, informal care, production losses and services (including AT provision; Kobelt et al., 2017b; Thompson et al., 2017).

It is believed that up to 50% of people with MS will use assistive technology (AT) at some point following diagnosis (Pittock et al., 2004; Souza et al., 2010) and many use multiple devices to help manage their condition as we, and others have reported (e.g. Johnson et al., 2009; Squires et al., 2016). AT devices are designed to help PwMS in managing their disabling symptoms which can include the loss of balance and limb function, fatigue, cognitive dysfunction, incontinence, pain, sexual dysfunction, and visual problems (Goodkin, 1992), all of which may fluctuate in severity, and overtime.

In spite of the potential positive outcomes of their use, as described in Chapters 1-3, AT devices are often abandoned or misused within the first year of receipt (Phillips & Zhao, 1993; Squires et al., 2013; Wessels et al., 2003), which suggests that the equipment is not meeting the needs of the user, for whatever reason. Non-use however may have a detrimental impact on those affected by MS given that avoiding AT use can result in poorer management of functional limitations and the experience of greater fatigue. Some PwMS have reported embarrassment due to lay perceptions of them 'being drunk', in fact due to their instability when not using walking aids (e.g. Dennison et al., 2010b; Chapter 3: Squires

et al., 2016). This highlights the importance of investigating the factors relating to the uptake and continued use of AT devices – as a method of coping with their symptoms and their consequences.

The Common Sense Model (CSM) of the Self-Regulation of illness introduced in Chapter 1 suggests that a person's illness representations (IRs) shape their response to their illness by virtue of influencing the resultant self-management behaviours, commonly referred to as coping responses, and their outcomes (Hagger & Orbell, 2003). These illness perceptions are considered to be dynamic constructs in that they are subject to change according to an individual's past and current experiences. For example, the CSM suggests that personal characteristics (e.g. gender, optimism) and external concepts (e.g. social support) can influence illness representations and coping responses (Leventhal et al., 1984). In response to stressors or illness, people either direct their coping efforts (e.g. cognitive, behavioural or emotional coping) at reducing the problem or increasing their resources to do so (i.e. problem-focused coping), or at reducing the negative emotions induced by the stressor (i.e. emotion-focused coping) (Folkman & Lazarus, 1980; Schulman-Green et al., 2012). Guided by the CSM, the uptake and use of AT could be considered to be a problem-focused coping response to the need for illness management. The success or failure of its use in achieving physical or psychological function would determine the continued use of the device (i.e. self-regulation).

Illness representations include the perceived identity of the disease, its perceived duration or timeline, its consequences and the extent to which the person believes they can control their condition, its treatment or other aspects. Research has demonstrated that poor physical and emotional adjustment to MS, and in-turn poor acceptance of MS, is not only associated with more severe symptoms, but also with individual beliefs in severe

consequences of MS, low beliefs in personal control, cyclical illness, and uncertainty about their illness or low illness understanding (Jopson & Moss-Morris, 2003, Dennison et al., 2010a). However, as seen in the focus group study (Chapter 3: Squires et al., 2016) wider constructs require investigation as it appears that demographics, illness features and illness representations alone do not contribute to the uptake of AT. In presenting qualitative data from MS patients accounts it emerged that there was a process of accepting MS as a serious condition with all its various associated symptoms and functional consequences and that this had to take place before acceptance of the need for AT, particularly more visual AT such as wheelchairs, could occur. The relationship between illness acceptance and AT acceptance has yet to be explored among PwMS and therefore is pursued empirically in this and subsequent chapters.

Starting with the individual, CSM recognises the personal influences on coping behaviours and outcomes. Optimism (i.e. expecting the best possible outcome from all situations: Scheier & Carver, 1992) is considered to be a key trait in patient resilience. For an unpredictable condition such as MS where patients are faced with challenging life events, frequent relapses and symptom progression (as highlighted in Chapter 3), a positive outlook may be considered adaptive and beneficial (Scheier, Carver & Bridges, 1994). For example, optimistic PwMS have been found to use positive coping strategies (e.g. such as seeking support) and adjust to their condition more positively than other neurological conditions (de Ridder, Schreurs & Bensing, 2000). Better adjustment (and thus acceptance) may lead to AT use as a self-management coping behaviour.

Social support – another key variable identified in the qualitative findings reported in Chapter 3 - is the level of support people feel that they are cared and loved for, this can be actual (received support) or perceived. Social support (nature and satisfaction of) has been

found to be a significant predictor of QoL in many chronic disease samples (Bennett et al., 2001; Kruithof, van Mierlo, Visser-Meily, van Heugten & Post, 2013) including amongst PwMS (e.g. Mikula et al, 2016). Generally, social support is considered to be made up of two components: structure and satisfaction (Uchino, 2006). The structure relates to the network of support (who, how much) and satisfaction relates to how satisfied one is with their level of support. Attributing this to the current study, PwMS may receive little physical support from their loved ones but they may be satisfied with this level of support if they wish to maintain a level of independence. The exploration of how support processes interact with AT use has not been examined in MS studies, although it has been found to be a significant contributor to adaptive coping (such as seeking information or additional support; McCabe et al., 2004).

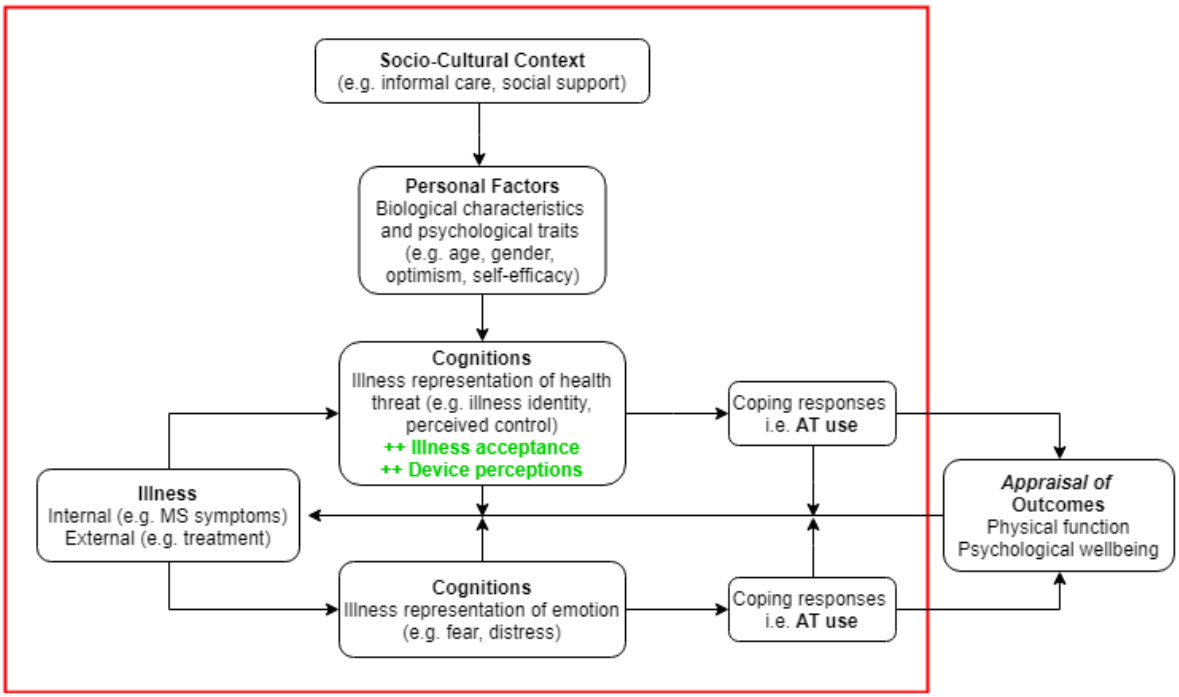

Figure 4.1: Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness. Chapter 4 to focus on the influences on AT use, including additional variables i.e.

illness acceptance and device perceptions.

In this chapter the relationships between personal, illness and device characteristics and the aforementioned psychosocial variables and the proposed coping behaviour of AT use (Squires et al., 2013; 2016) are examined (see Figure 4.1). More specifically, the concurrent associations between AT use and illness acceptance, perceptions of illness and AT device, optimism and social support are examined to address the following hypotheses:

AT use will be associated with:

(a) Clinical-demographic variables: time since diagnosis, MS type, receipt of MS treatment
(b) Higher levels of optimism
(c) Social support (two-tailed hypothesis)
(d) Higher perceived personal and treatment control
(e) Higher levels of perceived illness identity (i.e. greater N of perceived symptoms) and effect of MS
(f) Higher levels of illness acceptance
(g) Positive perceptions of the AT device

Method

Participants

Participants (*n*=125) were recruited over a 9-month period via MS Society UK branches, social media (Twitter), a local MS clinic in North Wales and previous research participation (i.e. focus group study reported in Chapter 3: Squires, et al., 2016). All participants aged 18+ with MS were included regardless of their level of AT experience to

allow comparisons between AT users and non-AT users. All participants were required to speak, write and understand English; and hold no current severe cognitive impairments (self-reported).

Design

The cross-sectional findings of a 3-wave longitudinal survey are reported in this chapter, with longitudinal data presented in Chapter 5.

Measures

Demographic and clinic characteristics Participants were asked to report their demographic characteristics including their age, gender, ethnicity, relationship status, employment, and clinical details such as MS type (relapse-remitting, primary- or secondary-progressive), severity of MS, and any comorbidities. Details relating to any informal carers (relationship, amount of care, and relationship quality) were also reported.

Optimism The 10-item revised Life Orientation Test (LOT-R; Scheier et al., 1994) was used to measure general optimism. Each item is scored on a 4-point Likert scale. Four items are fillers, with the remaining items scored so that higher scores reflect higher levels of optimism. The internal reliability was high (α=.87).

Social support The 10-item Duke Social Support Index (DSSI; Powers, Goodger & Byles, 2004) was used to measure current level of social support. Each item is scored on a 3-point scale with higher scores reflecting higher levels of social support. It consists of two subscales representing 'social network' (4 items, α=.63) and 'satisfaction' (6 items, α=.85) with good and high internal reliability respectively. Total scores were also computed to represent overall social support with good internal consistency (α=.82).

Illness perceptions Perceptions of MS were measured using the 8-item Brief Illness Perceptions Questionnaire (BIPQ; Broadbent, Petrie, Main & Weinman, 2006). Each item is scored on an 11-point Likert scale with higher scores representing a more threatening perception of MS. The items cover cognitive illness representations (consequences, timeline, personal and treatment control, and identity), emotional representations (concern, emotions) and illness comprehensibility. Given there is no known cause of MS, the causal item of the BIPQ was removed to remain valid and to not encourage misattribution in PwMS. Due to the single item per construct nature of this measure, no reliability coefficients can be determined.

Acceptance of MS The 10-item Acceptance of Chronic Health Conditions (ACHC; Stuifbergen et al., 2008) scale was used to measure current acceptance and adjustment to MS. Each item was scored on a 5-point Likert scale ranging from 'strongly agree'=1 to 'strongly disagree'=5, with higher scores reflecting higher levels of acceptance. Internal reliability was good (α=.79).

Device factors The authors created a 7-item scale to evaluate the most recently acquired AT device, rated on a 5-point Likert scale (1=Very Bad to 5=Very Good). The items addressed the cost, appearance, design (how it works), ease of learning to use, ease of use, time saving and enjoyment of use. The total score for the scale is the sum of all items, with higher scores reflecting a more positive perception of the device. The internal reliability of the scale was high (α =.79).

AT use Participants were given a checklist of different AT devices to record their current and previous use of AT. Given that participants could not be recruited at the time of AT provision, an attempt was made to evaluate the impact of AT devices at the earliest

point possible. In order to do this, PwMS were asked to complete the rest of the questionnaire in regards to their most recently acquired AT device. They were asked about their training, confidence in use, expectations of and needs being met by the AT device.

Procedure

Prior to approval, the MS Society Research Network approved the questionnaire materials. Ethical approval was received from Bangor University, School of Psychology Research Ethics Committee and research governance approval by the host NHS organisation (REC: 13/WA/0226). Participants were recruited from local MS Society UK branches, social media and at a local MS clinic. Potential participants and those that expressed interest taking part were sent a participant information sheet to enable them to make a fully informed decision about taking part. On consent, they were sent a postal or online questionnaire depending on their preference. Participation in the study was completely voluntary and unpaid. Over 9-months, 270 invitations were sent to individuals identified from MS Society UK branches and local advertisements, of which 69 were completed, and 45 were sent to patients identified at a local MS clinic, of which 23 were completed (=29% return rate). Over the final 46-days of recruitment, 33 PwMS were recruited through social media (Twitter) from 64 tweets sent out on a study-specific account (=0.52 PwMS recruited per tweet, similar to other health research e.g. O'Connor et al., 2014). Participants were thanked and debriefed on the completion of the final questionnaire.

Statistical Analysis

Data were analysed using SPSS version 22. Before analyses, data were screened for missing values. Missing values were substituted by the mean value of individuals'

measurement score (Tabachnick & Fidell, 2013) in situations where either measure specific limits were advised or when <30% of values were missing. If limits were exceeded the case was omitted from analyses. In the first step of analyses, frequencies for categorical data and descriptives for continuous variables were conducted. Independent t-tests and chi square analysis were conducted in order to explore differences of demographic and clinical characteristics on independent (IVs) and dependent variables (DVs). Correlational analysis was conducted to explore the relationships between the study variables and with AT use. Where the assumption of sphericity was violated, degrees of freedom were corrected using the Greenhouse-Geisser correction and Bonferroni correction was used for any post hoc pairwise comparisons. Due to multiple comparisons, an alpha level of .002 was set. To control for unequal sample sizes, Hedge's *g* effect size (Hedges, 1981) was calculated and reported where appropriate (Ellis, 2010).

Results

Demographics

A total of 87 females (70%) and 38 males completed the baseline questionnaire, which fits the estimated gender ratio of PwMS (approx. 2-3:1; Koch-Henriksen & Sorensen, 2010). Participants were aged from 20-79 years (*M*=51.89yrs, *SD*=12.96). PwMS were predominantly white British (one American, one Dutch, one Irish). More participants (67%, *n*=84) reported having a significant other (*n*=19 in a relationship; *n*=65 married) than those who did not (28%, *n*=35: *n*=13 single; 14=divorced/separated; *n*=8 widowed) at baseline. Most PwMS (71%, *n*=89) were unemployed at baseline, 54% of which reported to be due to their MS (*n*=68).

The length of time since diagnosis ranged from 0-42 years (*M*=13.40yrs, *SD*=9.29) with most PwMS reporting a progressive form of MS (51%, *n*=64; 16% primary and 35% secondary). Relapse-remitting MS was reported by 46 PwMS (36.8%) while 15 PwMS (12%) did not report their MS type. The mean value of illness severity reported by PwMS was 2.22 which is average (scored 0-4 with 0=’not severe at all’, 4=’extremely severe’). Co-morbidities were reported by 64 PwMS (51%). Seventy-four (59%) participants reported being in receipt of medical treatment for their MS symptoms.

Most PwMS were recruited via MS Society UK branches (52%, *n*=65) and social media (Twitter specifically, 26%, *n*=33) followed by a local MS clinic in North Wales (*Ysbyty Glan Clwyd*; 18%, *n*=23) and the rest (*n*=4) were previous participants (Squires et al., 2016: Chapter 3). Participants completed the questionnaire via post or online (*n*=72, 53 respectively). The majority of participants (74%, *n*=93) received no help in completing the questionnaires (vs. 18%, *n*=23 help from loved one; 7%, *n*=9 help from AT device).

50% of PwMS (*n*=62) reported receiving informal care from a loved one, which included support from a partner (*n*=49), child (*n*=5), parent (*n*=2), friend (*n*=2). Care had been provided from 4 months to 38 years (*M*=10.3 years, *SD*=7.88), and for an average of 68 hours per week (ranging from 2 hours to 24/7 care). Relationship quality was reported by PwMS as good/excellent (mean value=3.77; 0-4 with 0=’very poor’, 4=’excellent’).

AT Use

Of the whole sample, 103 (82%) were currently using AT, thus 22 PwMS (18%) were not currently using any devices, nine of whom reported never having used AT devices at any time since their MS diagnosis. Their data is therefore excluded from analysis relating to

perceptions of AT. PwMS on average had previous experience of eight AT devices, although this ranged from 0-20 devices. Mobility, environmental and bathing devices were the most commonly used among PwMS. Full AT experience is described in Table 4.1.

Given that participants could not be recruited at the time of AT provision (given the low incidence of MS, and the varying times to AT receipt, recruiting sufficient N within the time period and geographical constraints of a PhD study would be highly unlikely), an attempt was made to evaluate AT device use at the earliest point possible. In order to do this, PwMS were asked to complete the rest of the questionnaire in regards to their most recently acquired AT device. The average length of time for their most recent AT provision was 18 months (ranging from 0-180 months). For consistency, these devices were assessed at each subsequent time point by the individual. Most of the recently acquired devices were for mobility (*n*=55; vs. non-mobility devices, *n*=48; see Table 4.1) and were obtained privately (*n*=55; vs. health and social services, *n*=48).

Among the 103 current AT users, 89% of these different devices (*n*=92) were still being used by participants at the time the questionnaire was completed. In terms of receiving training to use their 'recent' AT device, only 37% of participants (*n*=38) reported having had training, with the majority (52%, *n*=54) reporting having received no training). The majority (88%, *n*=91) of participants reported confidence in using their AT device. Most participants reported their expectations (93%, *n*=96) and their needs (89%, *n*=92) as being met by their AT device. Overall, AT users reported a positive impact of using their most recently acquired AT device (*M*=1.47, *SD*=1.03).

In terms of participant scores on key measures, the means are presented in Table 4.2 where it can be seen that across all participants, the overall threat of MS appeared to be

quite high, as seen in the perceptions of chronicity, high consequences, concern, symptom experience, and emotional affect as well as low perceived personal control. PwMS also reported a high understanding of their condition and moderate beliefs in treatment control. They reported moderate levels of device perceptions, illness acceptance, optimism and social support (see Table 4.2).

Table 4.1 AT use among MS sample

	No. of PwMS (*n*=125)	**No. of current AT users (*n*=103)**
	Yes, ever used	**Most recent device**
Mobility	**106 (85%)**	**55 (53%)**
Manual wheelchair	63 (51%)	
Motorised wheelchair	23 (19%)	
Scooter	43 (35%)	
Walker	41 (33%)	
Cane	75 (61%)	
Crutches	39 (32%)	
Orthoses	25 (20%)	
FES	16 (13%)	
Other (e.g. TENS, trolley)	9 (7%)	
Environmental	**93 (75%)**	**19 (18%)**
Home adaptations	82 (66%)	
Computer access aids	16 (13%)	
Transfer aids	28 (23%)	
Vehicle adaptations	48 (39%)	
Other (e.g. ECS, handy-grabber)	11 (9%)	
Bathing aids	**91 (73%)**	**2 (2%)**
Adapted toilet	32 (26%)	
Adapted bath/shower	68 (55%)	
Grab bars	73 (59%)	
Commode	22 (18%)	
Wet room	12 (10%)	
Other (e.g. shower seat)	10 (8%)	

	No. of PwMS (*n*=125)	No. of current AT users (*n*=103)
	Yes, ever used	**Most recent device**
Medical devices	**52 (42%)**	**2 (2%)**
Continence devices	50 (40%)	
Other (e.g. pill organisers)	5 (4%)	
Memory aids	**52 (42%)**	**8 (8%)**
Daily planners	29 (23%)	
Electronic memory aids	33 (27%)	
Other (e.g. diaries)	3 (2.4%)	
Kitchen aids	**49 (40%)**	**2 (2%)**
Cooking aids	35 (28%)	
Eating aids	16 (13%)	
Other (e.g. perching stool)	12 (10%)	
Telecare	**30 (24%)**	**3 (3%)**
Alarms	23 (19%)	
Fall detector	4 (3%)	
Medication devices	11 (9%)	
Communication	**5 (4%)**	**4 (4%)**
Communication Book/Board	2 (1.6%)	
Voice Amplifier	1 (0.8%)	
Other (e.g. 'Dragon' computer software)	3 (2.4%)	
Miscellaneous devices	**44 (36%)**	**8 (8%)**
Dressing aids	21 (17%)	
Sex aids	8 (7%)	
Support aids	27 (22%)	
Other (e.g. vision aids)	4 (3%)	

Table 4.2. Participant Mean and Standard Deviation scores in relation to perceptions of illness and device, and the psychosocial variables (n=103 current AT users)

Variable		Total	
	Score	*M*	*SD*
Social support – Total (DSSI)	10-30	22.18	4.13
Optimism (LOTR)	6-30	19.34	5.71
BIPQ – Effect	0-10	7.30	2.20
BIPQ – Timeline	0-10	9.77	1.16
BIPQ – Personal control (rev)	0-10	6.40	2.68
BIPQ – Treatment control (rev)	0-10	4.82	2.71
BIPQ – Symptom	0-10	6.95	2.14
BIPQ – Concern	0-10	7.22	2.44
BIPQ – Coherence (rev)	0-10	2.24	2.48
BIPQ – Emotional affect	0-10	6.59	2.45
Acceptance (ACHC)	10-50	31.65	7.71
Device perceptions	15-35	27.55	4.39

Key: rev – reverse scored, so higher scores reflect 'higher threat' of illness (according to Brief Illness Perception Questionnaire; Broadbent et al., 2006)

Influence of Clinical and Demographic Variables on Psychosocial Variables

Prior to addressing the influences on the hypothesised variables upon AT use, the effects of key clinical-demographic factors upon these hypothesised correlates were explored through inferential statistics (in order to identify whether clinical or demographic factors have to be controlled for in subsequent analyses). Following Bonferroni adjustments due to multiple comparisons (.05/21=.002), there were no significant effects of questionnaire type, having a significant other, comorbidities, or current medication upon the study's key psychosocial variables (i.e. social support, optimism, illness perceptions, and acceptance of MS (full t-tests are presented in Appendix C^2). Males did however, perhaps unexpectedly, report significantly more symptoms (*M*=8.00, *SD*= 1.76) than females (*M*=6.49, *SD*=2.13), (*t*(120)=3.77, *p*<.001) and perceived MS as significantly more severe (males, *M*=2.73, *SD*=0.73; females, *M*=1.99, *SD*=0.92); (*t*(116)=4.34, *p*<.001). Unemployed participants were significantly older than employed participants, and reported significantly higher effects of MS, greater symptom experience, perceived severity of MS, and more hours of care than employed participants (see Tables 4.3-4.6 for full summary of t tests). People with a progressive type of MS were significantly older (and had had MS for significantly longer than those with relapse-remitting MS) and perceived MS as more severe and with greater effects than those with RRMS. Participants with a carer reported significantly higher MS severity (carer, *M*=2.52, *SD*=0.72; no carer, *M*=1.87, *SD*=1.02); (*t*(95.64)=3.90, *p*<.001) and perceived illness effect compared to those without a carer (carer, *M*=8.13, *SD*=1.63; no carer, *M*=6.37, *SD*=2.50); (*t*(89.14)=-4.42, *p*<.001). These influences are therefore controlled for in subsequent correlational analyses between the relevant psychosocial factor and AT use.

Table 4.3. Summary of t tests of control variables (see Appendix C[2] for non-significant results)

		Total sample		**Unemployed/ Retired (*N*=89)**		**Employed (*N*=31)**					
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*	ES (*g*)
BIPQ - Affect	0-10	7.30	2.20	7.86	1.89	5.81	2.44	4.82	117	.000***	1.00
BIPQ - Symptom	0-10	6.95	2.14	7.44	1.90	5.71	2.34	4.09	116	.000***	0.15
Age		51.89	12.96	55.79	11.24	43.32	12.64	-5.10	113	.000***	1.07
Severity of MS	0-4	2.22	0.93	2.45	0.80	1.53	0.94	-5.21	116	.000***	1.10
Hours of care		68.08	66.03	75.62	67.68	20.71	21.83	-4.18	28.94	.000***	0.92
		Total sample		**Progressive (*N*=64)**		**RRMS (*N*=46)**					
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*	ES (*g*)
BIPQ – Affect	0-10	7.30	2.20	8.10	1.75	6.24	2.25	4.84	107	.000***	0.94
Age		51.89	12.96	57.77	9.79	44.34	12.81	-5.83	77.06	.000***	1.20
Years since Dx		13.40	9.29	16.38	9.52	9.15	7.21	-4.51	106.83	.000***	0.84
Severity of MS	0-4	2.22	0.93	2.57	0.71	1.67	0.90	-5.83	107	.000***	1.13

Influence of Clinical and Demographic Variables on the Nature of AT Use

Given unequal sample sizes, caution should be given to interpreting the effect of some key study variables on AT use, AT abandonment, and confidence in use (all yes/no) however data are presented for exploratory purposes.

There were no significant effects of questionnaire type, having a significant other, comorbidities, or current medication upon the number of AT devices used or device perceptions. However it was found that unemployed PwMS reported using significantly more number of AT devices (M=9.62, SD= 4.95) than employed PwMS (M=5.10, SD=4.90), (t(118)=-4.39, p<.001). People with progressive MS also reported using more AT devices (M=10.23, SD= 4.92) than those with RRMS (M=5.96, SD=5.24), (t(108)=-4.38, p<.001). Also, PwMS receiving informal care used significantly more AT devices (M=10.35, SD= 4.54) than those without an informal carer (M=6.38, SD=5.48), (t(115)=4.29, p<.001). These influences are therefore also controlled for in subsequent correlational analyses.

Influence of Psychosocial Variables on the Nature of AT Use

To explore the nature of AT use among PwMS, inferential statistics were first carried out (i.e. t tests and chi squares) to explore the influences of psychosocial variables on AT use (vs. non-use), on AT device type (mobility vs. non-mobility) and on AT abandonment (continued vs. not). Correlational analysis next explored associates of the number of AT devices used, controlling for clinical-demographic factors where necessary from earlier inferential analysis.

Number of AT devices No significant associations were found between psychosocial variables and the number of AT devices used by PwMS following Bonferroni adjustments –

despite positive trends seen with perceived severity of MS (*r*=.25), and illness representations of effect (*r*=.23) and timeline (*r*=.29) when controlling for confounding variables (i.e. unemployment, MS type, carer).

AT Use vs. Non-use Lower levels of relationship quality were seen in current AT users compared to non-AT users, and more AT devices overall had been used during their illness experience by current AT users than by non-current AT users. There were also trends seen with higher levels of illness representations of illness effect, symptom experience, concern and lower levels of illness coherence seen among current AT users compared to those not currently using AT however these were not significant following Bonferroni's adjustment.

Chi-squared analyses identified further influences on AT use: employment (χ^2 (1) = 4.60, *p*=.03), having a carer (χ^2 (1) = 5.12, *p*=.02) and current medical treatment (χ^2 (1) = 10.17, *p*=.001; all dichotomous variables=yes/no) significantly influenced current AT use. The odds of current AT users:- being unemployed were 2.91 times higher than being employed; having a carer were 3.18 times higher than having no carer; and receiving medical treatment were 4.86 times higher than those receiving no medical treatment.

Table 4.4 Summary of t tests (current AT users vs. non-AT users) of key study variables

	Total sample			**AT Users (*N*=103)**		**Non-AT Users (*N*=22)**				
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*
Age	-	51.89	12.96	52.07	12.41	51.09	15.46	.320	118	.750
Years since diagnosis	-	13.40	9.29	13.60	8.68	12.37	12.22	.420	21.59	.679
Severity of MS	0-4	2.22	0.93	2.34	0.82	1.65	1.18	2.48	22.91	.021
Severity of comorbidities	0-4	2.14	1.20	2.21	1.18	1.78	1.30	.990	49	.327
Length of informal care (months)	-	123.57	94.57	122.98	94.34	128.00	105.35	-.121	49	.904
Hours of care	0-168	68.08	66.03	65.81	65.43	89.00	75.80	-.742	49	.461
Relationship quality	0-4	3.77	0.50	3.74	0.52	4.00	0.00	-3.824	57	.000
Social Support	10-30	22.18	4.13	4.12	0.41	4.27	0.91	-.343	123	.732
Optimism	6-30	19.34	5.71	5.46	0.54	6.64	1.45	-1.611	121	.110
BIPQ – Illness effect	0-10	7.30	2.20	7.66	1.89	5.52	2.75	-3.40	23.98	.002
BIPQ – Illness timeline	0-10	9.77	1.16	9.88	0.59	9.24	2.49	-1.174	20.461	.254
BIPQ – Personal control	0-10	6.40	2.68	6.49	2.67	6.00	2.72	-.756	122	.451
BIPQ – Treatment control	0-10	4.82	2.71	4.86	2.72	4.63	2.71	-.341	119	.734
BIPQ – Symptom experience	0-10	6.95	2.14	7.32	1.78	5.05	2.78	-3.518	22.131	.002
BIPQ _ Illness concern	0-10	7.22	2.44	7.43	2.38	6.24	2.57	-2.060	120	.042
BIPQ – Illness coherence	0-10	2.24	2.48	1.95	2.20	3.62	3.25	2.249	23.931	.034
BIPQ – Emotional effect	0-10	6.59	2.45	6.64	2.40	6.33	2.71	-.517	121	.606
Illness acceptance	10-50	31.65	7.71	7.76	0.76	7.53	1.64	-.760	122	.448

AT Abandonment To explore the clinical, demographic and psychosocial variables influences on AT abandonment, analysis was conducted only on those PwMS who had recently acquired AT (*n*=103).

Employment (χ^2 (1) = 5.11, *p*=.02) and confidence in AT use (χ^2 (1) = 8.00, *p*=.01) significantly influenced AT abandonment. The odds of continuing AT use:- were 5.33 times higher for those unemployed compared to those in employment; were 11.07 times higher for confident AT users compared to those who reported no confidence. There were no significant effects of key psychosocial variables upon AT abandonment or type of AT used (see full unadjusted t tests found in Appendix C^2). However there were trends seen in younger PwMS, those with longer informal care histories and those with less positive device perceptions abandoning their recently acquired AT device (see t-tests presented below).

Table 4.5 Summary of t tests (AT abandoners vs. continued use) of key study variables

		Total sample		**AT Abandonment (*N=8*)**		**Continued Use (*N=92*)**				
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*
Age	-	51.89	12.96	42.43	6.78	52.39	12.42	2.09	93	.040
Years since diagnosis	-	13.40	9.29	10.29	8.86	13.74	8.69	1.01	95	.313
Severity of MS	0-4	2.22	0.93	2.14	1.35	2.35	0.76	.407	6.31	.698
Severity of comorbidities	0-4	2.14	1.20	1.33	0.58	2.27	1.22	1.31	38	.198
Length of informal care (months)	-	123.57	94.57	276.00	164.97	112.05	79.92	-3.20	43	.003
Hours of care	0-168	68.08	66.03	77.67	82.92	64.98	65.18	-.321	44	.749
Relationship quality	0-4	3.77	0.50	3.67	0.58	3.75	0.52	.256	56	.799
Social Support - Total	10-30	22.18	4.13	23.86	2.72	22.13	4.14	-1.160	98	.249
Optimism	6-30	19.34	5.71	19.91	3.72	19.60	5.58	-.146	97	.884
BIPQ – Illness effect	0-10	7.30	2.20	7.13	2.36	7.73	1.80	.888	98	.377
BIPQ – Illness timeline	0-10	9.77	1.16	10.00	0.00	9.88	0.61	-.553	98	.581
BIPQ – Personal control	0-10	6.40	2.68	5.88	3.23	6.60	2.64	.730	98	.467
BIPQ – Treatment control	0-10	4.82	2.71	3.86	3.24	4.98	2.68	1.057	96	.293
BIPQ – Symptom experience	0-10	6.95	2.14	6.86	2.67	7.38	1.65	.771	97	.442
BIPQ _ Illness concern	0-10	7.22	2.44	7.43	2.57	7.46	2.35	.039	96	.969
BIPQ – Illness coherence	0-10	2.24	2.48	1.00	1.00	1.93	2.18	1.122	97	.264

		Total sample		**AT Abandonment (*N=8*)**		**Continued Use (*N=92*)**				
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*
BIPQ – Emotional effect	0-10	6.59	2.45	5.57	2.64	6.74	2.35	1.256	97	.212
Illness acceptance	10-50	31.65	7.71	36.88	7.79	31.51	7.66	-1.900	98	.060
Device perceptions	15-35	27.55	4.39	24.13	5.84	27.81	4.17	-2.32	98	.022
No. of AT devices	-	8.29	5.34	8.71	6.42	9.50	4.97	.395	97	.694
Length of AT use (months)	-	18.60	27.76	17.50	10.91	18.77	28.92	.107	87	.915

Intercorrelations between key study variables

The previous sections have tested for associations between the key study variables and AT use, however, as previous research suggests, many of the IVs are likely to themselves interact. In order to address whether such personal, clinical, device and psychosocial factors are associated with each other, bivariate and partial correlations were employed. This will enable the researchers to determine which variables to carry forward in regression analysis (with AT use as DV) in order to avoid entering confounded variables i.e. variables that themselves share too much variance (>.70; refer to Tabachnick & Fidell, 2013).

Other variables Age was, not unexpectedly, significantly correlated with years since diagnosis, r=.47, p<.001. Illness acceptance was found to be positively correlated with optimism, r=.47, p<.001. Optimism was also found to be positively associated with social support, r=.36, p<.001.

Correlates of illness beliefs The perceived severity of MS (r=.55), reported comorbidities (r=.54), high illness identity (r=.61), concern (r=.47) and emotional impact beliefs (r=.34, all p<.001) were all significantly associated with the overall negative effect of MS. Timeline beliefs were significantly related to relationship quality (r=.48, p<.001) i.e. whereby chronic timeline is more likely in those reporting a good relationship quality. Treatment control beliefs were significantly positively associated with personal control beliefs (r=.31), and negatively correlated with illness acceptance (r=-.34). Also negatively associated with illness acceptance was illness concern (r=-.61), coherence (r=-.37) and emotional impact beliefs (r=-.55).

Illness identity was significantly and positively associated with illness concern (*r*=.40) whereby PwMS who attached more symptoms to their illness identity, reported higher illness concern. Illness identity was also positively associated with the perceived severity of MS (*r*=.59), reported comorbidities (*r*=.61), and emotional impact beliefs (*r*=.47). Illness concern was also positively associated with perceived severity of MS (*r*=.33), reported comorbidities (*r*=.37), and emotional impact beliefs (*r*=.47), as well as being negatively correlated with optimism (*r*=-.36) i.e. those with higher illness concern reported low optimism. Emotional impact beliefs were negatively correlated with optimism (*r*=-.53) and social support (*r*=-.37).

Correlates of AT device perceptions Device perceptions (i.e. the appearance, design, ease of learning to use, ease of use, time saved by using it, enjoyment of use) were significantly associated with each other suggesting an overall 'device perceptions' score is appropriate (see Appendices). This score was computed (see Methods) and used in subsequent analyses. There were small positive trends seen in age (*r*=.22) and social support (*r*=.20) with device perceptions whereby older PwMS, and those with social support, had more positive perceptions, as well as a small negative trend seen with perceived personal control (*r*=-.27) whereby PwMS with lower personal control had more positive device perceptions. However, no trends remained significant following Bonferroni adjustment.

Table 4.6 Correlations and partial correlations of key study variables at baseline

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1.	Age	-															
2.	Yrs since diagnosis	**.473*** a,b**	-														
3.	Sev. of MS	-.033 a,b,c,d	.170 a,b,c,d	-													
4.	Sev. comorbidities	.006	.162	.335*	-												
5.	Length of care	.221	.414** b	.353*	.224	-											
6.	Hours of care	.061	.013	.323*	.121	.241	-										
7.	Relationship Quality	.133	.080	-.192	-.181	-.059	-.062	-									
8.	No. of devices	.111 a,b,c	.074 a,b,c	.254** a,b,c,d	.153	.017	.038	.038	-								
9.	Length of AT use	.106	.168	-.007	.004	.336*	.021	.160	-.133	-							
10.	Effect of MS	-.087 a,b,c	.052 a,b,c	**.551*** a,b,c**	**.538*** a ,b,c,d**	.122	.253	-.277* a,b,c	.229* a,b,c	.053	-						
11.	Timeline	.099	.002	.138	.216* a,b,c,d	.096	.143	**.483** *	.288** a,b,c	.063	.239* a,b,c	-					
12.	Personal control	-.030	-.076	.236*	.196* a,b,c,d	-.057	.291*	-.085	.131 a,b,c	.066	.229* a,b,c	.279**	-				
13.	Treatment control	.085 a,b	.142 b	.219*	.024	-.068	.107	-.146	.031	-.062	.115 a,b,c	.110	**.313***	-			
14.	Identity	.131	.057	**.588** * a,d**	**.605** * a,b,c,d**	.159	.352*	-.155	.183 a,b,c,d	.146	**.610** * a,b,c,d**	.298** a, d	.232* a,d	.129	-		
15.	Concern	-.215* a,b	-.006	**.329** *	**.371** * a,b,c,d**	-.167	.167	-.241	.069	-.185	**.468** * a,b,c**	.159	.248**	.204*	**.397*** a,d**	-	
16.	Coherence	.026	-.248* b	.009	.063	-.277*	.259	-.012	-.105	-.172	.039	.065	.065	.081	.029	.113	-

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
17.	Emotional impact	-.053	-.005	.297**	.321** a,b,c,d	-.155	.275	-.163	.051	.021	**.343** * a,b,c	.080	.151	.121	**.466*** a,d	**.642***	.157
18.	Acceptance of MS	.010	-.025	-.239* *	-.234* a,b,c,d	.157	-.292*	.085	-.072	.102	-.253* * a,b,c	-.016	-.233**	**-.340** *	-.138	**-.606** *	**-.365** *
19.	Optimism	.010	.105	-.098	-.121	-.172	-.046	.213	.063	-.007	-.294* * a,b,c	-.097	-.092	-.137	-.237*a, d	**-.356** *	-.221*
20.	Social Support	.042	.030	-.193*	-.196* a,b,c,d	.115	-.318*	.251*	.081	-.048	-.198* a,b,c	.107	-.066	-.222*	-.217*a, d	-.161	-.233**
21.	Device – Total	.218* a,b	.145	-.076	-.247	-.121	-.164	.207	.103	-.102	-.054	-.012	-.266**	-.200	-.073	-.036	-.042

[a] partial correlation controlling for employment; [b] partial correlation controlling for MS type; [c] partial correlation after controlling for carer; [d] partial correlation after controlling for gender *p< .05, **p< .01, ***p< .001 (including Bonferroni correction)

		17	18	19	20	21
17.	Emotional impact (BIPQ)	-				
18.	Acceptance of MS (ACHC)	**-.547***	-			
19.	Optimism (LOT-R)	**-.533***	**.469***	-		
20.	Social Support (DSSI)	**-.374***	.283**	**.356***	-	
21.	Device TOTAL	-.033	.010	.142	.195*	-

*p< .05, **p< .01, ***p< .001 (including Bonferroni correction)

Discussion

The primary objective of this chapter was to report the concurrent associations between a range of clinical, demographic and psychosocial variables derived from theory, empirical literature review and qualitative data (see Chapters 1-3 respectively) and AT use. Drawing specifically from illness self-regulation theory this chapter addresses the uptake and continued use of AT devices (considered as a means of coping with MS symptoms and consequences), focusing on the clinical-demographic and psychosocial influences thereon. These more specifically include illness perceptions (SRT) and given our previous findings (Chapter 3) further extend the model to include optimism, social support, acceptance, and AT device perceptions. It was hypothesized that AT use would be associated with:

(a) Clinical-demographic variables: time since diagnosis, MS type, receipt of MS treatment
(b) Higher levels of optimism
(c) Social support (2-tailed due to evidence of differential effects)
(d) Higher perceived personal and treatment control
(e) Higher levels of perceived illness identity (i.e. greater N of perceived symptoms) and effect of MS
(f) Higher levels of illness acceptance
(g) Positive perceptions of the AT device.

However, contrary to key hypotheses, neither optimism, perceived illness control (personal or treatment), illness acceptance nor the perceptions of AT device were significantly associated with AT use. There was a trend towards higher perceived illness effect and symptom experience amongst current AT users compared to non-users however

these differences were not significant following Bonferroni adjustments. While social support *per se (i.e. quantity and satisfaction of received social support)*, was not significantly associated with AT use, those who reported a lower relationship quality were more likely to use AT devices. Given the small correlation between social support and relationship quality, it appears that they do not measure the same thing and in this instance, the quality of relationship with an immediate loved one (typically acting as informal carer) is more influential than having a wider social network of friends and family.

It was found that AT use was influenced by being unemployed, having a carer and being in receipt of current medical treatment. AT abandonment was also found to be influenced by unemployment, but also by a lack of confidence in using the relevant device. It was also found that unemployed people reported a higher effect of MS on their lives, with higher perceived severity and more reported symptoms than those in employment suggesting that those participants were perhaps in higher need of AT, thus use it more. However due to the nature of analysis, causality cannot be determined and it may have been that more symptoms led to unemployment for PwMS. Unemployed participants also reported using significantly more devices than those in employment: it could be that those in employment are reluctant to use AT due to the stigma associated with use (as referred to in Ravneburg, 2012; Squires et al., 2016) however this would need further enquiry. Pointing to this, PwMS reported accessibility barriers to work and prejudice in the workplace after disclosing their MS condition (Rumrill, Roessler, Vierstra, Hennessey & Staples, 2004; MS Society UK, 2016c). Conversely, perhaps unemployed PwMS are able to spend more time integrating the use of AT in their home and daily life and thus have more frequent or more direct access, due to the receipt of benefits/welfare assessment, to health and social care

services. This would also support the notion that those in receipt of other medical treatment specifically for their MS were more likely to be AT users. A further influence on AT use was receiving informal care: individuals with informal carers reported being more affected by their MS and that it had a higher impact by means of perceived severity, and they used more devices than those without carers. It could be that those with carers receive support in accessing AT and are encouraged to use AT devices by their loved ones. Interestingly however, there were no significant associations between AT use and social support more broadly, nor did acceptance or optimism influence AT use, despite these being suggested to influence the use of AT in our earlier focus group findings (Chapter 3: Squires et al., 2016).

Perhaps unexpectedly, males reported significantly more symptoms and perceived their MS as worse than their female counterparts (as typically it has been widely reported than women are more likely to present to healthcare services with reported symptoms). The current findings perhaps support the notion of gender bias in research and clinical practice (Barsky, Peekna & Borus, 2001). For example, general assumptions regarding symptom experience may be held based on previous research however generalisations should not be made and it is important to consider any differences within each particular chronic health conditions such as MS. It is therefore important to consider these differences in further analysis.

While device perceptions were not found to be significantly associated with *use* directly, there were trends seen between positive device perceptions and older age, higher social support and lower personal control. This not only highlights the importance of considering device factors (i.e. good design, easy to learn and use, more time saved by using

the device, and enjoyment from use) in further studies but also the intercorrelation of potential predictors of AT use.

In addition, the unadjusted analysis revealed trends in illness perceptions whereby AT users reported being more concerned about, and having a greater understanding of, their MS compared to non-AT users ($p<.05$). However adjusted analysis was required in order to reduce the chances of Type I error ('false positive') due to the multiple comparisons being made in this exploratory study. That said, it is notable that some argue that the Bonferroni adjustment is overly conservative (Bender & Lange, 1999) and perhaps we can infer more from our findings than we do here. Nonetheless, further studies would benefit from a larger sample providing the concomitant increased statistical power of testing.

In support of further study, several of the illness perceptions were found to be significantly correlated with key psychosocial variables introduced into the current study as potential extensions to SRT i.e. illness acceptance and optimism following the qualitative findings reported in Chapter 3. Given what is known about the dynamic nature of illness and associated perceptions (Goodkin, 1992; Leventhal et al., 1980; 1992; 2003; Broadbent et al., 2015), it could be expected that many, if not all these variables will interact overtime. Although optimism was defined as a trait variable, evidence has shown this not to be fully the case (Squires et al., 2013). It is necessary to further explore these variables longitudinally, particularly with regards to the role that each may play in the physical and psychological outcomes of AT.

It is therefore proposed that a longitudinal approach will allow the researchers to examine whether any of the variables associated with AT use (i.e. employment, carer support, medical treatment, confidence in use) change over time. Additional personal,

clinical, device and psychosocial factors will be investigated where trends were found with AT usage variables as described above (i.e. illness perceptions, carer relationship). This wider inclusion is in order to address the suggestion that the Bonferroni adjustment is quite conservative and increases the chances of incorrectly accepting a null hypothesis. The next chapter of this thesis addresses these longitudinal questions.

Chapter 5

The physical functioning and psychological wellbeing of people living with MS: A longitudinal investigation of the role played by AT use in relation to psychosocial predictors

Abstract

Many biopsychosocial factors have previously been identified as associated with the physical and psychological outcomes of living with MS however few studies have examined the impact of Assistive Technology. Those that do exist have lacked theoretical underpinnings to the research questions. Furthermore their results have provided mixed evidence as to the positive or negative implications of using AT devices. The current study draws from the Common Sense Model of Self-Regulation of Illness in investigating AT use as a coping behaviour and examines its relation to other theorised influences (such as illness perceptions) upon the physical and psychological outcomes of living with MS. In this longitudinal questionnaire study seventy PwMS (*M*=53.19yrs, *SD*=12.44) completed a battery of measures at 4 time points, which included: demographic and clinical characteristics, the Revised Life Orientation Test (optimism), Duke Social Support Index, Brief Illness Perceptions Questionnaire, Acceptance of Chronic Health Conditions, AT use and AT perceptions and the Multiple Sclerosis Impact Scale (physical and psychological domains). A series of hierarchical regression analyses found that: (a) previous physical impact of MS (baseline, 3m, 6m), employment (3m), and the number of AT devices used (3m) significantly predicted the physical impact of MS at 12-months; (b) previous psychological impact of MS (baseline, 3m, 6m), MS treatment (baseline), optimism (3m, 6m) and the number of AT devices used (3m) significantly predicted the psychological impact of MS at 12-months. None of the hypothesised illness perception variables were predictive. The current study provided evidence for proposing AT use as a coping behaviour which has implications for MS outcomes. It also highlighted potential targets for intervention to improve physical and psychological outcomes of living with MS (i.e. optimism).

Introduction

Multiple Sclerosis is a chronic, incurable neurological condition where the immune system attacks the central nervous system causing a breakdown of communication between the brain and the rest of the body. This presents with intrusive and disabling symptoms including problems with walking, fatigue, continence (Goodkin, 1992; Holper et al., 2010). Around 75-80% of PwMS experience such problems within the first 10-15 years of diagnosis, and thus significantly contributes to one's sense of disability (Heesen et al., 2008; Marrie et al., 2017). In addition to the physical impact of this condition, PwMS report higher rates of anxiety and depression than the general population (Klevan et al., 2014; Mikula et al., 2016) and other chronic and neurological conditions (McCabe, Stokes & McDonald, 2009), for example 40% of PwMS experience depression in their lifetime (Gottberg et al., 2008). In contrast, positive outcomes are also reported by PwMS (Bowen et al., 2011; Pakenham & Cox, 2009) particularly following acceptance of the condition (Pakenham & Fleming, 2011; Squires et al., 2016) – an important factor also identified in relation to coping behaviour (i.e. using AT; see Chapter 3).

According to Bandura's (2001) Social Cognitive Theory (see Chapter 1), illness management in chronic conditions such as MS is determined by personal experiences and by observing others. The success of past experiences increases confidence and perceived control of the illness, and encourages continued self-management. Extending from this the Common Sense Model of Self-Regulation (CSM: Leventhal et al 1980; 2003: see Chapters 1 & 2) explains that in response to symptom experiences, certain cognitions (illness perceptions) and emotions are generated which then shape and predict coping and illness management behaviours. For example, when a person with MS experiences somatic symptoms they form

representations (beliefs) of their MS, described as illness perceptions. These perceptions are comprised of identity, timeline (chronic and cyclical), cause, consequences and control/cure. Identity refers to beliefs regarding their MS and the presenting symptoms (e.g. physical dysfunction, fatigue, pain); timeline relates to beliefs regarding the course of their condition and whether they believe it to be acute, chronic, or cyclical (i.e. progressive or relapse-remitting MS); control/cure refers to one's belief that they have control over their condition either personally or through treatment (e.g. medication, AT use); consequences refers to the potential physical and/or psychological impact of living with MS; finally, emotional representations are the emotional reactions to living with the condition for example, anxiety, concern, depression.

All of these perceptions can change over time and shape coping behaviours and outcomes (Hagger & Orbell, 2003; Leventhal et al., 1980). For example, Hagger and Orbell (2003) conducted a meta-analysis on illness perceptions, coping behaviours and outcomes and concluded that high personal control beliefs are positively associated with problem-focused coping behaviour, adaptive outcomes such as psychological wellbeing, social functioning and negatively associated with distress. They also concluded that holding beliefs of a strong illness identity/experience, chronic condition with severe consequences were associated with avoidant coping behaviours, and negatively associated with psychological wellbeing, physical and social function. Furthermore, avoidant coping behaviours are typically seen in chronic conditions considered to have no cure, like MS, (Affleck, Tennen, Pfeiffer & Fifield, 1987; Heijmans, 1999). The success or failures of such coping behaviours (e.g. using AT) are then evaluated to shape future responses with those responses being the individual's self-regulatory responses. This is important to consider in an unpredictable

chronic condition like MS, particularly given recent suggestions that these illness representations be explored in relation to long-term self-management, rather than the initiation of behaviour change (Leventhal, Phillips & Leventhal, 2016).

Jopson & Moss-Morris (2003) examined the illness perceptions, disability, fatigue, mood, and self-esteem of 168 PwMS in a cross-sectional study and found that perceived illness severity accounted for the majority of variance in concurrent physical dysfunction. Illness perceptions, particularly high illness identity and consequences, and low perceived control and coherence, were also significant predictors of social dysfunction, fatigue, anxiety and depression. These data suggest that illness perceptions may play a significant role in the adjustment to MS yet require further longitudinal study. The authors suggested that a condition that is believed to be 'controllable' may result in those affected i.e. PwMS seeking ways to manage their condition (e.g. using AT). They also found that PwMS hold a strong illness identity, low illness coherence, and perceptions of a chronic condition with severe consequences and low personal control. Perhaps unsurprisingly, this study identified that these negative illness perceptions were significantly associated with anxiety and depression. Such negative illness perceptions, emotions, and cognitions (e.g. catastrophizing, ruminating) have consistently been found to be significantly associated with poor psychological outcomes in PwMS, for example anxiety, depression, distress, and health-related QoL (Dennison et al., 2010a; Jopson & Moss- Morris, 2003; Osborne et al., 2007; Spain et al., 2007; Skerrett & Moss-Morris, 2006; Taillefer et al., 2002). Conversely, illness processes that are considered to be positive such as high levels of illness acceptance have been found to be significantly associated with positive QoL and better physical functioning, for example among a Belgian sample of PwMS (van Damme et al., 2016). Many studies

including meta-analyses have pointed to the predictive utility of illness representations however none have considered AT as a coping behaviour as we do here.

In the previous chapter, there were non-significant trends seen in the data with current AT users reporting higher perceptions of illness effect, symptom experience, illness concern and lower levels of illness coherence than those not using AT. Jessop and Rutter (2003) found that illness perceptions predicted adherence behaviour in chronic conditions yet Brandes and Mullan (2014) concluded in their meta-analysis that many studies examining illness perceptions and adherence behaviours exhibited small effect sizes suggestive of only a weak relationship. However, this synthesis itself mostly comprised of cross-sectional studies which limits the conclusions that can be drawn and again highlights the need for longitudinal analyses of illness processes.

As described earlier in this thesis (see the review in Chapter 2), it has been determined that AT devices can alleviate the negative consequences of living with MS. In the systematic review conducted by this author, there was some evidence from few longitudinal studies that physical and psychological quality of life could improve for PwMS following the use of AT equipment. The reported outcomes ranged from physical function, reduced perceived disability, fatigue, self-esteem however the review also revealed concerns regarding the negative impact of using some AT devices i.e. perceived stigma, embarrassment, and reduced quality of life as a result of dependency. The qualitative study described in Chapter 3 (Squires et al., 2016) went on to support such findings whilst highlighting other factors not considered previously in any integrated manner when looking at AT use and the physical and psychological impact of living with MS, for example, the influence of personal factors (i.e. optimism), cognitions (e.g. illness perceptions, acceptance

of MS and AT) and external factors (e.g. device perceptions, social support). While illness acceptance and device perceptions are not typically considered CSM constructs the data presented in this thesis so far have highlighted their potential contribution to illness coping behaviours (e.g. device perceptions considered before deciding whether to uptake and use AT device, see Chapter 3; Squires et al., 2016) and outcomes (e.g. positive MS outcomes among those accepting their MS condition, Pakenham & Fleming, 2011; Squires et al., 2016), and as such encouraged further study.

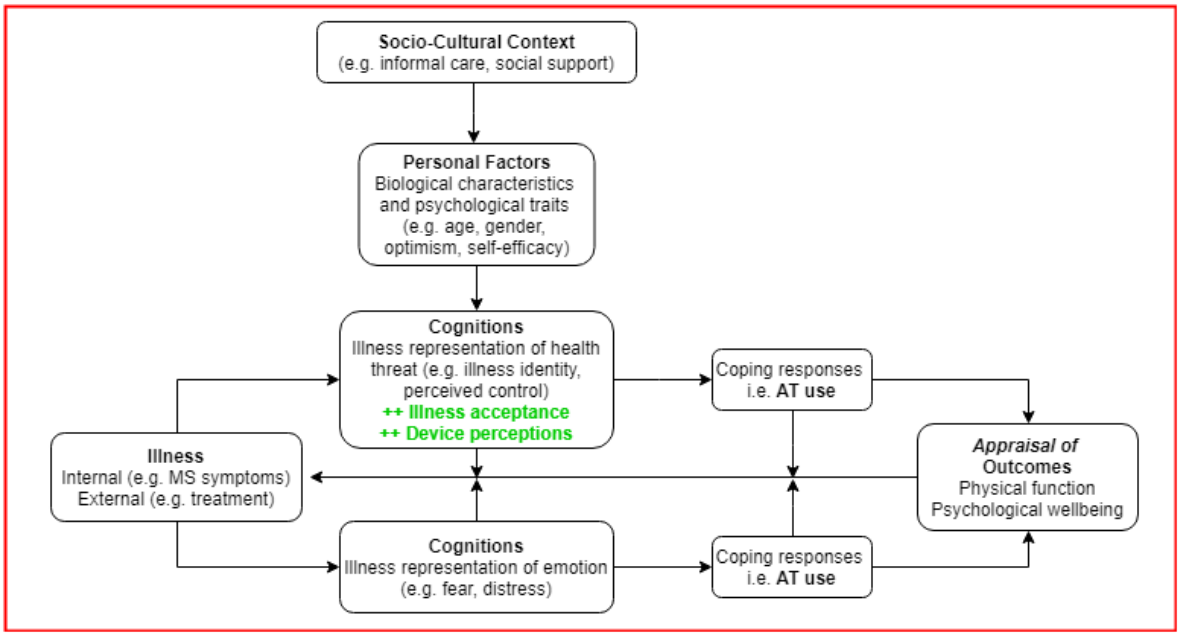

Figure 5.1 Leventhal's (1980; 1992; 2003) Common Sense Model of Self-Regulation of Illness. Chapter 5 to focus on the physical and psychological outcomes of MS and their predictors

As described in Chapter 1, the CSM model also recognises the personal factors (i.e. biological and psychological traits) that shape our illness perceptions and outcomes. For example, depression has been found to be more likely evident in PwMS of an older age and in those who had lived with MS longer (McIvor, Riklan & Reznikoff, 1984; Wood et al., 2013).

In addition to this, external influences on emotional outcomes have been identified with low social support found to be a significant predictor of depression and QoL in MS (McIvor et al., 1984; Mikula et al., 2016).

Given the relevance of the biopsychosocial factors identified above in the physical and psychological outcomes of PwMS and AT use, and the scant longitudinal evidence of MS impact - despite many researchers recognising the fluctuating and unpredictable nature of MS requiring long-term support - this chapter aims to address the questions of how these factors are associated with such outcomes in PwMS who use AT across a 12-month period (see Figure 5.1). Due to the mixed evidence, we look to further explore the relationship between AT use and levels of physical and psychological functioning, and establishing what role, if any, AT use contributes to the CSM of illness self-regulation. Based on the literature reviewed in Chapters 1 and 2, specifically the CSM, and our qualitative and baseline findings (Chapters 3 and 4 respectively), we hypothesise:

- Clinical and demographic factors (i.e. age, being unemployed, in receipt of informal care and receiving MS treatment) at each time point will be significantly associated with 12-month physical and psychological impact of MS
- Optimism at each time point will be significantly positively associated with 12-month physical and psychological impact of MS
- Social support at each time point will be significantly positively associated with 12-month physical and psychological impact of MS

- Cognitions (i.e. more positive illness perceptions, higher illness acceptance) at each time point will be significantly positively associated with 12-month physical and psychological impact of MS
- AT use* at each time point will be significantly positively associated with 12-month physical and psychological impact of MS

Method

Participants

Participants were 70 people with MS where a total of 51 females (73%) and 19 males completed the questionnaire at each time point.

Participants were aged from 26-79 years (*M*=53.19yrs, *SD*=12.44). PwMS were white British with the exception of one Dutch and one Irish participant. Most PwMS (74%, *n*=52) were unemployed, 53% of whom attributed this to their MS (*n*=37). More participants (67%, *n*=47) reported having a significant other than those who did not. Of those with a significant other, the mean value of relationship quality rated by PwMS was 3.83 (='excellent'; 0-4 with 0=, 4='excellent').

The length of time since diagnosis ranged from 0-42 years (*M*=14.39yrs, *SD*=9.98) with most PwMS reporting a progressive form of MS (56%, *n*=39; 16% primary and 40% secondary). Relapse-remitting MS was reported by 24 PwMS (34%) while 7 PwMS (10%) did not report their MS type. The mean value of severity reported by PwMS was 2.24 ('average'; 0-4 with 0='not severe at all', 4='extremely severe'). Co-morbidities were reported by 39 PwMS (56%). Thirty-nine (56%) participants reported being in receipt of

medical treatment for their MS symptoms. All participants were able to speak, write and understand English; and had no current severe cognitive impairment as self-determined.

Design

The longitudinal findings of a 4-wave longitudinal survey to explain MS outcomes from psychosocial variables drawn from SRT including number of AT devices used hypothesised as coping are reported in this chapter, with cross-sectional correlates of AT use having been presented in Chapter 4.

Measures and Procedure

The measures used and the study procedure are described in earlier Chapter 4, pages 110-114. These measures include:

- Demographic and clinical characteristics
- Life Orientation Test-Revised (optimism)
- Duke Social Support Index-10
- Brief Illness Perceptions Questionnaire
- Acceptance of Chronic Health Conditions
- AT use and device perceptions questionnaires

*One of the key aims of this thesis was to study the impact of AT use on the levels of physical and psychological functioning among PwMS however this could not be explored longitudinally due to insufficient numbers of PwMS that were not using AT at the subsequent time points (e.g. n=6, n=2, n=4). Therefore AT use was measured via the reported number of devices currently used.

In addition, the current chapter addresses, as dependent variables, the physical and psychological impact of MS as described below.

Physical and psychological impact of MS The 29-item Multiple Sclerosis Impact Scale (MSIS-29; Hobart, Lamping, Fitzpatrick, Riazi & Thompson, 2001) was used to measure the impact of MS over the last two weeks as reported by participants. Each item is scored on a 5-point Likert scale ranging from 1 to 5 with higher scores reflecting higher levels of impairment. The MSIS consists of two subscales assessing the physical (20 items) and psychological (9 items) impact of MS. The internal reliability of both subscales were excellent (physical, α=.96; psychological, α=.91).

Statistical Analysis

Data were analysed using SPSS version 22. Before analyses, data were screened for missing values. Missing values were substituted by the mean value of individuals' measurement score (Tabachnick & Fidell, 2013) in situations where either measure specific limits were advised or when <30% of values were missing. If limits were exceeded the case was omitted from analyses. In the first step of analyses, frequencies for categorical data and descriptives for continuous variables were conducted. Attrition analyses was also performed in order to identify potential differences between completers and non-completers. Independent t-tests and ANOVAs were conducted in order to explore differences of demographic and clinical characteristics on independent (IVs) and dependent variables (DVs). One-way repeated measures ANOVAs were performed to explore potential changes over time (T1, T2, T3, T4) in physical and psychological functioning (including anxiety and depression), illness perceptions, illness acceptance, optimism, self-efficacy and social support scores. Where the assumption of sphericity was violated, degrees of freedom were

corrected using the Greenhouse-Geisser correction and Bonferroni correction was used for any post hoc pairwise comparisons. To confirm potential predictors for regression analysis, and to check for multicollinearity of such predictors, bivariate and partial correlations were performed at each time point. Due to multiple comparisons, correlation requirement for inclusion to regression models was set an alpha level of .002. A series of hierarchical regression analyses were performed in order to determine the contributions of the independent variables at each time point on physical and psychological impact of MS (all absolute scores). Ideally, the sample size for regression is $N \geq 50+8*m$ (m=IVs) (Tabachnick & Fidell, 2013); however the lowest possible ratio is set to 5 cases per predictor (Coakes & Steed, 2009).

Results

Attrition Analyses

One hundred and twenty five participants completed the baseline assessment, 93 participants completed the 3 month assessment, 91 participants completed the 6 month assessment and 90 participants completed the final 12 month assessment. Of these 70 completed each time point and are thus used as the sample in the prospective analyses. Chi-square analyses were performed to examine potential differences in the distribution around categorical demographic (i.e. gender, employment, with significant other) and clinical characteristic variables (i.e. MS type, comorbidities, medication, AT use) between completers and non-completers. No significant differences were found i.e. non-completers were not more often single or diagnosed with other conditions to MS etc. In addition, when compared in term of the continuous variable of age, t-test analysis revealed no significant age differences between completers vs. non-completers ($t(118)= -1.26$, $p=$ ns.). There were

also no significant differences between completers vs. non-completers on any potential predictor variables (i.e. optimism, illness perceptions, acceptance of MS, number of AT devices) nor on any planned outcome variables (i.e. physical or psychological impact of MS). Taken together these analyses suggest that the final sample were representative of the recruited sample and as such those influencing factors identified in Chapter 4 can be carried through to the current analyses.

Influences of Demographic and Clinical Characteristics on Key Variables within the Final Sample

Due to the number of comparisons, a conservative Bonferroni adjustment was applied (.05/18=002). Thus, there were no significant effects of employment, significant others, MS type, comorbidities found on any key predictor or outcome variables (to see full unadjusted results, Appendix D).

The influence of gender Independent t-tests showed a significant gender difference in perceived illness symptoms, with males reporting more symptoms than females at each time point (3 months: $t(68)= -2.90$, $p= .001$, $M= 7.89$, $SD= 1.56$ vs. $M= 6.41$, $SD= 2.01$ respectively; 6 months: $t(68)= -3.36$, $p= .001$, $M= 8.32$, $SD= 1.38$ vs. $M= 6.82$, $SD= 1.74$ respectively; 12 months: $t(68)= -3.31$, $p= .001$, $M= 8.32$, $SD= 1.29$ vs. $M= 6.70$, $SD= 1.97$ respectively: see Appendix D for full analysis).

The influence of MS medication use vs non-use The following findings emerged at the 3-month time-point only. There were significant treatment effects on illness perceptions with those on medication for their MS reporting higher levels of perceived illness concern ($M= 7.49$, $SD= 2.35$ vs. $M= 5.13$, $SD= 2.83$; $t(68)= 3.69$, $p= .000$), and emotional effect of MS

(*M*= 6.91, *SD*= 2.31 vs. *M*= 4.91, *SD*= 2.45; *t*(68)= 3.34, *p*= .001) compared to those not on medication. Participants on medication for their MS reported significantly lower levels of illness acceptance (*M*= 31.09, *SD*= 7.00) compared to those not on medication (*M*= 38.11, *SD*= 6.80; *t*(68)= -3.98, *p*= .000).

There were no significant effects found of demographic or clinical variables on the physical or psychological impact of MS at any time point.

Nature of AT Use within the Final Sample

Due to insufficient numbers of PwMS **not** using AT at each of the study time points (i.e. 3 months, n=6; 6 months, n=5; 12 months, n=4), the impact of AT use *per se* (i.e. yes/no to use) could not be examined on the physical or psychological outcomes of MS. As a result AT use – i.e. engagement with self-management behaviour – will be measured by the number of AT devices used instead.

Similar to Chapter 4, the majority of AT devices recently acquired by PwMS were mobility and environmental aids (see Table 5.1). Other common devices included kitchen, medical, memory aids and telecare.

Table 5.1 Use of recently acquired AT device over time

	Baseline AT users (*n*=60)	**3-month AT users (*n*=64)**	**6-month AT users (*n*=65)**	**12-month AT users (*n*=66)**
Mobility	35 (58%)	38	37	39
Environmental	14 (23%)	14	16	15
Bathing aids	1 (1.7%)	1	1	1
Medical devices	1 (1.7%)	1	1	1
Memory aids	0 (0%)	1	0	0
Kitchen aids	1 (1.7%)	2	2	2
Telecare	3 (5%)	3	3	3
Communication	2 (3%)	1	2	2
Miscellaneous devices	3 (5%)	3	3	3

Telecare, communication and 'other' aids The use of these forms of AT could not be tested in terms of their impact on MS physical and psychological outcome due to an insufficient number of individuals using them (see Table 5.1).

Mobility and environmental devices

Following Bonferroni adjustment these findings became non-significant therefore being conservative, it cannot be concluded that these devices had a significant impact on any concurrent key study variables or upon physical and psychological outcomes at any time point (Bonferroni adjustment at $p<.002$; see Appendix D). Similarly, use of such devices at baseline, 3-months and 6-months showed no impact on 12-month study variables.

At 3 months, environmental device users reported lower concurrent psychological impact of MS ($t(37.04)= 2.31$, $p= .026$, $M= 25.43$, $SD= 8.70$ vs. $M= 21.21$, $SD= 5.03$). Participants using environmental devices, such as environmental control systems, held more threatening beliefs about MS treatment concurrently at 3 months ($t(62)= -2.22$, $p= .030$, $M= 4.18$, $SD= 3.03$ vs. $M= 6.14$, $SD= 2.51$) and 6 months ($t(63)= -2.24$, $p= .029$, $M= 4.55$, $SD= 2.51$ vs. $M= 6.20$, $SD= 2.72$).

Participants using mobility devices, such as wheelchairs, at 6 months reported less positive concurrent 'device perceptions' ($t(62)= 2.02$, $p= .048$, $M= 32.68$, $SD= 4.59$ vs. $M= 30.32$, $SD= 4.65$). Those using mobility devices at baseline reported greater psychological impact of MS at 12 months ($t(58)= -2.58$, $p= .012$, $M= 20.62$, $SD= 7.55$ vs. $M= 26.13$, $SD= 8.55$).

Changes in Study Variables Over Time

A summary of the repeated measures ANOVAs conducted in order to address questions regarding change in key IVs and DVs over time is presented in Table 5.2.

Physical functioning and psychological wellbeing The physical impact of MS remained stable over time $F(2.59, 178.51)= 2.17$, $p= .10$, $\eta_p^2= .030$; ($\chi^2(5) = 15.08$, $p= .01$, Greenhouse-Geisser correction $\varepsilon= .86$), as did the psychological impact of MS $F(3, 207)= 0.33$, $p= .81$, $\eta_p^2= .005$.

Illness and emotional representations Unlike the proposed outcome measures of wellbeing, some areas of significant change over time were seen in terms of the cognitive and emotional representations. Perceived illness effect decreased significantly over time, $F(3, 207)= 2.75$, $p= .04$, $\eta_p^2= 0.38$, with post hoc comparisons showing a significant decrease between baseline and 3 months ($p= .01$). Concern regarding illness also decreased significantly over time, $F(3, 204)= 3.04$, $p= .03$, $\eta_p^2= 0.43$, with post hoc comparisons showing a significant decrease between baseline and 12 months ($p= .02$). In addition, a small, significant decrease in perceptions of emotional effect was observed, $F(2.66, 181.06)= 3.41$, $p= .02$, $\eta_p^2= .048$; ($\chi^2(5) = 16.60$, $p= .005$, Greenhouse-Geisser correction $\varepsilon= .88$), however post hoc comparisons found this not to be significant ($p= .08$).

In contrast to these decreases, stability was seen in relation to perceptions of illness identity ($F(3, 204)= 1.59$, $p= .19$, $\eta^2= .023$), perceptions of illness timeline ($F(2.23, 153.77)= 0.67$, $p= .53$, $\eta_p^2= .01$; ($\chi^2(5) = 38.17$, $p= .000$, Greenhouse-Geisser correction $\varepsilon= .74$), perceptions of personal control ($F(3, 207)= 0.72$, $p= .54$, $\eta_p^2= .010$), perceptions of

treatment control $F(3, 204)= 0.51$, $p= .68$, $\eta_p^2= .007$), and perceived illness coherence ($F(3, 204)= 0.62$, $p= .60$, $\eta_p^2= .009$).

Acceptance, optimism and social support Acceptance of MS did not change over time $F(2.45, 169.31)= 1.06$, $p= .36$, $\eta_p^2= .015$; ($\chi^2(5) = 21.47$, $p= .001$, Greenhouse-Geisser correction $\varepsilon= .82$). A small, significant increase in optimism was observed $F(3, 204)= 3.65$, $p= .01$, $\eta_p^2= .051$, with post hoc comparisons showing that the significant increase in participants' optimism was between baseline and 3 months ($p= .04$) and between baseline and 12 months ($p= .03$). Social support (including network and satisfaction subscales) also showed no significant changes over time $F(3, 207)= 0.45$, $p= .72$, $\eta_p^2= .006$.

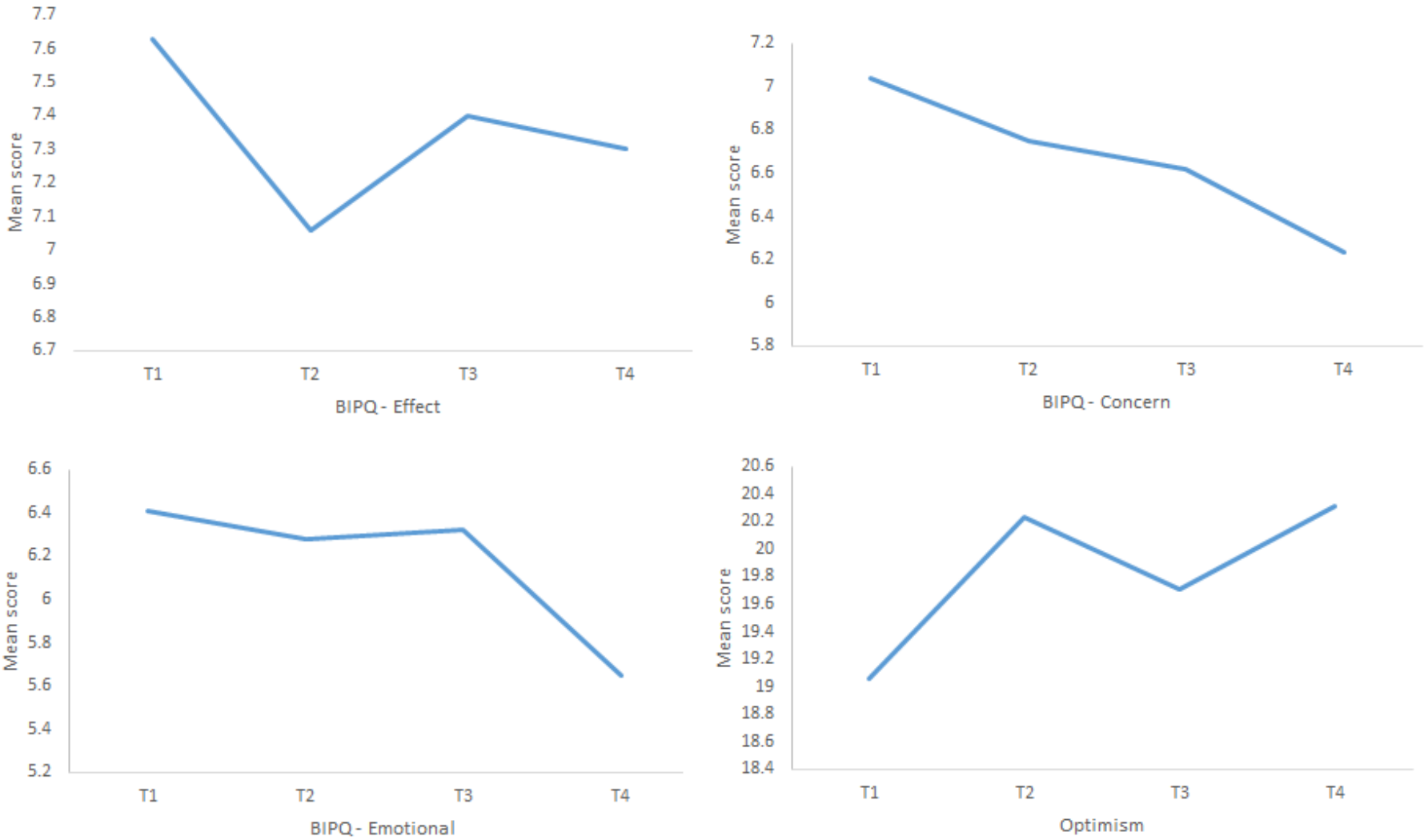

Figure 5.2 Changes over time in illness perceptions and optimism

Table 5.2 Summary of changes over time in all study variables including outcomes (physical and psychological impact of MS) (n=70)

	T1	T2	T3	T4		
Variable	M (*SD*)	M (*SD*)	M (*SD*)	M (*SD*)	*F*	*p*
MS-PHYS	67.01 (15.84)	64.68 (17.11)	67.73 (15.77)	67.86 (15.55)	2.17	.10
MS-PSYCH	24.46 (7.84)	24.12 (8.35)	24.60 (8.56)	23.94 (8.77)	0.33	.81
BIPQ – Effect	7.63 (1.68)	7.06 (2.06)	7.40 (1.86)	7.30 (1.94)	2.75	.04*
BIPQ – Timeline	9.85 (0.68)	9.72 (0.96)	9.66 (1.18)	9.76 (1.00)	0.67	.53
BIPQ – P. Control	6.21 (2.76)	6.26 (2.67)	5.87 (2.65)	6.33 (2.45)	0.72	.54
BIPQ – T. Control	4.90 (2.77)	4.65 (2.94)	4.96 (2.59)	5.04 (2.67)	0.51	.68
BIPQ – Symptoms	7.04 (1.87)	6.86 (1.99)	7.28 (1.74)	7.17 (1.94)	1.59	.19
BIPQ – Concern	7.04 (2.49)	6.75 (2.74)	6.62 (2.54)	6.23 (2.89)	3.04	.03*
BIPQ – Coherence	2.07 (2.33)	2.19 (2.28)	1.88 (2.01)	2.00 (2.00)	0.62	.60
BIPQ – Emotions	6.41 (2.43)	6.28 (2.54)	6.32 (2.52)	5.65 (2.81)	3.41	.02*
Acceptance	32.29 (7.62)	33.39 (7.64)	33.35 (7.76)	33.42 (7.48)	1.06	.36
Optimism	19.06 (5.72)	20.23 (5.10)	19.71 (5.74)	20.31 (5.64)	3.65	.01*
Social Support	22.00 (3.91)	22.02 (3.72)	21.93 (3.99)	21.68 (4.26)	0.45	.72

Abbreviations: MS-PHYS= physical impact of MS; MS-PSYCH= psychological impact of MS; BIPQ= brief illness perceptions questionnaire; P. Control= personal control; T. control= treatment control; *p<.05

Concurrent Correlational Analysis of All Key Study Variables

To confirm potential influencing variables on the physical and psychological impact of MS, correlations and partial correlations (controlling for previously identified influencing variables) were run at each time point. These were also run to identify any multicollinearity between potential predictors for any later regression analyses.

AT Use The number of AT devices used by PwMS was significantly positively correlated with the physical impact of MS at 3 months (r=.49, p<.001) thus those with greater physical impact of MS use more AT. A trend was also identified between the number of AT devices used and social support.

Table 5.3 Correlation and partial correlation analysis of key variables at 3 month (n=70)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Age	-																
2. Yrs fr. Diagnosis	**.537****	-															
3. Sev. of MS	.033	.136	-														
4. No. of devices	.230	.098	.207	-													
5. Device p'cepts	.024	-.060	-.178	.066	-												
6. Effect of MS	.015	.147	**.619****	.281*	-.136	-											
7. Timeline	-.107	.059	-.127	.025	.039	-.096	-										
8. Personal control	.084	-.135	.275*	.011	-.218	.168	.163	-									
9. T. control	.146	.152	.305*	-.113	-.257*	.181	.085	**.407****	-								
10. Identity	.029	.063	**.643****	.252*	-.153	**.675**^{**a}	-.097	.194	.220	-							
11. Concern	-.006	.031^{c}	**.469****	.196	-.143	**.637**^{**c}	-.297^{*c}	.128	-.094	**.419**^{**ac}	-						
12. Coherence	-.090	-.282*	-.027	-.021	-.291*	.013	-.100	.144	.065	.011	.068	-					
13. Emotions	-.079	-.116	.304*	.202	-.167	**.383**^{**c}	-.049	.184	.038	.230	**.447**^{**ac}	.186	-				
14. MS Acceptance	-.057	.045	**-.409****	-.191	.175	**-.322**^{**c}	.128	-.212	.073	-.246^{*ac}	**-.543**^{**ac}	-.291^{*c}	**-.483**^{**ac}	-			
15. Optimism	.055	.208	-.233	.053	.183	-.152	-.003	-.058	.042	-.009	-.338^{*c}	-.202	-.394^{**c}	-.374^{**c}	-		
16. Social Support	.120	.023	-.135	.124	.348**	-.135	.156	-.007	-.163	-.080	-.041	-.299*	**-.440**^{**c}	-.361^{**c}	**-.493**^{**c}	-	
17. MSIS PHYS	.147	.068	**.585****	**.492****	-.035	**.695****	.020	.309**	.176	**.631**^{**a}	**.457**^{**c}	.013	.349^{**c}	-.240^{c}	-.291^{*c}	**.693****	-
18. MSIS PSYCH	-.101	-.184	.360**	.212	-.096	**.415****	.140	.086	.050	**.480**^{**a}	.376^{**c}	.080	**.559**^{**c}	.384^{**c}	-.210^{ac}	.303*	**.529****

[a]partial correlation controlling for gender; [c]partial correlation controlling for medication; *p< .05, **p< .01, ****p*< .001 (including Bonferroni correction)**

Table 5.4 Correlation and partial correlation analysis of key variables at 6 month (n=70)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Age	1																
2. Yrs fr. Diagnosis	**.537*****	1															
3. Sev. of MS	.108	.266*	1														
4. No. of devices	.144	.059	.187	1													
5. Device p'cepts	.071	-.072	-.184	.117	1												
6. Effect of MS	.047	.107	**.597*****	.180	-.077	1											
7. Timeline	.072	.049	.016	-.020	-.049	.109	1										
8. Personal control	.090	-.065	.265*	-.171	-.164	.305*	.307**	1									
9. T. control	.159	.095	.090	-.116	-.101	.176	-.005	.283*	1								
10. Identity	.113	.052	**.555*****	.159^{a}	-.026	**.505**^{***a}	.371^{**a}	.272^{*a}	.140	1							
11. Concern	-.036	.068	**.407*****	.131	-.130	**.517*****	.323**	.083	-.072	**.438**^{***a}	1						
12. Coherence	-.156	-.359**	-.029	-.208	-.021	.124	.176	.370**	-.087	.030	.186	1					
13. Emotions	-.074	-.037	.222	.112	-.101	**.472*****	.097	.083	.131	.383^{**a}	**.549*****	.104	1				
14. MS Acceptance	-.164	-.167	-.367**	-.035	.121	-.359**	.009	-.214	-.009	-.182^{a}	**-.499*****	-.289*	**-.389*****	1			
15. Optimism	-.040	.134	-.039	.088	.083	-.295*	-.202	-.182	.011	-.160	**-.420*****	-.365**	**-.401*****	**-.474*****	1		
16. Social Support	.034	-.009	-.129	.299*	.043	-.334**	-.088	-.134	-.136	-.150	-.271*	-.306**	-.283*	-.296*	**-.506*****	1	
17. MSIS PHYS	.156	.172	**.560*****	.330**	-.224	**.523*****	.289*	.341**	.132	**.624**^{***a}	**.478*****	.083	**.394*****	**-.377*****	**-.460*****	**.762*****	1
18. MSIS PSYCH	-.045	-.156	.247*	.109	-.119	**.373*****	.297*	.179	.055	.380^{**a}	**.454*****	.163	**.667*****	**.532*****	**-.399*****	**.441*****	**.452*****

[a]partial correlation controlling for gender; *p< .05, **p< .01, ***p< .001 (including Bonferroni correction)**

Table 5.5 Correlation and partial correlation analysis of key variables at 12 month (n=70)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Age	1																
2. Yrs fr. Diagnosis	**.537*****	1															
3. Sev. of MS	.128	.117	1														
4. No. of devices	.099	.072	.117	1													
5. Device p'cepts	.036	.188	-.279*	.010	1												
6. Effect of MS	-.055	.066	**.526*****	.074	-.126	1											
7. Timeline	.028	-.108	.126	-.139	.146	.038	1										
8. Personal control	.036	-.175	.240*	-.079	-.257*	.222	.258*	1									
9. T. control	.036	.060	.154	.222	-.036	.284*	.007	.174	1								
10. Identity	-.057	-.067	**.436**^{**a}	.173	-.144	**.585**^{***a}	.055	.144	.114	1							
11. Concern	-.167	-.097	.349**	-.013	-.114	**.563*****	-.007	.022	.238*	**.451*****	1						
12. Coherence	-.101	-.255*	-.098	-.114	-.327**	.021	**-.399****	-.043	-.084	-.029	.201	1					
13. Emotions	-.198	-.225	.183	.003	-.220	**.481*****	-.076	.082	.156	**.365**^{**a}	**.753*****	.312**	1				
14. MS Acceptance	-.025	-.098	-.178	.081	.135	-.266*	.199	-.043	-.127	-.102	**-.497*****	-.311**	**-.502*****	1			
15. Optimism	-.022	.177	-.120	.244*	.150	-.267*	-.046	-.159	.100	-.254^{a}	**-.382****	-.296*	**-.514*****	**-.449*****	1		
16. Social Support	.016	.013	-.106	.329**	.189	-.286*	.058	-.299*	-.077	.033	-.325**	-.201	**-.435*****	**-.389****	**-.468*****	1	
17. MSIS PHYS	.059	.048	**.452*****	.293*	-.024	**.603*****	.064	.189	.298*	**.542**^{***a}	**.481*****	.010	**.492*****	**-.452*****	-.360**	**.806*****	1
18. MSIS PSYCH	-.155	-.196	.195	-.095	-.155	**.470*****	.211	.233	.138	.299^{*a}	**.567*****	.136	**.700*****	**.618*****	**-.472*****	**.516*****	**.534*****

[a]partial correlation controlling for gender; *p< .05, **p< .01, ***p< .001 **(bold=meets Bonferroni correction)**

Concurrent correlates of primary physical and psychological outcome variables

While controlling for gender and MS medication usage at the appropriate time-points, the perceived severity of MS, effect of MS, symptom experience, illness concern, and the psychological impact of MS was significantly positively associated with the physical impact of MS at each time point. The emotional impact of MS was also found to positively correlate with the physical impact of MS at two time points (see Tables 5.3-5.5). In addition, acceptance of MS significantly negatively correlated with physical impact of MS at 3 and 12 months i.e. lower impact in those accepting their MS.

Similarly, the perceived effect of MS and emotional impact were significantly positively correlated with the psychological impact of MS at each concurrent time point (see Tables 5.3-5.5). In addition, symptom experience (3 months only) and illness concern (6 and 12 months only) were significantly correlated with concurrent psychological impact of MS. Acceptance of MS, optimism and social support were found to significantly negatively correlate with psychological impact of MS i.e. higher impact in those not accepting of their MS.

Illness beliefs The overall negative effect of MS was significantly associated with the severity of MS, high illness identity, concern and emotional impact beliefs as well as low levels of acceptance (see Tables 5.3-5.5). Treatment control beliefs were significantly positively associated with personal control beliefs. Identity beliefs (while controlled for gender) were significantly associated with severity of MS and concern at each time point, as well as perceived emotional impact of MS at 12 months. Concern beliefs were significantly associated with severity of MS, emotional impact of MS, as well as negatively associated with acceptance of MS and optimism at 6 and 12 months. Finally, beliefs regarding the

emotional effect of MS was significantly associated with low acceptance of MS, social support and optimism.

Other psychological variables Finally, acceptance of MS was significantly associated with higher levels of optimism and social support at 6 months only.

Prospective Correlates of Primary Physical and Psychological Outcome Variables

Given the above evidence of the hypothesised concurrent associations between illness perceptions (i.e. severity, effect of MS, symptom experience, concern), psychosocial variables (i.e. acceptance, optimism and social support) and physical and psychological outcomes, the subsequent analysis then focused on identifying whether such relationships persisted prospectively i.e. examined the potential predictors of 12 month physical and psychological impact of MS. Those identified are subsequently selected for entry into regression analysis along with those that have been informed by previous literature (see Chapter 1) and thesis data (see Chapters 3-4).

While controlling for carer, employment, gender and MS type at the appropriate time-points, perceived MS affect, identity, physical and psychological impact of MS (at each earlier time point) were significantly correlated with the **physical impact** of MS at 12-months (see Tables 5.6-5.8). Perceived severity of MS at 3- and 6- months was also positively correlated with the physical impact of MS at 12-months. Perceived illness concern and emotional impact of MS at 6 months were also significantly correlated with the final physical impact of MS.

Table 5.6 Correlational analysis of potential **baseline predictor variables and 12-month MS physical and psychological outcomes** (Bonferroni = <.002)

	Age	Yrs since Dx	MS Severity	No. of AT devices	Device perceptions	MS Affect	Timeline	P. Control	T. Control	Identity	Concern	Coherence	Emotional effect	MSIS Physical	MSIS Psych	Acceptance	Optimism	Soc. Support
12m Physical impact	-.016[ac]	.021[c]	.317[*abc]	.082[abc]	-.067	**.463[**abc]**	.071	.199	.087	**.438[**a]**	.281[*]	.084	.296[*]	**.548[**ab]**	**.450[**]**	-.347[**]	-.150	-.197
12m Psych. impact	-.225[ac]	-.162[c]	-.012[abc]	-.027[abc]	-.195	.278*[abc]	-.007	.067	-.029	.223	.321[**]	.139	**.468[**]**	.338[**ab]	**.677[**]**	-.367[**]	**-.483[**]**	-.346[**]

[a,b,c,] Partial correlations, controlling for [a]=employment; [b]=carer; [c]=MS type

Table 5.7 Correlational analysis of potential 3-**month predictor variables and 12-month MS physical and psychological outcomes** (Bonferroni = <.002)

	MS Severity	No. of AT devices	Device perceptions	MS Affect	Timeline	P. Control	T. Control	Identity	Concern	Coherence	Emotional effect	MSIS Physical	MSIS Psych	Acceptance	Optimism	Soc. Support
12m Physical impact	**.540[**]**	.179	-.098	**.467[**]**	.086	.226	.183	**.487[**a]**	.316[**b]	.035	.262[*b]	**.709[**]**	**.573[**]**	-.215[b]	-.128	-.153
12m Psych. impact	.258[*]	-.080	-.284[*]	.196	.040	.025	.064	.150	.256[*b]	.169	**.402[**b]**	.294[*]	**.662[**]**	-.282[*b]	**-.501[**]**	-.343[**]

[a,b,] Partial correlations, controlling for [a]=gender; [b]=medication

Table 5.8 Correlational analysis of potential **6-month predictor variables and 12-month MS physical and psychological outcomes** (Bonferroni = <.002)

	MS Severity	No. of AT devices	Device perceptions	MS Affect	Timeline	P. Control	T. Control	Identity	Concern	Coherence	Emotional effect	MSIS Physical	MSIS Psych	Acceptance	Optimism	Soc. Support
12m Physical impact	**.539****	.210	-.088	**.490****	.067	.274*	.108	**.629**^{**a}	**.390****	.148	**.436****	**.738****	**.497****	-.328**	-.266*	-.208
12m Psych. impact	.233	-.064	-.222	.287*	.104	.046	-.035	.222	.346**	.255*	**.499****	**.374****	**.745****	**-.397****	**-.500****	-.305*

[a,] Partial correlations, controlling for [a]=gender

The emotional effect of MS and the psychological impact of MS from each prior time point significantly correlated with **psychological impact** of MS at 12-months. Optimism was also a negative correlate at each time point. Illness acceptance (6-month) was also negatively correlated with 12-month psychological outcomes. Finally, 6-month physical impact of MS was found to be significantly correlated with 12-month psychological impact of MS (see Tables 5.6-5.8).

Those variables related to physical and psychological impact for each time point were put forward in hierarchical regressions according to Self-Regulation of Illness theory i.e. beginning with generally non-modifiable variables (e.g. gender), then illness and personal factors (e.g. MS type), beliefs/cognitions (e.g. regarding illness severity), then mood (e.g. psychological wellbeing). Selected variables were screened and selected following multicollinearity checks (see Tables 5.3-5.5).

Predicting Physical Impact of MS (Regression analysis)

Predicting physical impact from baseline (Table 5.9) The model explained approximately 43% of the variance in the physical impact of MS on participants 12 months after baseline ($F(9, 53) = 4.48$, $p < .001$). Baseline clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) explained approximately 11% of the variance which was not significant. Baseline physical impact of MS added a significant 26% of the variance ($F_{change}(1, 56) = 23.31$, $p < .001$). Baseline cognitions (i.e. perceived illness effect and illness identity) added a non-significant 6% of the variance and finally, number of AT devices used at baseline added 0% of the variance ($F_{change}(1, 53) = 0.87$, $p = .77$)

Beta coefficients showed that baseline physical impact of MS was significantly related to physical impact of MS 12 months later (β= .39, t(62)= 2.67, p< .05).

Table 5.9 Hierarchical regression of physical impact of MS at 12 months from baseline variables (n=63)

Baseline Variables	B	SE B	*B*
Step 1			
Gender	5.91	4.50	.18
MS Type	0.58	4.99	.02
Employment	-1.27	5.10	-.03
Informal carer?	8.25	4.16	.26
MS treatment?	-2.20	4.56	-.07
Step 2			
Gender	6.80	3.82	.20
MS Type	-1.15	4.25	-.04
Employment	3.37	4.43	.09
Informal carer?	3.51	3.66	.11
MS treatment?	0.82	3.91	.03
Physical impact of MS	0.57	0.12	.56***
Step 3			
Gender	3.21	4.01	.10
MS Type	-0.62	4.16	-.02
Employment	5.17	4.37	.14
Informal carer?	4.54	3.72	.14
MS treatment?	1.49	3.83	.05
Physical impact of MS	0.38	0.14	.38**
Illness effect	1.44	1.27	.16
Illness identity	1.85	1.18	.23

Baseline Variables	B	SE B	*β*
Step 4			
Gender	3.12	4.06	.09
MS Type	-0.42	4.24	-.01
Employment	5.11	4.42	.14
Informal carer?	4.57	3.75	.15
MS treatment?	1.31	3.91	.04
Physical impact of MS	0.39	0.15	.39*
Illness effect	1.41	1.29	.16
Illness identity	1.82	1.19	.22
Number of AT devices	-0.10	0.35	-.03

Note. R^2 = .11 for Step 1; ΔR^2 = .26 for Step 2, p< .001; ΔR^2 = .06 for Step 3; ΔR^2 = .00 for Step 4; *p< .05; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Predicting physical impact from 3 months (Table 5.10) The model explained approximately 63% of the variance in the physical impact of MS on participants from 3-month variables ($F(9, 56) = 10.79$, $p < .001$). Clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) at 3-months significantly explained approximately 24% of the variance in physical impact of MS ($F_{change}(5, 60) = 3.84$, $p < .01$). Physical impact of MS at 3-months added a significant 36% of the variance ($F_{change}(1, 59) = 53.20$, $p = <.001$). In this instance, illness cognitions (i.e. perceived illness effect and identity) at 3-months added 0% of the variance. Finally, the number of AT devices used at 3-months explained a significant 3% of the variance ($F_{change}(1, 56) = 4.36$, $p < .05$).

Beta coefficients showed that employment ($\beta = .24$, $t(62) = 2.56$, $p < .05$), physical impact of MS ($\beta = .83$, $t(62) = 6.36$, $p < .001$) and the number of AT devices used ($\beta = -.21$, $t(62) = -2.09$, $p < .05$) at 3-months were significantly related to the physical impact of MS at 12-months.

Table 5.10 Hierarchical regression of physical impact of MS at 12-months from 3-month variables (n=66)

3-month Variables	B	SE B	*β*
Step 1			
Gender	4.65	3.95	.14
MS Type	6.91	4.10	.22
Employment	5.56	4.77	.15
Informal carer?	9.03	3.75	.29*
MS treatment?	-10.54	3.87	-.32**
Step 2			
Gender	3.41	2.89	.10
MS Type	3.68	3.03	.12
Employment	10.96	3.57	.29**
Informal carer?	1.39	2.94	.04
MS treatment?	-1.38	3.09	-.04
Physical impact of MS	0.66	0.09	.74***
Step 3			
Gender	2.94	3.07	.09
MS Type	3.76	3.08	.12
Employment	10.61	3.64	.28**
Informal carer?	1.47	3.03	.05
MS treatment?	-1.41	3.19	-.04
Physical impact of MS	0.65	0.11	.73***
Illness effect	-0.58	1.08	-.08
Illness identity	0.75	0.99	.10

3-month Variables	B	SE B	*β*
Step 4			
Gender	1.19	3.10	.04
MS Type	4.60	3.02	.15
Employment	9.24	3.60	.24*
Informal carer?	1.45	2.95	.05
MS treatment?	-2.57	3.15	-.08
Physical impact of MS	0.74	0.12	.83***
Illness effect	-0.85	1.06	-.11
Illness identity	0.90	0.96	.12
Number of AT devices	-0.85	0.41	-.21*

Note. R^2 = .24 for Step 1, p< .01; ΔR^2 = .36 for Step 2, p<.001; ΔR^2 = .00 for Step 3; ΔR^2 = .03 for Step 4, p<.05; *p< .05, **p< .01; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Predicting physical impact from 6 months (Table 5.11) The model explained approximately 60% of the variance in the physical impact of MS on participants from 6-month variables ($F(9, 54) = 9.10$, $p < .001$). Clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) at 6 months explained approximately 13% of the variance in the physical impact of MS, which was not significant. Physical impact of MS at 6-months added a significant 44% of the variance ($F_{change}(1, 57)= 58.59$, $p<.001$). Illness cognitions (i.e. perceived illness effect and identity) at 6-months added a non-significant 3% of the variance. Finally, the number of AT devices used at 6-months added 0% of the variance in the physical impact of MS ($F_{change}(1, 54)= 0.27$, $p= .61$).

Beta coefficients showed that the physical impact of MS at 6-months was significantly related to physical impact of MS at 12 months ($\beta= .56$, $t(62)= 4.49$, $p< .001$).

Table 5.11 Hierarchical regression of physical impact of MS at 12 months from 6-month variables (n=63)

6-month Variables	B	SE B	*β*
Step 1			
Gender	3.56	4.78	.10
MS Type	5.08	4.86	.16
Employment	2.43	5.29	.06
Informal carer?	7.54	4.27	.24
MS treatment?	-4.71	4.53	-.15
Step 2			
Gender	4.32	3.32	.12
MS Type	-0.57	3.50	-.02
Employment	1.55	3.72	.04
Informal carer?	2.39	3.08	.07
MS treatment?	0.58	3.25	.02
Physical impact of MS	0.70	0.09	.72***
Step 3			
Gender	1.57	3.54	.04
MS Type	-0.58	3.44	-.02
Employment	1.65	3.66	.04
Informal carer?	2.38	3.03	.07
MS treatment?	1.17	3.22	.04
Physical impact of MS	0.54	0.12	.56***
Illness effect	0.28	1.01	.03
Illness identity	2.08	1.19	.24

6-month Variables	B	SE B	*β*
Step 4			
Gender	1.16	3.65	.03
MS Type	-0.12	3.58	-.00
Employment	1.67	3.69	.04
Informal carer?	2.66	3.10	.08
MS treatment?	0.68	3.38	.02
Physical impact of MS	0.55	0.12	.56***
Illness effect	0.27	1.01	.03
Illness identity	2.17	1.22	.25
Number of AT devices	-0.22	0.41	-.05

Note. R^2 = .13 for Step 1; ΔR^2 = .44 for Step 2, p<.001; ΔR^2 = .03 for Step 3; ΔR^2 = .00 for Step 4; ***p< .001; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Predicting psychological impact of MS

Predicting psychological impact from baseline IVs (Table 5.12) The model explained approximately 55% of the variance in the psychological impact of MS on participants 12 months after baseline ($F(10, 52) = 6.33$, $p < .001$). Baseline clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) explained approximately 10% of the variance which was not significant. Baseline psychological impact of MS explained 41% of the variance, which was significant ($F_{change}(1, 56) = 46.10$, $p < .001$). Baseline optimism added a significant 4% of the variance ($F_{change}(1, 55) = 4.59$, $p < .05$). Illness cognitions (i.e. perceived emotional effect and acceptance of MS) at baseline added 0% of the variance. Finally, the number of AT devices used at baseline added 0% of the variance in the psychological impact of MS ($F_{change}(1, 52) = 0.16$, $p = .69$).

Beta coefficients showed that MS treatment ($\beta = -.24$, $t(62) = -2.15$, $p < .05$) and the psychological impact of MS ($\beta = .52$, $t(62) = 3.84$, $p < .001$) at baseline were significantly related to the psychological impact of MS 12 months later.

Table 5.12 Hierarchical regression of psychological impact of MS at 12-months from baseline variables (n=63)

Baseline Variables	B	SE B	*β*
Step 1			
Gender	-0.40	2.58	-.02
MS Type	0.66	2.86	.04
Employment	0.76	2.92	.04
Informal carer?	2.41	2.38	.14
MS treatment?	-5.73	2.61	-.32*
Step 2			
Gender	1.82	1.95	.10
MS Type	2.72	2.16	.15
Employment	1.57	2.19	.07
Informal carer?	0.15	1.81	.01
MS treatment?	-4.27	1.96	-.24*
Psychological impact of MS	0.76	0.11	.67***
Step 3			
Gender	1.80	1.90	.09
MS Type	2.68	2.09	.15
Employment	1.90	2.12	.09
Informal carer?	0.91	1.79	.05
MS treatment?	-4.33	1.90	-.25*
Psychological impact of MS	0.61	0.13	.54***
Optimism	-0.36	0.17	-.24*

Baseline Variables	B	SE B	*β*
Step 4			
Gender	2.01	1.95	.11
MS Type	2.54	2.14	.14
Employment	2.02	2.16	.10
Informal carer?	1.05	1.83	.06
MS treatment?	-4.43	1.93	-.25*
Psychological impact of MS	0.59	0.15	.53***
Optimism	-0.34	0.18	-.22
Illness emotional effect	0.33	0.53	.09
Illness acceptance	0.09	0.15	.08
Step 5			
Gender	2.14	1.99	.11
MS Type	2.39	2.20	.13
Employment	2.13	2.20	.10
Informal carer?	1.00	1.85	.06
MS treatment?	-4.27	1.99	-.24*
Psychological impact of MS	0.59	0.15	.52***
Optimism	-0.37	0.20	-.24
Illness emotional effect	0.32	0.54	.09
Illness acceptance	0.09	0.15	.08
Number of AT devices	0.08	0.19	.04

Note. R^2 = .10 for Step 1; ΔR^2 = .41 for Step 2, p< .001; ΔR^2 = .04 for Step 3 p<.05; ΔR^2 = .00 for Step 4; ΔR^2 = .00 for Step 5; * p< .05; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Predicting psychological impact from 3 months (Table 5.13) The model explained approximately 60% of the variance in the psychological impact of MS ($F(10, 55) = 8.12$, $p < .001$). Clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) at 3-months explained approximately 10% of the variance, which was not significant. Psychological impact of MS at 3-months explained 35% of the variance, which was significant ($F_{change}(1, 59) = 36.92$, $p < .001$). Optimism at 3-months explained approximately 11% of the variance which was significant ($F_{change}(1, 58) = 14.79$ $p < .001$). Illness cognitions (i.e. perceived emotional effect and acceptance of MS) at 3-months added a non-significant 1% of the variance. Finally, the number of AT devices used at 3-months added a significant 3% of the variance in the psychological impact of MS ($F_{change}(1, 55) = 4.10$, $p = <.05$).

Beta coefficients showed that the psychological impact of MS was significantly related to impact 9 months later ($\beta = .57$, $t(62) = 5.08$, $p < .001$). Optimism ($\beta = -.29$, $t(65) = -2.86$, $p < .01$) and the number of AT devices used ($\beta = -.20$, $t(62) = -2.03$, $p < .05$) were also significantly associated with the psychological impact at 12 months.

Table 5.13 Hierarchical regression of psychological impact of MS at 12-months from 3-month variables (n=66)

3-month Variables	B	SE B	*β*
Step 1			
Gender	0.13	2.41	.01
MS Type	1.93	2.50	.11
Employment	1.77	2.91	.08
Informal carer?	1.41	2.29	.08
MS treatment?	-5.74	2.36	-.31*
Step 2			
Gender	0.85	1.91	.04
MS Type	1.52	1.98	.09
Employment	1.57	2.30	.07
Informal carer?	-1.11	1.86	-.06
MS treatment?	-1.59	1.99	-.09
Psychological impact of MS	0.66	0.11	.64***
Step 3			
Gender	1.23	1.72	.06
MS Type	1.42	1.78	.08
Employment	2.36	2.09	.11
Informal carer?	-1.49	1.68	-.09
MS treatment?	0.05	1.84	.00
Psychological impact of MS	0.58	0.10	.56***
Optimism	-0.62	0.16	-.37***

3-month Variables	B	SE B	*β*
Step 4			
Gender	1.05	1.77	.05
MS Type	1.35	1.82	.08
Employment	2.78	2.18	.13
Informal carer?	-1.82	1.74	-.10
MS treatment?	0.75	2.02	.04
Psychological impact of MS	0.56	0.12	.54***
Optimism	-0.58	0.17	-.34**
Illness emotional effect	0.08	0.44	.02
Illness acceptance	-0.10	0.14	-.09
Step 5			
Gender	0.14	1.78	.01
MS Type	2.00	1.80	.11
Employment	1.70	2.19	.08
Informal carer?	-1.47	1.70	-.08
MS treatment?	-0.40	2.05	-.02
Psychological impact of MS	0.58	0.12	.57***
Optimism	-0.49	0.17	-.29**
Illness emotional effect	0.12	0.43	.03
Illness acceptance	-0.11	0.13	-.10
Number of AT devices	-0.47	0.23	-.20*

Note. R^2 = .10 for Step 1; ΔR^2 = .35 for Step 2, p< .001; ΔR^2 = .11 for Step 3, p<.001; ΔR^2 = .01 for Step 4; ΔR^2 = .03 for Step 5, p< .05; * p< .05; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Predicting psychological impact from 6 months (Table 5.14) The model explained approximately 66% of the variance in the psychological impact of MS on participants (F(10, 52) = 10.12, p< .001). Clinical-demographics variables (i.e. gender, MS type, employment, having a carer and MS treatment) at 6-months explained approximately 6% of the variance which was not significant. Psychological impact of MS at 6-months explained 54% of the variance, which was significant (F_{change}(1, 56)= 76.06, p< .001), with optimism adding a further significant 6% of the variance (F_{change}(1, 55)= 9.26, p< .01). In this instance, illness cognitions (i.e. perceived emotional effect and acceptance of MS) added 0% of the variance, as did the number of AT devices used at 6-months (F_{change}(1, 52)= 0.47, p=.50).

Beta coefficients showed that the psychological impact of MS was significantly related to impact at 12-months (β= .67, t(62)= 5.83, p< .001). Optimism was also significantly related to impact 6 months later (β= -.27, t(65)= -2.47, p< .05).

Table 5.14 Hierarchical regression of psychological impact of MS at 12-months from 6-month variables (n=63)

6-month Variables	B	SE B	*β*
Step 1			
Gender	-0.36	2.75	-.02
MS Type	-1.56	2.80	-.09
Employment	1.64	3.04	.07
Informal carer?	3.27	2.45	.18
MS treatment?	-2.42	2.60	-.14
Step 2			
Gender	1.12	1.81	.06
MS Type	-0.91	1.84	-.05
Employment	1.00	2.00	.05
Informal carer?	1.32	1.63	.07
MS treatment?	0.74	1.75	.04
Psychological impact of MS	0.76	0.09	.77***
Step 3			
Gender	0.99	1.69	.05
MS Type	-2.02	1.75	-.12
Employment	0.49	1.87	.02
Informal carer?	1.66	1.52	.09
MS treatment?	1.35	1.64	.08
Psychological impact of MS	0.64	0.09	.65***
Optimism	-0.41	0.14	-.27**

6-month Variables	B	SE B	*β*
Step 4			
Gender	1.05	1.78	.05
MS Type	-2.04	1.79	-.12
Employment	0.40	1.97	.02
Informal carer?	1.73	1.60	.10
MS treatment?	1.38	1.70	.08
Psychological impact of MS	0.65	0.11	.65***
Optimism	-0.43	0.15	-.28**
Illness emotional effect	-0.02	0.39	-.01
Illness acceptance	0.02	0.12	.02
Step 5			
Gender	0.88	1.80	.04
MS Type	-1.57	1.93	-.09
Employment	0.45	1.98	.02
Informal carer?	1.93	1.64	.11
MS treatment?	0.96	1.82	.05
Psychological impact of MS	0.66	0.11	.67***
Optimism	-0.40	0.16	-.27*
Illness emotional effect	-0.00	0.39	-.00
Illness acceptance	0.02	0.12	.02
Number of AT devices	-0.15	0.22	-.07

Note. R^2 = .06 for Step 1; ΔR^2 = .54 for Step 2, p< .001; ΔR^2 = .06 for Step 3, p< .01; ΔR^2 = .00 for Step 4; ΔR^2 = .00 for Step 5;* p< .05; female=0, male=1; relapse remitting MS=1, progressive MS=2; not employed=0, employed=1; no carer=0, carer=1; no treatment=0, MS treatment=1

Discussion

The aim of this chapter was to establish the nature of the physical and psychological impact of living with MS and identify predictors of impact. Hypothesised predictors included the personal, clinical, device and social factors that were associated with the physical and psychological impact of MS in the previous chapters (see Chapters 1 and 3). Guided by Leventhal et al.'s Common Sense Model of Illness Self-Regulation (1980; 1992; 2003), the predictors of AT use (see Chapter 4) were also considered due to our positioning of AT use as a coping behaviour; and the role of AT use was to be explored in relation to impact of MS. Hypothesised predictors included:

- Unemployment, in receipt of informal care and MS treatment
- Optimism
- Social support
- Cognitions (i.e. illness perceptions, illness acceptance)
- AT use

Associations and Predictors of the Physical Impact of MS

Perceived MS effect and illness identity, and the earlier physical impact of MS were consistently associated with 12-month physical impact of MS. Given that these illness cognitions are formed on the basis of physical impact, this should perhaps be no surprise. Perceived severity of MS was also associated with its' physical impact. According to self-regulation theory (Leventhal et al., 2003), emotional responses can also shape physical outcomes, as seen here with the perceived emotional effect of MS and illness concern (6-month; and trends at baseline, 3-month) as well as psychological impact of MS (3- & 6-month; and trends at baseline) all associated with 12-month physical impact of MS. It

appears that physical impact of MS is affected more consistently by the psychological impact of MS rather than the other way round. The psychological impact of MS (as measured by the MSIS-29) assessed anxiety, depression, worries but also includes items around sleep and fatigue. This perhaps supports the notion – as discussed in Chapter 2 – fatigue can be viewed as multifaceted due to the physical and psychological overlay of this construct.

Interestingly, trends were also found to be seen with higher acceptance associated with lower impact of MS supporting previous reports that positive processes (e.g. better acceptance) relates to better physical functioning and QoL (Dennison et al., 2010a; Pakenham & Fleming, 2011; van Damme et al., 2016).

Perhaps unsurprisingly, earlier physical impact of MS significantly predicted 12-month physical impact of MS from each preceding time point. It is widely considered that function at any given time can be a significant predictor of itself at a later date. Perceived illness effect and identity are typically strongly associated with concurrent physical impact of MS and in this case, may have been explained by the physical impact of MS. Despite previous literature (i.e. Dennison et al., 2010a; Jopson & Moss-Morris, 2003) reporting the predictive utility of illness perceptions over physical function in MS, in the current study these relations were not found. While other IRs showed positive trends with a conservative Bonferroni adjustment, it was noted that timeline, control and illness coherence held no associations with the physical impact of MS. This is perhaps expected as IRs of control and coherence are often associated with psychological outcomes such as distress and psychological QoL (Dennison et al., 2010a; Jopson & Moss-Morris, 2003). As for timeline within the Brief-IPQ, it asks PwMS how long they think it will last. Given that MS is a chronic

and currently incurable condition, there was little variation within these responses. Perhaps a timeline item measuring the cyclical/relapsing or linear/progressive nature of MS (as in the full IPQ-R measure: Moss-Morris et al., 2002) would allow exploration of how the unpredictability influences outcomes of living with MS.

Similar to the use of AT use, employment was found to be a significant predictor of physical impact of MS – this was found to be from 3-month time point only. This offers support to the CSM theory that socio-demographic factors can shape functional outcomes.

Associations and Predictors of Psychological Impact of MS

The perceived emotional effect of MS and psychological impact of MS at each time point were all associated with 12-month psychological impact of MS highlighting the different emotional responses that make up the psychological impact of living with such a condition. Higher levels of optimism were also found to be consistently associated with lower levels of psychological impact at 12-months. Along with the trends seen for illness acceptance and social support associations with psychological impact of MS, perhaps a positive outlook, and a good social network all contribute to a positive quality of life (Mikula et al, 2016) and therefore may be variables to focus on in further research when aiming to encourage positive processes of living with MS. Other IRs showed positive trends illness coherence and concern with the psychological impact of MS, as expected as these IRs are often associated with psychological outcomes such as distress and psychological QoL (Dennison et al., 2010a; Jopson & Moss-Morris, 2003).

Similarly to physical function, higher levels of acceptance at 6 and 12 months were associated with concurrent lower psychological impact of MS, again adding to previous

findings (Pakenham & Fleming, 2011; van Damme et al., 2016; Ward & Kiropoulos, 2017) and detail that better acceptance is associated with better psychological function.

Optimism significantly predicted the psychological impact from the later time points (i.e. 3- & 6- months). These findings support CSM in that personal factors influence psychological outcomes for people living with MS. Interestingly, acceptance did not predict psychological impact suggesting that acceptance is not particularly important to this outcome. However given the accounts given in the qualitative study (see Chapter 3) the associations between acceptance and impact of MS require further investigation. Given that optimism can contribute to processing and learning to manage life with a chronic condition (e.g. seeking information, expecting the best outcome) it may be a trait that requires focus when developing interventions on improving psychological outcomes in MS. As a trait optimism is conceptualised as stable feature of an individual's personality, a disposition, and therefore not particularly amenable to change, nor influenced by circumstances (Scheier et al., 1994), however more recent studies (Malouff & Schutte, 2017; Squires et al., 2013) have shown that optimism can change over a 12 month period which opens up the potential for optimism to be the target for an intervention. This has been demonstrated, for example in a meta-analysis by Malouff & Schutte (2017) where optimism training across 29 studies increased optimism. The 'Best Possible Self' intervention was found to be most beneficial whereby participants (a) visualise themselves in a future moment in time having achieved their goals, and (b) consider the characteristic strengths they will need to achieve this.

Treatment effects were also found with baseline reports of undergoing MS treatment predicting psychological impact of MS at 12-months. While we did not record the treatment participants were taken during the study, we know that there is no known cure

for MS, rather treatment is provided to reduce the impact of symptoms (e.g. steroids for relapses, muscle relaxants for spasms). Although there were no associations with treatment beliefs – to suggest that treatment is considered more threatening for example – it may be that the need for adherence to sometimes complex medical regimens and the trial-and-error approach to finding the right treatment to treat different fluctuating symptoms, may be contributing to psychological impact of MS.

AT Use

The longitudinal analyses described in this chapter sought to explore the nature of AT use among PwMS over time and to examine the associations between AT use and the physical and psychological impact of MS. As also revealed in qualitative data (Chapter 3) and in the baseline data (Chapter 4) the most common AT devices used were mobility and environmental devices. This is perhaps expected of a sample of PwMS with a mean duration of 14 years since diagnosis.

The number of AT devices used (at 3-months only) was significantly associated with the physical and psychological impact of MS suggesting that AT use is not just a reflection of the clinical and demographic variables but perhaps some behavioural form of coping. Interestingly, the beta coefficient showed a negative relationship suggesting that the more devices being used decreased the physical and psychological impact of MS. This gives support for the use of AT – as a coping behaviour – in helping alleviate the physical and emotional demands of living with MS. Nonetheless, these findings were inconsistent and therefore requires further investigation. This may be explained by the temporary need for AT devices given that they are often interchangeable depending on function and need for example crutches, wheelchairs can serve a temporary purpose are not necessarily needed

all the time nor for long periods of time for example PwMS may own devices but not necessarily be using them as they are not experiencing relapsing or progressive symptoms (Souza et al., 2010; Squires et al., 2016).

The majority of 'recently-acquired' AT devices were mobility devices making it difficult to look at the effects of AT device by type. However it was identified that mobility device users at baseline reported higher levels of psychological impact of MS at 12-months whereas environmental device users reported lower concurrent psychological impact of MS. This may be somewhat explained by the finding that mobility device users reported more negative perceptions of their device (i.e. design, ease of use, cost), which highlights the importance that AT designers and providers ensure that devices meet patient needs. This also demonstrates the contrasting impact that different device types can have on those living with MS, and thus the limited sub-analysis by AT type should be something to be considered in future research, particularly those AT devices that have been highlighted in previous chapters as lacking current and high-quality research e.g. communication, environmental aids.

In addition to these findings, trends were also seen between the number of AT devices and social support, and both related to MS outcomes. It has been previously suggested that the use of AT can help people with disabilities engage in social activities (Hoenig et al., 2004; Steel & Gray, 2009). Possibly those devices that were perceived to be better designed and more aesthetically pleasing are more likely to be used in social situations due to social acceptability. For example, mobile phones being used as memory aids does not attract any unwarranted attention due to the normality of using mobile phones in public. On the other hand, powered wheelchairs are not only a marker of

disability and stigma (as described in Chapter 3: Squires et al., 2016) but they can also be considered large, cumbersome and obstructive (Boss & Finlayson, 2006). It appears that such negative perceptions surrounding the device can deter PwMS from using equipment in social settings and feel satisfied with social support.

Change Over Time

Across the 12-month study period, three illness cognitions decreased over time: perceived illness effect, concern about the condition and emotional effects of MS (see Figure 5.2). This highlights the unpredictable and ever-changing nature of living with MS (i.e. relapse- and progressive- forms) and how illness cognitions are continuous processes being ever-informed by our experiences. It also suggests positive adjustment. These reductions in negative illness perceptions over time compliment the finding that physical and psychological impact of MS remained stable in that illness perceptions are formed to help shape future coping responses and self-management. The success or failure of these responses helping PwMS reach their desired physical or psychological outcome then continues to shape future coping responses. It could be argued that these reduced perceptions are helping PwMS regulate their beliefs and emotions to restore and maintain positive and stable outcomes.

However according to illness acceptance theories and self-regulation processes, not all beliefs about illness are expected to change. For example, the average duration of illness within the current sample was 14 years. Therefore these PwMS will have adapted and come to terms with their condition and the challenges that they may face, formed strong illness perceptions and constructed a strong understanding of their condition by this point (Jopson

& Moss-Morris, 2003; Tasmoc, Hogas & Covic, 2013). This would explain why no changes were observed in perceptions relating to illness coherence, control, timeline etc.

Limitations and Future Directions

Due to the exploratory nature of this study into the physical and psychological outcomes of living with MS, with a large number of comparisons made during the analysis and a modest sample size, a conservative *p* value was used. While 70 PwMS is not atypical in published studies particularly of a longitudinal design (see Chapter 2), this did reduce the power for some multiple variable analyses, and the number of identified variables that may have contributed to the physical and psychological outcomes of living with MS. Future research could target those variables that have now been identified, which would allow significant findings at .05 level.

It should also be noted that there were inconsistent findings surrounding the clinical-demographic factors and their predictive utility in relation to both the physical and psychological impact of MS. However even when not found to be statistically significant, they were found to explain 10-13% of the variance perhaps raising the question of clinical vs. statistical significance. These findings may be clinically relevant and may point to a need for different ways of working when it comes to age and different demographic groups.

As with questionnaire methodology studies, the question regarding appropriateness of measures is always apparent. In this study, measures of dispositional optimism were used which should show stable results across the study period, however it was seen to improve over time. The validity of this measure is therefore questioned as it may have been tapping into aspects of situational optimism rather than optimism as a trait. It has been suggested

that the contrast between general and task-specific optimism can be significant (Scheier & Carver, 1992) and they are likely to predict different patterns of psychological and physical health outcomes (Taylor & Aspinwall, 1990). As discussed in Chapter 3, a positive outlook that AT is of benefit and will enable one to manage their condition is likely to promote uptake and continued use of AT (if goals are met) compared to someone who does not recognise the potential benefits of using AT. Therefore it is suggested that a measure of AT-specific optimism would be suitable in terms of establishing expectancies surrounding AT use from PwMS.

To address the AT-related questions, we found that in the final sample there was not enough non-AT users to compare the differences between those who did and did not use AT, which is a point to improve on for future research. Moving forward, and in relation to self-management theories and the qualitative study (see Chapter 3: Squires et al., 2016), it would be expected that those using AT for specific symptom management will see improvements achieving those specific tasks and symptom management compared to those who do not use AT. The success of using such devices – and thus self-managing their condition – would bring on positive emotions in goal achievement suggesting that psychological gains will also be had by using AT compared to those who did not. Further research could also explore the differences in those who do and do not use AT in terms of their illness processes and coping strategies. This would encourage a better understanding of self-regulatory processes in the uptake and use of AT devices.

However, the main limitation of the current study is the use of an artificial baseline. Although attempts were made to capture people with MS using their AT at the earliest opportunity this was not possible. The time since first using their ‘newest’ device varied

largely and therefore limited the generalisability of these findings. This also meant the study was limited in investigating the genuine short-term effects of such devices, which would be a potential direction for future research. Future studies should aim to recruit patients from OT services who are due to receive AT equipment to gain an authentic baseline and follow them from there on to capture the true experience of using AT in the short-term and long-term if followed up accordingly. Taking a mixed methods approach, PwMS could also share their lived experiences from the beginning of their AT experiences through to whether they achieve their desired outcome, and the self-regulatory process in deciding as to whether to continue with their AT use. This could be underpinned with self-regulatory theory, and further explore how individual cognitions (on illness, device), and internal and external resources (as identified in Chapters 3 and 4) influence the process and overall outcome.

Chapter 6

General Discussion

The studies reported in this thesis set out to investigate the physical and psychological outcomes of MS and to explore the relationship of such outcomes with the use of assistive technology and illness perceptions. Given the high rate of AT abandonment, reasons for abandonment were also to be explored among PwMS. This was achieved using mixed methods. This thesis presents findings from three related and substantive pieces of work. Firstly, a systematic review (Chapter 2) of the literature was conducted to explore the nature of AT use among PwMS, where it was concluded that AT use had mixed effects (e.g. independence vs. stigma) however better research designs (i.e. longitudinal, theory-based) were needed. Secondly, focus groups were facilitated including participants with MS, carers, and a sample of Occupational Therapists that highlighted the importance of key personal (e.g. acceptance, optimism, illness beliefs) and external factors (e.g. the device itself, social support, service factors) that may influence the uptake and continued use of AT, and the outcomes of using such devices (Chapter 3). Finally, a longitudinal quantitative study was presented where a questionnaire was designed to assess a range of personal, cognitive, psychosocial and device related factors potentially related to AT use and the physical and psychological impact of living with MS (Chapter 4: cross-sectional findings; Chapter 5: longitudinal findings). Findings from this study highlighted the illness perceptions that predict physical and psychological outcomes of living with MS, and the potential role that AT devices play in illness self-regulation processes including self-management. This final chapter aims to review and discuss the key findings and synthesise theoretical contributions of this thesis before addressing the limitations, implications and future directions.

Predicting the physical and psychological outcomes of people with MS (PwMS), and determining the processes in which assistive technology may play in these outcomes is

considered important for several reasons. Research has shown that living with MS can have a significant physical, emotional and social impact on all those affected by the condition (including carers). However, as described in Chapters 1 and 2 research evidence to date has commonly been limited to that reported from cross-sectional studies which fails to address the changing nature of MS experience and outcomes, nor have many considered the role that assistive technology plays in these outcomes. These devices are used with the aim to improve physical and psychological function however again research is limited - particularly within PwMS who are beneficiaries of the UK NHS. Furthermore, research that existed (see review Chapter 2) often lacked a theoretical foundation on which to test their assumptions. In this thesis studies were guided by the Common Sense Model of Self-Regulation of illness (CSM: Leventhal et al., 1980). This model provides a useful framework for both the measurement of key constructs, such as illness perceptions, but also proposes the pathway through which cognitive and emotional perceptions of illness (and its treatment i.e. perceptions of AT) influence individual coping responses and their emotional and functional outcomes. The discussion therefore draws on this model in interpretation of findings, but also reflects on its limitations.

Summary of findings

Physical Impact of MS

Physical disability is commonly reported among PwMS (Heesen et al., 2008; Marrie et al., 2017) with our sample also reporting moderate levels of physical and psychological impact of MS. Previous self-report studies noted that PwMS may demonstrate an exaggerated perception of their (limited) function despite 'normal' scores, particularly in those with high levels of anxiety (e.g. Hayter et al., 2016). In the current study, anxiety and

depression (as measured by the MSIS-PSYCH subscale) within our sample displayed on average low-moderate levels which contrasts slightly to previous reports that PwMS have higher rates of anxiety and depression and lower quality of life compared to the general population (Jones et al., 2012; Klevan et al., 2014; Mikula et al., 2016) and other neurological conditions (McCabe et al., 2009; Riazi et al., 2003). That is not to say that participants in our study have not experienced higher levels of anxiety or depression during their MS experience. It is suggested that these processes are typically seen after diagnosis or facing new adjustments (i.e. new symptoms, relapses; Siegert & Abernethy, 2005) yet our sample had plenty of time to adjust to their condition given that the average time since diagnosis was 14 years.

The review evidence (Chapter 2) summarised that AT devices helped PwMS with the functional goal that their devices were designed for, for example, mobility aids helped PwMS achieve physical function and becoming mobile. However, there was mixed feedback in the focus group study (Chapter 3) regarding the gaining of independence through AT use with some suggesting it was promoted while others argued that it was lost by using AT devices. One limitation highlighted by the review was the evidence base for physical and functional outcomes which demonstrated a lack of consistency in the measures used and outcomes assessed, which made it difficult to synthesise the data and limited the generalisability of the findings.

The physical impact of MS at each time point (as measured by the MSIS-29) was found to be concurrently associated with various biopsychosocial factors in the hypothesised direction: high perceived severity of MS, effect of MS, symptom experience, illness concern, and high psychological impact of MS. The perceived emotional impact of MS

was also associated with the physical impact of MS at multiple time points across the longitudinal period. Low illness acceptance was significantly correlated with a greater physical impact of MS at three time points.

The **physical impact** of MS at 12-months was significantly correlated with MS affect, identity, physical and psychological impact of MS (at each earlier time point). Perceived illness severity, concern and emotional effect of MS all associated with 12-month physical impact of MS. Among the variables that were included in the predicting physical impact of MS model based on the CSM theory previous research and the identified associations within this thesis, employment (3 months), earlier physical impact of MS (each time point) and the number of AT devices used (3 months) were found to be the significant predictors of the physical impact of MS at 12-month time point in regression analyses.

Psychological impact of MS

Firstly, the review (Chapter 2) identified possible negative psychological experiences from using AT to manage MS including embarrassment and stigma however the qualitative study (Chapter 3) suggested that stigma attached to AT is reducing due to more positive media coverage (e.g. possibly the effect of increased awareness of disability as a result of sports coverage, and inclusion of TV presenters with physical limitations). Other positive outcomes described were confidence and social participation, particularly with the use of mobility aids. The benefits were also identified by carers of PwMS, restoring their dignity, health, identity and wellbeing. Finally, healthcare professionals supported these notions however raised concerns that replacing care with AT devices may reduce social activity.

One major critique of the evidence base around psychological outcomes of living with MS was the lack of linkage to AT use as a self-management behaviour. Similarly, studies

looking at the effects of using AT often neglected the psychological outcomes of such use, and those that did failed to apply any psychological theories to study development or interpretation. Previous research had suggested that illness outcomes depend on individual differences in personal outlook, expectations and coping responses (Pakenham, 2005). Also, Pakenham and Fleming (2011) found that higher levels of acceptance predicted lower levels of distress; coping strategies and social support are all linked to acceptance of MS (Pakenham, 2006). The current sample reported moderate levels of acceptance, optimism and social support, however in the studies presented in this thesis, these personal factors were also explored in relation to the uptake and continued use of AT. For example, acceptance was a key subtheme in the qualitative study (Chapter 3) found to influence the acquisition *and* use of AT; it also came in two parts: acceptance of MS *and* acceptance of AT. It is believed that such acceptance helps PwMS adjust and self-manage their condition via AT use. Dennison et al. (2010a) found that poor acceptance of MS was associated with stress and increased perceptions of severe consequences and uncertainty yet despite our sample reporting moderate levels of acceptance there were still signs of negative perceptions particularly relating to consequences, concern, symptom experience and emotional effect and low personal control. These levels are in line with previous reports in MS samples (Jopson & Moss-Morris, 2003), but despite negative beliefs, PwMS reported a high understanding of their condition and moderate beliefs in treatment control.

Similar to physical function, the effect of MS and emotional impact was significantly concurrently correlated with the psychological impact of MS at each time point in the expected direction i.e. greater perceived scores were reported concurrent to a high psychological impact of MS. Other concurrent correlates with the psychological impact of

MS included high symptom experience (baseline, 3 months), and high illness concern (baseline, 6 and 12 months). In contrast, high levels of acceptance of MS, optimism and social support all negatively correlated with the psychological impact of MS (e.g. higher impact in those not accepting of their MS).

The **psychological impact** of MS at 12-months was significantly correlated with emotional effect of MS, psychological impact of MS, and also negatively correlated with optimism at each time point. Psychological impact of MS at the final time point was also negatively correlated with prior acceptance (6month) and positively correlated with the earlier reported physical impact of MS (6 month). Among the variables that were suggested to predict the psychological impact of MS based on the CSM theory, previous research and the identified associations within this thesis, baseline treatment effects, previous psychological impact of MS (consistently), optimism (at 3 and 6 months) and the number of AT devices (at 3 months) were found to be significant predictors of the psychological impact of MS at 12-month time point in regression analyses.

AT Use

In the questionnaire study, it was not possible to determine the effects of AT use or AT abandonment on key physical or psychological outcomes among this UK sample of PwMS. Instead, AT use – i.e. engagement with self-management behaviour – was measured by the number of AT devices used. In support of our hypothesis, this was found to be significantly associated with the physical impact of MS yet interestingly, this was inconsistent overtime.

Limited subgroup analysis looking at device types found that environmental devices were associated with lower psychological impact of MS and more threatening illness

perceptions of MS treatment whereas mobility devices were associated with higher psychological impact of MS and negative perceptions of the device itself.

The likelihood of PwMS using AT devices was increased if they were unemployed, in receipt of a carer, perceived to have a low quality relationship with their loved one or received medical treatment for their MS. Similarly, PwMS who were unemployed, in receipt of a carer or living with progressive MS used more AT devices than their counterparts. Unemployed PwMS were also less likely to abandon AT devices as were those who reported being confident in using their AT device. Those 'confident' AT users also reported a more positive psychological impact of AT use than those with no confidence, and found it easier to learn to use new AT devices. When expectations and needs were met by AT use, PwMS reported the device as easier to use than if they were not met. Trends were also seen in relation to illness perceptions associated with the number of AT devices used and use vs. non-use (i.e. illness effect, timeline; illness effect, identity, concern and coherence respectively).

Unsurprisingly, less positive device perceptions (comprised of identified influential device factors from the literature and focus group study: design, ease of use, learning to use, time saving, and enjoyment of use) were reported by those who abandoned their AT devices. Trends were also seen in AT abandonment among those who were younger.

The systematic review identified the wide spread of AT devices available for PwMS and how these devices ranged from basic equipment (e.g. catheters) to complex motorised devices (e.g. Functional Electrical Stimulation). Across the focus group and questionnaire participant samples, mobility devices were the most common. Participants also reported experience with a wide range of devices that had not been identified by the review including

environmental, bathing, kitchen, memory, communication, dressing, sex and support aids. Within this review however studies were limited to mostly cross-sectional studies and the significant heterogeneity of AT devices limited synthesis. Many studies were excluded based on the lack of psychological outcome measures and of those that were included theoretical underpinnings relevant to hypotheses regarding AT use and outcomes among PwMS were absent.

As mentioned above, and in support to previous research and the study hypotheses, the AT use (i.e. number of AT devices used) predicted physical and psychological impact of MS however this was found to be inconsistent. The qualitative data presented in Chapter 3 highlighted the positive and negative effects of using AT including the contrasting perceptions of independence and stigma. This supports the notion that AT can be a 'double-edged sword' (Ravneberg, 2012) for PwMS particularly given that negative device perceptions were found to result in AT abandonment. This is particularly important for younger PwMS as they were also seen to abandon AT younger people perhaps hinting at social pressures to look 'normal' and the stigma that surrounds disability and AT use. Similar devices were used among this UK sample as to our American and European counterparts (i.e. mobility, environmental aids being the most common; as seen in Johnson et al., 2009; Marrie et al., 2017). Current findings also support previous literature in that unemployed people were more likely to have AT than those in employment. Those receiving medical treatment and with a carer were also found to be more likely to have AT devices. Additionally, it was in the focus group study that the biopsychosocial factors that influence AT use were first highlighted, with patients, carers and OTs all discussing the personal factors (e.g. type of MS, fatigue), psychological factors (e.g. acceptance, optimism), and social factors (e.g. social support, work) involved whilst also highlighting the influence of

the device itself (e.g. ease of use). This highlights the important role of considering a range of factors wider than the individual themselves. Leventhal's CSM (1980) has developed over time, with suggestions that other factors can influence the proposed processes from illness representations to coping strategies and outcomes (Hale, Treharne & Kitas, 2007). As seen in the current studies, the role of social economic status (i.e. employment), carers (e.g. social support) and MS treatment were all significant predictors of AT use. If AT use is considered as a problem-focused coping strategy for self-managing MS symptoms then it is important to consider these wider familial and social influences in order to reach the ultimate goal of attaining the best patient outcomes.

Reflection of Study Methods

The body of work presented in this thesis is the first to explore the physical *and* psychological effects of using AT devices among PwMS in the UK. Previous research typically focused on either the physical or psychological aspect of using such devices, as seen in the small number of retrieved articles in the systematic review (Chapter 2), thus neglecting the interactions that physical and psychological domains can have with each other. This was particularly highlighted in the longitudinal study where the physical and psychological impact of living with MS were found to be consistently associated with each other. The review also demonstrated that the main AT devices studied were for mobility, and our qualitative chapter highlighted the need for longitudinal study of the influences on use or abandonment of all device types and the outcomes of this. These provided rationale for the further empirical studies reported in Chapters 4-5.

This study took a more inclusive approach to AT than many of those reviewed in that it included users of devices that aided mobility, memory, environmental tasks, posture/support, toileting, vision and others. With good intentions this inclusivity enabled

the investigation of the effects of using a range of AT however it also limited analysis due to unequal sample sizes and inadequate differences among use vs. non-use longitudinally. It appears that those who completed each time point continued to use their AT device throughout making it difficult to capture the experiences of those who abandon their devices. This is something future research should consider and perhaps attempt to engage more with those who discontinue with their devices. It is recommended that our AT use findings should be interpreted with caution. Nonetheless, the overall aim of exploring the impact and influences of AT use was achieved through the qualitative research reported in Chapter 3 and the questionnaire study for which the baseline data of a decent sample N are presented in Chapter 4. The focus group study meets all requirements for excellent integrity and rigour in that the aims, procedures and analyses were made explicit, with acknowledgement of the author's theoretical background. These data informed the subsequent questionnaire study in terms of which relationships to explore further: for example, the qualitative findings of different personal and external influences on AT use and impact existed led to incorporating measures of illness acceptance, device perceptions, optimism and social support in the quantitative study.

To aid with recruitment and aiming to be inclusive of all PwMS, participants were recruited via many methods including an MS clinic, advertisements on MS Society UK website and social media, and an online questionnaire was made available to PwMS. On reflection, these methods served as both strengths and limitations. Online resources enabled accessible participation for a difficult-to-reach population while also providing anonymity for participants (O'Connor, Jackson, Goldsmith & Skirton, 2014). For example, PwMS representing all parts of the UK participated due to the social media advertisements and online questionnaire. However these methods may have inadvertently led to sampling

bias in that recent research suggests that people completing online surveys in health research are more likely to be more positively adjusted in their experience (Wright & Kiropoulos, 2017) suggesting that our sample were positively adjusted to their condition. This may have been reflected in the data, given that the time since diagnosis of our sample which was high (range=0-42 years; mean=14 years).

While there are limits to the generalisability of the current findings, the sample recruited across both qualitative and quantitative studies appears to be a good representation of the MS population for example, 70% of our sample were female (Browne, et al., 2014; Koch-Henriksen & Sorensen, 2010; Mackenzie, et al., 2014) and the questionnaire sample was split evenly between relapse-remitting and progressive types of MS. One major limitation of the questionnaire study however is the use of an artificial baseline, in that participants were not newly diagnosed with MS nor were they in immediate receipt of AT devices. Whilst significant efforts were made to capture AT acquisition at its earliest point, this was not possible (range=0-180 months; mean=18 months) given the low incidence of MS, the timeframe available for data collection, the membership of MS support groups, and the geographical location of the author limiting travel to clinics. Methods of capturing new cases is something to consider for further research - for example, developing gold-standard research (i.e. clinical trials) collaborating with OT services from both healthcare and social services settings and involving private AT providers would enable researchers to truly capture the challenges PwMS face when acquiring and learning to use AT but also the immediate effects of using such devices. When investigating the impact of AT devices, it is strongly recommended that measurement of key variables are attained from an authentic baseline. This will allow a clearer interpretation as to the immediate effects of AT, and the long-term effects through longitudinal study. As a

strength however, by virtue of its longitudinal design, the current study was able to identify changes across time in optimism and illness perceptions (specifically illness concern, and illness and emotional effect) acknowledging the dynamic nature of potential predictors of physical and psychological effects of living with MS.

The quantitative study described in Chapters 4-5 devised a 'device perceptions' measure comprised of the important factors relating to the device (e.g. design, ease of use, learning to use, time saving, and enjoyment of use). A further study is needed to ascertain the test-retest reliability and content validity of this measure to ensure that it is appropriate for future AT health research. If appropriate, this measure could be utilised to develop an understanding of those AT devices that are too often neglected in health research such as devices designed to improve memory, toileting, sexual function among other areas. Longitudinal study (including qualitative components would allow a rich understanding to the lived experiences of those living with MS – particularly if guided by Leventhal's Self-Regulation Model of illness as to how PwMS use AT to help adapt and self-manage their condition.

Implications for Theory

These findings have great potential implications for theory, particularly for illness process models such as described in Chapter 1 e.g. Leventhal et al.'s (1980; 1992; 2003) Common Sense Model of Self-Regulation of illness and AT models such as the Human Activity Assistive Technology (HAAT) model (Cook & Hussey, 1995: see Chapter 3), and how these may be integrated. For example, as biopsychosocial models, they incorporate the health condition, the individual cognitions and emotions and other available resources (e.g. healthcare service, social support) to contribute to illness and AT management (via coping).

We proposed that AT was a form of behavioural coping and it has been demonstrated that interestingly, but perhaps not surprisingly, AT use is also shaped by personal, psychological and external factors. It was seen in the findings that personal factors (e.g. type of MS), psychological factors (e.g. acceptance), and social factors (e.g. social support, employment) and device factors (e.g. ease of use) contributed to AT use including the uptake, abandonment, and volume of use.

A theory that became more apparent during this research was the dynamic between AT use (as a behavioural form of coping) and illness acceptance. In regards to the CSM, illness acceptance is often considered to be a coping responses in many coping measures and it became apparent from the qualitative work of the role that it played in AT use. Acceptance was described in two-parts: first, of the condition itself and secondly, of the AT device. From this we propose that illness acceptance (i.e. a cognitive-emotional coping response) influences AT use (i.e. uptake and continued use of AT).

It is believed that illness management is shaped by our responses to the success or failure of our coping behaviours. It appears that AT use has a similar self-regulatory reappraisal process whereby if positive outcomes are reached and AT meets expectations of physical and psychological needs then PwMS are more likely to continue using the device concerned. For example, those with low perceptions of their device were more likely to abandon their devices. Also, in the longitudinal study, the sample reported moderate levels of impact overall and AT use remained stable overtime limiting the analysis of AT use vs. non-use.

The number of AT devices emerges as a significant predictor of physical and psychological impact of MS after controlling for any clinical, demographic and personal

factors, which suggests to us that AT use is not just a reflection of these things but as a behavioural form of coping. While the questionnaire data presented in Chapters 4 and 5 could only identify inconsistent predictive utility of AT on physical or psychological outcome, the qualitative findings reported in Chapter 3 appear to support this theory i.e. that AT devices did influence such outcomes *in the minds of the user*. This highlights the importance of mixed-methods approaches in research as these methods have allowed access to such insights whereas one or other methods would perhaps lead to different and potentially incomplete explanations of AT use. This also brings into question whether and how the use and acceptance of AT plays a role in self-regulation and adjustment, and how our research methods may influence the conclusions drawn. Our mixed methods findings suggest overall that there is a need to broaden cognitive theories perhaps and also that the processes that AT plays in self-regulation of illness management be further explored. Drawing particular focus on acceptance and optimism, these personal qualities appear to be associated with not only the use of AT but also the physical and psychological effects of living with MS. For example, acceptance of MS was highlighted as a key issue in the MS experience in that it pre-empted the positive coping responses of understanding more about the condition (illness coherence) and putting steps into place to manage their symptoms and access treatment (i.e. AT devices). In the qualitative data we see that this then led to the acceptance of the need for AT devices. Acceptance was significantly associated with optimism throughout the study period, with the former variable consistently predicting psychological outcome of MS, and so perhaps a positive outlook on the world is necessary to accept chronic health challenges and reduce their negative impact.

These findings bring new suggestions for practice and policy as discussed below.

Implications for practice and policy

Recent NICE guidelines (Maw, 2013) recommended an annual review of MS progress and treatment (including AT provision) however the unpredictable nature of MS requires more frequent assessment, especially as our findings highlighted the dynamic changes in optimism and illness perceptions over a 12-month period, which in turn influenced outcome. More frequent assessments are also required for those PwMS who are not able to access MS services due to lack of information or social support (as highlighted by campaigns run by the MS Society UK 2013; 2016a; 2017). These campaigns also highlight the need for AT across the country as their 'Postcode Lottery' campaign (2013) showed the lack of resources in many parts of the UK despite the physical and psychological benefits of using such equipment as evident in our review and qualitative study.

A **biopsychosocial approach to AT provision** should be adhered to, starting with identifying the symptom experience, the individual needs and capabilities, and ideally matching AT devices to what that individuals functional and psychological goals are. AT providers should then focus on the personal and psychological barriers and facilitators relating to the uptake and use of AT, drawing particular focus on acceptance and optimism.

Optimism was found to be a significant predictor of psychological impact of MS at each time point and, although theorised and measured here as a 'trait', has been shown to change over time in the current study and in other reports (Squires et al., 2013). If optimism is amenable to change and shows predictive utility then it offers up intervention potential. Given the associations identified between optimism, acceptance and social support, targeting optimism in a structured intervention could have other benefits than just a psychological impact. For example many PwMS described a 'trial and error' process of acquiring and using AT yet those who persevere and gain benefit from AT were likely to express optimistic thoughts (Squires et al., 2016). Therefore by encouraging PwMS to be

more optimistic may encourage other proactive coping behaviours. A recent meta-analysis (Malouff & Schutte, 2017) reported that optimism can be increased through cognitive behavioural therapies among people with chronic health conditions (e.g. HIV; Chesney Chambers, Taylor, Johnson & Folkman, 2003) with effects maintained at 6 and 12 months post-intervention. These interventions are often psychoeducation programmes that incorporate skill-building workshops and relaxation techniques to build a framework of adaptive coping strategies (including problem-focused, emotion-focused) and effective use of social support. By integrating the use of AT as a problem-focused coping strategy as part of these interventions could perhaps encourage PwMS to build confidence and the skills to use new AT equipment, and learn to adapt and self-manage effectively.

Healthcare providers should also consider the wider influences on AT use and its impact including the acceptance and social support offered to the PwMS by the carer e.g. do PwMS have the right support in place from friends and family to optimise their use of these devices? The current data adds to a scant but important literature demonstrating the important role carers can play in the AT process as highlighted in both the qualitative and quantitative studies presented in this thesis. For example, having a carer significantly increased the odds of using AT among PwMS (Chapter 4) and participants spoke of the influence that carers have in continuing use of devices (e.g. support vs. discouragement: Chapter 3). The contrast in **support offered by carers** may relate to the theory of AT acceptance discussed earlier among PwMS. Carers may experience similar processes when facing challenging situations: from seeing their loved ones in relapse/progression, adapting their role from spouse to 'carer' and then potentially being displaced by AT from their new role. The carers influence, and interaction with PwMS, holds important implications for clinician communication as they need to also consider carer perceptions when they enter

into discussions of AT with those living with MS. By acknowledging the influences of acceptance among carers and PwMS, it could be suggested that healthcare professionals could perhaps work with PwMS and carers and encourage emotional acceptance by helping recognise the changes in functional limitations, and adapt behaviour for activity and social reintegration – through the use of AT. Through this they could discuss the potential benefits of AT use not only for the PwMS but also their carers (as identified in Chapter 3).

The limited subgroup analysis of AT device types requires further investigation. It was found in the current study that environmental devices were associated with lower psychological impact of MS whereas mobility devices were associated with higher psychological impact of MS and negative perceptions of the device itself. This not only hints at a **hierarchy of AT** (as described in Chapter 3) in that some devices provide better outcomes than others but more importantly highlights questions surrounding why these effects are found. Mobility devices were found to be less thought of in their design, ease of use and as such may impact their emotions and mood. This calls out for AT designers to produce better and user-friendly devices for PwMS to feel better about using such equipment. Whereas environmental devices (including environmental control systems, grab bars) may be considered to be less stigmatising as they are often well-known and integrated into the home, and as such having less of a psychological impact on those using those devices.

In extension of this, the qualitative data reported here offer important information in that the PwMS themselves highlighted the important factors that **AT developers and providers** need to consider when matching AT to PwMS (e.g. ease of use, good design). Perhaps more **user-involvement** would encourage positive perceptions surrounding AT, and

reduce stigma and embarrassment that are often attached to such devices. By being actively involved in the design or decision-making process PwMS may strengthen their perceptions of the devices that they are to use. This is something that PwMS want – more choice and involvement with AT and OT services (Preston et al., 2012; Squires et al., 2016) and that is currently being pushed for (Williamson et al., 2015). While OTs often report going 'beyond' their role to meet individual needs (Chapter 3: Squires et al., 2016), shared-decision making and user-involvement in AT design is suggested to lead to best matched devices and continued use (Johnston et al., 2014). Other ideas may involve an exposure therapy where PwMS can alleviate any anxieties that they may have relating to AT and learn to use their devices for an extended period of time before deciding whether to use such equipment. This may encourage confidence and their self-efficacy beliefs of using their AT devices which was particularly important in the current study as PwMS were less likely to abandon their device when confident in use. Lower abandonment rates are not only crucial for PwMS to gain the best possible outcome in meeting their physical and psychological needs but also for the NHS to potentially save millions on healthcare costs in an economic climate that is particularly uncertain.

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Appendices

Appendix A[1] – Full search strategy (PubMed)

1. Multiple Sclerosis
2. Disseminated Sclerosis
3. 1 OR 2
4. Wheelchair*
5. Walker*
6. Cane*
7. Walking stick*
8. Crutch*
9. Brace*
10. Communication aids for disabled
11. Speech recognition software
12. Telemedicine
13. TENS
14. Sensory aid*
15. Hearing aid*
16. Catheter*
17. Environmental Control System*
18. Scooter*
19. Voice Amplifier*
20. Communication book*
21. Communication board*
22. Grab bar*
23. Hoist*
24. Commode*
25. 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25
26. Self-help
27. Assistive
28. Smart home
29. Adaptive
30. Mobility
31. Communication
32. Transfer
33. Continence
34. Memory
35. Kitchen
36. Cooking
37. Eating
38. Bath*
39. Dressing
40. Telecare
41. Washroom
42. Restroom

43. Toilet*
44. 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43
45. Technolog*
46. Device*
47. Product*
48. Tool*
49. Aid*
50. Equipment*
51. Adapatation*
52. 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51
53. 44 AND 52
54. 25 OR 53
55. Activities of daily living
56. Independent living
57. Social participation
58. Chronic limitation of activity
59. Anxiety
60. Depression
61. Quality of Life
62. Personal satisfaction
63. Physical function
64. Function
65. Mood
66. Wellbeing
67. Life Qualit*
68. Depressive symptoms
69. Satisfaction
70. Life Satisfaction
71. Independen*
72. 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 OR 66 OR 67 OR 68 OR 69 OR 70
73. 3 AND 54 AND 72

Appendix A[2] – Data extraction form

ID (author/date): Title:

Background/Rationale:	
Aims/Objectives:	Confirmed Hyp? Yes No ?
Study Design: Time Points: Study Setting:	Appropriate (Qual/MM) Yes No ?
Recruitment Strategy:	Matched Ps/Control?
Inc/Exc Criteria: Sample Size: Attrition Rates:	Yes No ? Ethics? Yes No ?
Data Source/Measurement (Qual/MM Only):	Address bias (QualMM) Yes No ?

SAMPLE

Age:	Gender:	Education:
Type of MS:		
AT Users (YES / NO)	Length of AT use:	
AT Devices:		

MEASURES

Level of AT use?	Function?
Wellbeing?	Quality of Life?
Depression?	Anxiety?
Other measures?	

FINDINGS

Analyses? KEY Findings:	
Limitations of study (inc. bias):	
Interpretation (Quant):	Credible (Qual) / Integration (MM)
Generalisability (Quant):	Valuable (Qual)

Appendix A[3] - Quality assessment tool (quantitative)

Criteria	Nilsagard 2006	Castel-Lacanal 2013	James 2014	McClurg 2009	Gentry 2008	Sutliff 2008	Souza 2011	Woollard 2005	Al-Smadi 2003	Miller 2006	Warke 2006	Warke 2004	Devitt 2003	Fay 2003	Barrett 2010	Chang 2011	Downing 2014	Mayer 2015	Ratchford 2010	Taylor 2014	Van der Linden 2014
A. Objectives described																					
B. Study design																					
C. Sample source described																					
D. Recruitment method described																					
E. Eligibility criteria described																					
F. AT (described)																					
G. Appropriate AT measure																					
H. Validated AT measure																					
I. AT data reported appropriately																					
J. Outcomes (defined)																					
K. Appropriate outcome measures																					

L. Validated outcome measures	
M. Outcome data reported appropriately	
N. Appropriate analysis for research question	
O. Attrition described	
P. Limitations described	
Q. Interpretation (cautious)	
R. Generalisability (ext. validity)	
Total Score (out of 36)	

Appendix A[4] – Quality assessment tool (qualitative)

Criteria	Boss 2006	Dewey 2004	Bulley 2014
1. Clear statement of the aims? ***(Consider: research goal? Why it was thought important? Relevance?)***			
2. Qualitative methodology appropriate? ***(i.e. seeks to interpret or illuminate actions or experiences of participants; is qualitative right for goals?)***			
3. Research design appropriate to address research aims? ***(i.e. justified/discussed how they decided which method to use?)***			
4. Recruitment strategy appropriate to research aims? ***(i.e. explained selection, and why they were most appropriate to provide study insight, discussed non-participants?)***			
5. Data collected in way that addressed research issue? ***(i.e. justified setting, data collection, methods, mention topic guide, modified during study – how and why, data saturation)***			
6. Relationship between researcher and participants been adequately considered? ***(i.e. examined researcher bias, responded to study events and considered implications of any changes?)***			
7. Ethical issues been taken into consideration? ***(i.e. discussed ethical issues – informed consent, confidentiality and debrief etc, ethics approval sought?)***			
8. Was data analysis sufficiently rigorous? ***(i.e. in-depth analysis process, thematic analysis – how categories/themes derived from data; explains how data were selected to demonstrate analysis process, sufficient quotes/data, discuss contradictory data, examined own role, bias during analysis)***			
9. Clear statement of findings? ***(i.e. explicit findings, discusses for and against findings, credibility – triangulation, respondent validation, more than one analyst, relates to original hyp/aims)***			
10. Valuable is the research? ***(i.e. discussed contirubution to knowledge or understanding – practice or policy, identify new areas? transfer to other populations?)***			
Total Score (out of 20)			

Appendix A[5] – Quality assessment tool (mixed-methods)

Criteria	Flensner 1999	Flensner 2001
S1. Clear mixed methods research questions/objectives?		
S2. Collected data addresses research question? ***(e.g. consider follow-up period is long enough for outcome to occur)***		
1.1. Qualitative – data sources relevant to address research questions?		
1.2. Qualitative – data analysis process relevant to address research question?		
1.3. Qualitative – appropriate consideration to how findings relate to the context ***(e.g. the setting of data collection)***		
1.4. Qualitative – appropriate consideration to how findings relate to researchers' influence ***(e.g. through interactions with participants)***		
4.1. Quantitative descriptive – relevant sampling strategy to address quantitative research question?		
4.2. Quantitative descriptive – sample representative of the population?		
4.3. Quantitative descriptive – appropriate measurements (clear origin, or validity known, or standard instrument)?		
4.4. Quantitative descriptive – acceptable response rate (60% or above)?		
5.1. Mixed methods – is the mixed methods research design relevant to address the qualitative and quantitative research questions?		
5.2. Mixed methods – relevant integration of qualitative and quantitative data to address research question(s)?		
5.3. Mixed methods – appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data in triangulation?		
Total Score (out of 26)		

Appendix A[6] – PRISMA Statement

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	35
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	36
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	37
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	38
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	38
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	38
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	38
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix

Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	39
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	39-40
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	39-40
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	40
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Table 2.1
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	40-41
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	42
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 2.1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Appendix
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Figures

Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Figures
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	65-66
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	67-69
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	70
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Appendix B[1] – Focus Group study documents

Risk Assessment

Working away from the school and after hours:

Risks:

- Some research recruitment and interviewing may be conducted away from the School of Psychology, in a suggested venue that is central to all selected participants and where informal gatherings of the target population already occur (such as MS Gwynedd/Ynys Mon, Conwy, Flintshire, Chester and Ellesmere Port branches; Carers Outreach Groups and Carer UK in Gwynedd, Conwy, Flintshire etc.).

Actions:

- The researcher will familiarise themselves with the location in advance, and bring this to the attention of PhD supervisor. Where possible, a second researcher will accompany the group sessions for note-taking purposes primarily.
- Permission from managers of selected venues will be sought and received beforehand.
- The researcher will always carry a mobile phone and money, in case of emergency.
- The researcher will inform their PhD supervisor that they have arrived safely at the data collection site and then verify when they have finished the data collection and left the site.
- The researcher will provide the office phone number, specific for research purposes as opposed to using personal contact number.

Information Sheet (PwMS)

Research Study Title:

The level and impact of Assistive Technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Invitation:

We are conducting research into the level of Assistive Technology (AT) use among people living with Multiple Sclerosis (MS). This includes identifying the current level of use and the impact of using AT devices on individual functioning, wellbeing and quality of life. To gain a broad understanding, we are inviting people living with MS, caring for someone with MS or working in MS health or social care.

What do we mean by Assistive Technology?

These are **ANY** devices that are perceived as improving the independence of those living with a disability and can range from simple devices such as canes, memory aids, specialised cutlery devices to the complex high-end devices such as motorised wheelchairs, environmental control systems, GPS tracking devices.

Before you decide whether or not you wish to take part, it is important for you to understand why it is being carried out and what it will involve. This information sheet aims to inform you about the study and why it is being conducted, so that you can make an informed decision as to whether to participate or not. If you have any questions, please contact the researcher, Luke Squires, whose details are at the end of this information sheet.

Thank you for taking the time to read this.

What is the purpose of the study?

Little is known about the level of AT use and its impact on individual functioning, wellbeing or quality of life in general, but in particular there is very little known about the experience of those affected by MS. Our study aims to bridge this gap by exploring the different opinions and experiences of those affected by or working with those with MS who use AT through guided discussion.

We would like to invite you to take part in a discussion group regarding your experience as someone living with assistive technology **and** multiple sclerosis. The discussion group will be in English and involve 6-8 people with MS (PwMS). The groups will not be mixed to remain confidential, i.e. it will be a PwMS-only discussion group, and will be audiotaped. Please be reassured that **all** data (paper and tapes) **will remain confidential** as no personal identifiers are used.

Do I have to participate?

Your participation in this study is completely voluntary, and you have the right to withdraw at any time without having to provide a reason.

What will happen to me if I take part?

If you decide to take part, we would ask that, having read this information sheet that you sign the consent form provided, and then proceed to completing the short questionnaire provided. This brief questionnaire is to gather basic contact information and essential information regarding your experience with AT and MS so that the research team can arrange the appropriate groups. This should take no more than 10 minutes of your time.

Once you have completed these, we would ask that you return the consent form **and** short questionnaire back to us using the **FREEPOST** envelope provided.

Within a few weeks of this, we will get in touch to let you know when and where the focus group discussion will take place. You will then be asked to share your experiences and opinions of assistive technology and multiple sclerosis (for example, 'what does assistive technology mean to you?', 'what impact does AT have on your life?')

If you would like to take part in the study, please sign the consent form and complete the short questionnaire and return in the envelope provided.

Are there any benefits or risks from taking part?

In the unlikely event, that the questions in the discussion groups cause you distress, the researcher will encourage you to take a break before asking whether or not you wish to continue. You will also be reminded of your right to withdraw from the study. While there may not be any *immediate* benefits to you, there is great potential in helping develop assistive technology as well as identifying the impact of using such technologies among those living with Multiple Sclerosis. It is our hope that by describing the relationship between AT and MS, data from this study will help develop our larger-scale research programme and combined these may also help better inform the development of assistive technology and service provision.

Do I get paid?

You will receive a payment of £10 following completion of the discussion. Expense forms will be provided at the session if you require reimbursement for travel and respite costs.

Will my information be kept confidential?

Your participation will remain completely confidential, as full names will not be used during the group session. Only the research team will have access to your identifying contact

information and this information will be stored in a secure archive separate from the recordings and transcripts.

Therefore, whilst you will discuss your opinions of assistive technology and multiple sclerosis with others, and will be audio recorded on audiotape, **ALL** data will remain completely confidential. Only the researcher will have access to the audiotapes.

Who is organising this study?

This study is being carried out by Luke Squires as part of his PhD research at Bangor University under the supervision of Dr Val Morrison (chartered Health Psychologist and Reader in Health Psychology) and Dr Nefyn Williams (GP and Clinical Senior Lecturer).

Who has reviewed the ethics of this study?

Bangor University, School of Psychology Research Ethics and Governance Committee have reviewed and approved this study.

What happens after the study?

If you would like to receive a summary of the findings once the study has been completed please simply tick the relevant box on the Consent Form. If you would also like to be considered for taking part in our questionnaire study about assistive technology and multiple sclerosis, please tick the relevant box for option, also on the Consent Form.

Who do I contact for further information?

If you have any questions or would like any further information regarding the study, please feel free to contact the researcher or the supervisor:

Luke Squires: psp03a@bangor.ac.uk 01248 383010

Dr Val Morrison (Principal Supervisor): v.morrison@bangor.ac.uk

Complaints:

If you have any complaints about the study, please contact:

Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.

Thank you for taking the time to read this information sheet.

If you would like to take part, please sign the consent form and complete the short questionnaire, and return them using the FREEPOST envelope.

Information Sheet (Carer)

Research Study Title:

The level and impact of Assistive Technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Invitation:

We are conducting research into the level of Assistive Technology (AT) use among people living with Multiple Sclerosis (MS). This includes identifying the current level of use and the impact of using AT devices on individual functioning, wellbeing and quality of life. To gain a broad understanding, we are inviting people living with MS, caring for someone with MS or working in MS health or social care.

What do we mean by Assistive Technology?

These are **ANY** devices that are perceived as improving the independence of those living with a disability and can range from simple devices such as canes, memory aids, specialised cutlery to the complex high-end devices such as motorised wheelchairs, environmental control systems, GPS tracking devices.

Before you decide whether or not you wish to take part, it is important for you to understand why it is being carried out and what it will involve. This information sheet aims to inform you about the study and why it is being conducted, so that you can make an informed decision as to whether to participate or not. If you have any questions, please contact the researcher, Luke Squires, whose details are at the end of this information sheet.

Thank you for taking the time to read this.

What is the purpose of the study?

Little is known about the level of AT use and its impact on individual functioning, wellbeing or quality of life in general, but in particular there is very little known about the experience of those affected by MS. Our study aims to bridge this gap by exploring the different opinions and experiences of those living with, caring for or working with those with MS who use AT through guided discussion.

We would like to invite you to take part in a discussion group regarding your experience as someone caring for someone with multiple sclerosis who uses assistive technology. The discussion group will be in English and involve 6-8 people who provide care to friend or family members with MS. The groups will not be mixed to remain confidential, i.e. it will be a carer-only discussion group, and will be audiotaped. Please be reassured that **all** data (paper and tapes) **will remain confidential** as no personal identifiers are used.

Do I have to participate?

Your participation in this study is completely voluntary, and you have the right to withdraw at any time without having to provide a reason.

What will happen to me if I take part?

If you decide to take part, we would ask that, having read this information sheet that you sign the consent form provided, and then proceed to completing the short questionnaire provided. This brief questionnaire is to gather basic contact information and essential information regarding your experience with AT and MS so that the research team can arrange the appropriate groups. This should take no more than 10 minutes of your time.

Once you have completed these, we would ask that you return the consent form **and** short questionnaire back to us using the **FREEPOST** envelope provided.

Within a few weeks of this, we will get in touch to let you know when and where the focus group discussion will take place. You will then be asked to share your experiences and opinions of assistive technology and multiple sclerosis (for example, 'what does assistive technology mean to you?', 'what impact does AT have on your life?')

If you would like to take part in the study, please sign the consent form and complete the short questionnaire and return in the envelope provided.

Are there any benefits or risks from taking part?

In the unlikely event, that the questions in the discussion groups cause you distress, the researcher will encourage you to take a break before asking whether or not you wish to continue. You will also be reminded of your right to withdraw from the study. While there may not be any *immediate* benefits to you, there is great potential in helping develop assistive technology as well as identifying the impact of using such technologies among those living with Multiple Sclerosis. It is our hope that by describing the relationship between AT and MS, data from this study will help develop our larger-scale research programme and combined these may also help better inform the development of assistive technology and service provision.

Do I get paid?

You will receive a payment of £10 following completion of the discussion. Expense forms will be provided at the session if you require reimbursement for travel and respite costs.

Will my information be kept confidential?

Your participation will remain completely confidential, as full names will not be used during the group session. Only the research team will have access to your identifying contact

information and this information will be stored in a secure archive separate from the recordings and transcripts.

Therefore, whilst you will discuss your opinions of assistive technology and multiple sclerosis with others, and will be audio recorded on audiotape, **ALL** data will remain completely confidential. Only the researcher will have access to the audiotapes.

Who is organising this study?

This study is being carried out by Luke Squires as part of his PhD research at Bangor University under the supervision of Dr Val Morrison (chartered Health Psychologist and Reader in Health Psychology) and Dr Nefyn Williams (GP and Clinical Senior Lecturer).

Who has reviewed the ethics of this study?

Bangor University, School of Psychology Research Ethics and Governance Committee have reviewed and approved this study.

What happens after the study?

If you would like to receive a summary of the findings once the study has been completed please simply tick the relevant box on the Consent Form. If you would also like to be considered for taking part in our questionnaire study about assistive technology and multiple sclerosis, please tick the relevant box for option, also on the Consent Form.

Who do I contact for further information?

If you have any questions or would like any further information regarding the study, please feel free to contact the researcher or the supervisor:

Luke Squires: psp03a@bangor.ac.uk 01248 383010

Dr Val Morrison (Principal Supervisor): v.morrison@bangor.ac.uk

Complaints:

If you have any complaints about the study, please contact:

Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.

Thank you for taking the time to read this information sheet.

If you would like to take part, please sign the consent form and complete the short questionnaire, and return them using the FREEPOST envelope.

Information Sheet (HCP)

Research Study Title:

The level and impact of Assistive Technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Invitation:

We are conducting research into the level of Assistive Technology (AT) use among people living with Multiple Sclerosis (MS). This includes identifying the current level of use and the impact of using AT devices on individual functioning, wellbeing and quality of life. To gain a broad understanding, we are inviting people living with MS, caring for someone with MS or working in MS health or social care.

What do we mean by Assistive Technology?

These are **ANY** devices that are perceived as improving the independence of those living with a disability and can range from simple devices such as canes, memory aids, specialised cutlery devices to the complex high-end devices such as motorised wheelchairs, environmental control systems, GPS tracking devices.

Before you decide whether or not you wish to take part, it is important for you to understand why it is being carried out and what it will involve. This information sheet aims to inform you about the study and why it is being conducted, so that you can make an informed decision as to whether to participate or not. If you have any questions, please contact the researcher, Luke Squires, whose details are at the end of this information sheet.

Thank you for taking the time to read this.

What is the purpose of the study?

Little is known about the level of AT use and its impact on individual functioning, wellbeing or quality of life in general, but in particular there is very little known about the experience of those affected by MS. Our study aims to bridge this gap by exploring the different opinions and experiences of those affected by or working with those with MS who use AT through guided discussion.

We would like to invite you to take part in a discussion group regarding your experience as someone who works in MS health and social care with assistive technology. The discussion group will be in English and involve 6-8 people who work with people affected by MS. The groups will not be mixed to remain confidential, i.e. it will be a HCP-only discussion group, and will be audiotaped. Please be reassured that **all** data (paper and tapes) **will remain confidential** as no personal identifiers are used.

Do I have to participate?

Your participation in this study is completely voluntary, and you have the right to withdraw at any time without having to provide a reason.

What will happen to me if I take part?

If you decide to take part, we would ask that, having read this information sheet that you sign the consent form provided, and then proceed to completing the short questionnaire provided. This brief questionnaire is to gather basic contact information and essential information regarding your experience with AT and MS so that the research team can arrange the appropriate groups. This should take no more than 10 minutes of your time.

Once you have completed these, we would ask that you return the consent form **and** short questionnaire back to us using the **FREEPOST** envelope provided.

Within a few weeks of this, we will get in touch to let you know when and where the focus group discussion will take place. You will then be asked to share your experiences and opinions of assistive technology and multiple sclerosis (for example, 'what impact does AT have on MS?', 'how available is AT to prescribe?')

If you would like to take part in the study, please sign the consent form and complete the short questionnaire and return in the envelope provided.

Are there any benefits or risks from taking part?

There are no expected risks and while there may not be any *immediate* benefits to you, there is great potential in helping develop assistive technology as well as identifying the impact of using such technologies among those living with Multiple Sclerosis. It is our hope that by describing the relationship between AT and MS, data from this study will help develop our larger-scale research programme and combined these may also help better inform the development of assistive technology and service provision.

Do I get paid?

You will receive a payment of £10 following completion of the discussion. Expense forms will be provided at the session if you require reimbursement for travel and respite costs.

Will my information be kept confidential?

Your participation will remain completely confidential, as full names will not be used during the group session. Only the research team will have access to your identifying contact information and this information will be stored in a secure archive separate from the recordings and transcripts.

Therefore, whilst you will discuss your opinions of assistive technology and multiple sclerosis with others, and will be audio recorded on audiotape, **ALL** data will remain completely confidential. Only the researcher will have access to the audiotapes.

Who is organising this study?

This study is being carried out by Luke Squires as part of his PhD research at Bangor University under the supervision of Dr Val Morrison (chartered Health Psychologist and Reader in Health Psychology) and Dr Nefyn Williams (GP and Clinical Senior Lecturer).

Who has reviewed the ethics of this study?

Bangor University, School of Psychology Research Ethics and Governance Committee have reviewed and approved this study.

What happens after the study?

If you would like to receive a summary of the findings once the study has been completed please simply tick the relevant box on the Consent Form. If you would also like to be considered for taking part in our questionnaire study about assistive technology and multiple sclerosis, please tick the relevant box for option, also on the Consent Form.

Who do I contact for further information?

If you have any questions or would like any further information regarding the study, please feel free to contact the researcher or the supervisor:

Luke Squires: psp03a@bangor.ac.uk 01248 383010

Dr Val Morrison (Principal Supervisor): v.morrison@bangor.ac.uk

Complaints:

If you have any complaints about the study, please contact:

Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.

Thank you for taking the time to read this information sheet.

If you would like to take part, please sign the consent form and complete the short questionnaire, and return them using the FREEPOST envelope.

CONSENT FORM (SITE MANAGER)

Research Study Title:

The level and impact of assistive technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Researchers: Dr Val Morrison, Dr Nefyn Williams and Mr Luke Squires

---

PLEASE TICK

I have read and fully understood the information sheet provided and have had the opportunity to ask any questions. [ ]

I authorise the researcher to discuss the project with the support group members. [ ]

I allow for the focus group sessions to take place in the usual support group venue. [ ]

I would like to receive a summary of the findings after the study. [ ]

_____ _____ _____

Name (Block Capitals) **Date** **Signature**

Address **Phone**

E-Mail

Please sign and return with the completed questionnaire in the pre-paid envelope provided. You will then receive a postcard confirming the venue, date and time of the session.

PARTICIPANT CONSENT FORM

Research Study Title:

The level and impact of assistive technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Researchers: Dr Val Morrison, Dr Nefyn Williams and Mr Luke Squires

---

PLEASE TICK

I have read and fully understood the information sheet provided and have had the opportunity to ask any questions. [ ]

I understand that my participation is completely voluntary and that I have the right to withdraw at any moment without having to provide a reason. [ ]

I would like to continue and participate in the audiotaped discussion group. [ ]

I would be happy to be contacted for a related questionnaire study to take place next year. [ ]

I would like to receive a summary of the findings after the study. [ ]

_____ _____ _____

Name (Block Capitals) **Date** **Signature**

Address **Phone**

E-Mail

Please sign and return with the completed questionnaire in the pre-paid envelope provided. You will then receive a postcard confirming the venue, date and time of the session.

Focus Group Questionnaire

Firstly, we would like to **THANK YOU** for taking the time to participate in this study.

Secondly, please ensure that you have read and fully understood the information sheet and that you have signed the consent form before continuing with this questionnaire.

Please read each question carefully before giving **YOUR** full and honest answer. There are no 'right or wrong' answers but we ask you answer all of the questions according to your current situation and feelings. All information that you provide will be coded and remain completely confidential.

Demographic Questionnaire - PwMS

Gender: Male [ ] Female [ ] Age: _____

Birthplace: _____

Ethnicity (please tick):

White – English [ ] White – Irish [ ] White – Scottish [ ] White – Welsh [ ] White – Other [ ]	Black - African [ ] Black - Caribbean [ ] Black – British [ ] Black - Other [ ]	Asian – Indian [ ] Asian – Pakistani [ ] Asian – Bengali [ ] Asian – Chinese [ ] Asian – British [ ] Asian – Other [ ]
If you have selected other, please specify:		

Marital status: _____

Occupation: _____ Previous occupation (if retired):_____

MS diagnosis: _____

How long since MS diagnosis? _____

Please rate the severity of the MS diagnosis (1 = Not severe at all, 2 = Not very severe, 3 = Average, 4 = Quite severe, 5 = Extremely severe)

1 2 3 4 5

Please note any other current health conditions and rate the severity of each using the same scale as above *(e.g., if you suffer from arthritis and believe it to be 'quite severe' then write "Rheumatoid Arthritis, 4")*

_____
_____
_____

Who is your primary support person/caregiver and for how long have they provided you with care related to your MS? (e.g., "daughter, provided care for four years) ____

_____
_____

On average, how many hours per week do they provide care for you? _____
_____

THANK YOU FOR COMPLETING THE QUESTIONNAIRE.

Please add any further comments on reverse.

AT Checklist

Do you have experience with any of the following AT devices (please tick)?

Mobility

Manual wheelchair		Motorised wheelchair		Scooter	
Walker		Cane		Crutches	
Orthotics		Other (please state)			

Communication

Voice amplifier		Communication book/board		Other (please state)	

Environmental

Home modifications *e.g. wider doorways, grab bars, lift, ramp, mounts etc.*	
Computer access aids *e.g. voice recognition, special mouse/keyboard, screen enlargement, etc.*	
Environmental Control System	
Other (please state)	

Vehicle

Control adaptations *e.g. hand, voice*		Transfer adaptations *e.g. lift, hoist, cushion*		Other (please state)	

Medical

Functional electrical stimulation (FES)		Continence aids		Other (please state)	

Memory aids

Daily planner		Electronic aid *e.g. computer, phone*		Other (please state)	

Kitchen aids

Cooking aids *e.g. electric can opener, stabiliser, specialised microwave*	
Eating aids *e.g. specialised cutlery, guards, wrist supports*	
Other (please state)	

Bathroom aids

Raised toilet or seat		Seated bath or shower		Grab bars	
Commode		Other (please state)			

Telecare

Alarm systems		Fall detectors		Medication devices	

Please note any other AT devices that you do not think have been covered:

Focus Group Brief

Welcome and Introduction

Introduce myself, and focus group roles:

- I'll be asking questions and "listening to all the different things you have to say and helping to make sure that we hear from each of you."

Introduce second researcher:

- They will take notes and observe the session.

Briefly describe goals:

- The project is about AT experience including perceptions and impact among those living with, caring for and working with MS. We will discuss your thoughts and feelings of using AT, when and why you started using AT, and how your experience has changed over time.

Remind sessions are taped

- Remain anonymous in the final report
- Only the research team will listen to the tapes.

Guidelines

Before we begin I just need to discuss some guidelines with you:

1. Because the session is being taped, I would like to ask you all to please talk clearly and only one at a time
2. Please refer to each other on a first name basis
3. Even if you don't agree with someone please listen respectfully
4. I am interested in everyone's point of view so please can I hear from everyone today.

Ask everyone to introduce themselves for the tape (first name only!)

Probe questions:

- Would you explain further?
- Can you give me an example?
- Is there anything else…
- Please describe what you mean…

Debrief

- We have come to the end of the session.
- Are there any other questions or comments anyone would like to raise?
- Thank everyone, hand out debrief sheets and pay them.

Debriefing Sheet

Research Study Title:

The level and impact of assistive technology use by those living, caring and working with Multiple Sclerosis: A focus group study.

Thank you for taking part in this study. The purpose of this discussion group was to explore the different views held by those living, caring and working with Multiple Sclerosis about assistive technology (AT).

The findings of this study will help us to develop a better understanding of assistive technology, including the level and impact of AT use within the MS population. The topics discussed today will be used later to develop a questionnaire, which will investigate further the use and impact of using AT and the psychosocial support needs associated with AT use i.e. beliefs, expectations.

The findings of this study should be completed by June 2013 and if you have yet to indicate that you would like a summary of the findings, please contact the researchers on any of the details provided below.

We hope that you have enjoyed participating in this study. Again, we would like to thank you for your participation and apologise for any undue stress that may have been caused during the study.

If you have any complaints about the way this study has been conducted, please contact:

Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.

If you have any further questions and comments about the study or would like a summary of the results please contact the researcher or supervisor:

Luke Squires: psp03a@bangor.ac.uk 01248 383010

Dr Val Morrison (Principal Supervisor): v.morrison@bangor.ac.uk

c/o School of Psychology, Brigantia Building, Penrallt Road, Bangor, Gwynedd, LL57 2AS.

Appendix B^2 – Focus Group topic guide

Figure 1: PwMS focus group topic guide

1.	What would you say is the purpose of Assistive Technology (AT)?
2.	What AT have you used (past or present) for your MS?
3.	What were your experiences when you first started using AT?
4a.	What are your thoughts now about AT?
4b.	Have your experiences/thoughts changed over time?
5a.	What impact does AT have on your MS?
5b.	What impact does AT have on your lives (outside of your MS)? /relationships?
6.	If any, what are the benefits of using AT?
7.	Are there any limitations of AT?
8.	What influences you to use AT?
9a.	How available is AT for you?
9b.	How do you get access to AT?
10.	Do you have any experiences of using AT for work purposes?

Appendix C[1] – Questionnaire Study Documents

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

NISCHR RES Research Ethics Service
Gwasanaeth Moeseg Ymchwil

Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin
North Wales Research Ethics Committee - West

Bwrdd Iechyd Prifysgol Betsi Cadwaladr
Ysbyty Gwynedd
Swyddfa Academaidd Glinigol
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nrec.nhs.uk

Mr Luke Squires
PhD Student
School of Psychology
Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd
LL57 2AS psp03a@bangor.ac.uk

02 August 2013

Dear Mr Squires,

Study title: **Illness acceptance, AT use, and the functioning and wellbeing of people living with MS or caring for those affected by MS.**
REC reference: **13/WA/0226**
IRAS project ID: **135323**

Thank you for your application for ethical review, which was received on 01 August 2013. I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 15 August 2013.

Meeting arrangements

The meeting will be held in the Llewelyn Room, Ysbyty Gwynedd Hospital, Bangor, Gwynedd, LL57 2PW on 15 August 2013. The Committee would find it helpful if you could attend the meeting to respond to any questions from members. Other key investigators and a representative of the sponsor are also welcome to attend. This may avoid the need to request further information after the meeting and enable the Committee to make a decision on the application more quickly.

If you have a disability and need any practical support when attending the REC meeting you may wish to contact the REC office so appropriate arrangements can be made if necessary. If you are unable to attend the meeting the Committee will review the application in your absence.

The review of the application has been scheduled for 5.30 pm. Please note that it is difficult to be precise about the timing as it will depend on the progress of the meeting. We would kindly ask you to be prepared to wait beyond the allocated time if necessary.

If you cannot attend, it would be helpful if you could be available on the telephone at the time of the review. **Please let me know whether or not you would be available to attend the meeting or be available on the telephone.**

Committee meetings are occasionally attended by observers, who will have no vested interest in the applications under review or take any part in discussion. All observers are required to sign a confidentiality agreement.

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

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

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

Ariennir gan Lywodraeth Cymru Funded by Welsh Government

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Covering Letter		02 August 2013
REC application (submission 135323/484609/1/163)		05 August 2013
Protocol	1	31 July 2013
Participant Information Sheet: Patient	4	01 August 2013
Participant Information Sheet: Carer	3	01 August 2013
Participant Information Sheet: PwMS and Carers	2	31 July 2013
Participant Consent Form: Questionnaire	2	01 August 2013
Participant Consent Form: Interview	1	01 August 2013
GP/Consultant Information Sheets	1	31 July 2013
Questionnaire: PwMS	1	01 August 2013
Questionnaire: Carer	1	01 August 2013
Interview Schedules/Topic Guides	1	01 August 2013
Other: Debrief form: Questionnaire	3	01 August 2013
Other: Debrief form: Interview	3	01 August 2013
Investigator CV (PhD Student - Mr L Squires)		31 July 2013
Other: Academic Supervisor CV (Dr V. Morrison)		31 July 2013
Evidence of Insurance or Indemnity		01 August 2013

No changes may be made to the application before the meeting. If you envisage that changes might be required, you are advised to withdraw the application and re-submit it.

Notification of the Committee's decision

You will receive written notification of the outcome of the review within 10 working days of the meeting. The Committee will issue a final ethical opinion on the application within a maximum of 60 days from the date of receipt, excluding any time taken by you to respond fully to one request for further information or clarification after the meeting.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at ttp://www.rdforum.nhs.uk

There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs

file copy

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor and to the R&D office for Betsi Cadwaladr University Health Board.

It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisations involved in the study are kept informed of the progress of the review, as necessary.

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

13/WA/0226	Please quote this number on all correspondence

Yours sincerely

Rossela Roberts

Dr Rossela Roberts
Committee Co-ordinator
E-mail: rossela.roberts@wales.nhs.uk

file copy

Enclosure: Further information about REC membership and meeting arrangements

Copy: Sponsor: Mr Hefin Francis
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd , LL57 2AS h.francis@bangor.ac.uk

Academic Supervisor: Dr Valerie Morrison
School of Psychology, Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd
LL57 2AS v.morrison@bangor.ac.uk

R&D Office: Mrs Lona Tudor-Jones
Betsi Cadwaladr University Health Board
Research and Development Office
Holywell Community Hospital
Holywell, CH8 7TZ Lona.TudorJones@wales.nhs.uk

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

NISCHR RES
Gwasanaeth Moeseg Ymchwil | Research Ethics Service

Pwyllgor Moeseg Ymchwil Gogledd Cymru - Y Orllewin
North Wales Research Ethics Committee - West

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk
Website : www.nres.nhs.uk

Mr Luke Squires
PhD Student
School of Psychology
Bangor University
Adeilad Brigantia, Penrallt Road
Bangor, Gwynedd
LL57 2AS psp03a@bangor.ac.uk

23 August 2013

Dear Mr Squires,

Study title: **Illness acceptance, AT use, and the functioning and wellbeing of people living with MS or caring for those affected by MS.**
REC reference: **13/WA/0226**
IRAS project ID: **135323**

Thank you for your letter of 22 August 2013.

I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 August 2013

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter – documents submitted in compliance with additional conditions		22 August 2013
Protocol	2	22 August 2013
Participant Information Sheet: Patient	5	19 August 2013
Participant Information Sheet: Carer	4	19 August 2013
Participant Information Sheet: PwMs adn Carers	3	19 August 2013

(end of list)

file copy

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		02 August 2013
Covering Letter – documents submitted in compliance with additional conditions		22 August 2013
REC application (submission 135323/484609/1/163)		05 August 2013
Protocol	2	22 August 2013
Participant Information Sheet: Patient	5	19 August 2013
Participant Information Sheet: Carer	4	19 August 2013
Participant Information Sheet: PwMs and Carers	3	19 August 2013
Participant Consent Form: Questionnaire	2	01 August 2013
Participant Consent Form: Interview	1	01 August 2013
GP/Consultant Information Sheets	1	31 July 2013
Questionnaire: PwMS	1	01 August 2013
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Interview Schedules/Topic Guides	1	01 August 2013
Other: Debrief form: Questionnaire	3	01 August 2013
Other: Debrief form: Interview	3	01 August 2013
Investigator CV (PhD Student - Mr L Squires)		31 July 2013
Other: Academic Supervisor CV (Dr V. Morrison)		31 July 2013
Evidence of insurance or indemnity		01 August 2013

file copy

You should ensure that the sponsor has a copy of the final documentation for the study.

It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WA/0226	Please quote this number on all correspondence

Yours sincerely

Rossela Roberts

Dr Rossela Roberts
Committee Co-ordinator

E-mail: rossela.roberts@wales.nhs.uk

Participant Information Sheet

Impact of using assistive technology among people living with MS

Invitation:

I am writing to you on behalf of a research team at the School of Psychology, Bangor University who are conducting a research study in part-collaboration with Betsi Cadwaladr University Health Board. We would like to invite you to take part in this study. We are investigating the effect of assistive technology on those living with multiple sclerosis in terms of physical functioning and psychological wellbeing. We are interested in how the beliefs, emotions and feelings of people living with multiple sclerosis influences their use of assistive technology.

By 'assistive technology' we refer to **ANY** device or equipment that people use to improve their independence. These can range from simple devices (such as canes, dressing aids, specialised cutlery etc) to complex electronic devices (such as motorised wheelchairs, environmental control systems, GPS tracking devices).

Before you decide whether or not you wish to take part in this study, it is important that you understand why it is being carried out and what it will involve. This information sheet aims to help you make an informed decision as to whether to participate or not. Please take your time to read this information carefully and discuss it with relatives or friends if you wish. You should feel under no obligation to take part. If you have any questions, please contact the researcher, Luke Squires, whose details are at the end of this information sheet.

Thank you for reading this.

What is the purpose of this study?

Little is known about the relationship between AT use and physical functioning, wellbeing or quality of life, but in particular there is very little known about the experience of those affected by MS. Our study aims to bridge this gap by asking those affected by MS about their beliefs, feelings and AT use through completing assessments at four time points over a 12 month period.

As someone living with multiple sclerosis we would like to invite you to complete a questionnaire at four time points; at initial recruitment, and in 3, 6 and 12 months time. In this way we will be able to examine how different beliefs can influence the use of assistive technology and also the impact that it has on your daily life.

What do we mean by Assistive Technology?

Assistive technology refers to **ANY** device or equipment that people use and are perceived as improving the independence of those living with a disability. These can range from simple devices (such as canes, memory aids, specialised cutlery etc) to complex electronic devices (such as motorised wheelchairs, environmental control systems, GPS tracking devices). We would like to know about the experience you have with assistive technology, and that includes any opinions you may have even if you have not used such equipment.

Why have I been contacted?

There are two reasons you may have been contacted.

You may have been identified by your local health care team as someone who is eligible to take part in the study and may be interested in taking part. **Your contact details have not been passed on to any members of the research team at Bangor University. These will only be given once you have given consent to do so at the end of this information sheet.**

Alternatively, you may have expressed your interest in participating by replying to our study invitation letter or local advertisement, thank you. This fuller information is to enable you to decide whether you wish to participate in the study.

Do I have to take part?

Your participation in this study is completely voluntary. It is your decision as to whether you wish to take part or not, and even if you change your mind afterwards, you can still withdraw from the study at any time without having to provide a reason. In this case, we will ask you whether you are happy

for us to retain the data that we have collected so far. **Whether you decide to participate in the study or not, this does not affect your treatment or care in any way.**

What will happen to me if I decide to take part? What do I have to do?

If you agree to participate, you are required to sign the consent form at the end of this information sheet and decide whether you wish to complete the postal version of the questionnaire, or the online version. We ask that you then return it to me, Mr Luke Squires, in the FREEPOST envelope provided. If you choose the online completion option, a website link will be sent for you to access the questionnaire. If you indicate a preference to complete on a hard copy, a copy of the questionnaire will be sent to you by post. The questionnaire will ask about your illness experience, your day-to-day life, your wellbeing and your technology use or non-use. Completing the questionnaire by either method should take approximately 30-40 minutes.

We would be really grateful if you could complete and return your questionnaire BEFORE January 2014. Receipt of your first completed questionnaire will act as your giving of consent to us to send you a questionnaire at 3, 6 and 12 months later.

Following completion and return of the final 12 month questionnaire, we will send you a debrief form and a summary of our study findings will be provided to you once analysis has been completed if you request so on the Consent Form.

Are there any disadvantages, benefits from taking part in this study?

We know of no disadvantages or risks associated with taking part in this study, and whilst there may be no immediate benefits to yourself, there are potential long-term benefits to other people living with MS. We hope that our study will help our understanding of how equipment is helping people with MS, and what could be done to improve use of these devices.

In the unlikely event that completing our questionnaire causes any distress, please contact a member of your healthcare team, your GP, or if you prefer, contact one of the following helplines and organisations for support or information:

- MS Helpline - 0808 800 8000 (Monday-Friday 09.00am-09.00pm)
  helpline@mssociety.org.uk
  http://www.mssociety.org.uk/ms-support/emotional-support/ms-helpline

  (This service is confidential and provides emotional support and information related to MS).

- Carers Direct Helpline - 0808 802 0202 (Monday-Friday 09.00am-08.00pm; Saturday-Sunday 11am-4pm)

http://www.nhs.uk/carersdirect/carerslives/updates/pages/carersdirecthelpline.aspx

(This service is confidential and provides you with informational support and help with your support needs).

Will my taking part in the study be kept confidential?

Your participation in the study will remain confidential. Only Luke Squires PhD student at Bangor University will see your personal details, which will be immediately detached from the questionnaire on its receipt and stored separately from your data. You will be assigned a unique code for your questionnaire so that your data is not identifiable. The reason we require your personal details is solely for the purposes of contacting you with regards making available the questionnaires at the later timepoints. All information used in reports, scientific papers or presentations will be anonymous.

What happens to the results of the study?

This study is being carried out for the completion of Mr Luke Squires' doctoral studies at Bangor University. It is intended that the results of the study will be shared with health care professionals and relevant patient and carer groups (such as the MS Society, Carers UK, etc) as well as being submitted for publication and presented at academic meetings and relevant health conferences.

If you would like to receive a summary of the findings once the study has been completed please simply tick the relevant box on the Consent Form.

If you would also like to be considered for taking part in our interview study about assistive technology and multiple sclerosis, please tick the relevant box on the Consent Form.

Who is organizing the study?

This study is being carried out by Luke Squires as part of his doctoral research at Bangor University under the supervision of Dr Val Morrison (chartered Health Psychologist and Reader in Health Psychology) and Dr Nefyn Williams (GP and Clinical Senior Lecturer).

Who has reviewed the ethics of this study?

The study has been reviewed and approved by the School of Psychology, Bangor University Research Ethics and Governance Committee and the North Wales Research Ethics Committee.

Who can I contact for further information?

If you have any questions or would like any further information regarding the study, please feel free to contact the researcher or the supervisor:

Mr Luke Squires: psp03a@bangor.ac.uk 01248 383010

Dr Val Morrison: v.morrison@bangor.ac.uk

Complaints:

If you have any complaints about the study, please contact:

Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.

Thank you for taking the time to read this information sheet.

If you would like to take part, please sign the consent form and the assistive technology checklist, and please return them using the FREEPOST envelope.

QUESTIONNAIRE CONSENT FORM

Researchers: Mr Luke Squires, Dr Val Morrison and Dr Nefyn Williams

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PLEASE INITIAL

I confirm that I have read and fully understood the study information sheet provided and have had the opportunity to ask any questions. ☐

I understand that my participation is entirely voluntary and that I am free to withdraw at any time without reason, and without my medical care or legal rights affected. ☐

I understand that in order to obtain information about my treatments and health condition, responsible individuals from my health care team and the researcher Luke Squires may look at sections of my medical records. I give permission for these individuals to have access to my records. ☐

I want to take part in the above study. ☐

I am happy for my name and contact details to be held on record by Mr Luke Squires, so that he can contact me to participate in the follow up phases of the questionnaire. ☐

I would like to receive a summary of the final study findings. YES ☐ NO ☐

I would like you to tell my GP about my participation in the study. YES ☐ NO ☐

I am happy to be considered and contacted to take part in a related interview study at a later stage. YES ☐ NO ☐

PLEASE WRITE IN BLOCK CAPITALS.

Name:	Date:	Signature:
Postal Address:		
		Post Code:

Telephone Number:	
E-Mail Address:	

I would like to be complete the questionnaire via POST ☐ ONLINE ☐

Please complete all three copies of this form and keep one copy for yourself. The researcher will retain one copy and the other will be kept on your medical records.

Do you have a close friend or family member who helps provide care for you and who would also be interested in taking part in our study? If so, we would really appreciate it if they could state their name and sign to agree having an invitation sent to them.

Name:	Date:	Signature:
Postal Address:		
		Post Code:
Telephone Number:		
E-Mail Address:		

GP Notification Letter

RE: Impact of using assistive technology among people living with MS

Dear Dr (insert name),

I am writing on behalf of a research team at the School of Psychology, Bangor University who are conducting the study referenced above. I am required to inform you that your patient, (insert name and date of birth), has given consent to participate in this research study. As a participant they will complete four questionnaires; on initial recruitment, and at 3, 6 and 12 months after. You do not need to do anything and nor does this affect the way that they are cared or treated for.

If you have any queries regarding your patient's participation then please feel free to contact me on 01248 38 30 10, or by email: psp03a@bangor.ac.uk

Yours sincerely,

Mr Luke Squires

(PhD Candidate)

Assistive Technology & Multiple Sclerosis

Questionnaire 1

Surname: _____

First Name(s): _____

Address: _____

_____

_____

Telephone Number: _____

E-Mail: _____

Date completed: _____/_____/_____

For office use only – code: _____

Firstly, we would like to thank you for taking the time to participate in this study. Secondly, please ensure that you have read and fully understood the study information sheet and that you have given consent before continuing with this questionnaire.

Throughout this questionnaire, the individual who carries out activities/tasks for you may be referred to as a 'carer' or 'caregiver'.

Please read each question carefully before giving your full and honest answer. There are no 'right or wrong' answers but we ask that you answer all of the questions according to your current situation and feelings (unless stated otherwise). All information that you provide will be coded and remain completely confidential.

PART ONE

First, we would like to know a little more about you.

Gender: Male [ ] Female [ ] Other: _____

Date of Birth: ____/_____/_19____

Ethnicity: White [ ] Asian [ ] Black [ ] Mixed [ ] Other: _____

Nationality: British [ ] English [ ] Irish [ ] Scottish [ ] Welsh [ ]

Other: _____

Marital status: Single [ ] In a relationship [ ] Married [ ]

Divorced/Separated [ ] Widowed [ ]

Occupation: _____

If retired/unemployed, previous occupation: _____

If retired/unemployed, is this related to your MS? Yes [ ] No [ ]

Approximately, when did you receive your MS diagnosis? _____

Type of MS at diagnosis *(relapsing remitting, progressive – primary, secondary etc)***:**

_____

Type of MS currently *(relapsing remitting, progressive – primary, secondary etc)***:**

_____

Please rate the severity of your MS at diagnosis *(please circle)***:**

Not severe at all	Not very severe	Average	Quite severe	Extremely severe

Please rate the severity of your MS currently (*please circle)***:**

Not severe at all	Not very severe	Average	Quite severe	Extremely severe

Please note any other health conditions that you may have and rate the severity of each one using the same scale as above: *(For example, if you also have arthritis and believe it to be not very severe then write "Rheumatoid Arthritis, not very severe")*

_____

_____

_____

_____

Do you have a primary carer? Yes [ ] *go to next question*
No [ ] *go to next page*

Who is your primary carer and how long have they provided care for you? *(For example, "daughter, 4 years")*

_____

On average, how many hours per week do they provide care for you? __

Please rate the quality of your relationship with your carer *(please circle)***:**

Excellent	Good	Average	Poor	Very Poor

PLEASE CONTINUE TO PART TWO

PART TWO

Do you have experience with any of the following AT devices *(please tick all that apply)***?**

Mobility

Manual wheelchair		Motorised wheelchair		Scooter	
Walker		Cane		Crutches	
Orthotics (brace)		Other *(please state)*			

Communication

Voice amplifier		Communication book/board		Other *(please state)*	

Environmental

Home modifications *(e.g. wider doorways, grab bars, lift, ramp etc)*	
Computer access aids *(e.g. voice recognition, adapted mouse/keyboard)*	
Transfer aids *(e.g. hoist, lift, slide sheets, turners etc)*	
Vehicle adaptations *(e.g. automatic, hand control, voice control etc)*	
Other *(please state)*	

Medical

Functional electrical stimulation (FES)		Continence aids		Other *(please state)*	

Memory aids

Daily planner		Electronic aid *(e.g. computer, phone etc)*		Other *(please state)*	

Kitchen aids

Cooking aids *(e.g. electric can opener, adapted microwave etc)*	
Eating aids *(e.g. specialised cutlery, wrist supports etc)*	
Other *(please state)*	

Bathroom aids

Raised toilet or seat		Seated bath/shower		Grab bars	
Commode		Other *(please state)*			

Telecare

Alarm systems		Fall detectors		Medication devices	

Miscellaneous

Dressing aids *(e.g. button hooks, shoehorns, sock aids, etc)*	
Sex aids *(e.g. cushions, slings, toys etc)*	
Support aids *(e.g. specialised cushions/seating)*	

Please note any other devices that you do not think have been covered:

PART THREE

Please think of the most **RECENT** assistive technology device that you have had.

What is that device?

_____

_____

When did you get this device? _____ (days / weeks / months ago)

How did you get this device? Bought [ ] Occupational Therapist [ ]

Other way: _____

Each word or phrase below describes how using an assistive device may affect a user. Some might seem unusual but it is important that you answer each of the 10 items.

For each word or phrase, put an "X" in the appropriate box to show how you are affected by the assistive device you have just named.

How has the device affected your:	Very much worse		A little worse	No difference	A little better		Very much better
Ability to adapt to the activities of daily living?	-3	-2	-1	0	1	2	3
Ability to participate?	-3	-2	-1	0	1	2	3
Ability to take advantage of opportunities?	-3	-2	-1	0	1	2	3
Eagerness to try new things?	-3	-2	-1	0	1	2	3
Happiness?	-3	-2	-1	0	1	2	3
Independence?	-3	-2	-1	0	1	2	3
Productivity?	-3	-2	-1	0	1	2	3
Quality of life?	-3	-2	-1	0	1	2	3
Self-esteem?	-3	-2	-1	0	1	2	3
Sense of control?	-3	-2	-1	0	1	2	3

Do you still use this device? Yes [ ] No [ ]

If possible, please explain your reasons for this: _____

PART FOUR

Please continue thinking of your most **RECENT** assistive technology device when answering the following questions.

Please answer the questions as honestly as possible, and feel free to provide a separate piece of paper if you have run out of space.

1) Did you receive any training in using your most recent device?
[ ] No [ ] Yes [ ] N/A

2) Did you feel confident in using that device most recently?
[ ] No [ ] Yes [ ] N/A

3) Did you feel that your device met your expectations (has done what you *expected* it to do for you?)
[ ] No [ ] Yes [ ] N/A

4) Do you feel that your most recent device has met your needs (has done what you *need* it to do for you?)
[ ] No [ ] Yes [ ] N/A

5) Please rate the above device on a few aspects *(please circle)***:**

	VERY BAD	BAD	NEITHER	GOOD	VERY GOOD
	1	2	3	4	5
a) Cost	1	2	3	4	5
b) Appearance (how it looks)	1	2	3	4	5
c) Design (how it works)	1	2	3	4	5
d) Ease of learning to use	1	2	3	4	5
e) Ease of use	1	2	3	4	5
f) Time saving	1	2	3	4	5
g) Enjoyment of use	1	2	3	4	5

PART FIVE

These questions ask about your MS and some might seem unusual but we ask that you answer honestly to your current thoughts and feelings. Please circle the number that best corresponds to your views:

1. How much does your illness affect your life?

0 1 2 3 4 5 6 7 8 9 10
no affect at all — severely affects my life

2. How long do you think your illness will continue?

0 1 2 3 4 5 6 7 8 9 10
a very short time — forever

3. How much control do you feel you have over your illness?

0 1 2 3 4 5 6 7 8 9 10
absolutely no control — extreme amount of control

4. How much do you think your treatment can help your illness? *(NB – If you are not currently receiving treatment please write 'N/A' and then answer hypothetically i.e. as if you were)*

0 1 2 3 4 5 6 7 8 9 10
not at all — extremely helpful

5. How much do you experience symptoms from your illness?

0 1 2 3 4 5 6 7 8 9 10
no symptoms — many severe

6. How concerned are you about your illness?

0 1 2 3 4 5 6 7 8 9 10
not at all concerned — extremely concerned

7. How well do you feel you understand your illness?

0 1 2 3 4 5 6 7 8 9 10
don't understand at all — understand very clearly

8. How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0 1 2 3 4 5 6 7 8 9 10
not at all affected emotionally — extremely affected emotionally

PART SIX

The following questions ask for your views about the impact of MS on your day-to-day life during the past two weeks. For each statement, please circle the one number that best describes your situation. Please answer **all** questions.

In the past two weeks, how much has your MS limited your ability to:		Not at all	A little	Moderately	Quite a bit	Extremely
1.	Do physically demanding tasks?	1	2	3	4	5
2.	Grip things tightly (e.g. turning on taps)?	1	2	3	4	5
3.	Carry things?	1	2	3	4	5
In the past two weeks, how much have you been bothered by...		**Not at all**	**A little**	**Moderately**	**Quite a bit**	**Extremely**
4.	Problems with your balance?	1	2	3	4	5
5.	Difficulties moving about indoors?	1	2	3	4	5
6.	Being clumsy?	1	2	3	4	5
7.	Stiffness?	1	2	3	4	5
8.	Heavy arms and/or legs?	1	2	3	4	5
9.	Tremor of your arms or legs?	1	2	3	4	5
10.	Spasms in your limbs?	1	2	3	4	5
11.	Your body not doing what you want it to do?	1	2	3	4	5
12.	Having to depend on others to do things for you?	1	2	3	4	5
13.	Limitations in your social and leisure activities at home?	1	2	3	4	5

In the past two weeks, how much have you been bothered by...		Not at all	A little	Moderately	Quite a bit	Extremely
14.	Being stuck at home more than you would like to be?	1	2	3	4	5
15.	Difficulties using your hands in everyday tasks?	1	2	3	4	5
16.	Having to cut down the amount of time you spent on work or other daily activities?	1	2	3	4	5
17.	Problems using transport (e.g. car, bus, train, taxi, etc.)?	1	2	3	4	5
18.	Taking longer to do things?	1	2	3	4	5
19.	Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?	1	2	3	4	5
20.	Needing to go to the toilet urgently?	1	2	3	4	5
21.	Feeling unwell?	1	2	3	4	5
22.	Problems sleeping?	1	2	3	4	5
23.	Feeling mentally fatigued?	1	2	3	4	5
24.	Worries related to your MS?	1	2	3	4	5
25.	Feeling anxious or tense?	1	2	3	4	5
26.	Feeling irritable, impatient, or short tempered?	1	2	3	4	5
27.	Problems concentrating?	1	2	3	4	5
28.	Lack of confidence?	1	2	3	4	5
29.	Feeling depressed?	1	2	3	4	5

Please check that you have circled ONE number for EACH question

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PART SEVEN

These questions help us know how you are feeling. Please read every sentence and tick the box that best describes how you have been feeling during the **LAST WEEK**. You do not have to think too much to answer. Your first response is best.

1. I feel tense or 'wound up':
- Most of the time ☐
- A lot of the time ☐
- From time to time (occasionally) ☐
- Not at all ☐

2. I still enjoy doing the things I used to enjoy:
- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

3. I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

4. I can laugh and see the funny side of things:
- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

5. Worrying thoughts go through my mind:
- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

6. I feel cheerful:
- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

7. I can sit at ease and feel relaxed:
- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

8. I feel as if I am slowed down:
- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

9. I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

10. I have lost interest in my appearance:
- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

11. I feel restless as if I have to be on the move:
- Very much indeed ☐
- Quite a lot ☐
- Not very often ☐
- Not at all ☐

12. I look forward with enjoyment to things:
- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

13. I get sudden feelings of panic:
- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

14. I can enjoy a good book or radio/TV programme:
- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

PART EIGHT

The following questions ask for your current thoughts and feelings about MS. For each statement, please circle the one number that best describes your situation. Please answer all questions.

1. I've come to terms with my MS

1	2	3	4	5
strongly agree				strongly disagree

2. I'd give all my money to get rid of MS

1	2	3	4	5
strongly agree				strongly disagree

3. I think of MS as a curse

1	2	3	4	5
strongly agree				strongly disagree

4. I can't conquer MS but I can adapt to it

1	2	3	4	5
strongly agree				strongly disagree

5. My fondest dream is that I'll awaken without my MS

1	2	3	4	5
strongly agree				strongly disagree

6. Having a disease like MS is just a part of my life

1	2	3	4	5
strongly agree				strongly disagree

7. MS is a focal point in my life

1	2	3	4	5
strongly agree				strongly disagree

8. I spend a lot of time wondering why I have MS

1	2	3	4	5
strongly agree				strongly disagree

9. I think of MS as just part of who I am

1	2	3	4	5
strongly agree				strongly disagree

10. I think a lot about what my life would be like without MS

1	2	3	4	5
strongly agree				strongly disagree

PART NINE

We would like to know about your general outlook. Please answer each question independently, not to allow one statement influence your answer to another. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

1 = I agree a lot
2 = I agree a little
3 = I neither agree nor disagree
4 = I disagree a little
5 = I disagree a lot

	agree a lot	agree a little	neither	disagree a little	disagree a lot
1. In uncertain times, I usually expect the best.	1	2	3	4	5
2. It's easy for me to relax.	1	2	3	4	5
3. If something can go wrong for me, it will.	1	2	3	4	5
4. I'm always optimistic about my future.	1	2	3	4	5
5. I enjoy my friends a lot.	1	2	3	4	5
6. It's important for me to keep busy.	1	2	3	4	5
7. I hardly ever expect things to go my way.	1	2	3	4	5
8. I don't get upset too easily.	1	2	3	4	5
9. I rarely count on good things happening to me.	1	2	3	4	5
10. Overall, I expect more good things to happen to me than bad.	1	2	3	4	5

PART TEN

Here are some questions about your support network. Please read each question carefully and select your best answer. There are no right or wrong answers.

PLEASE CIRCLE ONE ANSWER ONLY FOR EACH QUESTION

1. Other than members of your family how many persons in your local area do you feel you can depend on or feel very close to?	None	1-2 people	More than 2 people
2. How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?	None	1-2	3+
3. How many times did you talk to someone, friends, relatives or others on the telephone in the past week (either they called you, or you called them)?	0-1	2-5	6+
4. About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?	0-1	2-5	6+
5. Does it seem that your family and friends (i.e. people who are important to you) understand you?	Hardly ever	Some of the time	Most of the time
6. Do you feel useful to family and friends (i.e. people important to you)?	Hardly ever	Some of the time	Most of the time
7. Do you know what is going on with your family and friends?	Hardly ever	Some of the time	Most of the time
8. When you are talking with your family and friends, do you feel you are being listened to?	Hardly ever	Some of the time	Most of the time
9. Do you feel you have a definite role (place) in your family and among your friends?	Hardly ever	Some of the time	Most of the time
10. Can you talk about your deepest problems with at least some of your family and friends?	Hardly ever	Some of the time	Most of the time

FINAL PART

These are statements commonly made by people about their lives. Read each one carefully and decide to what extent you agree with them. *Please use the following key and answer by circling the most appropriate number.*

1	2	3	4
Not at all true	Hardly true	Moderately true	Exactly true

I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
If someone opposes me, I can find the means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
I am confident that I could deal efficiently with unexpected events.	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
I can solve most problems if I invest the necessary effort.	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
If I am in trouble, I can usually think of a solution.	1	2	3	4
I can usually handle whatever comes my way.	1	2	3	4

Finally, did you receive any help filling in this questionnaire via

- Friend/Family member? [ ] Yes
- Assistive technology device? [ ] Yes

  If so, what device: _____

Thank you for completing the questionnaire. If you have any further comments about the questionnaire, please feel free to write them on the back of this page. If this questionnaire has caused any distress or you require further assistance, please refer back to the information sheet for extra informational and emotional support.

Please return this completed questionnaire in the FREEPOST envelope provided.

QUESTIONNAIRE DEBRIEF

Title: Impact of using assistive technology among people living with MS

Dear **_____, (Participant name)**

On behalf of the research team, I would like to thank you for taking the time to complete our questionnaires. We can confirm that we will not send you any more questionnaires as part of this study. We would like to remind you that all data you have provided will be used for our final report and all personal information will be made anonymous.

Your participation is greatly appreciated and will help inform a better understanding of how assistive technology (AT) impacts those living with multiple sclerosis (MS), as well as those providing care for people with MS. We also hope to identify factors that influence people's use of AT.

We are unable to provide individual feedback on our findings; however, if you have opted to receive the study summary then you will receive an information booklet of our findings following analysis (in approx. 6-9 months time). Please feel free to contact us if you have any further questions about the study in the meantime, or if you wish to confirm that you would like a study summary.

Finally, we hope that this experience has been a pleasant one for you and wish you all the best for the future.

Yours sincerely,

Luke Squires Tel: 01248 38 3010 E-Mail: psp03a@bangor.ac.uk

(Research student, PhD candidate)

Dr Val Morrison & Dr Nefyn Williams (Supervisors)

Study Checklist

Inclusion and Exclusion Criteria and Patient Clinical Information

If **ANY** item receives a tick in the **'EXCLUDE'** column, then please do **NOT** invite this patient to the study. Instead, keep this form and patient ID on file.

Patient Inclusion and Exclusion Criteria	**INCLUDE**	**EXCLUDE**
1 Does the adult patient have a confirmed diagnosis of Multiple Sclerosis?	☐ YES	☐ NO
2 – Does the adult patient struggle to speak, understand and write in English?	☐ NO	☐ YES
3 – Does the patient have a severe cognitive impairment (e.g. dementia)?	☐ NO	☐ YES

PLEASE WRITE IN BLOCK CAPITALS

Name of patient's GP:	
Address of patient's GP:	
	Post Code:

Please send the study invitation letter to the patient, providing **ALL** items in the **'INCLUDE'** column are ticked.

Appendix C^2 – Full *t* tests of baseline study

Unadjusted t tests of questionnaire type (post vs online)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	2.164	122	.032	.85065	.39306
BIPQ – Illness timeline	1.384	63.208	.171	.32453	.23449
BIPQ – Personal control	1.180	122	.240	.57242	.48528
BIPQ – Treatment control	1.616	119	.109	.79818	.49391
BIPQ – Symptom experience	1.154	120	.251	.45055	.39039
BIPQ _ Illness concern	1.534	120	.128	.68179	.44449
BIPQ – Illness coherence	1.707	119.956	.090	.74160	.43449
BIPQ – Emotional effect	1.534	121	.128	.68093	.44398
MSIS29 – Physical impact	.977	123	.331	3.44955	3.53182
MSIS29 – Psychological impact	1.048	123	.297	1.75496	1.67476
Illness acceptance	-1.891	122	.061	-2.61976	1.38569
Optimism	-1.505	121	.135	-1.55959	1.03610
Social Support - Total	-.361	123	.719	-.27096	.75068

Unadjusted t tests of gender

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	2.553	122	.012	1.07704	.42194
BIPQ – Illness timeline	-.664	122	.508	-.15204	.22889
BIPQ – Personal control	1.255	122	.212	.65797	.52430
BIPQ – Treatment control	1.526	119	.130	.81684	.53545
BIPQ – Symptom experience	3.771	120	.000	1.50588	.39931
BIPQ _ Illness concern	.320	120	.750	.15554	.48646
BIPQ – Illness coherence	.180	121	.858	.08799	.48947
BIPQ – Emotional effect	-.775	121	.440	-.37335	.48167
MSIS29 – Physical impact	.989	123	.325	3.75169	3.79411
MSIS29 – Psychological impact	-1.283	123	.202	-2.30369	1.79534
Illness acceptance	-.417	122	.677	-.63411	1.51891
Optimism	.903	121	.368	1.02203	1.13159
Social Support - Total	.183	123	.855	.14737	.80682

Unadjusted t tests of marital status (partner vs. no partner)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	.912	116	.363	.41527	.45514
BIPQ – Illness timeline	.154	116	.878	.03707	.24060
BIPQ – Personal control	.208	116	.835	.11275	.54138
BIPQ – Treatment control	.884	114	.378	.49399	.55871
BIPQ – Symptom experience	.618	115	.538	.27286	.44130
BIPQ _ Illness concern	-.127	115	.899	-.06514	.51206
BIPQ – Illness coherence	.780	116	.437	.39776	.50963
BIPQ – Emotional effect	-.889	116	.376	-.44958	.50562
MSIS29 – Physical impact	-.362	117	.718	-1.43156	3.95565
MSIS29 – Psychological impact	-.450	117	.654	-.84936	1.88766
Illness acceptance	1.100	116	.274	1.71027	1.55499
Optimism	-.620	115	.537	-.72597	1.17152
Social Support - Total	.822	117	.413	.69446	.84466

Unadjusted t tests of employment

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	4.817	117	.000	2.05718	.42707
BIPQ – Illness timeline	-.643	117	.521	-.15811	.24579
BIPQ – Personal control	1.536	68.256	.129	.74450	.48481
BIPQ – Treatment control	3.151	82.775	.002	1.42827	.45327
BIPQ – Symptom experience	4.086	116	.000	1.72710	.42273
BIPQ _ Illness concern	.647	116	.519	.33547	.51822
BIPQ – Illness coherence	-.762	117	.448	-.39883	.52335
BIPQ – Emotional effect	1.224	117	.223	.63233	.51648
MSIS29 – Physical impact	4.804	118	.000	17.95276	3.73672
MSIS29 – Psychological impact	.846	118	.399	1.64843	1.94897
Illness acceptance	-1.410	117	.161	-2.23570	1.58598
Optimism	.257	116	.798	.30679	1.19297
Social Support - Total	-.375	118	.708	-.32966	.87886

Unadjusted t tests of MS type (progressive vs. relapsing)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	4.843	107	.000	1.85611	.38323
BIPQ – Illness timeline	-.871	107	.386	-.13208	.15162
BIPQ – Personal control	-.021	106.660	.983	-.01035	.48790
BIPQ – Treatment control	2.223	105	.028	1.16328	.52333
BIPQ – Symptom experience	2.446	106	.016	.98095	.40110
BIPQ _ Illness concern	.128	106	.898	.06172	.48196
BIPQ – Illness coherence	-.558	107	.578	-.26259	.47054
BIPQ – Emotional effect	.995	107	.322	.48516	.48776
MSIS29 – Physical impact	3.550	108	.001	12.60164	3.54944
MSIS29 – Psychological impact	-.462	78.462	.645	-.88798	1.92074
Illness acceptance	-.381	107	.704	-.57078	1.49978
Optimism	.464	106	.644	.51907	1.11976
Social Support - Total	-.697	108	.488	-.56264	.80762

Unadjusted t tests of co-morbidities (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	-.074	122	.941	-.02917	.39649
BIPQ – Illness timeline	-.809	122	.420	-.16932	.20939
BIPQ – Personal control	-1.155	122	.250	-.55521	.48050
BIPQ – Treatment control	-.999	119	.320	-.49226	.49271
BIPQ – Symptom experience	.157	120	.876	.06088	.38868
BIPQ _ Illness concern	.007	120	.995	.00303	.44415
BIPQ – Illness coherence	-.501	121	.617	-.22511	.44892
BIPQ – Emotional effect	.328	121	.743	.14539	.44307
MSIS29 – Physical impact	-.422	123	.673	-1.47984	3.50276
MSIS29 – Psychological impact	-.739	123	.462	-1.22561	1.65948
Illness acceptance	.151	122	.880	.21013	1.39154
Optimism	.780	121	.437	.80397	1.03092
Social Support - Total	.055	123	.957	.04048	.74255

Unadjusted t tests of carer (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	-4.416	89.140	.000	-1.75866	.39825
BIPQ – Illness timeline	-1.133	67.975	.261	-.26304	.23218
BIPQ – Personal control	-2.090	114	.039	-1.00956	.48296
BIPQ – Treatment control	-2.359	112	.020	-1.18483	.50224
BIPQ – Symptom experience	-2.468	113	.015	-.98179	.39782
BIPQ _ Illness concern	-.945	113	.347	-.43938	.46513
BIPQ – Illness coherence	.226	114	.821	.10514	.46450
BIPQ – Emotional effect	-1.151	114	.252	-.53106	.46146
MSIS29 – Physical impact	-4.660	115	.000	-15.64349	3.35722
MSIS29 – Psychological impact	-1.017	115	.311	-1.76505	1.73490
Illness acceptance	.739	114	.461	1.05328	1.42477
Optimism	-.118	113	.906	-.12641	1.06915
Social Support - Total	1.123	115	.264	.87937	.78336

Unadjusted t tests of mobility AT use

		Total sample		**Mobility AT (*N=55*)**		**Non-Mobility AT (*N=48*)**				
Variable	Score	M	SD	M	SD	M	SD	*t*	*df*	*p*
Age	-	51.89	12.96	52.00	11.08	52.15	13.78	-0.58	96	.954
Years since diagnosis	-	13.40	9.29	13.94	8.86	13.21	8.56	.418	98	.677
Severity of MS	0-4	2.22	0.93	2.29	0.75	2.39	0.91	-.615	96	.540
Severity of comorbidties	0-4	2.14	1.20	2.05	1.05	2.36	1.29	-.858	40	.396
Length of informal care (months)	-	123.57	94.57	118.90	91.66	126.24	98.18	-.257	43	.799
Hours of care	0-168	68.08	66.03	61.88	58.35	69.42	72.37	-.390	43.33	.698
Relationship quality	0-4	3.77	0.50	3.75	0.59	3.73	0.45	.122	56	.903
Social Support	10-30	22.18	4.13	22.61	4.38	21.82	3.81	.962	101	.339
Optimism	6-30	19.34	5.71	19.52	6.23	19.94	4.43	-.400	96.971	.690
BIPQ – Illness effect	0-10	7.30	2.20	7.64	1.80	7.69	2.00	-.137	101	.892
BIPQ – Illness timeline	0-10	9.77	1.16	9.89	0.69	9.87	0.47	.212	101	.832
BIPQ – Personal control	0-10	6.40	2.68	6.42	2.83	6.56	2.52	-.272	101	.786
BIPQ – Treatment control	0-10	4.82	2.71	5.03	2.83	4.65	2.60	.704	99	.483
BIPQ – Symptom experience	0-10	6.95	2.14	7.44	1.63	7.19	1.93	.728	100	.468
BIPQ - Illness concern	0-10	7.22	2.44	7.24	2.68	7.64	1.97	-.850	99	.397
BIPQ – Illness coherence	0-10	2.24	2.48	1.69	1.92	2.25	2.47	-1.296	100	.198
BIPQ – Emotional effect	0-10	6.59	2.45	6.56	2.40	6.73	2.42	-.363	100	.717
Illness acceptance	10-50	31.65	7.71	31.50	8.29	32.34	7.17	-.544	101	.588
Device perceptions	15-35	27.55	4.39	27.02	4.75	28.18	3.92	-1.34	101	.183
No. of AT devices	-	8.29	5.34	9.13	4.88	9.54	5.32	-.408	100	.684
Length of AT use (months)	-	18.60	27.76	20.04	28.08	16.93	27.63	.531	89	.597

Unadjusted t tests of AT Training (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	.889	91	.377	.35470	.39912
BIPQ – Illness timeline	1.463	59.103	.149	.15954	.10904
BIPQ – Personal control	1.025	91	.308	.57550	.56146
BIPQ – Treatment control	.793	89	.430	.45998	.58030
BIPQ – Symptom experience	.871	90	.386	.31592	.36267
BIPQ _ Illness concern	-1.372	89	.173	-.69961	.50986
BIPQ – Illness coherence	-.300	90	.765	-.13788	.45995
BIPQ – Emotional effect	.220	90	.826	.11272	.51205
MSIS29 – Physical impact	2.944	91	.004	10.34550	3.51418
MSIS29 – Psychological impact					
Illness acceptance	1.004	91	.318	1.51595	1.51012
Optimism	.281	91	.779	.46723	1.66343
Social Support - Total	.167	91	.868	.10154	.60877

Unadjusted t tests of AT confidence (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	-.987	96	.326	-.81935	.83006
BIPQ – Illness timeline	-.480	96	.633	-.13366	.27871
BIPQ – Personal control	-.993	96	.323	-1.20215	1.21051
BIPQ – Treatment control	-2.194	94	.031	-2.99109	1.36333
BIPQ – Symptom experience	-1.146	95	.255	-1.02419	.89373
BIPQ _ Illness concern	-1.022	94	.309	-1.23598	1.20927
BIPQ – Illness coherence	-.450	3.057	.683	-1.07527	2.39170
BIPQ – Emotional effect	-.101	95	.920	-.12634	1.25582
MSIS29 – Physical impact	-.755	96	.452	-5.80100	7.68133
MSIS29 – Psychological impact	.023	96	.981	.09843	4.19364
Illness acceptance	.332	96	.740	1.23302	3.70991
Optimism	.536	95	.593	1.38261	2.57861
Social Support - Total	1.002	96	.319	1.87687	1.87399

Unadjusted t tests of AT meeting expectations (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	-1.602	99	.112	-1.75170	1.09338
BIPQ – Illness timeline	-.362	99	.718	-.12684	.35082
BIPQ – Personal control	-2.161	99	.033	-3.28912	1.52216
BIPQ – Treatment control	-1.594	97	.114	-2.51677	1.57897
BIPQ – Symptom experience	-.674	98	.502	-.70103	1.03980
BIPQ _ Illness concern	-.873	97	.385	-1.22615	1.40418
BIPQ – Illness coherence	-.536	2.019	.645	-1.70790	3.18752
BIPQ – Emotional effect	.242	98	.809	.34708	1.43318
MSIS29 – Physical impact	-2.201	99	.030	-22.24720	10.10837
MSIS29 – Psychological impact	-1.262	99	.210	-6.63126	5.25262
Illness acceptance	.486	99	.628	2.26331	4.65834
Optimism	.550	98	.584	2.18980	3.98212
Social Support - Total	1.094	99	.277	2.60628	2.38263

Unadjusted t tests of AT meeting needs (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	-.982	99	.328	-.72188	.73512
BIPQ – Illness timeline	-.564	99	.574	-.13223	.23428
BIPQ – Personal control	-1.080	99	.283	-1.10334	1.02159
BIPQ – Treatment control	-2.092	97	.039	-2.19053	1.04718
BIPQ – Symptom experience	-.883	98	.379	-.60983	.69048
BIPQ _ Illness concern	.185	97	.854	.17396	.94067
BIPQ – Illness coherence	-1.898	98	.061	-1.70046	.89599
BIPQ – Emotional effect	.573	98	.568	.54531	.95250
MSIS29 – Physical impact	-2.283	99	.025	-15.38032	6.73557
MSIS29 – Psychological impact	-.084	99	.933	-.29795	3.55280
Illness acceptance	.059	99	.953	.18482	3.12959
Optimism	.137	98	.891	.32199	2.35022
Social Support - Total	1.676	99	.097	2.61283	1.55919

Unadjusted t tests of MS medical treatment (yes/no)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
BIPQ – Illness effect	.090	122	.929	.03622	.40392
BIPQ – Illness timeline	-.780	122	.437	-.16644	.21335
BIPQ – Personal control	1.292	122	.199	.63135	.48885
BIPQ – Treatment control	2.877	119	.005	1.40556	.48854
BIPQ – Symptom experience	-1.989	120	.049	-.77759	.39099
BIPQ _ Illness concern	-.676	120	.500	-.30562	.45190
BIPQ – Illness coherence	.522	83.811	.603	.25262	.48371
BIPQ – Emotional effect	-.201	121	.841	-.09101	.45226
MSIS29 – Physical impact	.219	122	.827	.77325	3.53458
MSIS29 – Psychological impact	-1.036	122	.302	-1.76095	1.69933
Illness acceptance	-.059	122	.953	-.08353	1.41774
Optimism	.968	121	.335	1.01397	1.04771
Social Support - Total	-1.411	91.577	.162	-1.10623	.78427

Appendix D – Full *t* tests of longitudinal study

Unadjusted t tests of gender at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.035	68	.304	1.03612	1.00115
Device perceptions	-.562	60	.576	-.74818	1.33056
BIPQ _ Illness effect	-1.844	68	.070	-1.00516	.54519
BIPQ – Illness timeline	1.407	20.087	.175	.50959	.36223
BIPQ – Personal control	-.090	68	.929	-.06708	.74591
BIPQ – Treatment control	-.201	67	.841	-.15086	.75101
BIPQ – Illness experience	-2.900	68	.001	-1.48297	.51136
BIPQ – Illness concern	-1.428	68	.158	-1.04231	.72972
BIPQ _ Illness coherence	.158	67	.875	.10000	.63375
BIPQ – Emotional effect	.305	68	.761	.20846	.68273
MSIS29 – Physical impact	-1.200	68	.234	-5.50255	4.58467
MSIS29 – Psychological impact	.040	68	.969	.08953	2.26167
Illness Acceptance (ACHC)	1.528	68	.131	3.10882	2.03511
Optimism (LOT-R)	.004	68	.997	.00516	1.37118
Social Support - Total	-1.328	68	.189	-1.31968	.99376

Unadjusted t tests of gender at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.215	68	.830	.22807	1.06073
Device perceptions	-.377	61	.707	-.50156	1.32963
BIPQ _ Illness effect	-1.821	68	.073	-.89577	.49182
BIPQ – Illness timeline	.326	68	.745	.10458	.32045
BIPQ – Personal control	-.090	68	.929	-.06708	.74591
BIPQ – Treatment control	-.201	67	.841	-.15086	.75101
BIPQ – Illness experience	-3.361	68	.001	-1.49226	.44394
BIPQ – Illness concern	-.884	68	.380	-.60165	.68024
BIPQ _ Illness coherence	.158	67	.875	.10000	.63375
BIPQ – Emotional effect	.774	68	.441	.52322	.67560
MSIS29 – Physical impact	-.879	68	.382	-3.73304	4.24638
MSIS29 – Psychological impact	.575	68	.567	1.32921	2.31262
Illness Acceptance (ACHC)	1.492	68	.140	3.08219	2.06646
Optimism (LOT-R)	.608	67	.545	.96078	1.58023
Social Support - Total	-.039	68	.969	-.04162	1.07979

Unadjusted t tests of gender at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-.348	68	.729	-.35088	1.00853
Device perceptions	.008	64	.993	.01111	1.33836
BIPQ _ Illness effect	-2.325	68	.023	-1.17750	.50652
BIPQ – Illness timeline	.639	68	.525	.17234	.26968
BIPQ – Personal control	-.090	68	.929	-.06708	.74591
BIPQ – Treatment control	-.201	67	.841	-.15086	.75101
BIPQ – Illness experience	-3.314	68	.001	-1.61726	.48794
BIPQ – Illness concern	-1.907	68	.061	-1.44688	.75870
BIPQ _ Illness coherence	.158	67	.875	.10000	.63375
BIPQ – Emotional effect	-.889	68	.377	-.66770	.75126
MSIS29 – Physical impact	-1.685	68	.096	-6.95037	4.12381
MSIS29 – Psychological impact	-.369	68	.713	-.87552	2.37152
Illness Acceptance (ACHC)	1.079	68	.285	2.16442	2.00673
Optimism (LOT-R)	.755	67	.453	1.17124	1.55043
Social Support - Total	-.073	68	.942	-.08463	1.15242

Unadjusted t tests of employment at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	2.203	68	.031	2.32727	1.05648
Device perceptions	.193	60	.847	.29640	1.53224
BIPQ _ Illness effect	1.998	68	.050	1.17576	.58841
BIPQ – Illness timeline	-.340	68	.735	-.09618	.28254
BIPQ – Personal control	.974	68	.334	.78182	.80286
BIPQ – Treatment control	1.478	67	.144	1.21361	.82115
BIPQ – Illness experience	1.349	68	.182	.78182	.57976
BIPQ – Illness concern	1.362	68	.178	1.07879	.79189
BIPQ _ Illness coherence	-.125	67	.901	-.08831	.70399
BIPQ – Emotional effect	1.140	68	.258	.83636	.73345
MSIS29 – Physical impact	2.492	68	.015	11.97779	4.80637
MSIS29 – Psychological impact	.027	68	.979	.06515	2.45114
Illness Acceptance (ACHC)	-1.906	68	.061	-4.16568	2.18548
Optimism (LOT-R)	-.445	68	.658	-.66061	1.48387
Social Support - Total	.102	68	.919	.11150	1.09080

Unadjusted t tests of employment at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.824	68	.413	.99460	1.20740
Device perceptions	.223	61	.824	.34186	1.53083
BIPQ _ Illness effect	.033	68	.974	.01889	.57597
BIPQ – Illness timeline	-.642	68	.523	-.23457	.36563
BIPQ – Personal control	.087	68	.931	.07422	.85298
BIPQ – Treatment control	.543	67	.589	.47930	.88340
BIPQ – Illness experience	.861	68	.392	.46964	.54526
BIPQ – Illness concern	-.486	68	.629	-.37922	.78100
BIPQ _ Illness coherence	-.695	67	.489	-.51754	.74434
BIPQ – Emotional effect	-.332	68	.741	-.25776	.77535
MSIS29 – Physical impact	1.118	35.009	.271	3.72559	3.33232
MSIS29 – Psychological impact	-.257	68	.798	-.68016	2.64971
Illness Acceptance (ACHC)	-1.607	68	.113	-3.78896	2.35706
Optimism (LOT-R)	.600	67	.551	1.06456	1.77463
Social Support - Total	.387	68	.700	.47785	1.23344

Unadjusted t tests of gender at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.124	67	.902	.16667	1.34389
Device perceptions	.264	63	.793	.44942	1.70414
BIPQ _ Illness effect	1.784	67	.079	1.22778	.68829
BIPQ – Illness timeline	1.192	8.461	.266	.73889	.61975
BIPQ – Personal control	1.142	67	.258	1.10000	.96346
BIPQ – Treatment control	1.419	66	.161	1.47200	1.03768
BIPQ – Illness experience	1.310	67	.195	.91042	.69473
BIPQ – Illness concern	.572	67	.569	.59383	1.03786
BIPQ _ Illness coherence	.571	66	.570	.50833	.88974
BIPQ – Emotional effect	.718	67	.475	.71667	.99793
MSIS29 – Physical impact	1.253	67	.215	6.87964	5.49084
MSIS29 – Psychological impact	.445	67	.658	1.39236	3.13151
Illness Acceptance (ACHC)	.211	67	.833	.56111	2.65515
Optimism (LOT-R)	-.958	66	.342	-1.94275	2.02836
Social Support - Total	-.630	67	.531	-.96784	1.53511

Unadjusted t tests of significant other at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-.007	23.881	.994	-.00855	1.18301
Device perceptions	-.582	60	.563	-.84018	1.44422
BIPQ _ Illness effect	-1.200	68	.234	-.67521	.56248
BIPQ – Illness timeline	-.928	21.918	.364	-.30212	.32572
BIPQ – Personal control	-.380	68	.705	-.28846	.75818
BIPQ – Treatment control	-.637	67	.526	-.48533	.76191
BIPQ – Illness experience	-1.476	22.972	.154	-.94658	.64137
BIPQ – Illness concern	-1.709	68	.092	-1.26068	.73786
BIPQ _ Illness coherence	1.537	22.284	.138	1.17974	.76774
BIPQ – Emotional effect	-.716	68	.477	-.49573	.69254
MSIS29 – Physical impact	-1.439	68	.155	-6.68068	4.64380
MSIS29 – Psychological impact	-.689	68	.493	-1.57959	2.29324
Illness Acceptance (ACHC)	.230	68	.819	.48384	2.10508
Optimism (LOT-R)	-.260	68	.795	-.36325	1.39444
Social Support - Total	.031	68	.975	.03164	1.02415

Unadjusted t tests of significant other at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.285	68	.776	.30769	1.07899
Device perceptions	.292	61	.772	.41158	1.41095
BIPQ _ Illness effect	-1.361	68	.178	-.68803	.50564
BIPQ – Illness timeline	-.214	68	.831	-.06974	.32620
BIPQ – Personal control	-.084	68	.933	-.06410	.75895
BIPQ – Treatment control	.349	67	.728	.26631	.76352
BIPQ – Illness experience	-.788	68	.434	-.38248	.48557
BIPQ – Illness concern	-.980	68	.331	-.67735	.69124
BIPQ _ Illness coherence	1.421	22.052	.169	1.10458	.77732
BIPQ – Emotional effect	-1.307	68	.196	-.89103	.68193
MSIS29 – Physical impact	-1.106	68	.272	-4.76449	4.30649
MSIS29 – Psychological impact	-.406	68	.686	-.95726	2.35588
Illness Acceptance (ACHC)	.199	68	.843	.42513	2.13606
Optimism (LOT-R)	-.397	47.580	.693	-.50980	1.28339
Social Support - Total	-.170	68	.866	-.18669	1.09843

Unadjusted t tests of significant other at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-.772	67	.443	-.82901	1.07334
Device perceptions	-.246	63	.807	-.36519	1.48672
BIPQ _ Illness effect	-1.231	67	.222	-.67807	.55066
BIPQ – Illness timeline	-1.749	15.448	.100	-.81840	.46779
BIPQ – Personal control	-.638	67	.526	-.50236	.78716
BIPQ – Treatment control	-.550	66	.584	-.43697	.79451
BIPQ – Illness experience	-.503	67	.616	-.28184	.55979
BIPQ – Illness concern	-2.173	19.861	.042	-2.04137	.93942
BIPQ _ Illness coherence	1.783	66	.079	1.17308	.65782
BIPQ – Emotional effect	-2.134	67	.037	-1.65684	.77649
MSIS29 – Physical impact	-2.080	67	.041	-8.88587	4.27205
MSIS29 – Psychological impact	-1.267	67	.209	-3.16804	2.49979
Illness Acceptance (ACHC)	1.732	67	.088	3.63048	2.09639
Optimism (LOT-R)	.155	66	.877	.25288	1.63352
Social Support - Total	1.382	67	.171	1.64521	1.19008

Unadjusted t tests of MS type at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.759	64	.083	1.63889	.93198
Device perceptions	-1.243	57	.219	-1.40755	1.13203
BIPQ _ Illness effect	1.844	64	.070	.92222	.50019
BIPQ – Illness timeline	-.190	64	.850	-.04694	.24668
BIPQ – Personal control	-.135	64	.893	-.09444	.70035
BIPQ – Treatment control	2.100	63	.040	1.43944	.68543
BIPQ – Illness experience	1.091	64	.279	.55000	.50418
BIPQ – Illness concern	1.610	64	.112	1.10000	.68323
BIPQ _ Illness coherence	-1.021	63	.311	-.60153	.58901
BIPQ – Emotional effect	-.245	64	.808	-.15556	.63585
MSIS29 – Physical impact	1.953	64	.055	8.24570	4.22258
MSIS29 – Psychological impact	.048	64	.962	.10139	2.11311
Illness Acceptance (ACHC)	-.948	64	.347	-1.82344	1.92373
Optimism (LOT-R)	-.088	52.159	.930	-.11667	1.32276
Social Support - Total	-.621	63.658	.537	-.56664	.91240

Unadjusted t tests of MS type at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.983	62	.052	1.86905	.94252
Device perceptions	.867	55	.389	1.03295	1.19077
BIPQ _ Illness effect	1.397	62	.167	.63889	.45741
BIPQ – Illness timeline	-.524	62	.602	-.16167	.30872
BIPQ – Personal control	-.379	62	.706	-.26587	.70110
BIPQ – Treatment control	1.724	61	.090	1.21713	.70607
BIPQ – Illness experience	1.383	62	.172	.62698	.45341
BIPQ – Illness concern	.242	62	.809	.15873	.65473
BIPQ _ Illness coherence	.092	61	.927	.05556	.60428
BIPQ – Emotional effect	-1.328	62	.189	-.86111	.64861
MSIS29 – Physical impact	1.922	62	.059	7.72663	4.02112
MSIS29 – Psychological impact	-.964	62	.339	-2.14286	2.22250
Illness Acceptance (ACHC)	-1.712	62	.092	-3.38099	1.97491
Optimism (LOT-R)	-.671	61	.505	-1.00714	1.50023
Social Support - Total	-.386	62	.701	-.37496	.97097

Unadjusted t tests of MS type at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.894	63	.063	1.78500	.94259
Device perceptions	.459	59	.648	.56373	1.22780
BIPQ _ Illness effect	1.367	63	.176	.69500	.50830
BIPQ – Illness timeline	.263	63	.794	.05000	.19030
BIPQ – Personal control	-.349	63	.728	-.24500	.70242
BIPQ – Treatment control	1.915	62	.060	1.34550	.70262
BIPQ – Illness experience	1.158	63	.251	.56563	.48850
BIPQ – Illness concern	.547	63	.586	.39575	.72377
BIPQ _ Illness coherence	.420	62	.676	.25000	.59478
BIPQ – Emotional effect	-.069	63	.945	-.05000	.72532
MSIS29 – Physical impact	2.259	63	.027	8.62966	3.81960
MSIS29 – Psychological impact	-.151	63	.880	-.34000	2.25124
Illness Acceptance (ACHC)	-.585	37.544	.562	-1.22332	2.08972
Optimism (LOT-R)	-.302	62	.764	-.45026	1.49250
Social Support - Total	-.443	63	.659	-.47487	1.07124

Unadjusted t tests of co-morbidities at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-.020	68	.984	-.01809	.90071
Device perceptions	-.461	60	.647	-.55825	1.21148
BIPQ _ Illness effect	-.675	68	.502	-.33553	.49703
BIPQ – Illness timeline	.131	68	.896	.03041	.23290
BIPQ – Personal control	.185	68	.854	.12336	.66573
BIPQ – Treatment control	.843	67	.402	.56558	.67108
BIPQ – Illness experience	.226	56.630	.822	.11184	.49567
BIPQ – Illness concern	.888	68	.378	.58388	.65731
BIPQ _ Illness coherence	1.602	53.404	.115	.92275	.57597
BIPQ – Emotional effect	-.852	55.064	.398	-.53125	.62358
MSIS29 – Physical impact	.503	68	.616	2.07811	4.12807
MSIS29 – Psychological impact	-.882	68	.381	-1.77138	2.00751
Illness Acceptance (ACHC)	-.642	56.984	.523	-1.21131	1.88590
Optimism (LOT-R)	.007	68	.995	.00822	1.22402
Social Support - Total	-.591	68	.556	-.52985	.89624

Unadjusted t tests of co-morbidities at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.463	68	.645	.43921	.94846
Device perceptions	-1.142	61	.258	-1.36729	1.19750
BIPQ _ Illness effect	1.514	68	.135	.67163	.44350
BIPQ – Illness timeline	-.495	68	.622	-.14182	.28660
BIPQ – Personal control	.031	68	.975	.02068	.66781
BIPQ – Treatment control	.492	67	.624	.33128	.67341
BIPQ – Illness experience	.939	68	.351	.40033	.42644
BIPQ – Illness concern	.469	68	.640	.28701	.61150
BIPQ _ Illness coherence	.594	67	.555	.33701	.56774
BIPQ – Emotional effect	.268	68	.789	.16294	.60718
MSIS29 – Physical impact	.095	68	.925	.36268	3.82290
MSIS29 – Psychological impact	-1.638	68	.106	-3.33499	2.03563
Illness Acceptance (ACHC)	-.150	68	.881	-.28235	1.87972
Optimism (LOT-R)	-1.686	67	.096	-2.31795	1.37474
Social Support - Total	-1.138	68	.259	-1.08993	.95762

Unadjusted t tests of co-morbidities at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-.520	68	.605	-.46683	.89746
Device perceptions	-1.530	64	.131	-1.79844	1.17577
BIPQ _ Illness effect	.998	68	.322	.46437	.46543
BIPQ – Illness timeline	.241	68	.810	.05815	.24086
BIPQ – Personal control	1.126	68	.264	.74120	.65842
BIPQ – Treatment control	1.097	67	.277	.73030	.66583
BIPQ – Illness experience	2.078	68	.042	.94380	.45428
BIPQ – Illness concern	1.873	68	.065	1.26717	.67649
BIPQ _ Illness coherence	1.850	67	.069	1.02273	.55289
BIPQ – Emotional effect	1.016	68	.313	.67895	.66808
MSIS29 – Physical impact	1.603	68	.114	5.90089	3.68072
MSIS29 – Psychological impact	1.629	68	.108	3.37930	2.07469
Illness Acceptance (ACHC)	-.632	68	.529	-1.13676	1.79764
Optimism (LOT-R)	-1.826	67	.072	-2.44324	1.33812
Social Support - Total	-1.033	68	.305	-1.05190	1.01872

Unadjusted t tests of AT use at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-3.220	68	.002	-4.80729	1.49306
Device perceptions	-1.107	68	.272	-.97396	.87953
BIPQ _ Illness effect	-.198	68	.844	-.23438	1.18462
BIPQ – Illness timeline	.711	67	.479	.84413	1.18647
BIPQ – Personal control	-1.043	68	.301	-.89063	.85428
BIPQ – Treatment control	-1.461	68	.149	-1.69271	1.15840
BIPQ – Illness experience	2.174	67	.033	2.11111	.97122
BIPQ – Illness concern	-2.951	68	.004	-3.01563	1.02182
BIPQ _ Illness coherence	-1.673	68	.099	-12.06711	7.21268
BIPQ – Emotional effect	-1.268	68	.209	-4.50391	3.55103
MSIS29 – Physical impact	-1.912	68	.060	-3.48698	1.82409
MSIS29 – Psychological impact	-1.996	68	.050	-3.29688	1.65145
Illness Acceptance (ACHC)	.328	5.258	.755	.41147	1.25400
Optimism (LOT-R)	.546	68	.587	.65938	1.20741
Social Support - Total					

Unadjusted t tests of AT use at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-2.790	68	.007	-7.48529	2.68295
Device perceptions	-2.306	68	.024	-2.98529	1.29478
BIPQ _ Illness effect	1.194	68	.237	2.35294	1.97059
BIPQ – Illness timeline	-.204	67	.839	-.40776	1.99963
BIPQ – Personal control	-.763	1.009	.584	-2.29412	3.00687
BIPQ – Treatment control	-2.417	68	.018	-4.23529	1.75245
BIPQ – Illness experience	1.830	67	.072	3.01493	1.64707
BIPQ – Illness concern	-2.256	68	.027	-3.94118	1.74711
BIPQ _ Illness coherence	-1.873	68	.065	-20.82088	11.11582
BIPQ – Emotional effect	-2.076	68	.042	-12.45588	6.00079
MSIS29 – Physical impact	-1.908	68	.061	-5.67397	2.97439
MSIS29 – Psychological impact	-1.064	68	.291	-2.83574	2.66530
Illness Acceptance (ACHC)	-.615	68	.540	-.78426	1.27451
Optimism (LOT-R)	.913	68	.364	1.88824	2.06798
Social Support - Total					

Unadjusted t tests of AT use at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	-2.790	68	.007	-7.48529	2.68295
Device perceptions	-2.306	68	.024	-2.98529	1.29478
BIPQ _ Illness effect	1.194	68	.237	2.35294	1.97059
BIPQ – Illness timeline	-.204	67	.839	-.40776	1.99963
BIPQ – Personal control	-.763	1.009	.584	-2.29412	3.00687
BIPQ – Treatment control	-2.417	68	.018	-4.23529	1.75245
BIPQ – Illness experience	1.830	67	.072	3.01493	1.64707
BIPQ – Illness concern	-2.256	68	.027	-3.94118	1.74711
BIPQ _ Illness coherence	-1.873	68	.065	-20.82088	11.11582
BIPQ – Emotional effect	-2.076	68	.042	-12.45588	6.00079
MSIS29 – Physical impact	-1.908	68	.061	-5.67397	2.97439
MSIS29 – Psychological impact	-1.064	68	.291	-2.83574	2.66530
Illness Acceptance (ACHC)	-.615	68	.540	-.78426	1.27451
Optimism (LOT-R)	.913	68	.364	1.88824	2.06798
Social Support - Total					

Unadjusted t tests of medication at time 2 (3 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.535	68	.130	1.44126	.93918
Device perceptions	-1.033	60	.306	-1.34498	1.30196
BIPQ _ Illness effect	2.193	68	.032	1.12118	.51114
BIPQ – Illness timeline	.777	68	.440	.19115	.24595
BIPQ – Personal control	1.180	35.075	.246	.90194	.76409
BIPQ – Treatment control	-1.799	67	.077	-1.26517	.70329
BIPQ – Illness experience	2.183	68	.032	1.08326	.49611
BIPQ – Illness concern	3.685	68	.000	2.35893	.64017
BIPQ _ Illness coherence	1.519	67	.134	.90716	.59738
BIPQ – Emotional effect	3.339	68	.001	2.00185	.59956
MSIS29 – Physical impact	2.278	68	.026	9.63029	4.22809
MSIS29 – Psychological impact	2.873	68	.005	5.80920	2.02213
Illness Acceptance (ACHC)	-3.982	68	.000	-7.02600	1.76465
Optimism (LOT-R)	-2.563	68	.013	-3.17761	1.23969
Social Support - Total	.669	68	.506	.63561	.94987

Unadjusted t tests of medication at time 3 (6 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	.982	68	.329	.93440	.95118
Device perceptions	-.834	61	.407	-1.01341	1.21459
BIPQ _ Illness effect	1.257	68	.213	.56518	.44950
BIPQ – Illness timeline	-.204	68	.839	-.05892	.28943
BIPQ – Personal control	-1.039	68	.303	-.69386	.66813
BIPQ – Treatment control	-1.083	67	.283	-.73349	.67748
BIPQ – Illness experience	1.612	68	.112	.68461	.42475
BIPQ – Illness concern	.748	68	.457	.46005	.61509
BIPQ _ Illness coherence	.736	67	.465	.42247	.57431
BIPQ – Emotional effect	1.824	68	.073	1.09083	.59814
MSIS29 – Physical impact	.846	68	.400	3.24532	3.83504
MSIS29 – Psychological impact	1.617	68	.111	3.32044	2.05370
Illness Acceptance (ACHC)	-.146	68	.884	-.27759	1.89548
Optimism (LOT-R)	-1.299	67	.198	-1.80862	1.39221
Social Support - Total	.795	68	.429	.77121	.97030

Unadjusted t tests of medication at time 4 (12 months from baseline)

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference
Number of AT devices	1.160	68	.250	1.05943	.91320
Device perceptions	-.377	64	.707	-.46280	1.22740
BIPQ _ Illness effect	.013	68	.990	.00603	.48078
BIPQ – Illness timeline	-.136	68	.892	-.03359	.24708
BIPQ – Personal control	.335	68	.738	.22825	.68092
BIPQ – Treatment control	-1.991	67	.051	-1.33961	.67288
BIPQ – Illness experience	1.494	68	.140	.70618	.47274
BIPQ – Illness concern	.224	68	.823	.15935	.71116
BIPQ _ Illness coherence	.623	67	.535	.36315	.58262
BIPQ – Emotional effect	.890	68	.377	.61068	.68633
MSIS29 – Physical impact	.578	68	.565	2.21642	3.83590
MSIS29 – Psychological impact	1.095	68	.278	2.35347	2.14988
Illness Acceptance (ACHC)	-.414	68	.680	-.76487	1.84659
Optimism (LOT-R)	-.892	67	.375	-1.24286	1.39265
Social Support - Total	2.622	68	.011	2.63058	1.00338