



PRIFYSGOL
BANGOR
UNIVERSITY

Matching and accepting assistive technology in multiple sclerosis: A focus group study with people with multiple sclerosis, carers and occupational therapists

Squires, Luke A; Williams, Nefyn; Morrison, Val L

Journal of Health Psychology

DOI:

[10.1177/1359105316677293](https://doi.org/10.1177/1359105316677293)

Published: 01/03/2019

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Squires, L. A., Williams, N., & Morrison, V. L. (2019). Matching and accepting assistive technology in multiple sclerosis: A focus group study with people with multiple sclerosis, carers and occupational therapists. *Journal of Health Psychology*, 24(4), 480-494.
<https://doi.org/10.1177/1359105316677293>

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

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

Luke A Squires, Nefyn Williams and Val Morrison

Luke A Squires

(School of Psychology,) Bangor University, UK

Nefyn Williams

(School of Healthcare Sciences,) Bangor University, UK

Val Morrison

(School of Psychology,) Bangor University, UK

Corresponding author

Luke Squires, School of Psychology, Bangor University, Brigantia Building, Penrallt Road,

Bangor, LL57 2AS, UK

Email: luke.squires@nottingham.ac.uk

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

Abstract

To explore experiences and perceptions of assistive technology, 14 people with Multiple Sclerosis (MS), five carers and four occupational therapists participated in focus groups. Transcripts were analysed thematically drawing from illness self-regulation theory. Identified themes: *Critical MS Events* (developing symptoms/disability; delayed diagnosis and coping; public reaction; MS progression to AT); *Matching AT for Continued Use* (acceptance of MS and AT; realistic expectations; OT responsiveness; timing is crucial; carers and others); *Impact of AT* (promoting or losing independence; stigma and embarrassment; redefining the carer). Acceptance and communication among those involved ensures AT matches needs, and maximises health and psychosocial outcomes.

Keywords

assistive technology, multiple sclerosis, acceptance, carers, qualitative methods

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 et al., 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. 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'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.

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 record 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 where they were perceived as a symbol of disability this 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. REF) suggest 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, interaction-interface? and functional outcome of device use???. 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; Rigby et al., 2005; 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, 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. MS participants were included if they were aged 18+ with MS diagnosis received with ***years, and if they had previous experience of AT device use. Individuals with self-identified severe communication or cognitive difficulties were excluded due to the nature of the study following a discussion with their??whose? branch manager. Carers were defined as, and OT's were eligible if they....

Table 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; |

| | | | | |
|--------------|-------------|----------|---|---|
| Bill (65) | SPMS (30) | Average | Manual wheelchair, crutches, orthoses | Home adaptations 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 |
| 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 |

| | | | | |
|----------------------------|-----------------------------|-------------------|----------------------------------|---|
| Gabby (43) | SPMS (12) | Quite | Manual wheelchair, scooter | vehicle adaptations Bathing aids; Home modifications |
| Norah (n.g.) Eli (n.g.) | Unknown (14) Unknown (6) | Quite Not very | Crutches, scooter FES, walker | Home modifications 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 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. 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;

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, 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 (see Appendix for topic guide). The lead researcher (LS) led all sessions with a co-facilitator (EM) acting as observer and note-taker. 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, 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 1-3.

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.

INSERT TABLES 1-3 HERE

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.

INSERT TABLE 4 HERE

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, 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.

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 et al. 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., 2010). 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 et al., 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, and this has important implications for clinicians when they enter into discussions of AT with those with MS, but importantly their loved ones/carers.. .

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 their carers too. There were suggestions that AT can validate a person's condition both positively and negatively, and some concerns 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, and this requires monitoring in the longer term than is currently the norm??.

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 et al., 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.

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. This was achieved through our qualitative methods allowing interpretation of data at both the individual and group level (Wilkinson 1998). Conducting multiple focus groups also enhances 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. 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. Key issues include acceptance, optimism, social support (carer), and service delivery.

Acknowledgements

Thanks to EM for co-facilitating and analytic assurance, the participants and the MS Society UK branches that helped integrate the research as part of their Society meetings.

Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

- Aspinwall LG and Taylor SE (1997) A stitch in time: Self-regulation and proactive coping. *Psychological Bulletin* 121: 417-436.
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2): 77-101.
- Chaudoir SR, Earnshaw VA and Andel S (2013) "Discredited" versus "Discreditable": Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic and Applied Social Psychology* 35(1):75-87.
- Corry M and While A (2009) The needs of carers of people with multiple sclerosis: A literature review. *Scandinavian Journal of Caring Science* 23: 569-588.
- Dennison L, Moss-Morris R and Chalder T (2009) A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review* 29: 141-153.
- Dennison L, Moss-Morris R, Silber E, Galea I and Chalder T (2010) Cognitive and behavioural correlates of different domains of psychological adjustment in early-stage multiple sclerosis. *Journal of Psychosomatic Research* 69(4): 353-361.

- Edmonds P, Vivat B, Burman R, Silber E and Higginson IJ (2007) 'Fighting for everything': Service experiences of people severely affected by multiple sclerosis. *Multiple Sclerosis* 13: 660-667.
- Goodkin DE (1992) The natural history of multiple sclerosis. In: Riddick RA and Goodkin DE (eds) *Treatment of multiple sclerosis: Trial design, results and future perspectives*. New York: Springer-Verlag, pp.17-45.
- Gottberg K, Einarsson U, Ytterberg C, Fredrikson S, Von Koch L and Widén Holmqvist L (2008) Use of health services and satisfaction with care in people with multiple sclerosis in Stockholm County: A population-based study. *Multiple Sclerosis* 14: 962-971.
- Hoening H, Taylor DH Jr and Sloan FA (2003) Does assistive technology substitute for personal assistance among the disabled elderly? *American Journal of Public Health* 93: 330-337.
- Johnson KL, Bamer AM, Yorkston KM and Amtmann D (2009) Use of cognitive aids and other assistive technology by individuals with multiple sclerosis. *Disability and Rehabilitation: Assistive Technology* 4(1): 1-8.
- Johnston P, Currie LM, Drynan D, Stainton T and Jongbloed L (2014) Getting it "right": how collaborative relationships between people with disabilities and professionals can lead to the acquisition of needed assistive technology.

Disability and Rehabilitation: Assistive Technology 9(5): 421-431.

Jones LH, Ford DV, Jones PA, John A, Middleton RM, Lockhart-Jones H, et al. (2013) The physical and psychological impact of multiple sclerosis using the MSIS-29 via the web portal of the UK MS Register. *PLoS One* 8(1). Doi: 10.1371/journal.pone.0055422.

Kidd PS and Parshall MB (2000) Getting the focus and the group: Enhancing analytic rigor in focus group research. *Qualitative Health Research* 10(3): 293-308.

Leventhal H, Brissette I and Leventhal EA (2003) The common-sense model of self-regulation of health and illness. In: Cameron LD and Leventhal H (eds) *The self-regulation of health and illness behaviour*. London: Routledge, pp.42-65.

Leventhal H, Diefenbach M and Leventhal E (1992) Illness cognition: using common sense to understand treatment adherence and effect cognitive interactions. *Cognitive Therapy and Research* 16(2): 143-63.

Leventhal H, Meyer D and Nerenz D (1980) The common sense model of illness danger. In: Rachman S (ed) *Medical Psychology*, Vol. 2. Pergamon, New York, pp.7-30.

Maw S (2013) The impact of the NICE guidelines on the experience of being diagnosed with multiple sclerosis. *British Journal of Occupational Therapy* 76(3) 143.

Meyrick J (2006) What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of Health*

Psychology 11(5): 799-808.

Mikula P, Nagyova I, Krokavcova M, Vitkova M, Rosenberger J, Szilasiova J, et al. (2016)

Self-esteem, social participation, and quality of life in patients with multiple sclerosis. *Journal of Health Psychology*. Epub before print doi:

10.1177/1359105315621778

Mortenson WB, Demers L, Fuhrer MJ, Jutai JW, Lenker J and deRuyter F (2012) How

assistive technology use by individuals with disabilities impacts their caregivers:

A systematic review of the research evidence. *American Journal of Physical Medicine & Rehabilitation* 91(11): 984-998.

Moss-Morris R (2013) Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology* 18: 681-686.

MS Society UK (2013) *A lottery of treatment and care – MS services across the UK*.

MS Society UK (2015) Symptoms of MS are mistaken for other condition, survey reveals. Available at: <http://www.mssociety.org.uk/ms-news/2015/05/symptoms-ms-are-mistaken-other-conditions-survey-reveals> (accessed 22 March 2016).

Okoro CA, Strine TW, Balluz LS, Crews JE and Mokdad AH (2010) Prevalence and correlates of depressive symptoms among United States adults with disabilities using assistive technology. *Preventive Medicine* 50: 204-209.

Pakenham KI (2005) Relations between coping and positive and negative outcomes in carers of persons with multiple sclerosis (MS). *Journal of Clinical Psychology in Medical Settings* 12: 25-38.

Pakenham KI and Fleming M (2011) Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychology & Health*, 26(10): 1292-1309.

Phillips B and Zhao H (1993) Predictors of assistive technology abandonment. *Assistive Technology*, 5(1): 36-45.

Preston J, Haslam S and Lamont L (2012) What do people with Multiple Sclerosis want from an Occupational Therapy service? *British Journal of Occupational Therapy* 75(6): 264-270.

Rigby P, Ryan SE, Joos S, Cooper BA, Jutai J and Steggles E (2005) Impact of electronic aids to daily living on the lives of persons with cervical spinal cord injuries. *Assistive Technology* 17(2): 89-97.

Scherer M, Jutai J, Fuhrer M, Demers L and DeRuyter F (2007) A framework for modeling the selection of assistive technology devices (ATDs). *Disability Rehabilitation: Assistive Technology* 2: 1-8.

- Schou L, Høstrup H, Lyngsø EE, Larsen S and Poulsen I (2012) Validation of a new assessment tool for qualitative research articles. *Journal of Advanced Nursing* 68(9): 2086–2094.
- Solari A (2014) Effective communication at the point of multiple sclerosis diagnosis. *Multiple Sclerosis* 20(4): 397-402.
- Squires LA, Rush F, Hopkinson A and Morrison V (2013) The physical and psychological impact of using a computer-based environmental control system: A case study. *Disability and Rehabilitation: Assistive Technology* 8(5): 434-443.
- Stuifbergen A, Becker H, Blozis S and Beal C (2008) Conceptualization and development of the Acceptance of Chronic Health Conditions scale. *Issues in Mental Health Nursing* 29(2): 101-114.
- Telford K, Kralik D and Koch T (2006) Acceptance and denial: Implications for people adapting to chronic illness: Literature review. *Journal of Advanced Nursing* 55(4): 457-464.
- Wessels R, Dijcks B, Soede M, Gelderblom GJ and de Witte L (2003) Non-use of provided assistive technology devices, a literature review. *Technology and Disability* 15: 231-238.
- Wilkinson S (1998) Focus groups in health research: Exploring the meanings of health and illness. *Journal of Health Psychology* 3(3): 329-348.

World Health Organisation (2001) *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO.

Appendix 1

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?
-

Table 4. Illustrative quotes from PwMS, carers and occupational therapists.

| THEMES/Subthemes | Quotes |
|--|--|
| CRITICAL MS EVENTS | |
| <i>Developing Symptoms and Disability</i> | <p>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)</p> <p>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)</p> |
| <i>Delayed Diagnosis and Coping</i> | <p>"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)</p> <p>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)</p> |
| <i>Establishing Public Reaction</i> | <p>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)</p> |
| <i>MS Progression to AT</i> | <p>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)</p> <p>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)</p> |
| 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)

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)

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)
