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**Adjustment modes in the trajectory of progressive multiple sclerosis: a qualitative study and conceptual model**

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## **Abstract**

**Objective:** We examined cognitive and behavioural challenges and adaptations for people with progressive multiple sclerosis (MS) and developed a preliminary conceptual model of changes in adjustment over time. **Design:** Using theoretical sampling, 34 semi-structured interviews were conducted with people with MS. Participants were between 41 and 77 years of age. Thirteen were diagnosed with primary progressive MS and 21 with secondary progressive MS. Data were analysed using a grounded theory approach.

**Results:** Participants described initially bracketing the illness off and carrying on their usual activities but this became problematic as the condition progressed and they employed different adjustment modes to cope with increased disabilities. Some, scaled back their activities to live a more comfortable life, others identified new activities or adapted old ones, whereas at times people disengaged from the adjustment process altogether and resigned to their condition. Relationships with partners, emotional reactions, environment and perception of the environment influenced adjustment, while people were often flexible and shifted among modes. **Conclusions:** Adjusting to a progressive condition is a fluid process. Future interventions can be tailored to address modifiable factors at different stages of the condition and may involve addressing emotional reactions concealing/revealing the condition and perceptions of the environment.

**Keywords:** multiple sclerosis, adjustment, model, partners

A progressive illness confronts patients with several on-going demands and ever-changing adaptive tasks. For a variety of progressive illnesses the patient will have to prepare for an uncertain future, maintain relationships, daily activities, emotional balance and self-esteem and deal with pain, fatigue, and other symptoms of the disease. Health psychologists' challenge is to design effective interventions to help people navigate through the various demands of the illness. Recently, Moss-Morris (2013) argued that the adaptation process will be influenced by background factors, e.g. early life experiences, personality and environment, and illness characteristics. Patients will use a variety of adaptation strategies to restore their equilibrium, and different strategies might be useful at different stages. For example, if a disease becomes progressive, factors such as acceptance and self-compassion may be more important than active problem-solving strategies. Here, we explore further adaptation processes as illness progresses. How do people change their adaptation strategies, goals, and self-standards and what prompts these changes? What factors influence an individual's dominant mode of adjustment? Understanding psychological adjustment processes specifically associated with a progressive condition will help to tailor provision of care to this particularly challenging form of illnesses.

We will use multiple sclerosis (MS) as an exemplar. MS affects more than 2.5 million people worldwide, including 127,000 in the United Kingdom (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan, 2013). MS is a condition that presents unique challenges for the individuals, as it usually starts with minimal physical and cognitive dysfunction which progresses over time. There are three types of MS. The most common type of MS is relapsing-remitting (RR, 85%-90% of MS cases) which is characterised by

unpredictable attacks (relapses) of new or increasing neurological symptoms that are followed by periods of partial or complete recovery (remissions) (Compston & Coles, 2008). The secondary progressive (SP) course develops in approximately 82% of those with RRMS by 20 years of onset (Fisniku et al., 2008). In SPMS function suddenly declines without periods of remission (Compston & Coles, 2008). Finally, a minority of people (10%) will be diagnosed with the primary progressive (PP) course that involves a steady disability increase without attacks (Lublin & Reingold, 1996). MS symptoms vary from person to person but some symptoms are more common in the progressive type than others. Around 80% of people with primary progressive MS will develop problems with mobility (Miller & Leary, 2007). Also, people with progressive MS are more likely to experience bladder and bowel function impairments (Ford, Gerry, Johnson, Tennant, 2001), experience more cognitive deficits (Denney, Sworowski, & Lynch, 2005; Papathanasiou, Messinis, Georgiou, & Papathanasopoulos, 2014), and there may also be sexual problems such as erectile dysfunction (Demirkiran, Sarica, Uguz, Yerdelen, & Aslan, 2006). The progressive worsening of these symptoms may increase the challenges to social and personal identity.

Few studies exploring adjustment to MS have differentiated between people affected by RRMS and those with a progressive (PP or SP) form of the illness. People affected by PPMS have to live with a disease that steadily progresses from the start together with the uncertainty of how quickly this will happen. SPMS also provides unique challenges. People have to move from accommodating to a disease that shows some improvement during remissions and can respond in part to disease modifying medications, to accepting a condition where deterioration and increasing disability is inevitable and medications only provide some symptomatic relief. Progressive types of MS demand more frequent adjustments to more severe challenges compared to RRMS (Gaudino, Chiaravalloti, DeLuca,

& Diamond, 2001; Heaton, Nelson, Thompson, Burks, & Franklin, 1985) and there is some evidence that people with SPMS show increased distress compared to those with RR and PPMS (Montel & Bungener, 2007; Vleugels et al., 1998). Despite the particular challenges of progressive MS, most of the new MS treatments and research focuses on RR disease. The international collaborative statement appealed for a concerted effort for research into progressive MS (Fox et al., 2012). In this study, we will focus on the progressive types of MS.

Qualitative studies using mixed MS type samples showed that whereas the MS diagnosis is met with a negative reaction, after the first few years, many people reported finding a way to preserve usual activities (Dennison, Yardley, Devereux, & Moss-Morris, 2011; Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Qualitative studies also showed that as functional limitations increase in MS, people find it difficult or impossible to identify new, fulfilling activities and they may give up efforts to adjust altogether (Lexell, Lund, & Iwarsson, 2009; Wilkinson & das Nair, 2013). Further, people (n=15) who perceived their MS as severe reported that they felt social excluded and were less willing to express their unmet needs (Galushko et al., 2014). The current study aims to explore how adjustment processes change with diagnosis of progressive type of MS, as these processes might differ to people with RRMS.

Studies examining specific influences in MS adjustment have identified environmental and contextual factors as becoming increasingly important for adjustment as the illness progresses. Factors that influence how people accommodated their needs within their environment include coming to terms with using mobility aids, making a conscious decision to acquire equipment initially (Finlayson & van Denend, 2003) and interventions from family and friends to explore adaptations and remove physical barriers in the environment (Fong, Finlayson, & Peacock, 2006). Relationships are also important, and



potentially challenging. When people with MS were unable to perform tasks as the disease progressed they let significant others assume many more responsibilities that ultimately led to exacerbated frustration and sense of loss of independence and self-worth (Blundell Jones, Walsh, & Isaac, 2014; Deibel, Edwards, & Edwards, 2013).

Here, we move beyond the identification of specific influences that was the focus of previous qualitative research studies. We aim to bring various adjustment factors under a conceptual model using grounded theory to feed into future interventions. It is important to explore these issues from participants' own perspectives in order to gain more nuanced, complex insight that might be afforded from standardised questionnaires of coping or self-management. A qualitative method will also capture more dilemmas and fluidity in participants' strategies. In order to identify specific factors associated with adjustment, we needed to narrow the focus to progressive disease, to be able to understand the how and why of the adjustment processes. In this study we aim to capture the different aspects of adjustment and also identify potential factors associated with them. This study also addresses some important methodological limitations of previous studies. Most existing studies in MS fail to differentiate between the different types of MS. They cannot therefore conclude what factors are specifically important for people with progressive type of the condition. It also addresses sampling problems inherent in existing research. Many studies do not distinguish between patients at different points in their disease trajectories, where adjustment issues may differ. Therefore, we specifically sampled patients early on in their disease trajectory, within five years of their diagnosis of progressive disease.

## **Method**

### *Sampling*

Before commencing the study, we obtained ethical approval through the West of Scotland Research Ethics Committee (14/WS/0077). We recruited participants nationally through National Health Services (NHS) MS clinics across the UK and online adverts on UK MS Society website and through our database of people interested in taking part in MS-related research. People were included if they were diagnosed with PPMS or had transition to SPMS within the last five years and were fluent in English.

Eighty-seven people with MS expressed interest in participating in the study. Fifteen (17%) did not meet the inclusion criterion of diagnosis within five years. The remaining 72 completed a short screening questionnaire that included demographic questions, as well as questions about MS duration, symptoms and walking ability. This screening questionnaire was used in order to make sampling decisions. Initially, we chose to interview people using maximum variation sampling to represent differing age groups, gender and ethnicity and differences in symptoms and walking abilities, and length of MS diagnosis. Through the initial analysis, it became apparent that the partners of people with MS played a significant role in patients' adjustment. We, therefore, adopted a theoretical sampling approach (Charmaz, 2006) and recruited three more people who lived alone to explore this aspect of the analysis further. By the end of the project, we had interviewed 25 women and nine men

Five participants (15%) were recruited from MS clinics, ten participants were recruited through the MS Society website and talks at MS Society events (29%) and 19 participants (38%) were recruited through a circular email to people in our database. All

participants provided written consent before interviews. The interviews were conducted between April 2014 and February 2015.

### *Interviews*

Participants were given the option of face-to-face or telephone interviews. All participants chose phone interviews. The interviews were carried out by *(initials removed for blind review)*, who explained that the interviews were about people's experiences with MS and what they found useful or not in adjusting to their condition over time. The interviews lasted between 26 minutes and 2 hours and 42 minutes (average 1 hour and 10 minutes). First, *(initials removed for blind review)* used a narrative approach, inviting people to talk spontaneously about the time they were diagnosed with progressive MS and events after the diagnosis. Second, prompting and clarifying were used to explore further issues and challenges identified by the participant and how they dealt with them (see topic guide Table 1). In the first nine interviews participants were asked what adjusting to MS meant to them. Participants were confused with this question and it was dropped in subsequent interviews. Further, themes around concealing/revealing MS, the progression and the relationship with the partner came up early on in the analysis (between the fifth and seventh interview), therefore participants were prompted further when participants mentioned those topics in the interviews but no additional questions were added to the topic guide. Following each interview *(initials removed for blind review)* wrote a case-based summary of participants' experiences. All interviews were audiotaped with consent and transcribed verbatim.

### *Data analysis*

We used grounded theory to analyse the interviews (Charmaz, 2006). Grounded theory analysis is a rigorous methodology that gives an in-depth understanding of complex phenomena or processes within contexts leading to the development of theory (Charmaz, 2006; Strauss & Corbin, 1998). We drew upon a social constructionist framework (Charmaz, 1990), as our research aims were exploratory and applied. Furthermore, it has been argued that a constructionist version and application of grounded theory is the most relevant methodology to examine processes in chronic medical conditions (Charmaz, 1990). Such a framework acknowledges that people's unique experiences are valid and explores the ways in which people view the world and construct meaning as they engage in everyday activities. Each participant's story reflects a unique vantage point on the issue under consideration.

The first author analysed the data with co-authors interrogating the first author's analysis. In the initial coding, ideas were identified inductively from early data with the codes being kept as similar to the data as possible. After the first few interviews, we had a large amount of data and many initial codes that captured how people adjusted as the illness progressed. People also talked about the role of their families and partners and outlined different adjustment strategies. We decided that the progression of the condition, relationship with partners and adjustment strategies should become focused codes as these were central codes throughout the entire dataset and the study. We used qualitative software (NVivo10) to manage the data for the initial and focused coding. In the third step of theoretical coding, we refined the focused codes along with the collection of new data and made connections among those codes. This involved a process of constant comparison (Charmaz, 2006). For

example, we compared the adjustment strategies of people with SPMS to those with PPMS and individuals who reported severe symptoms and rapid progression versus people who reported less severe symptoms and a slow progression. We also compared the narratives of people who had completed higher education to those who had finished secondary school and the descriptions of people in different age groups at the time of the interviews or time of initial diagnosis. We modified the grounded theory approach slightly as the analysis was shared and corroborated with two further people with progressive MS, rather than current participants. This research is part of a larger research project and those two individuals are part of our user involvement committee and they have helped with different aspects of the project from the initial conceptualization of the study, to feedback of the topic guide to feedback of the analysis. In this study they gave us feedback on an initial version of our conceptual model. They inquired about whether the experiences of people with PPMS and SPMS differ, whether the experiences differ based on age of diagnosis or whether the people who described 'resigning' strategies had also reported cognitive difficulties. Following this, we checked the emerging themes to identify any patterns or differences in themes of people with different demographic characteristics. The two people with MS also suggested to explore further the experience of diagnosis and the importance of receiving the diagnosis of a SPMS from a health care professional. Issues around diagnosis will be addressed in a future paper. Finally, they commented on clarity of description and presentation of the results, for example they made some suggestions about the diagram and asked for a few additional quotes at places to better illustrate themes.

## **Findings**

Participants were between 41 and 77 years old (see Table 2). Thirteen were diagnosed with PPMS and 21 with SPMS. The majority of the sample was female (n=25, 73.5%), which reflect the prevalence ratio of women to men in MS (2.3-3.5:1) (Ahlgren, Oden, & Lycke, 2011; Wallin et al., 2012). Half of the sample was unemployed or retired due to MS (n=19, 56%). Twenty-three participants (68%) currently or previously held professional occupations, such as higher managerial roles, psychologists, teachers, accountants. Most people (n=26, 76%) lived with their partners. Four (12%) patients had some ambulation difficulties and were able to walk at least 300 meters, 19 (56%) patients had significant challenges with walking and needed to use sticks or crutches and 11 (32%) patients could walk a few steps or less and used wheelchairs.

Analysis of the interviews led to the development of an initial conceptual model of the trajectory and modes of adjustment to progressive MS including illness-related, environmental, social and psychological influences on adjustment (see figure 1). Firstly, people talked about how their struggles increased, as symptoms became more severe, and concealing the condition became increasingly difficult. Whereas initially bracketing the illness off and carrying on, as usual, was a helpful strategy it became problematic. Secondly, participants employed different adjustment modes to cope with their increased disabilities: scaling back, finding alternatives and resignation. We also consider the influences that underlie these different modes of adjustment. When comparing narratives between people with PPMS and people with SPMS, we did not identify any differences, we also did not find any different adjustment patterns when we looked at different age groups at the time of the interview or time of diagnosis. However, there were differences in adjustment modes

regarding employment, and education, speed of progression and severity of symptoms, which will be discussed below. In presenting the findings, participants' names have been changed to protect confidentiality.

### **Pre-mode of adjustment**

#### ***Maintaining things as usual***

As shown in Figure 1, after the initial diagnosis of MS, the majority of participants described small struggles, but they were able to maintain things as usual. The speed of progression and the severity of the symptoms influenced how long people stayed in this initial phase that lasted from a few months to several years. Most people carried on their usual activities for as long as their symptoms did not interfere. For example, Chloe (married, retired PE teacher), although diagnosed with RRMS for 16 years, she carried on her work and her usual activities. However, when she transitioned to SPMS, things changed fast, and she needed to find new ways of adjusting, as she says: *"things have gone downhill in the last five years, an awful lot. My life has changed incredibly. Until then, I have dealt with it, but I got to a stage where I could no longer, oh I don't know, lie to people that I wasn't in pain."*

Concealing or revealing the condition also influenced how long people maintained their usual activities. Some participants on finding out about their condition wanted to 'forget about it' and they did not want to be involved in MS charities or MS support groups. They avoided talking about MS with others or revealing it for as long as their symptoms allowed. Keeping MS concealed made it easier to carry on life as usual but made managing symptoms more difficult.

*I didn't tell anyone because I was freelance, I kept it [MS] hidden because, which in hindsight was, well I don't know, I can't think it. So that's how I managed it by getting other people to do things and trying to arrive late on location so I could get up in the morning. Do you know what I mean? This kind of constant managing and juggling and trying to keep it hidden, and I did, I think. (Ava, SPMS, living alone, retired associate producer)*

Participants, who did not talk about concealing their condition or ambivalence regarding assuming MS as part of their identity, talked about searching for information on MS charity websites and later on they talked about joining MS local groups and attending MS related conferences and seminars.

### **Three modes of adjustment**

As the condition progressed and struggles increased, adjusting to MS appeared to involve three key adjustment modes with people often moving in and out of these modes.

As shown in Figure 1, the majority of participants interviewed described a combination of scaling back, finding alternatives and sometimes resigning, while trying to find new balances and adjust to their condition. For example, Amelia (SPMS, married, legal assistant) described how her symptoms progressed rapidly after transitioning to SPMS and her inability to keep things as usual but also talked about new activities, pacing and resigning to the fact she will not be able to get loads of things done *"I still do things, you know. I still go away and, I've got things to talk about, and I do work in that I'm doing fundraising stuff for my committee, I do phone calls for my*



*husband's company. I'd have to look at it that I'm doing it in other ways. I do things with my mum, other family, you know, my cousins. But I just have to learn to pace it and if I'm having the bad day then I know I can't get loads done."*

### ***'Scaling back' mode***

The majority of the participants described letting go of previous activities when the effort required took away the enjoyment of the activity. For example, Jessica (SPMS, married, accountant) described adaptations around the house and at her workplace to enable her to carry on her usual activities but also acknowledged that she had to let go of certain activities she used to enjoy: *"I haven't hung washing out for years, and that's one thing. I miss being able to go out and hang washing out, but it's not worth it, it's not worth the hassle of everything I think would have to be in place for me to do it we would have to have all sorts, we would have hand rails, oh no, no."*

Relationships with significant others played a role on participants' move to 'scaling-back' mode. Participants also described how building stronger relationships with their partner and more meaningful relationships with other family members gave them enjoyment even though they were now restricted in the things they were able to do. Emily below describes a common experience among participants interviewed.

*I cannot do things that I used to do obviously, I have got a wonderful family, children, and grandchildren who come along and jolly me along if you like, but things are very dull because there is no way you can do things that you used to do. (Emily, SPMS, married, retired actress)*

For some participants, cutting out activities was necessary to make their life more comfortable. However, for others, scaling back did not happen after consideration and reflection but the speed of progression forced them to scale back.

*The first two months it [losing my job] really was hard, I kept saying, I should be out working, I should be doing something, I should be, even having lost that job, I should be looking for another job because I knew I couldn't do it, because the MS was progressing too fast. (Ruby, PPMS, married, retired science technician)*

Feelings of embarrassment, fear and lack of confidence led participants to scale back some activities. A lot of the participants also described feeling upset for having to scale back, and worried about future scaling back.

*I can't go out a lot; I just haven't got the confidence going out on my own or with other people. (Jack, SPMS, single, retired bank manager)*

Further, participants talked about environmental factors and their perceptions of the environment that led to their decision to scale back activities. For example, how easy or difficult it was for them to make necessary modifications around the house, find appropriate mobility aids or how other people perceived them.

*People will now perceive me differently because I feel the same inside you know sort of thing, but they are seeing me differently, and they are relating to me differently because they see the person who is wobbling around and can't get out of the chair and things (Lily, SPMS, married, clinical psychologist)*

### **'Finding alternatives' mode**

Participants described adapting to the progressive nature of the condition by finding alternative ways to make life fulfilling. For example, participants described working as volunteers, finding new hobbies or being involved in their local MS groups. As shown in Figure 1, relationships with partners and significant others, emotional reactions, environment and perceptions of environment all influenced how people moved between the different modes of adjustment. Relationship with the partner and significant others facilitated the identification of new enjoyable activities. For instance, Emma (PPMS, married, retired teacher) described how she and her husband found new ways to spend quality time together: *"I am also aware of... if we have gone to the hospital for me, then after I have gone for an appointment or physio or whatever, afterwards we may go for a coffee so we will try and turn round, to take advantage of our situation."* Spending time with friends and family members and organising activities and holidays with family was something that was frequently discussed in the interviews.

In some cases, partners also helped patients to move between 'scaling back' and 'finding alternatives' modes. For example, Emily (SPMS, married, retired actress) preferred to scale back but her husband helped her to also find alternative ways to retain some activities. *"My husband put me in the car, and we went to ((city)) where there is a big shopping unit. I hadn't been there for a few years because I wasn't able and we had a marvellous time. So there you are, that's what my husband did. And without the wheelchair, I couldn't have done that, so it's silly to rebel these things. You have got to have them to make life a normal living if you like, you have got to get on with it."* Oliver (PPMS, married, retired project manager), on the other hand, favoured

finding alternative ways to carry on doing the things he enjoyed, but sometimes he ran the risk of overexerting himself. His wife helped him to find a balance and scale back when necessary. *"I probably don't find it [balance] very well, I probably need my wife to tell me that actually I am being too stubborn now and then I am just making myself more tired than I need to because I am being too stubborn and so, I am not sure left on your own you necessarily can find a balance."*

Commonly, participants who described switching to 'finding alternatives' mode also expressed some distress when reflecting on the changes MS posed. For example, Noah (PPMS, living with partner, retired tutor) talked about how he found a sense of control and mastery over his condition and identified new fulfilling activities and at the same time he expressed some distress in relation to his physical boundaries and life-limitations due to MS. *"I became a landscape painter and artist, so I am now just painting, and I am involved in charity, working with charities. That's changed a lot, but things have been very difficult because I am not working and earning money. Having to rely on benefits and having to rely on help in that way, that's a big change as well. Again it makes you feel vulnerable because you know you have to be reliant on benefits."*

Participants in this mode also described environmental factors that influenced their adjustment mode and their perceptions of the environment, such as access to health services close to where they live, accessible places in their community and understanding from other people.

*Certain places are less accessible than others. But actually around ((city)) ...  
((city)) has become so much more accessible in the last sort of 10/20 years than*

*it used to be because I grew up in ((city)). If I, you know, if I was a 46-year-old man with MS living in ((city)) of the 1970s, that would be very, very difficult getting around. Erm, whereas now it's so much easier and there are so many things to help people. So I like to look at it on the positive side. And yeah, it's not perfect, but nothing's perfect so hey. (Noah, PPMS, living with partner, retired tutor)*

### ***Resigning to progressive MS***

Some participants as their MS symptoms progressed, described 'resigning' to their condition. Sometimes people moved from that mode to 'scaling back' or 'finding alternatives', but a few participants have mainly resigned and found it difficult to move to other modes of adjustment (see Figure 1). This was particularly true for people who struggled to find alternative activities to the ones before MS and scaling back was described as life limiting, "*not having a life but existence.*"

*You can't do anything without planning it. I also get fatigued very quickly. My concentration goes very quickly and I get quite short-tempered very quickly. I don't know certain things get me cross, unnecessarily cross. I think it's robbed me of a lot of my life [...] I just feel my world has shrunk because obviously we don't go places that we would go if I was fit. (Evie, SPMS, married, retired administrator).*

Some participants, who described significant difficulties in scaling back or finding alternatives, also described strain in their relationships with their partners. Olivia (married, nursery play group) had to remind her husband about her condition: "*I think*

*my husband finds it hardest actually, because he has known me...we have been together 25 years, and he can remember me being fit and able to carry things, and walk up mountains, and run, and I think he finds it most difficult that I am so restricted in what I can do. I think sometimes he gets a bit impatient about that."* However, it was not clear from these accounts whether the strain in their relationships was an outcome or a contributing factor in participants' difficulties.

As shown in Figure 1, relationships with the partners was an important factor that influence participants move among the adjustment modes. A theme that ran through the narratives of all people, who described resignation, was the dependent relationship they had formed with their partners due to the severity of their condition and their inability to perform certain activities. The partners organised their lives around the participants, and participants reported relying solely on them to perform everyday tasks and felt insecure when their partner was not around, in case of an accident or an emergency.

*"I absolutely despise dependency, I hate it, being dependent on other people. I have always been very independent, and my husband worked away from home for thirty years so I was on my own with the children and you know, Monday to Friday, he would be away and I would just do everything, and now my husband does the tasks I cannot do and it is very, very frustrating and I don't want, luckily my children are grown up and gone now, I don't want him to become a carer. He took early retirement eight months ago."* (Chloe, SPMS, married, retired PE teacher)

The emotional reaction to MS also played a role in the disengagement from adaptive tasks. Especially, embarrassment, lack of confidence and fear of accidents were the most frequently cited emotional reactions that led people to avoid activities that could have been enjoyable and resulted in a lifestyle that was restricted.

*I don't tend to put myself now in situations. For instance, say the ((town)) Flower Show, if you go somewhere and there's crowds, it's just a nightmare because you keep getting, you know, if you get jostled, you fall over. I tend not to put myself in situations now where I'm at risk, if you see what I mean? [...] I mean, I don't know, I don't do much now, if that makes sense. I sort of, I feel a bit safer in the house. (Isabella, PPMS, living with partner, cook)*

Participants' environmental context often played a role in resignation. People who described 'resignation' all had a routine or manual type of occupation and most of them retired due to MS. They emphasised how incompatible their previous leisure or work activities were with their current physical limitations, and this brought further difficulties in identifying appropriate alternative activities. They often talked about avoiding going out, socialising or going on holidays with the main reasons given being complicated planning, lack of accessibility, difficulties interacting with people with the 'wrong attitude'. Also detrimental were perceptions of the lack of supportive health services. A lot of participants described their frustration with the lack of support from the health care system.

*I am really, really not well, I'm really not well. And then to be in that situation and not have access to it, not have access to the help is so frustrating. So frustrating, so - you feel so bereft, you know, as though you're there, you are*

*unwell and there's no one, you know, there's just no one. And particularly, being on my own* (Grace, SPMS, living alone, retired business owner)

People that lived alone also described a rapid progression and expressed disappointment with the health system regarding physical or psychological support. Clementine (PPMS, living with children, retired social worker) talked about how difficult it was for her to adjust. She was diagnosed with depression and she sought psychological support. At the time of the interview, she felt better equipped to overcome her challenges. Freya (SPMS, living alone, retired administrator), on the other hand, was the only person living alone who described 'finding alternatives' as her dominant adjustment mode. She talked about finding new hobbies as the disease progressed, finding voluntary work when she could not work anymore and then finding a less demanding voluntary work as her illness progressed. She also talked about how much she valued travelling and how she had to adjust her destinations as the illness progressed. Freya attributed her motivation to make those adjustments to the fact that she was living alone: *"if I had family around, I may be sort of using a wheelchair now, because I may not be pushing myself as hard. If I knew my husband would push me in a wheelchair everywhere, I wouldn't bother maybe trying to walk, you know."*

A few participants described having 'resigned' to their condition in the past but finding some resolution through psychological support or alternative therapies. As Noah (PPMS, living with partner, retired tutor), who was diagnosed with PPMS and his condition, progressed rapidly, describes: *"I have been seeing a clinical psychologist, which has been very helpful, for about six months. My consultant referred me to a clinical psychologist, so that has really been helping with the way my illness affects the*



*way I think about myself or the way I deal with the emotional side of things, the way I deal with the mental side of things, you know, how to make sense of a long-term illness, and how to do things different, it's been really, really helpful."* In his interview Noah described 'scaling back' and 'finding alternatives' modes that made his life more comfortable but still fulfilling.

## **Discussion**

A preliminary model of adjustment to long-term conditions suggested that the aim of adjustment is to restore psychological equilibrium and that adjustment is likely to be influenced by personal background and environmental factors as well as illness characteristics (Moss-Morris, 2013). Although the model acknowledged that adjustment might be an ongoing process in relation to new critical illness related incidents, how adjustment changes and whether adjustment outcomes themselves might change, was not elucidated. These latter factors were the focus of this in-depth qualitative study, which is the first to qualitatively explore adjustment to progressive MS over time. We identified three modes of adjustment to progressive MS: a) finding alternatives, b) scaling back, c) resigning. People described one of these three modes as their predominant way of adjusting but also moved among different modes of adjustment. For example, people talked about resigning to their condition but then through help from family or professionals they shifted between 'finding alternatives' and 'scaling back' modes.

According to Carver and Scheier (1999) cybernetic model of self-regulation, emotions emerge from discrepancies between one's behaviour or related outcomes and one's goals and self-standards. For example, if someone's personal goal is to get a

promotion in a very competitive industry but due to their condition and the increased fatigue they cannot always deliver high quality projects on short period of time, there will be a great discrepancy between their work outcome and their goal of promotion. One way to overcome these discrepancies may be to 'scale back' goals and focus on one or two important areas when faced with severe cognitive and functional limitations (Carver & Scheier, 2000). Similarly, the model presented here shows how people when faced with a chronic progressive condition either adapt their activities and goals, scale them back or suspend them. Emotions not only emerge from these changes but also drive these changes. For example, feelings of embarrassment, fear of accidents and lack of confidence led participants to scale back some activities or avoid activities altogether. Further, given the severity of symptoms and other life circumstances people will choose different ways to adapt and often fluctuate among different modalities of adaptation.

Prior research has suggested that people with MS report better psychological adjustment, i.e. less negative emotional states, when they use active coping strategies (problem-solving, planning, suppression of competing activities), whereas avoidant coping (denial, mental disengagement, behavioural disengagement) was linked to worse adjustment, i.e. more negative emotional states (Arnett et al., 2002; Rabinowitz & Arnett, 2009; Lode et al., 2009). This categorisation of coping strategies and adjustment as better or worse, might not be helpful when we look at the progressive type of MS in particular. People have different responses to different illness challenges and life circumstances. For example, in our study, participants who described resignation, also talked about having no further choice due to the severity of their

symptoms. Resignation is part of the adjustment process and it might not necessarily be linked to avoidance or denial but it might serve as a way to protect agency.

Alternatively, our model highlights the importance of the fluidity among different adjustment modes. People may have preferred modes but being able to move to a different mode when circumstances or personal goals change is important to psychological wellbeing. Knowing the different modes of adjustment and the factors associated with moving among those factors can inform future interventions.

Previous qualitative research in MS has identified that personal relationships (Ghafari, Khoshknab, Norouzi, & Mohamadi, 2014; McPheters & Sandberg, 2010) and environmental factors (Dennison et al., 2010; Finlayson & van Denend, 2003; Fong et al., 2006) are especially important as the condition progresses. Similarly, in our study, we showed that contextual factors like relationship with partners, living alone, a low socio-economic status, and having limited access to health care services are important factors for adjustment. However, we also showed the impact of perceptions of these contextual factors. For example, perceptions of how useful it is to visit a health care professional or the perceived risks of being out of the house or perceptions of what others may think have an effect on people's adjustment mode.

Another key contribution of this study is the better understanding of the resignation mode. Resignation was associated with the most difficult emotions, however people still talked about the positive role of their family members and friends and also talked about challenges that they would like to address in the future. It is important to make sure that people still engage in activities that they enjoy and make their lives rich and meaningful. Resignation can be a short-lived phase, and people can

move to other ways of adjusting if they receive the appropriate support from health professionals or significant others.

The findings of this qualitative study should be viewed within the context of the following methodological considerations. First, although, we tried to recruit participants with diverse demographic characteristics, the majority of our sample consisted of white British professionals with advanced education. The main challenge of conducting research in secondary care is to identify individuals from low socio-economic status or minority groups who are willing to participate in research. Second, the method of data collection may have affected the responses, particularly in sensitive areas. Although participants were offered a face-to-face interview, all participants opted for a telephone interview, which might have been viewed as less intrusive and easier to arrange. It is hard to establish rapport over the phone, and non-verbal communication is less easy to pick up. Research indicates that both telephone and face-to-face interviews can be used productively in qualitative research (Sturges & Hanrahan, 2004), with the former potentially allowing participants to feel more relaxed and willing to disclose sensitive information (Novick, 2008), thus enhancing the trustworthiness of the data. The rich descriptions and the length of our interviews support the notion that telephone interviews can provide uncompromised and rich data. The model suggested here could have been better corroborated by sharing it with participants before refining. Finally, the cross-sectional design of the study does not allow exploring the validity of the model over longer periods of time and whether people increase or decrease in their fluidity between modes adjustment as the illness progresses. Future studies with a longitudinal design will be able to assess the fit of the

model over time. Further, quantitative studies could use questionnaires to capture the modes of adjustment and the factors associated with those and test the fit of the model in a larger more representative sample.

Regardless of the above limitations, the results of this study can help guide appropriate choice of psychological interventions or support for people with progressive MS. Although some of the factors identified as influencing adjustment are difficult to modify (e.g. illness progression and social environment) other factors are easier to modify (e.g. emotional reactions, concealing/revealing the condition and perceptions of environment). The modifiable factors might be even more important as the illness progresses and could be incorporated into future interventions. For example, incorporating activities diaries that can then be discussed and negotiated with a therapist to find a balance between scaling back and finding alternatives, or address fear associated with scaling back or finding alternatives. Health care professionals might need to monitor patients' willingness to disclose their condition to key people in their environment, i.e. employers, family member, this will ease decision on helpful adaptations to increase patients' quality of life. Further, cognitive behavioural therapy, acceptance commitment therapy or mindfulness interventions can help patients manage emotional responses to MS challenges or help patients to work out dilemmas around concealing/revealing their condition or explore their perceptions of environmental barriers and identify ways to work around those barriers. When somebody is in the resigned mode yet has realistically exhausted all viable ways of scaling back or finding alternatives, approaches such as mindfulness or acceptance based interventions might be useful with helping people feel more at ease with an

existence that even with the best of efforts is not in line with their previous life or aspirations. Support programmes that invite people from the patients' social environment to participate, especially people from the close family environment, might be useful. For example, a relationship enrichment programme significantly improved relationship satisfaction in couples living with MS, as well as improved mental health-related quality of life, communication, conflict resolution and ability to handle MS-specific functioning (Tompkins, Roeder, Thomas, & Koch, 2013).

The findings presented here highlight certain important issues about adjustment as an illness progresses, which have potential efficacy implications for interventions delivered in a standard way to all people. The adaptation to a progressive illness is a fluid process with patients often moving from one mode to another and occasionally going back to an earlier mode. Consideration of these modes, along with position on the illness trajectory and the modifiable factors described here can be used to determine which therapeutic approach might be most helpful. Therefore, by assessing and addressing factors like the emotional state and perceptions of the individuals as well as the objective environment, we can facilitate individuals' flexibility in adaptive tasks. Further, interventions can be put in place early on when patients are in the 'maintaining things as usual', pre-mode of adjustment to facilitate the adjustment as illness progress and the struggles increase.

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Table 1. Topic guide

Questions	Prompts
Can you start by telling me all about what you thought and felt when you were first diagnosed with primary/secondary progressive MS?	Main issues, explore concerns, feelings, (physical, psychological, family issues) what did he/she do about each problem that was identified?
Can you tell me about what you think and feel about having MS now?	Examples of issues identified?  Feelings and thoughts on support interventions
Can you tell me about all the things you found helpful when dealing with challenges of MS?	they were offered or sought/ how did they apply the advice given (if given)
Can you tell me about all the things you found particular unhelpful when dealing with the challenges of MS?	
Describe a bad day. What kind of things do you do on a bad day?	
Describe a good day. What kinds of things do you do on a good day?	
Are there any other relevant issues we haven't covered that you would like to mention?	

Table 2. Demographic characteristics of participants (n=34)

	<b>Demographic</b>	<b>%</b>	<b>n</b>
Type	Primary progressive	38	13
	Secondary progressive	62	21
Gender	Female	73.5	25
	Male	26.5	9
Education	Secondary school	26.5	9
	College or equivalent	32	11
	University	41	14
Employment status	Employed	26.5	9
	Unemployed	21	7
	Retired	53	18
Marital status	With partner/spouse	76.5	26
	No partner/spouse	23.5	8
Age	Mean years (SD)	55.12 (9.35)	
	Range	39-77	

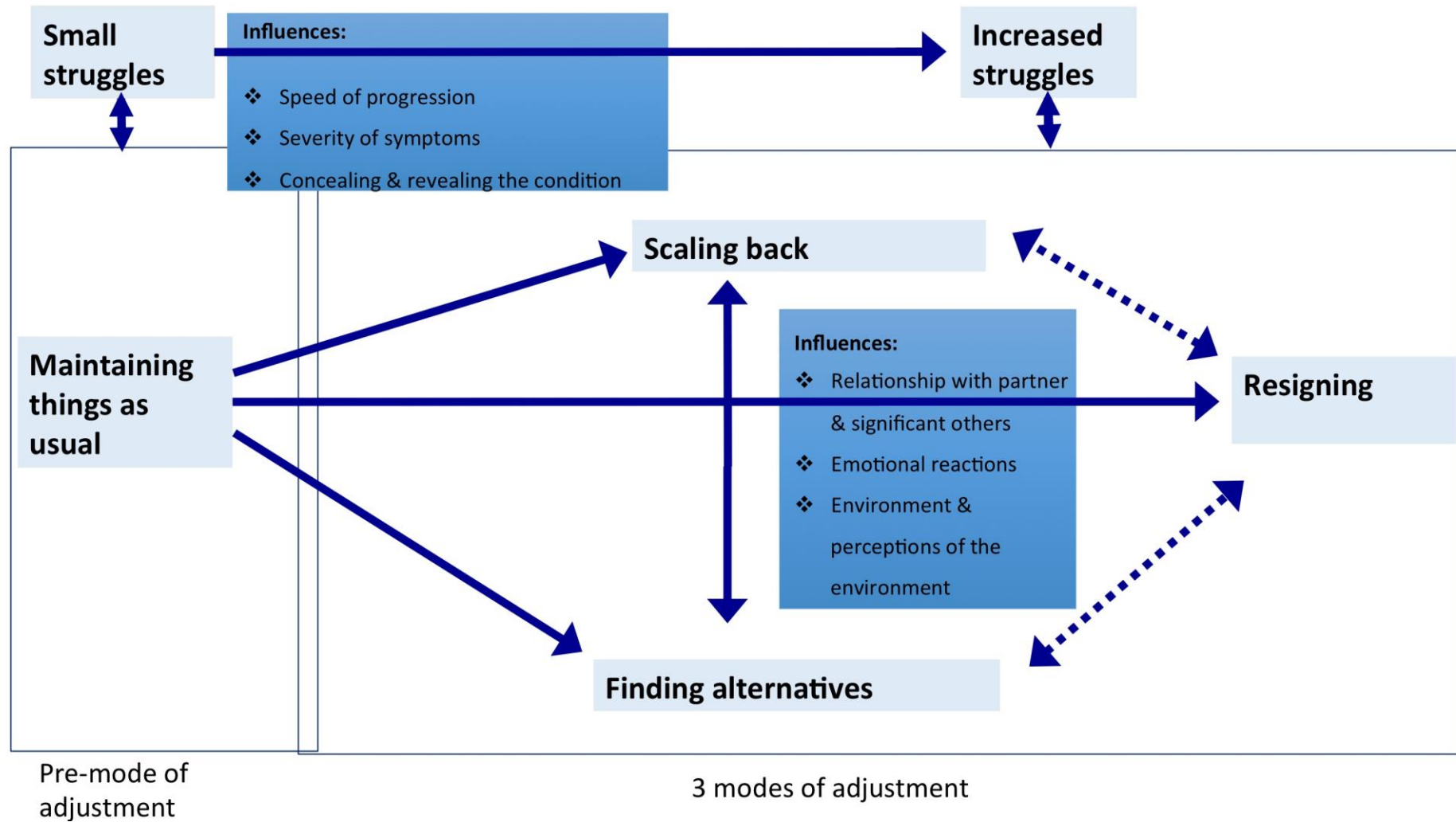


Figure 1. Model of adjustment to progressive multiple sclerosis