

A qualitative investigation of lay perspectives of diagnosis and self-management strategies employed by people with progressive Multiple Sclerosis.

Journal:	<i>Health</i>
Manuscript ID	Health-16-0044.R2
Manuscript Type:	Original Manuscript
Keywords:	Chronic illness and disability, Patient-physician relationship, Quality of life, Experiencing illness and narratives, Gender and health
Abstract:	<p>This paper explores how people with progressive Multiple Sclerosis (MS) give meaning to their experiences. It builds upon the self-management literature, which has captured the tension between the desire for retaining normalcy and the increasing burden of self-management associated with chronic disease progression. This repeat interview study is empirically grounded in twenty eight interviews with fourteen people with progressive MS. We identified gender differences in diagnosis-seeking which impacted upon subsequent sense-making. Male respondents found a diagnosis of MS difficult to come to terms with, and an enduring sense of loss or anger could inhibit further sense-making. A diagnosis of MS was more difficult to obtain for women respondents, and any sense of certainty that diagnosis provided framed their subsequent sense-making strategies. The complex sequelae of MS require that self-management strategies are both contextual and timely; although even the most accomplished self-managers can lose their sense of self with neurodegeneration. Disease progression can be associated with suicidal ideation, suggesting the need for greater dialogue to ensure that people with MS are adequately supported to fulfil their quality of life at all stages of neurodegeneration. These lay perspectives emphasise the articulation of affect rather than the rendering of a medical diagnosis, although diagnosis may provide a degree of certainty in the short term. The ethos of self-management ensures people attempt to retain their sense of 'normality' and existent social roles for as long as possible, but this ethos can negate both ones' ability to self-manage and the management of self.</p>

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4 **management strategies employed by people with progressive Multiple**
5 **Sclerosis.**
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10 **Abstract**

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14 meaning to their experiences. It builds upon the self-management literature, which
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16 increasing burden of self-management associated with chronic disease progression.
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28 suggesting the need for greater dialogue to ensure that people with MS are
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34 sense of 'normality' and existent social roles for as long as possible, but this ethos
35 can negate both one's ability to self-manage and the management of self.
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3 Keywords: diagnosis; Multiple Sclerosis; qualitative; self-management; suicide;
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5 symptoms.
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8 **Funding**

9
10
11 This research was funded by the MS Society (Grant no. 908).
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13

14 **Acknowledgement**

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16
17 We thank the men and women who took part in the study and the anonymous
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19 reviewers for their advice and comments.
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Background

Multiple Sclerosis (MS) is a chronic neurological disease which may lead to severe disability (Isaksson et al 2006). In approximately 60% of people it begins as a relapsing-remitting disease which evolves into a progressive neurological illness (Weinshenker 1994). People generally report subjectively experienced symptoms to their doctor, who diagnose MS on the basis of scientific test results. Symptoms may include deterioration of mobility, vision, sensation, continence and fatigue, all of which may follow an uncertain course. The delay between the appearance of symptoms can take many years and people diagnosed with MS may subsequently live with greatly diminished quality of life (NICE 2014).

Diagnosis

Diagnosis of MS includes clinical and paraclinical studies which may require 'objective clinical evidence' identified from cerebral spinal fluid and magnetic resonance imaging (McDonald et al 2001). An 'attack' (indicative of exacerbation or relapse) is defined as a patient reported episode of symptoms, lasting more than twenty four hours in the absence of fever or infection (Polman et al 2011). While clinically useful, these signs and symptoms are 'scientifically arbitrary' because of the difficulty of setting a ceiling at which MS exists (Weinshenker 1994). Although life expectancy is unchanged for people with MS, their rate of suicide is seven times that of the general population (Weinshenker 1994).

Early sociological studies of health and illness focused on the salience of diagnosis as category and process infused with social, cultural and historical significance (Blaxter 1978). While Parsons (1958) noted the legitimising function of diagnosis, allowing 'sick' individuals' exceptions from society and access to health services,

1
2
3 Foucault (1973) and Illich (1976) identified the rendering of diagnosis and associated
4
5 medical surveillance as potentially disempowering. Stewart et al (1982) employed
6
7 MS as an example of a chronic condition to critique Parson's notion of the 'sick role'
8
9 as more suited to theorising acute episodes of illness; while Robinson (1990) used a
10
11 narrative approach to analyse four hundred and fifty written accounts provided by
12
13 people who attended a Multiple Sclerosis support group. Robinson (1990) concluded
14
15 that most respondents provided a 'heroic' or 'courageous' progressive personal
16
17 narrative, indicative of a particular narrative genre associated with 'living with' and
18
19 'overcoming' the physical manifestations of their disease; but also identified a more
20
21 minor 'tragic' narrative, which became manifest as symptoms increased and people
22
23 with MS became less able to participate in the world around them.
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27
28 With progressive MS diagnosis may not be a one off event, rather reframing may
29
30 occur as symptoms progress or new symptoms replace or magnify those already in
31
32 existence. While the patient may cast their symptoms within a subjective context,
33
34 health professionals use an array of 'objective' classification systems for 'doing'
35
36 diagnosis (Frank 1995). The heterogeneous and shifting nature of neurological
37
38 symptoms make them particularly difficult to name and control (Nettleton 2006;
39
40 Locock et al 2009), and a diagnosis of MS can be hard won and subsequently
41
42 rescinded as symptoms change or fail to meet diagnostic criteria (Nettleton 2006).
43
44 For Nettleton et al (2004), these neurological narratives are examples of Frank's
45
46 (1995) *chaos narrative* (with no clear beginning or ending), rather than Robinson's
47
48 *heroic narrative*. If, as Sointu (2015) contends, one's capacity for sense making of
49
50 health and illness is shaped by the dominance of biomedicine as the primary means
51
52 of defining and treating ill health, we need to explore the experience and impact of
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2
3 the diagnostic process on sense making processes, and subsequent management
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5 strategies employed by people with MS.
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8 ***Self-Management***

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10 Like diagnosis, notions of self-management for MS are complex. In the UK, the NICE
11
12 guideline for MS (NICE 2014) recommends 'self-management' (NICE 2014b).
13

14
15 Exercise regimens are recommended for the management of fatigue and immobility
16
17 and self-titration of medication is suggested for the management of spasticity but,
18
19 between reviews by health professionals, people with MS are encouraged to self-
20
21 manage (NICE 2014). The MS guidance (NICE 2014) incorporates qualitative
22
23 studies, but while none *define* self-management, collectively they *describe* implicit
24
25 expectations that patients devise their own mechanisms for 'going away and living
26
27 with it' (e.g. Malcomson et al 2008). More recent qualitative studies have identified a
28
29 lack of ongoing provision to support self-management (Deibel et al 2013) and shown
30
31 how people with MS often receive generic rather than tailored information and
32
33 education (Chaplin et al 2012).
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38
39 The term 'self-management' has received much critical attention. Formal
40
41 programmes originated from the Chronic Disease Self-Management Program
42
43 (CDSMP) developed in the USA in the 1990s and provided groups of patients with a
44
45 course about their conditions and tasks to utilise fewer health care resources (Lorig
46
47 et al 1999). Kendall et al (2007) suggest that the CDSM approach to self-
48
49 management was adopted as a formal policy initiative in the UK to reduce the
50
51 financial burden of chronic conditions and involve patients in health care delivery
52
53 (DoH 2000). Three layers of management were enshrined in this policy (DoH,2004):
54
55 *case management* for patients with multiple complex conditions, *disease*
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3 *management* supported with packages of incentivised support in primary care, and
4
5 *self-management* for low risk patients (70-80% of those with chronic conditions)
6
7 (Kendall et al 2007). However, Kendall et al (2007) also differentiate between formal
8
9 *self-management strategies* which refer to the practical steps taken to employ
10
11 resources and minimise difficulties in everyday life, and a more insidious *self-*
12
13 *management* whereby people try to retain their sense of self in the face of their
14
15 condition.
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17

18
19 In the UK, Bury et al (2005) cautions that evidence for CDSMP based interventions
20
21 has been overstated, mediating factors have been underexplored, and any long term
22
23 benefits have yet to be determined; while Townsend et al (2006) suggest that self-
24
25 management policies and practices need to recognise the burden associated with
26
27 balancing symptom management along with social roles and activities of daily life.
28
29 They identify a range of strategies that patients employ to maintain balance,
30
31 including pacing activities, talking to others, use of medication, use of formal services
32
33 and informal networks. Self-management has been used variously to denote self-
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35 care in accordance with the knowledge of experts, as the domain of experts, and as
36
37 a form of emancipation (Kendall et al 2011). However, the normalisation of self-
38
39 management obscures the hard work involved and the lengths to which patients go
40
41 to maintain normal daily life; and self-management needs to be supported in ways
42
43 which acknowledge and accommodate contextual factors which enable patients to
44
45 meet their own goals, rather than merely managing symptoms (Morden et al 2011;
46
47 Ong et al 2011; May et al 2014; Ong et al 2014).
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53 The utility of self-management enshrined in the NICE guideline for MS specifically
54
55 (2014) has been challenged by an international consensus conference which
56
57 identified a paucity of evidence to support the use of self-management interventions
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3 in MS, noting that where evidence exists it tends to concern one symptom rather
4 than the many that typify the condition (Fraser et al 2013). Furthermore, despite the
5 introduction of a new quality standard to drive improvement (NICE 2016), MS
6 charities in the UK remain sceptical due to the lack of additional resource provision
7 (Robinson 2016).
8
9

10
11 MS is more prevalent among women and research has identified how MS is
12 gendered. Explorations of help seeking more generally have identified the lengths
13 that many women go to before their symptoms are legitimated (Werner et al 2003),
14 while studies with men have challenged the stereotype of reluctant care seekers,
15 noting how gender intersects with notions of risk and responsibility (Robertson
16 2006), health beliefs (O'Brien et al 2007), and occupational category (2011). Payne
17 and Doyal (2012) also contend that recent neoliberal policies have reinforced gender
18 inequalities, such that women's domestic responsibilities have increased, while men
19 have been further disenfranchised from help seeking. With regards to MS, studies
20 have identified how women respond to the spatial and temporal changes that
21 disease progression brings by restructuring their roles and activities (Dyck 1995),
22 strategically avoiding physical exertion, and seeking out supportive social
23 relationships (Schneider et al 2010). In contrast, men experience MS as a form of
24 social loss (Kohler-Reissman 2003), and battle against symptoms such as fatigue,
25 which in turn leads to lower self-efficacy than women (Smith 2015).
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49 The research questions that this paper seeks to answer are:
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- 51 • Is the on-going process of diagnosis oppressive or empowering?
- 52 • Is self-management burdensome or an expression of autonomy?
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57 **Methods**

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3 Lay perspectives of people with progressive MS were gathered by purposive
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5 sampling (Pope and Mays 1999), including both participants active in the MS
6
7 community and those in contact with specialist MS services. We gave a presentation
8
9 about the research at MS Society meetings in two cities in South West England, and
10
11 provided information to sixteen people with MS who expressed interest in this study.
12
13 We also enlisted MS Specialist Nurses (MSSNs) to identify people with various
14
15 stages of MS symptomology and diagnosis using the Expanded Disability Status
16
17 Scale (EDSS) which quantifies disability and changes over time (Kurtze 1983), and
18
19 criteria which neurologists use to diagnose MS (McDonald 2001; Polman 2011). The
20
21 MSSNs identified and gave information packs to ten further people who met the
22
23 study's inclusion criteria. Fourteen people with progressive MS consented to be
24
25 interviewed, seven from the MS Society meetings, and seven identified by MSSNs.
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30 A topic guide was developed based upon a review of the existing literature, clinical
31
32 experience, and input from an advisory group (comprising two senior qualitative
33
34 researchers with expertise in MS and rehabilitation, a neurologist, and a person with
35
36 relapsing remitting MS). It included demographic information, the broader context of
37
38 the illness experience, sources of support, and lay perspectives of living with MS. It
39
40 was piloted with two people with MS, and upon review a decision was made to split
41
42 the data collection into two separate interviews, to prevent the interviewees from
43
44 becoming fatigued and for us to tailor the questions in the repeat interview
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46
47 (Dickinson-Swift et al 2008).
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51 Initial interviews were conducted (AA) in participants' homes in 2010, lasted between
52
53 thirty and ninety minutes and were digitally recorded. Repeat interviews were
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55 conducted with all participants (AA) six months later, and lasted thirty to sixty
56
57 minutes. Interviews were transcribed verbatim and thematically analysed (AA and
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1
2
3 BB) using iterative readings and summary sheets to record key themes and
4
5 narratives (Mishler 1996). Their inclusion in an Nvivo managed dataset allowed
6
7 within-case and across-case analysis (AA, BB and CC) (Holland et al 2006). Our foci
8
9 were the process of diagnosis and the long-term sequelae of MS and its sociological
10
11 contexts.
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14 15 16 17 18 **Results**

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21 Fourteen people with primary progressive (n=9), or secondary progressive Multiple
22
23 Sclerosis (n=5) participated. Ten were women and four were men. The duration of
24
25 MS ranged from four to fifteen years, and mobility ranged from unaided to wheelchair
26
27 use. Participants' mobility, their socioeconomic circumstances and age were
28
29 reflected in their accommodation, with some living independently and others living in
30
31 assisted or modified social housing. Nine identified walking as their most important
32
33 symptom, three identified mobility more generally, and the remaining three each
34
35 identified breathing, pain and depression. **[Table 1 here]**
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38 39 **The diagnostic process and 'certainty'**

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42 There were gendered differences in the experience of diagnosis. The men did not
43
44 consider themselves to have symptoms of MS and found the diagnosis difficult to
45
46 come to come to terms with, whereas the women found it harder to establish a clear
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48 diagnosis of MS, or welcomed a diagnosis as a form of validation.
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52 The men interviewed responded to their diagnosis with a mixture of shock and fear.
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54 All reported that 'something was wrong', with some undertaking self- diagnosis or
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56 retrospectively attributing their diagnosis of MS to longstanding symptoms which
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3 they had not previously reported to a doctor. Arthur, a businessman, had always
4
5 experienced poor co-ordination and lacked the co-ordination to run, and experienced
6
7 a sudden exacerbation of symptoms at the office:
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9

10
11 So I've always found it hard work doing things like, I've never been top, a top
12 performer at things like that...I always thought I can't do this, you know, I'll,
13 ah, but until it was diagnosed of course, I mean I died when I was told 'you've
14 got MS.'... (Arthur)
15

16 In contrast, Brian, an engineer, had symptoms identified by his wife and did not
17 understand why he was referred to a neurologist. He was shocked by his
18
19 unconfirmed diagnosis of MS, which he subsequently looked up on the internet:
20
21
22
23

24 W: Then you went to the Eye Infirmary... And they referred you to the
25 neurologist.

26 P: Yeah, and I thought 'why are they doing that?' But anyway, they referred
27 me there and course, they give me the note, I'm sat there waiting and course,
28 'well, I'll just read' and this, a doctor put down, um...Question mark,
29 possibility, um, MS and I thought to myself, 'what the hell's MS?' Course I
30 looked it up...Frightened myself [laughter], frightened me to death, I thought
31 'bloody hell'. (Brian)
32
33
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35 When Clive, a salesman, began to experience increasing numbness in his leg, it was
36 a family member, also a physician, who referred him to a neurologist. He too found
37
38 the diagnosis difficult to accept:
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43 [Relative] was a consultant there and one of her sort of friends, who was a
44 neurologist.... he sort of saw me... said, you've got MS, it might never happen
45 or it might do. Lots for my walking I had hundreds of bloody tests, and vision
46 tests and coloured dyes in the eyes and god knows what else...Very difficult.
47 They've made a mistake! (Clive)
48
49

50 Finally, David, a surveyor, had a history of 'fumbling and stumbling' like Arthur, and
51 similar to Clive he questioned the diagnosis of MS, taking years to come to terms
52
53 with it:
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3 It's taken me a number of years actually to finally get used to the fact that I've
4 got MS because in the initial days I used to say, are you sure? Are you really
5 sure? (David)
6

7
8 The duration of symptoms before help-seeking in these accounts is indicative of
9
10 men's general reluctance to help- seek until 'minor symptoms' become more serious
11
12 (O'Brien et al 2005) , overlaid with MS specific symptoms which can lead to
13
14 perceptions of a failure of both masculinity and medicine.
15

16
17 In contrast, the women interviewed expressed that when they sought a diagnosis
18
19 they were not believed, or were 'fobbed off' with a psychosomatic reason (Payne et
20
21 al 2012), with some believing that their diagnosis was withheld. Ivy, an administrator,
22
23 with pre-existing symptoms for many years, believes that the diagnosis of MS was
24
25 added to her medical notes without her being informed:
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27

28
29 Now when I moved here [GP] came to introduce herself and she said when
30
31 were you diagnosed? I said 2003, oh no she said I read your notes through;
32
33 you were actually diagnosed in 1979. But all the specialists then said to me,
34
35 we know what's wrong with you but we think any treatment might be worse
36
37 than the actual symptoms, just carry on, so that was it. But I'd fallen from late
38
39 teens and of course with MS your knees don't bend, you just go flat on your
40
41 face. (Ivy)
42

43
44 Nancy was a nurse with caring responsibilities for her family, and her diagnosis of
45
46 MS was rescinded and then subsequently reinstated:
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48

49
50 P: That's a joke; my GP told me that I had a mild form of MS, it was called, it
51
52 was called Uthoff's phenomenon, then I went and saw the Consultant and he
53
54 told me I didn't have it, and then I saw a different Consultant and he told me I
55
56 had primary progressive...

57
58 I: And then did it take years to get a proper diagnosis or?

59
60 P: Probably took about 4... in hindsight... I didn't have a clue, (Nancy)

61
62 Similarly, although Hannah, a pharmacist and keen runner, had co-ordination
63
64 problems for many years, her GP was quick to diagnose her with migraines:
65
66

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2
3 Yeah I had a club foot. Well you know what it's like with the motion of running,
4 I felt like I was carrying a club foot with... thick shoes, that's how it felt... I
5 went to my doctor, [GP] ...it took about 18 months to diagnose cos they
6 thought it was a migraine. (Hannah)
7

8
9 Joan, an ex-barrister, used a keyboard to provide her account as her symptoms
10 impeded her communication, and suggests that her symptoms continue to be
11 considered as psychosomatic:
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14
15
16 I was diagnosed Aug 2002. It was very quick, woke up in middle of July 2002
17 with sensory symptoms R side, the sort of thing which could have been
18 nothing but equally you knew would not be unreasonable to take to a GP.
19 Waited 2 weeks, hadn't got better, went to GP (private), referred to
20 neurologist, he said either a stroke or brain tumour or MS, did tests came back
21 in 2 weeks, MS. Confirmed it with EVP. Just on MRI, no LP.... I find it hard to
22 buy into any psych explanation but am willing to give it a try. I would prefer
23 them to say "we don't understand", rather than "therefore it must be pschy",
24 explanation given that all is electrical/chemical at cellular level anyway. (Joan)
25
26
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28
29 Werner et al (2003) contend that a lack of diagnosis and/or a diagnosis that is
30 deemed 'psychological' conflates symptoms with immaterial and fictitious origins,
31 and renders women's experience invisible.
32
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35
36 Two women described the diagnosis, and the perceived certainty that it brought, in
37 terms of relief. Diagnosis can come with an 'affective clout', as a form of validation,
38 which permits the symptoms to be considered 'true' (Sointu 2015). For Edna, a yoga
39 teacher, the certainty of a diagnosis was in sharp relief to the uncertainty of
40 progressive symptoms which had made her question her existence:
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47
48 [Diagnosis] I, I think almost a relief because I'd just known there was
49 something wrong you see for all those years and almost as soon as I'd had
50 my hip replacement you see, and I thought there is something horribly
51 wrong... I mean at the time I'd sort of said to people 'you know, I'd rather be
52 dead than live like this', you know, I, I really would. (Edna)
53
54

55
56 Whereas Kate, a businesswoman who had just started her own business when
57 diagnosed, experienced relief because even her own Consultant disbelieved her:
58
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1
2
3 Kept turning me feet over and falling down...well the diagnosis was a relief
4 because even my Consultant, who wasn't an MS specialist, would imply that I
5 was making things up (Kate)
6

7
8 Where diagnosis was hard one, it became a signifier of control, albeit an illusory and
9
10 often transient signifier:

11
12
13 I have so often wished that when I saw my neurologist and told him of a
14 development he would plot a point on a graph and say ok, this is how things
15 are going now. Rather like a midwife doing a baby's weight. and I sort of felt
16 that with people saying that the best guide to future is how disease had gone
17 in the past, you really need a good way of measuring how it has gone in the
18 past...But it must be hard because the patient's baseline is constantly
19 changing. I can't imagine now what it must be like to go out and go shopping
20 for example. (Joan)
21
22

23
24 Although Joan wanted to know how 'her' MS would progress, she was aware that
25
26 this was clinically difficult to predict, and progression unpreventable.
27

28
29 There was often an assumption that diagnosis would (finally) facilitate access to
30
31 resources which would empower respondents and facilitate their independence, but
32
33 (as detailed below) this was often not the case. Where a diagnosis was not believed
34
35 or perceived as hidden, this eroded trust and inhibited further help-seeking and
36
37 sense making activities (Sointu 2015).
38
39

40 41 **Sense making and uncertainty** 42

43
44 Gender differences were also evident in the sense making process. Women
45
46 employed a range of strategies that enabled them to carry on with important aspects
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48 of their lives, while men were more likely to contextualise MS in relation to the loss of
49
50 valued roles and functions.
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54 Women were more willing to employ a range of positive strategies to assist with
55
56 sense making, and maintaining their credibility (Werner et al 2003). To enable her to
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3 continue working, Edna employed both contingency (by getting her students to
4
5 assist) and disclosure (being honest with clients about what to expect):
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7

8 There's very little that I can demonstrate anymore but, but my students are so,
9 so fit you know ... I'm keeping everybody else really fit and... if someone rings
10 me and says you know, 'can I start coming to your classes' and I have to say
11 ... 'well, I will tell you that I've actually got MS because you'll notice when I'm
12 walking that I, you know, I'm very sort of crippled but, um, apart from that I'm
13 alright'. (Edna)
14
15

16 Similarly, Kate found that using a wheelchair enabled her to continue working and
17
18 ensure customer relations:
19
20

21 [If] somebody new came in at the door behind me, turning round was an
22 awful effort and by the time I turned round I was glaring at this new person, so
23 I went to a manual wheelchair quite quickly because it solved that problem...
24 with a little manual wheelchair I was able to whirl round and still have a grin
25 on me face and that seemed to work brilliantly and people would say you
26 know, what are you doing in a wheelchair, and I said oh I've got MS and I
27 never, never hid it. (Kate)
28
29
30

31 Both women suggest honesty and contingency allow them to continue aspects of
32
33 their life which are valued. This is echoed by Joan, who similarly views a wheelchair
34
35 as merely a device for empowerment:
36
37

38 everything books etc all have "wheelchair" as the epitome of serious problems
39 but in fact wheelchair is like wearing glasses I guess lots of things when you
40 get close up you see distinctions which weren't there before so an able bodied
41 person thinks "wheelchair" and views the expression "wheelchair user" as
42 being just PC but in fact difference between "user" and "dependant" and
43 "confined to" which are significant. (Joan)
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47 Many respondents dreaded the increased use of aids, but retrospectively their value
48
49 in facilitating the maintenance of independence was acknowledged.
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52 In contrast, the men reported or feared being perceived as 'drunk' which Isaksson et
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54 al (2006), identified can lead to feelings of shame and lower self-esteem and erodes
55
56 one's long term ability to manage. Arthur's experience of sensory symptoms, and his
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3 doctors' perception that he had been drinking alcohol, inhibited his ability to
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5 communicate and subsequent confidence:
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8 The doctors thought I were drunk, before I was first diagnosed... I wasn't
9 drunk, which used to annoy me something chronic cos I didn't even drink...
10 me brain knows what it wants to say but me mouth says something a bit odd,
11 in a different way... Well, it was me voice for one thing, which sounded drunk
12 and me memory and, and I thought to meself: it is, well, you know, cos, I'm,
13 I'm a communicator! (Arthur)
14
15

16 Similarly, Brian was accused of being drunk by a client, which resulted in him being
17
18 investigated by his boss and loss of his professional autonomy:
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20

21 I said 'so, what, what's going on here?' he said 'well, I'll tell you the truth', he
22 said, he said, 'I can see there's absolutely nothing wrong' he said 'but we've
23 had a phone call when, and they, from, um, the manager of a store or
24 something saying you were drunk.' (Brian)
25
26
27

28 These men also described a sense of anger about their loss. Like those interviewed
29
30 by Kohler-Reissman (2003) anger was associated with the decline of their bodies
31
32 and their social worlds. This immediate impact is recognisable in Clive's response:
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34

35 Well it frightened the wife off, I was that pissed off with the world... The anger
36 of it [Diagnosis]...I suppose it always shows itself to those closest to you
37 (Clive)
38
39

40 Whereas David described a slower process of loss:
41

42 To be honest that is just what it was doing, it was a very slow, gradual
43 process that, you know I found it more and more difficult to do certain things,
44 you know... I can't even stand on a pair of steps to put a lightbulb in or
45 anything like that, I can't do anything practical, nothing at all. (David)
46
47

48 These findings substantiate research which suggests that women's perceptions of
49
50 their disease state, relative to men, ensures that they are better able to
51
52 "psychologically buffer" the debilitating aspects of MS (Miller et al 2006). Here,
53
54 resilience appears to enable self-efficacy, whereas perceived loss of control inhibits
55
56 adjustment.
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Self-management and Management of self

Although respondents were asked about formal self-management programmes, they described their own self-management strategies (Townsend et al 2006; Ong et al 2014); suggesting both a lack of awareness of formal strategies for MS (NICE 2014; NICE 2014b) and individualised responses to the heterogeneous nature of symptoms.

Approaches to self-management strategies were symptom specific. Joan, who has cognitive difficulties, uses memories associated with her functional ability to remember specific events temporally and to chart her own disease progression:

I tend to try to identify times etc by whether using stick, or crutches, or manual chair, or manual chair with power wheels, or electric chair. (Joan)

In order to manage fatigue, Edna uses meticulous planning and pacing, either undertaking tasks early in the day or setting the day aside for evening events:

Yeah, it's probably better when I get up in the morning ... When I go to do my grocery shopping I go really early in the morning, at eight o'clock in the morning, which suits me fine and then just sort of leaning on the trolley. (Edna)

Olivia, with multiple symptoms, fostered a 'use it or lose it' mentality, which involves restructuring and reframing temporal space in order to maximise quality of life:

I very much feel that you keep going and you use it otherwise you know if I didn't do it I wouldn't be able to do it. (Olivia)

This 'can do' attitude was particularly evident in accounts where a respondent was also a carer for someone else. Caring was perceived as a form of social participation, a means of demonstrating control, and a way of retaining normalcy, even when their own wellbeing was jeopardised (Townsend et al 2006; Kendall et al

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2
3 2007). As both Arthur and Nancy suggest, caring for someone else can also be a
4
5 device for not worrying about oneself:
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8 I probably would be worse actually [without wife to care for], at least I've got
9 someone to focus on apart from me...I don't worry about meself much
10 anyway. (Arthur)
11

12 You've got to get on with it, yeah I look after me mum, I cook her meals and
13 you know sleep over there...first of all I was just a pain, I felt so sorry for
14 myself, why me, why me, it probably took about six or seven years to accept it
15 easily, but now I've got me mobility scooter, you know, I just get on and do
16 what I can. (Nancy)
17

18 Both were independently mobile when interviewed, but 'feared' for a time when they
19 or those they cared for might require care beyond their capacity.
20
21

22
23 In contrast, Clive, who walked with bilateral aids, contested his diagnosis and
24 subsequently lost his marriage and job, was unable to detail his strategies for self-
25 management. Instead he spent time information seeking and was hopeful for a cure:
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31 There might be a cure!... I spent quite a while on the internet...This Italian guy
32 has found what he thinks is a cure, um I think that's all quite promising. ... the
33 year 2015, no more MS, and I thought well no-one's going to make that kind
34 of statement unless they know something. (Clive)
35
36

37 Clive's experience exemplifies earlier findings which identified that when the
38 diagnosis of MS is difficult, sense making is inhibited, and role negotiation (such as
39 the adoption of the sick role and associated rights and responsibilities) is
40 subsequently hindered (Stewart et al 1982).
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46 Women seemed better able to manage the loss of their working identity, and this
47 may be due women already having more flexible strategies for managing the social
48 and private spheres, because of gendered career opportunities, the experience of
49 motherhood and other caring activities:
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56 Because like I say it's a family-run company, and it's only me so I couldn't
57 work in the office opposite the lady who owned the business because that
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3 would mean I'd need liability insurance to cover me in case I was there in the
4 office on my own ...So it came to a mutual agreement that I should, that I'd
5 leave. (Grace)
6

7 Grace seemed resigned to giving up her post because of the uncertainty associated
8 with continued relapses, and her realisation that there were increasingly tasks which
9 she could no longer perform.
10
11

12 Flexible self-management strategies were also required to undertake leisure
13 activities, perceived as essential for maintaining both function and quality of life. For
14 example, Nancy, a very physically active nurse described how she moderated her
15 exercise as her MS has progressed:
16
17

18 I used to do a lot of walking, I used to play squash and badminton and then I
19 couldn't do that cos the foot kept flapping...I bought a really decent exercise
20 bike and actually this leg was really flabby... I do at least an hour a day.
21 (Nancy)
22
23

24 However, with time and disease progression several respondents detailed how they
25 had stopped cherished activities, which were indicative of the failure of self-
26 management more generally:
27
28

29 I used to go swimming with the local swimming classes that were run for sort
30 of disabled people but I had to give that up ... one of the problems I had was
31 that on this bad leg my toes tend to curl under when I walk, you know, and
32 therefore it was very uncomfortable, very painful to go into the water to be
33 able to swim. (David)
34
35

36 Strong supportive social networks have been described as key resources for people
37 self-managing chronic conditions. Ong et al (2014) have cautioned against premising
38 self-care on obligational relations among friends, family and neighbours, and this
39 research has demonstrated social networks diminish for people with progressive MS,
40 as they lose their ability to participate in wider society and thus experience
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3 cumulative disadvantage (May et al 2014). Exceptional examples were provided by
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5 those active in the MS community:
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8 I've just taken on being chairman of the MS places locally...I think one adapts
9 one's life around it. (Clive)
10

11 I've actually led a much higher profile life since I've become disabled because
12 I've become pretty much a leader in the disabled community, and one of the
13 first things that happened was that I won a place on the [committee] (Kate)
14
15

16 Both suggested that their charitable roles fostered their self-esteem and a sense of
17 importance and, like those in the MS community interviewed by Robinson (1990),
18 these were the only respondents whose altruism reflected a *heroic* narrative.
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23 **Fear for the future and death as the only certainty** 24

25
26 As isolation and dependence increase with neurodegeneration, quality of life
27 decreases. These narratives included heightened emotional responses and suicidal
28 ideation, and a sense was gained that death becomes the only certainty with late
29 stage MS.
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36 Those with prior experience of caring for people with neurodegeneration suggested
37 that this experience increased both their anxieties and fear for the future:
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41 If I be quite honest with you I fear for the future, I fear if anything happens to
42 the husband cos I couldn't manage to live here on my own...I fear for how
43 much worse I could get yes definitely do... each time when I go to the toilet in
44 the night I think to myself how much longer can I manage this, is it going to
45 get worse, I think I frighten myself but you know it's always in the back of your
46 mind... how it's going to end? Because, I mean I've seen people at the worst
47 end. (May)
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52 Several respondents had contemplated suicide, and as with other neurological
53 conditions (Nettleton 2004; Locock et al 2009), suicidal ideation was particularly
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3 prevalent in those who experienced isolation or dependence, although in Ivy's case,
4
5 disease progression had denied her the means by which to take her life:
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7

8 Truthfully, if I could get to Zurich I would be there because my mother was 94
9 when she died, if I take after her I can't spend that long just sat in a
10 chair....Oh I don't dwell on it, I say it funnily but I'm really snookered, I've no
11 bath so I can't drown myself, I'm allergic to Ibuprofen, paracetamol and aspirin
12 so no way would I overdose in case it went wrong cos I know what the
13 symptoms are when it does go wrong, I can't walk down to the sea to drown
14 myself [laughter] so I'm just snookered there. (Ivy)
15
16

17
18 Good days were noteworthy amidst a growing sense that their ability to manage and
19
20 subsequent quality of life were diminishing:
21
22

23 I know I should be saying what I can do, that's the positive side of things, I
24 should be saying I can still do this, I can still do that, but there's not a lot of
25 things that I still can do that I used to do...Because that's the way I always
26 were before [MS] and I'm not like that now, so. It's like it's gone (Grace)
27
28

29 Wollin et al (2006) found that in the absence of a cure, and as with other chronic
30
31 conditions requiring palliative care, people with MS can require support as their
32
33 physical, emotional and spiritual needs increase. More recently Methley et al (2016)
34
35 identified reluctance among both people with MS and their designated health
36
37 professionals to label mental health difficulties as pathological, in some cases seeing
38
39 low mood as part of the normal disease process. Furthermore, their recommendation
40
41 that the familiarity associated with continuity of care fosters psychological security is
42
43 at odds with the self-management ethos that fails to acknowledge the diminution of
44
45 one's capacity to manage over time:
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48

49 I get so emotional it drives me nuts... even when I don't feel upset I find
50 myself blubbing. (Olivia)
51
52

53 For those men identified as having a persistent sense of anger, their enduring
54
55 emotional burden further undermined their ability to 'help themselves':
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3 I think for years and years I've always given to NSPCC and, um, I thought I'll
4 get a little bit more into that. And then they sent me some stuff and that, and
5 they sent me – and I think I can't be doing this, this is too upsetting, you know,
6 the...And then, not, they don't tell you specific but they tell you a specific story
7 of, not you know, you think oh, bloody hell and I'm thinking...I feel like I could
8 kill someone. (Brian)
9

10
11 Even for those women who had previously described their own efficacious self-
12 management strategies, their loss of independence negated future planning and now
13
14 management strategies, their loss of independence negated future planning and now
15 reduced them to living in the present:
16

17
18
19 One step at a time I think. There is an element of dread that it will go, it will
20 progress further and there have been one or two signs that my hands aren't
21 as strong as they were. (Kate)
22

23
24 Ultimately, the 'dull inevitability' of neurodegeneration erodes resilience and
25 ultimately leads to the loss of hope:
26

27
28 I have got to the stage when I rather want it to get on with it and finish me off
29 ... Now I am just tired... In a bored sort of way. Yes, I don't feel depressed as
30 such, but it is the sort of dull inevitability of it. And I am quite uncomfortable
31 most of the time. Hate that word, but with the breathing, imagine you can hold
32 your breath for 1min, and think how you would feel after 50sec. That is how it
33 feels. I want to be able to take a rest from breathing, but of course body won't
34 let you do that. (Joan)
35
36

37
38 These findings indicate self-management is ultimately burdensome, suggesting that
39 strategic approaches to MS must be both supportive (of psychosocial and physical
40 wellbeing) and supported (resourced by health professionals and access to aids and
41 services) in the long term, and appropriately tailored to individual needs.
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46 47 **Discussion**

48
49 We identified a clear gendered response to the experience of living with MS; which
50 suggests that men and women may have different needs, both at the time of
51 diagnosis and during subsequent sense making. However, gender differences tend
52 to diminish with disease progression, as both men and women express fears for the
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3 future and express suicidal ideation. Such fears can be compounded by additional
4
5 caring responsibilities, while active participation in the MS community can provide a
6
7 supplementary source of support.
8
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10 While earlier research described processes through which medical diagnosis of MS
11
12 was 'disclosed' (Robinson 1990), our analysis has identified how people self-
13
14 diagnose or refute an MS diagnosis. Some were surprised when they were
15
16 diagnosed with MS, but more gave accounts of incoherent diagnoses, suggesting
17
18 that poor communication and medical uncertainty add to the perception of fear and
19
20 ambiguity, rather than the diagnosis *per se* (de Seze 2012). Others expressed
21
22 disbelief or fear, suggesting that health professionals need to explore an individual's
23
24 experiential knowledge and lay interpretations, in order to better support them
25
26 (Lowden et al 2014). While male respondents expressed surprise at their diagnosis,
27
28 women often expressed relief. Diagnosis acts as a (albeit transient) explanatory
29
30 framework (Sointu 2015) which legitimates access to medical treatment and
31
32 expertise (Nettleton et al 2006) but may not necessarily change the experience of the
33
34 disease.
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40 These respondents did not frame their experience in relation to state-sponsored self-
41
42 management programmes, because they were either unavailable or deemed
43
44 unhelpful (Deibel 2013). Instead they detailed a range of personally developed
45
46 coping mechanisms and individually tailored self-management practices. Whereas
47
48 Robinson (1990) identified a dominant *heroic* narrative, our wider sampling frame
49
50 provided accounts more akin to Robinson's notion of a *tragic* narrative, in that for
51
52 many disease progression was associated with suicidal ideation; or (after Frank)
53
54 Nettleton's more recent *chaos* narrative (2004) in that the uncertain path of
55
56 progression inhibited planning, as previously successful strategies were surpassed.
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3 These findings suggest the need for disease specific self-management strategies
4 which are tailored to the individual needs of patients within their social contexts
5 (Morden et al 2011; May et al 2014; Ong et al 2014). Less palatable for policy
6 makers and providers could be the suggestion that, in the absence of appropriate
7 *self-management strategies*, some people with MS might want or need *disease*
8 *management* or *case management* approaches (DoH 2004), which are more
9 resource intensive approaches to the management of long term conditions (Bury et
10 al 2005).

11
12 A significant finding of this research is that many respondents have contemplated
13 suicide. Locock (2009) found that people diagnosed with motor neurone disease, a
14 rapidly progressing neurological condition, typically described it as a 'death
15 sentence' (*biographical abruption*) from which some at least sought to salvage the
16 semblance of self (*biographical repair*). In this research, some people with MS
17 appeared to describe this process in reverse, such that diagnosis acted as a
18 (temporary) form of narrative *repair*, which overtime was replaced by *abruption* or a
19 burgeoning awareness of gradual decline. One fifth of English people who kill
20 themselves have a chronic illness (Bazalgette 2011), and it is imperative that self-
21 management of MS is a meaningful choice for people and adjunct to, rather than
22 instead of, high quality medical treatment and social support (Methley et al 2016).

23
24 As the loss of a sense of self is eroded with disease progression, so is an individual's
25 ability to manage (Townsend et al 2006; Lowden et al 2014). Respondents described
26 employing techniques for maintaining both normalcy and independence for as long
27 as possible (McLaughlin et al 1993). However, dwindling self-management could
28 contribute to isolation and uncertainty in the long term and ultimately 'diminish
29 returns' for the required effort (May et al 2014). Self-management should be one of a
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3 range of strategies for people with MS (Chaplin 2012), and a more individualised
4
5 approach would view self-management not as a stable category, but as something
6
7 which diminished over time, and we propose the adoption of a more mutable concept
8
9 of self-management.
10

11
12 Like Kohler- Reissman (2003) we found that men's stories are infused with the
13
14 experience of loss which compounds their experience of symptoms (Smith et al
15
16 2015), and may inhibit their ability to achieve their own goals which erodes self-
17
18 efficacy. An initial response to diagnosis of disbelief or anger can hinder subsequent
19
20 abilities to problem solve and undertake flexible strategies of self-management, and
21
22 a lack of self-efficacy and resilience, resulting from diagnosis of MS, can be
23
24 associated with increased depressive symptoms in the long term (Tan-Kristano et al
25
26 2015). However, unlike studies that have identified variation in men's accounts of
27
28 help-seeking generally - along lines of sexuality (Robertson 2006), younger age
29
30 (O'Brien et al 2005), and high economic status (Farrimond 2011) - we did not identify
31
32 a reconstituted masculinity. This may be due to the men interviewed all being middle
33
34 aged (53-66), semi-professional, living in a semi-rural environment; with all
35
36 identifying the loss of their role as breadwinner as a significant milestone (O'Brien et
37
38 al 2005). Thus, while our sample reflected the prevalence of MS (two to three times
39
40 more prevalent among women- Fraser et al 2013), future research with a wider sample
41
42 of men may elicit a more nuanced response and better enable the tailoring of
43
44 provision. In contrast, women typically described a diversity of responses that better
45
46 equipped them to develop malleable self-management strategies which were
47
48 responsive to both symptoms and roles. As with other studies of help-seeking
49
50 (Werner et al 2003) and those with neurological symptoms specifically (Nettleton
51
52 (2006), the women interviewed described the 'hard work' involved in having their
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3 symptoms confirmed. However, we did not find that women drew on friends and
4
5 relatives for support (Schneider et al 2010), and an important finding from our study
6
7 is that the progressive nature of MS diminishes social relationships for both men *and*
8
9 women, to the extent that an important resource for self-care, assumed to underlie
10
11 current policies for self-management, may diminish over time and with disease
12
13 progression (Ong et al 2014). Only the two respondents (Clive and Kate) who
14
15 identified themselves as active in the MS community were able to draw on this
16
17 network as a positive resource. In contrast, those with caring responsibilities (Arthur
18
19 and Nancy) feared for the future and ever diminishing support.
20
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23
24 We have identified how people give meaning to the 'dull inevitability' of living with
25
26 *progressive* neuro-degeneration. Some respondents described their earliest
27
28 symptoms with remarkable clarity, whilst others were less clear as to when their MS
29
30 'started'. This could be mediated by both their willingness and ability to accept its
31
32 degenerating nature, as well as other chronic illnesses. Some were clearly struggling
33
34 to live with a condition which erodes their ability to undertake once taken for granted
35
36 tasks and activities. By virtue of the heterogeneity of symptoms and experience,
37
38 these findings may have relevance for people experiencing other progressive
39
40 conditions. However, this sample were all white British, living in South West England,
41
42 where people from minority ethnic backgrounds are under-represented (ONS 2011);
43
44 therefore our findings cannot be generalised to people from minority ethnic
45
46 backgrounds.
47
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51 *Prospective* research is now required to explain how lay perspectives reconfigure as
52
53 people with MS move from diagnosis through to disease progression; and explore
54
55 how changing resilience and vulnerability might impact upon one's ability to self-
56
57 monitor and effectively self-manage their condition (May et al 2014; Sointu 2015).
58
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1
2
3 Decades after the identification of the varied life trajectories and illness experiences
4
5 of people with MS, there remains a need for more assistance to be given to people
6
7 who are coming to terms with a diagnosis of MS and living with its progressive
8
9 impact (NICE 2016). For some people with MS diagnosis is empowering in the short
10
11 term but, in the absence of tailored formal self-management programmes of support,
12
13 individually identified coping strategies become burdensome *over time*. We therefore
14
15 call for greater public discussion of what it is like to live with a progressive and
16
17 degenerative condition so that both health services and lay support might adequately
18
19 address the needs of people with Progressive MS and assist them to achieve quality
20
21 of life where possible.
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For Peer Review

Table 1: Participants experience of Multiple Sclerosis and demographic data

Participant	Type of MS	Duration (years)	Primary symptom	Secondary symptoms	Disability levels	Age	Gender	Occupation /Retired	Housing Owner Occupied/ Rented	Relation ship status	Carer F/T P/T LA (Local authority)	Dependents
Edna	Primary	4	Walking	N/A	Unilateral aid	66	Female	Yoga teacher	Owner	Widow	P/T	None -2 adult children
Arthur	Secondary	13	Pain	Falls, speech, memory, pains in legs and chest	Furniture	67	Male	Retired-Senior manager	Owner	Married	F/T (wife)	1 - and 1 adult child
Brian	Secondary	10	Walking	Vision, pain in back, speech, balance, fatigue	Unilateral aid	54	Male	Retired – Refrigeration engineer	Rented	Married	P/T (LA)	None – 2 adult children
Grace	Secondary	7	Depression	Tingling hands, memory, walking, incontinence	Independent	53	Female	Retired – administrator	Owner	Married	F/T (Husband and daughter)	None – 1 adult child
Clive	Secondary	15	Walking	Tingling hands, numbness, balance	Bilateral	53	Male	Technician P/T	Rented	single	P/T (LA)	None
Hannah	Secondary	11	Walking	Drop foot, heavy leg	Independent	53	Female	Retired – factory worker	Rented	L/T Partner	Family and friends	None – 3 adult children
Ivy	Primary	16	Walking	Balance, incontinence	No mobility at all	66	Female	Retired - administrator	Owner	Widow	F/T (LA)	None – 3 adult children
Joan	Primary	11	Breathing	Speech, facial	Wheelchair	40	Female	Retired - lawyer	Owner	single	F/T (LA)	None

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				expressions, non-weight bearing								
Kate	Primary	11	Walking	Incontinence, non-weight bearing	Wheelchair	73	Female	Retired - IT	Owner	Divorced	P/T (daughter)	None – adult daughter
Louise	Primary	7	Walking	Numbness in hand and arm	Independent	66	Female	Retired – Teacher and IT	Owner	Single	None	None
May	Primary	10	Mobility	Swallowing	Furniture	53	Female	Retired - catering	Owner	Married	F/T (husband)	None – 3 adult children
Nancy	Primary	10	Mobility	N/A	Independent	53	Female	Retired - Nurse	Owner	Married	F/T (husband)	None - 1 adult
David	Primary	11	Walking	Balance, co-ordination, pain in back, numbness	Independent	66	Male	Retired – civil servant	Owner	Married	P/T (wife)	None – 1 adult
Olivia	Primary	9	Walking	Neuritis, numbness, balance	Independent	67	Female	Retired – Pub owner	Owner	Married	F/T (Husband)	None – 1 adult and 1 adult deceased