



Shifts in Self and Identity when Living with Multiple Sclerosis

Submitted by Abbie Turner, to the University of Exeter
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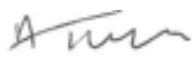
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SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

LITERATURE REVIEW

**Negotiating Self and Identity when Living with Multiple Sclerosis - A
Systematic Review**

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Abstract

Being diagnosed with multiple sclerosis (MS) is a non-normative transition which can cause challenges to a person's self and identity. With its unpredictable course and multiple disabilities, navigating challenges to self and identity can be ongoing. This can impact on a person's psychological wellbeing, satisfaction with life and illness management. Services can neglect to consider these challenges, tending to focus predominantly on the biomedical care of people with MS (pwMS). This systematic review aimed to review the qualitative research on MS and identity to understand the identity challenges that pwMS face and how they navigate these. A systematic search of four databases was conducted, and 12 papers meeting the inclusion criteria were reviewed. A summary, critical evaluation and meta-synthesis of the studies are presented. All papers were of an acceptable quality. Themes from the studies and meta-synthesis showed pwMS navigated challenges around maintaining a coherent self and identity and agency over self and identity. These challenges were heightened during times of illness progression or loss of roles, and influenced by wider context. Negotiating self and identity was often a conscious process for the pwMS in the studies, who used different strategies. Findings suggest professionals supporting pwMS should be aware of the identity challenges pwMS face. Implications for support are outlined.

Negotiating Self and Identity when Living with Multiple Sclerosis - A Systematic Review

Multiple sclerosis (MS) can cause ongoing challenges to a person's self and identity (Mohr & Cox, 2004). However, some people with MS (pwMS) maintain a sense of coherence, integrating illness into self and identity without becoming defined by it, which is positive for psychological wellbeing and life satisfaction (Bogart, 2015; Topcu et al., 2020). Understanding when illness is disruptive to self and identity and how pwMS negotiate these challenges is incomplete. This is important because the psychological impact of living with MS can get overlooked and pwMS report wanting more emotional support (Dennison et al., 2010; MS Society, 2020). Understanding how pwMS negotiate challenges to self and identity and how this influences wellbeing may guide recommendations for how pwMS's psychological needs may be supported. This review synthesises qualitative studies to consider how disruptive MS is to self and identity, under what conditions, and how pwMS negotiate these challenges. Self, identity and MS are discussed in the introduction to set the scene for the review.

Self and Identity

Within this review self and identity are seen as separate but closely related constructs which at the simplest level answer the question "who am I" (Bamberg, 2011). Self refers to a first order reflexive process of who one is at an immediate time point. Identity refers to a sense of self-sameness across time influenced by the self and relationships with others (Lichtwarck-Aschoff et al., 2008). This review takes a social constructionist perspective assuming that identity formation is a dynamic

process taking place within interaction, and as such negotiable and context-dependent (Bamberg & Georgakopoulou, 2008).

Self, Identity and Multiple Sclerosis

MS is a disease of the central nervous system resulting in symptoms including physical, psychological and cognitive impairment (Mohr & Cox, 2004). Different disease types vary in symptom course, with people either experiencing periods of exacerbated symptoms and a return to baseline functioning (relapse remitting MS; RRMS), or a gradual worsening of symptoms over time (progressive MS; PMS; Mohr & Cox, 2004).

People differ in how much they integrate MS into their identity which can influence wellbeing. Mohr & Cox (2004) suggest ideally one will acknowledge the implications MS has and incorporate these into their life story, however they note that commonly people become consumed by illness or hold rigidly to a former self-image (Mohr & Cox, 2004). A metareview into psychosocial adjustment found pwMS often used avoidance coping or denial following diagnosis in an attempt to preserve pre-diagnosis identity. This seemed to be maladaptive and associated with poor adjustment as participants who focused on retaining their previous identity were more likely to experience negative emotions (Topcu et al., 2020). Acknowledging and incorporating disability into one's identity is associated with lower rates of depression and anxiety in pwMS (Bogart, 2015; Kiropoulos et al., 2019). These studies provide a rationale for why self and identity should be considered post diagnosis. Whilst it is known that there are identity effects of living with MS, pulling all of the evidence together will help understand this more. Knowing what challenges pwMS face, under what circumstances and how people negotiate these will help

inform different sources of support on how best to help pwMS negotiate these challenges.

Due to the unpredictable nature of MS and the development of new symptoms, negotiating changes to self and identity are likely to be ongoing (Mohr & Cox, 2004). Viewing identity from a fluid viewpoint may therefore be helpful. Paterson (2001, p.4) describes chronic illness “as an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their world”. She suggests people foreground ‘illness’ or ‘wellness’ in their identities depending on their social and personal context at the time. Bamberg (2011) suggests people navigate three contrasting spaces whilst constructing identities within social interactions: (1) a sense of sameness versus difference to others, (2) a sense of sameness in the face of constant change, and (3) the construction of self as agentic or an undergoer of outside forces. These perspectives may hold significance for pwMS who face uncertainty and change, often feel and are positioned as different within society, and may be dealing with symptoms and situations that are outside of their control.

Research considering self and identity as important in the adjustment process to living with MS has implications for supporting pwMS. Whilst identity is considered important from a psychological perspective, evidence suggests services neglect to consider this. PwMS have expressed maintaining biographical continuity, including meaning and identity, as an unmet need (Galushko et al., 2014). Physicians identified identity challenges as a primary existential issue caused by MS, but found this challenging to deal with in clinics due to the biomedical approach in the healthcare system and medical training (Andersen et al., 2020). These studies were

conducted in Germany and the different healthcare system may limit transferability of results. Within the UK, research suggests geographical variability in how well the psychological needs of pwMS are supported (Simpson et al., 2020). PwMS access psychological support from different sources (friends/family, peers, charities, health services) at different times in their illness trajectory (Morris-Bankole & Ho, 2022). Reports suggest accessing appropriate support can be problematic due to a lack of specialist MS provision and further work is needed to improve service pathways to meet the psychological needs of pwMS (Simpson et al., 2020). Research considering how best to support pwMS in incorporating MS into their life story in a way that is not all encompassing may add to this.

Summary, Rationale and Review Question

Living with MS can impact on a person's self and identity (Mohr & Cox, 2004). Outcome studies show incorporating illness into one's identity is associated with emotional wellbeing and daily functioning in pwMS (Bogart, 2015; Topcu et al., 2020), less is known about what identity challenges pwMS are facing, under what circumstance and how they navigate these. Such research has implications for how people engage with society and manage MS (Mohr & Cox, 2004; Oyserman et al., 2012), and could have implications for support provision. This study aims to systematically review previous findings to understand the following questions:

- (1) What identity challenges do pwMS experience over the course of their illness?
- (2) Under what conditions do these identity challenges occur?
- (3) In what ways do pwMS negotiate these challenges?

Method

Adhering to the preferred reporting items for systematic reviews and meta-analyses protocol (PRISMA, Page et al., 2021) allowed a standardised approach and reduced bias.

Screening and Sampling

Characteristics of studies included in the review were based on the sample, phenomenon of interest, design, evaluation, research type (SPIDER) criteria described (Cooke et al., 2012; Table 1). The review included qualitative research sampling people with MS which included in depth information on a person's self or identity. Research using mixed samples including various illnesses were excluded as the voices of pwMS would have been hard to isolate jeopardising the trustworthiness of the findings. Research was included if it had a central focus on self and identity in MS, or where self and identity were discussed in depth as a theme in the results and discussion section. Studies looking at an element of identity construction such as motherhood were included as the focus was still on the direct relationship between identity and MS. Papers focusing predominantly on the effects of a mediating factor (e.g. physical exercise) on identity change and MS were excluded. Quantitative research was excluded because the review focused on process rather than outcomes, and self and identity as defined in this paper are not simple constructs that can easily be measured numerically. Grey literature, discussion papers or reviews were excluded due to risk of lower methodological quality, the absence of raw data for synthesis, and risk of data duplication. Only articles published in English were included due to no means for translation.

Table 1*Inclusion and Exclusion Criteria*

Aspect of Interest	Inclusion	Exclusion
Sample	Diagnosis of MS (relapsing remitting, primary progressive or secondary progressive MS) Any age and gender	Mixed sample with various illnesses (not specifically MS)
Phenomenon of interest	Central focus of the research is on patient's experiences of their identity or sense of self and their MS Research with a different focus but where identity or sense of self is discussed in depth within the results and conclusion section	General illness experience Couples' experiences of identity or sense of self if the individual voice cannot be clearly extracted Only a brief mention of self or identity for example as a single point in the paper Family, carer, partners viewpoint without view of the patient Self or identity in relation to mediating factor (e.g. physical activity)
Design and Evaluation	Methods yielding in-depth descriptive data about individual experience for	Methods yielding numerical data or short survey responses

	example individual interviews or focus groups	
Research type	Qualitative or mixed method studies with substantive qualitative element	Quantitative research
Publication type	Published in a peer reviewed journal	Grey literature, books, literature reviews, theoretical papers, opinion articles, and conference proceedings
Language	Published in the English language	Published in languages other than English

Searches were completed on PsychINFO, MEDLINE, Web of Science and Cumulative Index to Nursing and Allied Health (CINAHL). Search terms (Table 2) were arrived at by running initial searches and scanning papers for synonyms (Higgins & Thomas, 2019). To balance sensitivity and precision, the term self was not included but instead the map to subject heading function on PsychoINFO was used to generate concepts and identify specific terms relevant to this review. Terms such as 'self-esteem' and 'self-efficacy' were excluded, returning quantitative measure based, rather than qualitative, studies. Terms were combined with Boolean operators "AND" and "OR". Searches were limited to title and abstract. Studies published before the last search date (04/11/2021) were included. Following a progressive screening procedure (Figure 1) the search returned 830 records, 248 duplicates were removed. The remaining 582 papers were screened at title and abstract, those not meeting inclusion criteria were removed. Reasons were mainly

Table 2*Example of Search Terms Used in Database Search*

Search A (OR)	Search B (OR)	Search C (OR)
Sense of self	MS	Qualitative
Identity	Multiple sclerosis	Theme*
Self identity		Thematic
Self concept		Interview*
Self view		Discourse
Self perception		Phenomenological
Self psychology		Narrative
Self evaluation		Grounded theory
Perception of self		IPA
View of self		Framework analysis
Ego		Content analysis
Biograph*		

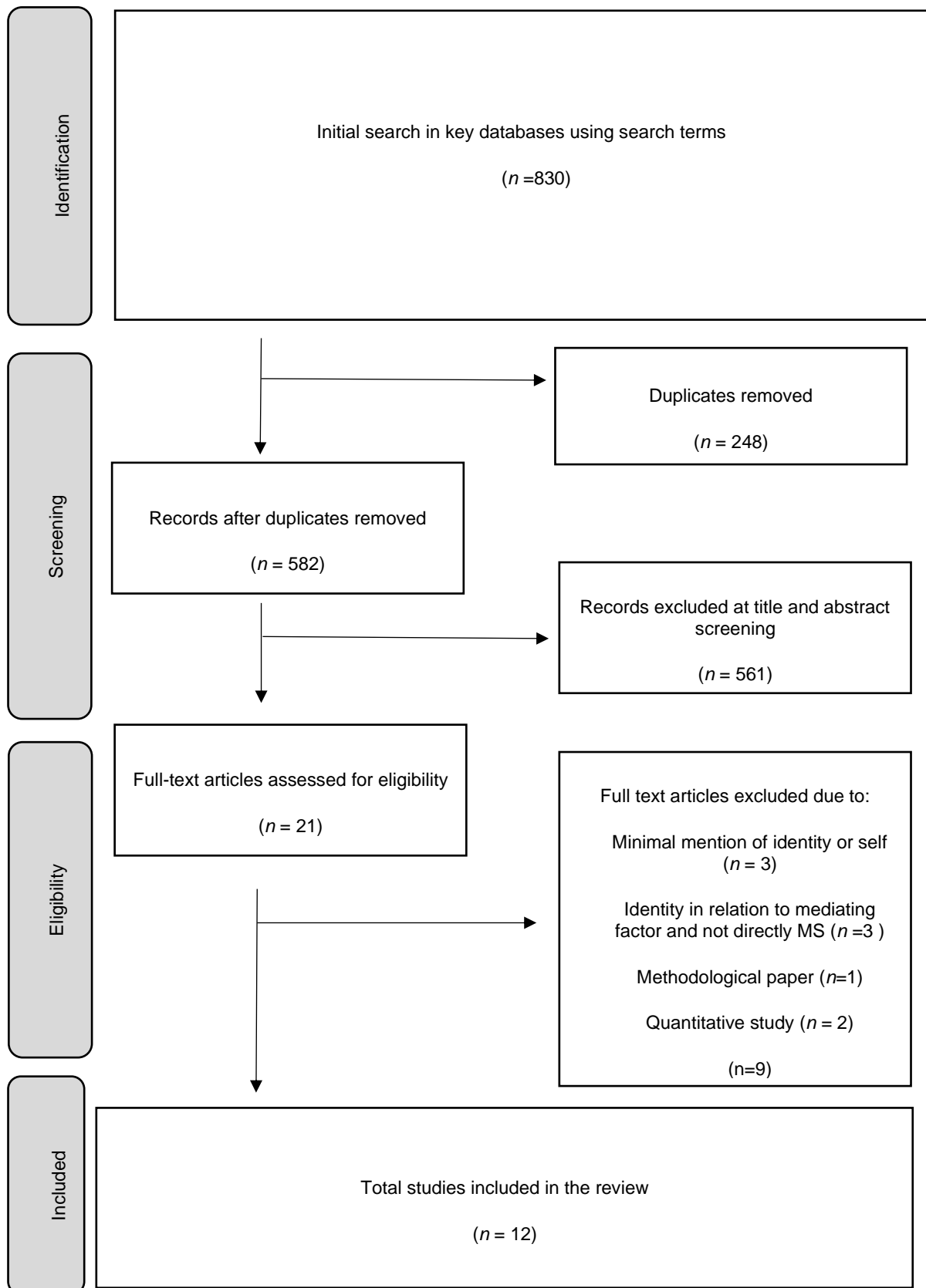
Final search: A, B, and C terms
combined with "AND"

that the term identity had been used in a different sense (e.g. to confirm identity of a gene) or MS was used as an abbreviation for mass spectrometry.

Twenty-one abstracts met criteria for full-text screening. Nine papers were excluded at full-text read. Three focused on general illness experience with no mention of self or identity within the results section, three focused on the impact of

Figure 1

Flowchart Detailing the Search Procedure



identity in relation to a mediating influence (art making ($n=1$), physical activity ($n=2$)), one was a methodological paper and two were quantitative papers. A second rater (trainee clinical psychologist) independently reviewed six papers for inclusion/exclusion. Initial consensus was gained on all six papers. Reference lists of suitable papers were checked for additional relevant papers, no non-duplicates met inclusion criteria. A total of 12 papers were included in the review.

Critical Appraisal

There lacks consensus on the most appropriate way of evaluating qualitative research in systematic reviews (Butler et al., 2016; Hannes, 2011). Eligible papers were evaluated against the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP, 2018), chosen because the prompts reduce ambiguity over the questions and can support novice reviewers with the critical appraisal (Newton et al., 2011). The CASP does not recommend a scoring criteria and tools of this type are used in various ways (Hannes, 2011). For this paper, a scoring system was developed to assist the synthesis of CASP results (Appendix A). Caution should be ascribed when interpreting the quality scores as the criteria for quality changes over time and the use of a universal checklist can undermine the diversity of qualitative methods (Newton et al., 2001). Quality assessments are also subjective and the ratings were influenced by the perspectives of the reviewers. The second-rater reviewed the quality of three studies and substantial agreement was met (Weighted Cohen's $k = 0.69$, calculated using MedCalc statistical software). This should be interpreted with caution due to the lack of consistency over minimum acceptable interrater agreement (McHugh, 2012) . Disagreements were discussed

until agreement was met. Studies were not excluded based on quality, instead this has been considered in the synthesis.

Analysis

Thematic synthesis was used to synthesise the results sections from all included studies (Thomas & Harden, 2008). This was chosen because thematic synthesis can help reveal commonalities across similar studies, and is recommended when a specific review question is being addressed in comparison to an explorative question (Thomas & Harden, 2008). However, context is considered important within qualitative research and thematic synthesis risks de-contextualising findings (Thoman & Harden, 2008). Therefore, the original study aims and findings are reported to go some way in preserving the context of the primary studies.

The inductive analysis included three stages. First, information relevant to self and identity within the results section of each paper were extracted and coded according to meaning and content without hierarchical structure (Appendix B). Next, similarities and differences between codes were sought as they were grouped into descriptive themes. At this point the themes did not extend beyond the findings from the primary studies (Appendix C). Finally descriptive themes were considered in relation to the review question, and more analytical themes emerged (Thomas & Harden, 2008).

Results

A summary of the twelve papers included in the review is presented in Table 3. This is expanded on below along with a critique of the studies, followed by the thematic synthesis of the results.

Table 3*Overview of Papers Included in the Review*

Authors	Participants	Aims	Methodology	Analysis	Key findings / themes identified by the authors	CASP Score
#1 Barker, Smal e, Hunt, Lincoln & das Nair (2019)	16 pwMS (11 women, 5 men) Mean age of 47.3 (SD 11.9) Ethnicity: 14 White British and 2 Asian MS type: 9 RRMS, 2 secondary progressive MS (SPMS), and 5 other Mean years since diagnosis 8.1 (SD 6.6) Study conducted in the UK	“To investigate the subjective experience of identity change and subsequent adjustment to MS”	Participants identified from separate study Semi-structured interviews conducted either in university setting or participant’s home by 2 researchers Interviews were recorded and transcribed Eco-mapping completed for some to facilitate discussion	Thematic analysis applying the social identity model of identity change as a lens for understanding the data	Themes: (1) concealing the disease, (2) presenting a more positive identity, (3) effects of increasing symptoms/changing relationship with others, (4) social support, (5) family as a secure base for identity reconstruction, (6) self-reflected appraisal, (7) integration of MS identity into changing sense of self, (8) compartmentalising the MS identity, (9)	16

					assimilating the MS identity into self-concept.	
#2 Boeijs, Duijnsteek, Grypdonck & Pool (2002)	22 people with advanced stages of MS (13 women, 9 men) Ages ranged between 31-78 years Time since diagnosis ranged between 4-54 years (M=19) Participants were living in Belgium or Netherlands	“To ascertain how people in the advanced stages of MS accommodate to their illness with a focus on biographical work in terms of body, biographical time and self-concept”	Purposive sampling Semi-structured interviews conducted within participants own homes by two interviewers Interviews were recorded and transcribed	Described as involving two activities: fragmenting and connecting.	Case stories: (1) I try to make the most of it, (2) MS will never have the upper hand, (3) I allow MS to take control over me, (4) I have nothing to do with MS.	16
#3 Finlay, (2003)	1 woman with MS diagnosed for 1 year Study conducted in the UK	“To elucidate the existential impact of the early stages of multiple sclerosis.”	Case study approach Non-directive interview conducted by one interviewer across two consecutive days in participants own home	Narrative and existential-phenomenological analysis	Themes: (1) embodiment: alienated, out of control and inescapable, (2) identity and project: compartmentalised and derailed, (3) relations with others: threat, contamination and shame,	15

(4) living uncertainty:
disrupted time.

#4	<p>8 pwMS (7 women, 1 man)</p> <p>Ages ranged between 36 – 63 years</p> <p>Years since diagnosis ranged 5 - 20</p> <p>Study conducted in the UK</p>	<p>“To explore the subjective experiences of living with, and adjusting to MS.”</p>	<p>Purposive sampling</p> <p>Semi-structured focus group interview with one researcher facilitating discussion and one acting as note taker</p> <p>Focus group conducted in location normally used by members of MS charity for social events</p> <p>Recorded and transcribed</p>	IPA	<p>Themes: (1) reaction to being diagnosed / impact of being diagnosed with MS, (2) social activity, (3) role in society and self-worth, (4) relationships and dependency, (5) attitudes/ reactions of others, (6) changing outlook/ perceptions of adjustment and changes in self-concept and identity.</p>	14
#5	<p>21 pwMS (15 girls, 6 boys)</p> <p>Ages ranged between 8 – 18 years</p> <p>Ethnicity: 17 White 4 South Asian</p>	<p>“To explore how young people experience an MS diagnosis”</p>	<p>Purposive sampling</p> <p>Semi-structured interviews conducted by one interviewer in participants’ home</p>	Grounded theory	<p>Themes: (1) a changed and changeable body, (2) an altered identity, (3) changed relationships.</p> <p>“</p>	25

	Study conducted in the UK		18 participants chose to have their parents present			
			Interviews were recorded and transcribed			
#6	12 women with MS		Participatory action research	The crisis and negotiation model (Kelly & Field, 1996)	Case stories: (1) story of extraordinariness, (2) story of ordinariness.	15
Kralik, Koch & Eastwood (2003)	Ages ranged between 30-60 years Australia	“To outline understandings about the construction of sexuality and the impact of a changing body for women living with MS”	h All participants attended 5 focus groups, 9 participants attended an additional individual interview	guided the interpretive framework		
			Semi-structured interviews conducted by three interviewers. Focus group had the same three interviewers facilitating discussion			
			Interviews were recorded and transcribed			

#7 Mozo-Dutton, All white British Simpson & Boot (2012)	12 pwMS (8 women, 4 men) Ages ranged between 34-71 years Times since diagnosis ranged between 6 – 28 years Type of MS RRMS 3, PPMS 1, SPMS 5, other 3 UK	“To explore the impact of multiple sclerosis (MS) on perceptions of self as well as the emotional, social and practical implications of any self-reported changes”	Purposive sampling Semi-structured interviews conducted by one researcher, mostly in participants own home Interviews were recorded and transcribed Written post interview reflections were completed by 2 participants	IPA Thematic decomposition analysis	Themes: (1) ‘my body didn’t belong to me’: the changing relationship to body, (2) ‘I miss the way I feel about myself’: the changing relationship to self, (3) ‘let’s just try and live with it’: incorporating yet separating MS from self. Themes: (1) ‘I’m not the best mum’: the ‘failing mother’, (2) fear of judgment and burdening others, (3) ‘I don’t think it’s changed the way I parent’: the ‘normal mother’, (4) managing illness for ‘normal motherhood’.	24 18
#8 Parton & Ussher (2019)	20 mothers with MS Ages ranged between 26-54 years Time since diagnosis ranged between 2 months - 21 years	“To examine how women construct their subjectivities as mothers in the context of living with MS”	Purposive sampling Telephone semi-structured interviews conducted by 2 researchers Interviews were recorded and transcribed	Thematic decomposition analysis	Themes: (1) ‘I’m not the best mum’: the ‘failing mother’, (2) fear of judgment and burdening others, (3) ‘I don’t think it’s changed the way I parent’: the ‘normal mother’, (4) managing illness for ‘normal motherhood’.	18

6 participants
 were diagnosed before
 having their first child

MS type: 18 RRMS 2 SPMS

Ethnicity: 15 Anglo-
 Australian, 2 Aboriginal-
 Australian, 1 Latin
 American, 1 Indian and 1
 not specifying

Study conducted
 in Australia

<p>#9 Riessman (2 003)</p>	<p>2 men with MS (aged 38 & 43) Both at different stages of disease</p>	<p>“To explore and compare an aspect of each man’s illness narrative: masculinity in the face of a disease that challenges capacities usually</p>	<p>Case study approach Revisiting interviews conducted in early 1980s as part of a study on marital separation</p>	<p>Narrative analy Case stories: (1) ‘Do it sis using two now’: Randy’s version of different masculinity, (2) wanting a theoretical job and someone to love: perspectives – Burt’s version of a structural masculinity. and a performative reading</p>	<p>17</p>
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			associated with masculinity”			
#10	10 pwMS (8 women, 2 men)	“To explore the lived experience of the meaning of being diagnosed with multiple sclerosis on the individual's sense of self”	Purposive sampling	IPA	Themes: (1) road to diagnosis, (2) the liminal self, (3) learning to live with MS: an uncertain future.	20
Strickland, Worth & Kennedy (2017)	Ages ranged between 25-45 Time since diagnosis ranged between 0-7 months Study conducted in the UK		Semi-structured interviews within participants own home Second interview 6-12 month following the first 5 participants chose to have a support person present			
#11	16 mothers with MS	“Exploring the perceived influence of MS on the identity of mothers in the socio-cultural context of Italy”	Purposive sampling	IPA	Themes: (1) self and identity, (2) challenges and support within society, (3) relationships with others.	21
Willson, Tetley, Lloyd, Messmer Uc celli & Macki an (2018)	8 aware of MS diagnosis before having a child 6 women with some level of impairment which impacted on their everyday function. 5 women who had a greater		Semi-structured interviews by one Italian speaking interviewer, with English speaking researcher present			

degree of physical impairment, which regularly impacted on their everyday function. 5 women who were severely physically impaired and were regular wheelchair users.

Study conducted in Italy

Mostly in participants own homes (exception of 2 participants interviewed in offices)

Interviews recorded and transcribed into Italian and then translated to English. Three transcripts back-translated to check for accuracy

#12 14 pwMS (8 women, 6 men) “To explore the sense of dignity experienced by pwMS”
 Ziakova, Mier Ages ranged between 25-61
 tova, Gurkov years
 a & Kurucova
 (2020) Time since diagnosis ranged between 4–22 years
 Study conducted in Slovakia

Purposive sampling
 Face to face, semi-structured interviews conducted within a hospital setting by two interviewers
 Interviews were recorded and transcribed

IPA

Themes: (1) loss of a fully- fledged life: violating the dignity-of-self, (2) to accept and fight: promoting the dignity-of-self, (3) contempt and rudeness: indignity-in-relation, (4) those who know and see, help: promoting dignity-in-relation.

Participants

Across the 12 studies, 154 pwMS participated. Where reported, participants' age ranged from eight to 78, two studies did not report the ages of participants (#3, #10) and one reported mean age (#1). More women ($n=119$) than men ($n=35$) were included. The MS female: male ratio is 2:1 meaning men were underrepresented in these studies (Compston & Confavreux, 2005). Within the three papers reporting MS type (#1, #7, #8), participants were most commonly diagnosed with RRMS. Where reported, time since diagnosis ranged from 0 months to 54 years. Level of disability varied throughout and sometimes within the studies. Six studies took place within the UK and all took place within Western countries. MS is common in Europe relative to other geographic areas and so this is perhaps unsurprising (Compston & Confavreux, 2005).

Aims

Aims of the studies broadly grouped into the following categories:

- Exploration of living with or adjusting to MS
- Exploration of one aspect of identity or self (e.g. identity as mothers with MS)
- Exploration of perceptions of the impact of MS on self and identity

Design and Evaluation

Methodology

Ten papers used individual interviews as their primary source of data collection, including Riessman (2003) who revisited data from interviews conducted as part of an unrelated study on divorce. Where reported, interviews were mainly conducted in participants' homes ($n=7$). One study conducted telephone interviews (#8). Alongside interviews, one study used eco-mapping (drawing a visual

representation of social systems) to gain insight into participants' social lives before and after MS diagnosis (#1), and one study included written post-interview reflections submitted by two participants (#7). Two papers used focus groups (#4, #6), in one paper (#6) these were accompanied by individual interviews for participants who were not able to talk openly ($n=9$). Most studies used semi-structured interviews guided by a script or research questions, with some flexibility ($n=11$). Common questions related to thoughts and feelings before and after MS diagnosis including how participants saw themselves and others at these times, what day-to-day life was like for them with MS, and their values and beliefs. Finlay (2003) used a non-directive interview.

Analysis

A variety of analyses were used, including thematic analysis (#1), discourse analysis (#8), IPA (#4, #7, #10, #11, #12), grounded theory (#5), narrative analysis (#9), existential-phenomenological analysis (#3). Reporting of analysis method was unclear for two papers (#2, #6).

Quality assessment

The quality of all studies was considered acceptable. The criterion of adequate consideration of the relationship between researcher and participants was not met in most studies ($n=8$). Ethical issues were inadequately addressed in seven papers.

Risk of Bias

Conceptual definitions

Two studies explored identity (#5, #9), two explored the self (#7, #8). The remaining studies used both words, often interchangeably. The concepts were often not defined which is a weakness of the studies ($n=10$). Kralik et al., (2003, p.14) used the following definition “the self is the ‘existential me’ and identity is the label imposed by others on the self”. Riessman (2003) described identity construction through narrative performances.

Participant Samples

All studies used purposive sampling to recruit pwMS in line with the aims of the research to gain information rich accounts of the phenomena of interest (Campbell et al., 2020). Most also used convenience sampling methods, advertising through MS charities or hospital settings. This is likely to miss harder to reach populations who may be without support, or those functioning well without MS services.

Recruitment criteria were based on having MS. Further diversity of participants was not always considered which may have affected the interpretation. This could affect transferability and the depth of analysis that was possible. For instance, IPA suggests recruiting a homogenous sample to allow detailed exploration of a phenomena within a specific group (Smith & Osborn, 2003). One paper acknowledged this as a limitation (#11).

Characteristics of participants' MS were often not documented: three papers included information on MS type (#1, #7, #8), and four papers commented on level of impairment (#2, #7, #9, #11). Duration of illness was more widely reported with only

two papers not documenting this (#6, #11). Reporting this information could have strengthened the conclusions and understandings coming from the papers.

One paper used a single focus group with eight participants (#4), where the use of three to six groups is recommended (Guest et al., 2016). Transferability and generalisability of these finding is therefore brought into question.

Data Collection

Methods of data collection were typically appropriate to address the study aims. Five studies used multiple interviewers (#1, #2, #6, #8, #12) which may have added inconsistencies in interviews. The interviews in one study were conducted and transcribed in Italian and then translated to English (#11). The authors acknowledged the potential for cultural differences in questions which were piloted in both English and Italian, and back-translated three transcripts to check for accuracy. Within two studies, some interviewees chose to have a relative present during the interviews, which may have influenced the results (#5, #10).

Analyses

Studies varied in the amount of detail provided on data analysis, two provided little detail on method of analysis (#4, #9). In three studies analyses were completed by multiple researchers independently and then discussed until consensus was reached (#2, #4, #12), in one study two researchers analysed the text collaboratively (#6). Cross case analysis was conducted on transcripts in three studies to allow comparison of more than one qualitative perspective (#1, #10, #12). Three studies discussed data triangulation, either by checking against support person's interviews (#1), or analytical triangulation (#2, #12). These approaches strengthen the research

findings and reduce bias. Three studies took the analysis back to participants for member checking (#3, #4, #7) which shows good research practice and may improve credibility (Caretta & Perez, 2019). One paper commented on the dilemmas arising from this (#3).

On study (#4) used IPA on data collected from a focus group. The analysis for IPA should focus at the individual level, whilst focus groups privilege the collective group voice making extracting ideographic accounts difficult (Tomkins & Eatough, 2010).

Findings

All studies used some direct quotes from participants to support their findings. The amount varied considerably. Eight papers were thorough in their use of quotes adding to the trustworthiness of the findings reported (#1, #2, #5, #7, #8, #10, #11, #12; Eldh et al., 2020). The remaining papers used minimal quotes to support their claims which undermined the credibility of the findings. In seven studies it was unclear how many participants were represented for each theme due to the use of general language (e.g. some participants).

Researcher Reflexivity

Four studies consider researcher reflexivity (#5, #7, #9, #11). This is a weakness of most papers given that researcher reflexivity helps to ensure transparency, rigour and quality (Harper & Thompson, 2011). It is unclear whether this was because researcher reflexivity was neglected during the research or whether it was excluded due to publication word limits (Mitchell et al., 2018).

Ethical Considerations

Details on ethical considerations were often limited to ethical approval and consent (#1, #3, #4, #6, #8). Two papers contained no information on any ethical considerations (#2, #9). Other considerations included right to withdraw (#7, #10), confidentiality (#5, #10, #7) and acknowledging potential participant distress (#5, #10). Studies neglected to consider the potential for MS symptoms to impact on participants engagement or wellbeing during the study, and how the cognitive impairments sometimes associated with MS may have impacted on gaining informed consent. This is a significant gap considering the nature of the studies.

Thematic Synthesis of Results

This review aimed to understand what challenges to self and identity pwMS experience, in what circumstance these occur and how pwMS negotiate these challenges. All studies identified that participants navigated challenges to self and identity which were influenced by disease course and wider social and cultural contexts. Participants used different strategies to negotiate these challenges. Themes arising from the synthesis are expanded on below.

Challenges to Self and Identity

Across all studies, participants negotiated challenges to self and identity which were categorised into two themes: (1) maintaining a coherent self/identity, (2) maintaining agency over self/identity.

Maintaining a Coherent Self/Identity. Participants in all studies negotiated the challenge of maintaining a stable self and identity in the face of change:

“I don’t think I’ll ever be the same person I was kind of thing. You get stuff that you wouldn’t have thought anything about before I mean I still try and be me kind of thing at the end of it but I can’t always do the same amount I used to do.” (Strickland et al., 2017, p.1718)

Within some studies participants described the challenge of living with uncertain futures (#3, #4, #9, #10). In most studies ($n=7$), participants compared current situations to life before MS, and participants negotiated loss of past identities (#6, #7, #12). Participants negotiated how much to foreground an illness identity. In all studies there were times where participants described multiple aspects of self and identity:

“I have worked, had a family, I’m always active, I do tons of things ... when I’m looking at myself I think well also there’s a bit now that’s added on that’s got MS onto it, so that’s another facet of my personality or being me now.” (Strickland et al., 2017, p.1718)

Whilst other times when participants described a self and identity dominated by illness (#2, #11, #12).

“You are a prisoner of your own body. What makes it worse is that I used to be very healthy..., but lately I can’t stand the fact that I am afflicted.” (Boeije et al., 2002, p.885)

Across all studies there was a sense of wholeness in participants’ self and identity at times and self and identity were presented as more fragmented at other times. Participants negotiated how to present themselves to others. This sometimes

meant a discrepancy between how participants presented outwardly to others and their internal felt self (#1, #2, #3, #11).

“And they [friends], they probably don’t realise there’s a difference but, cause, there is a difference, because I’m not, I’m not the same person. On the outside I am, but not on the inside.” (Barker et al., 2019, p239)

Maintaining Agency over Self/Identity. All studies showed participants navigating challenges associated with agency. For example, MS had power over some participants’ lives and challenged their ability to maintain control over self and identity e.g. losing ability to work (#1, #2, #3, #9, #11, #12). Participants negotiated a lost sense of control over their bodies (#2, #3, #6, #7, #8) which influenced how they felt about themselves and how others viewed them.

“...the thing I miss most [is] I miss the way I feel about myself. I’m useless you know...I don’t put any input into anything ‘cause there’s no input to give...with not being able to walk I can’t do the things I want to do, and [I’d] like to do, so that’s what perturbs me most” (Mozo-Dutton et al., 2012, p. 1213)

Participants’ accounts also suggested a lack of control over how they were positioned by others. A challenge reported in the majority of studies ($n=7$) was the contradiction between participants’ preferred self and how others responded to or treated them. Participants negotiated challenges around being seen as less than human or positioned in the patient role (#1, #2, #4, #6, #11 #12):

“If people see the [walking] stick, they’ve got a completely different attitude towards you.” (Barker et al., 2019, p239)

Under what Circumstances did these Challenges Occur

Across the studies, challenges to self and identity appeared to be more prominent in the following circumstances: (1) at points of disease progression, (2) times of loss of role, (3) within certain social and cultural contexts.

Disease Progression. Participants across all studies spoke about their changing bodies. Challenges to self and identity were brought to the forefront as physical symptoms progressed. At these points participants negotiated a conflict between limits imposed by the physical body and maintaining valued aspects of self and identity. Physical symptoms impacted on engagement with the world and interrupted participants doing things that had been central to pre-illness identities (#1, #2, #3, #5, #7).

“I felt severely undervalued – I used to be on top of my profession and everything and then to fall down like that ... I was a totally decline ... I didn't want to talk to anyone ... I felt as if I had been completely forgotten.” (Ziakova et al., 2020, p.690)

Physical markers also made illness visible to others which meant participants no longer had choice over whether to conceal the illness (#1, #5) and influenced how others responded to them, in turn affecting their self (#1, #4, #12).

Loss of Role. Loosing roles and responsibilities led to a sense of loss over their identity and self as participants were unable to function exactly as before MS (#2, #3, #7, #9, #11, #12). Gender roles featured within this. The loss of roles associated with a sense of masculinity (e.g. sports, DIY) were particularly important for men (#2, #9, #12):

“But now, my wife has to drill holes in the wall because I can’t use a hammer and nails and that is hard for a man to take.” (Boeije et al., 2002, p.889)

The loss of caring and domestic roles were significant for women (#4, #7, #8, #11). The mothering role (#3, #6, #8, #10, #11) and work roles (#1, #2, #3, #9, #12) were salient, and allowed some to maintain a positive identity:

“I’ve done everything that the other mothers have, I haven’t done anything less!” (Wilson et al., 2018, p.1463).

Whilst others a failing identity:

“I don’t even know where they keep the...mmm... I don’t know, the slippers when they arrive at the nursery school! I don’t know anything! And it makes me feel really bad!” (Wilson et al.,2018, p.1463)**Social and Cultural Context.** Participants across seven studies described the influence others had on their self and identity. For some this influence was valuable in facilitating acceptance and a positive self (#2, #6, #11). Others spoke of the negative effects of labelling, judgment, stigma and insensitive remarks on the self (#4, #6, #8, #11, #12). Participants negotiated internalised social constructions, cultural beliefs, and expectations from others (e.g. expectations of having energy and being physically active with children), which impacted on how they saw themselves (#6, #8, #11).

“This isn’t the mum that I wanted to be.” Parton & Ussher, 2019, p.521)

Remaining socially connected was important, and those who became isolated lost aspects of self and identity (#2, #9, #11).

How were Challenges Negotiated

Participants negotiated the challenges in different ways which grouped into three themes: (1) shifting identities, (2) managing the social world, (3) accepting a compromised identity.

Shifting Identities. The multiplicity of self and identity was used by participants to negotiate a shifting self and identity. Participants placed more or less attention on different elements of self and identity for example prioritising old identities and remaining roles (#1, #2, #3, #4, #5, #7, #9, #10, #11), emphasising positive and valued identities (#1, #2, #6, #8, #9, #10, #11), and minimising stigmatised identities (#1, #6, #7).

“One year when I got ill, I was going in [to work], going in, going in and I was pushing through, pushing through, pushing through...” Barker et al., 2019, p.238)

Participants differed in how much they foregrounded illness identities. Some ‘compartmentalised’ MS (#1, #2, #3, #7), some became dominated by illness identities (#2, #9, #11), others integrated MS into their existing identities (#1, #2, #6, #7, #10), or re-evaluated their identities for example changing priorities and values and giving new salience to old relationships and activities (#1, #2, #3, #4 #7, #8).

“it’s just an appreciation of everything . . . I appreciate the smaller things, the quiet times as well.” Irvine et al., 2009, p. 604)

Participants negotiated the challenges of loss of salient roles and responsibilities in a number of ways: some became more defined by illness identities (#2, #9, #11), whilst others looked for new roles and identities (#2, #9). Some made

adaptations or used mobility aids to allow them to continue valued aspects of their lives, however this often impacted on how others perceived them (#1, #2, #3, #6, #7, #12).

Managing the Social World. Social relationships could support or challenge preferred identities and participants developed different ways of navigating these: actively choosing how to present to others (#1, #3, #4, #5, #6, #8), concealing illness from others as a way of maintaining pre-illness identities (#1, #3, #4, #5), choosing not to associate with others with MS as a way of avoiding stigmatised identities (#1, #3):

“It’s something about labels . . . I phoned up the multiple sclerosis Society . . . and they were keen for me to go along to the meetings and things. And I thought, ‘I actually do not want to meet other people with multiple sclerosis . . . I don’t want that identity. I am not yet disabled in a visible way’.”
(Finlay, 2003, p.163).

Participants in several studies negotiated the amount of support needed from others to maintain some sense of an independent self (#2, #4, #6, #8), others found this challenging to negotiate and felt hopeless or pitied (#2, #4 #11). Several studies highlighted the use of social comparison (#8, #9, #11). Some emphasised the difference between them and others and constructed themselves as failing (#8, #11), whereas others normalised symptoms such as tiredness, enabling them to present themselves as similar to others and to construct positive identities (#8, #9):

‘I’ve heard from people who have MS fatigue, it’s like they can’t get out of bed basically because they’re so tired. And I do get tired, but I think it’s normal parenting tired’ (Parton & Ussher, 2019, p.254)

Accepting a Compromised Identity. Some participants across seven studies positioned themselves as having no agency over the illness and its impact on identity. Their self and identity were dominated by illness (#2, #6, #9, #11), and they were unable to develop or renegotiate new aspects of self or identity (#2, #6, #8, #11). These participants positioned themselves as having no control over the illness or life decisions and had a sense of loss over former identities. They accepted other positioning them within the patient role and were not able to reinvent their self or find new meanings.

“I used to talk much more, I was much more companionable. I had more stories to tell and that is getting less now. I feel sad more often. That’s how it feels, I am empty. I cannot get a hold on it; I just cannot grasp it.”

Boeije et al., 2002, p. 889)

Discussion

This systematic review synthesised qualitative evidence on how MS influences a person’s self and identity to consider how this knowledge might in the future be used to improve support available to pwMS, discussed below in the implications section. Across the studies, pwMS negotiated challenges to self and identity over the course of illness, including maintaining a coherent identity, and agency over self and identity. These challenges increased with progressing physical symptoms and loss of social roles, and were influenced by social and cultural contexts. Participants either navigated these identity challenges or accepted a compromised identity imposed by others.

Within the studies, pwMS negotiated challenges of maintaining a stable self and identity, oscillated between positions of agency and dependency, and negotiated

different social positions. These findings suggest Bamberg's (2011) proposed identity dilemmas (constancy vs change, sameness vs difference, agency vs undergoer) were relevant to pwMS in these studies. Changes to self and identity took place as a constant navigation process often conscious to participants. This provides some support to Bamberg's (2011, p.8) claims of the "groundedness of self and identity in sequential, moment-by-moment interactive engagements". Within these studies, navigating identity challenges seemed more conscious and reflective than suggested in Bamberg's (2011) paper, perhaps implying negotiating identity is more effortful for pwMS compared to the general population. This review adds complexity to ideas presented in quantitative literature on identity and MS (Bogart, 2015; Kiropoulos et al., 2019) which present identity in a more static way (e.g. illness is accepted or rejected from identity). Instead, this research demonstrates that participants foregrounded different identities depending on context and illness status.

Participants negotiated the balance of wellness and illness in their identities as described by Paterson (2001). Some participants constructed identity absorbed by illness, presenting the self and identity entwined with the failing physical body. Paterson (2001) argues that this position can be protective at times of perceived threat of control, e.g. worsening symptoms, as it encourages people to attend to their illness. Wellness was placed in the foreground at other times, as multiple selves (not the diseased body) were prominent in participant's identity. Reporting within the studies made it unclear how factors such as MS type or stage of illness contributed to shifts in perspectives, however one author suggested RRMS provided opportunities for people to reconnect with previous notions of self during symptom free periods, whereas PPMS did not (Mozo-Dutton et al., 2012).

Authors of the studies noted participants held internalised cultural beliefs and expectations, supporting the argument that illness experience is embedded in culture and context (Charmaz, 2019). Discourses around the moral value of work and activity are common within Western countries, and may make it hard for participants to promote identities defined by illness and rest. This was possibly reflected by participants striving to maintain old identities and roles. Reissman (2003) noted different social structures embedded in the participants narratives, and how participants social positioning was amplified by their illness experience. Across studies some participants were agentic in distancing themselves from cultural expectation whilst others became conflated with them. The role of social relationships also seemed important. Validation of positive identity from others appeared supportive, and participants struggled to maintain a positive self when others undermined or devalued their identity. This supports the idea that identity is a relational process (Combs & Freedman, 2018), and maintaining meaningful relationships may be important for self and identity for pwMS.

The multiplicity of selves helped some participants maintain a positive and coherent self and identity alongside illness. These findings suggest the multifaceted nature of self may allow people to focus on selves that remain unaffected by illness as a means to construct continuity. Within the studies there was some evidence that in the face of illness, salient selves could be reinforced enhancing self-worth (Boeije et al., 2002; Finlay, 2003). Authors reported maintaining valued aspects of self and identity alongside MS was important for wellbeing (Boeije et al., 2002; Mozo-Dutton et al., 2011; Kralik et al., 2003). Recognising the multiplicity of selves may be an important treatment goal for some pwMS, and helping pwMS maintain or develop valued aspects of self may support wellbeing.

Implications

Challenges to self and identity were common for pwMS in all studies, it is therefore recommended that sources supporting pwMS are aware of these challenges to self and identity. Offering pwMS a space to consider the wider psychological impact of diagnosis alongside medical care may be pertinent for pwMS, and given that pwMS demonstrated self and identity entwined with the physical body, services may work to better integrate thinking about the mind and body within service delivery. PwMS may be referred for more specialist psychological support and professionals providing this could consider identity issues within therapy. Focusing on selves unaffected by illness allowed some to construct identity continuity. Therefore, rather than focusing solely on illness experience, focusing on wider identities and pre-illness experiences may help people move away from problem saturated stories and hold a more integrated life story, this is congruent with narrative approaches (Combs & Freedman, 2018). Maintaining other valued identities alongside illness was important for wellbeing. Therefore, focusing on people's values and helping pwMS explore activities that give their life meaning could support new identity claims. Acceptance and commitment therapy could be used to guide such work (Hayes et al., 2012). Given the impact of social and cultural influence found across the studies, it is important to view identity and self in illness as an evolving and dynamic process that goes wider than the individual. Consideration should be given to how people around those living with MS interact with them to help them support and validate positive identity development. Attention to the stigma and inequalities faced by pwMS could help address systemic factors maintaining these.

Strengths, Limitations and Future Research

The subjective nature of producing second order interpretation from qualitative literature is a limitation of this paper (Bearman & Dawson, 2013). The papers were read through the lens of clinical psychology and the interpretations and synthesis are rooted in the researcher's values and experience. For example, the belief that the mind and body are inextricably linked and clinical psychology has an important role in physical health care. This will have influenced the synthesis and themes drawn. The different contexts of the original studies and the multiplicity of analysis methods made the synthesis an imperfect process.

Self and identity are abstract constructs which can be conceptualised differently. The definitions used in this paper could be critiqued and the indistinctness of the construct made the review challenging. For example, it raised dilemmas when refining search terms and inclusion/exclusion criteria. The majority of papers had not defined the use of terms making it unclear what researchers were looking at. Participant's interpretation of these abstract concepts were also likely to have varied. Establishing greater clarity over constructs should be prioritised in future research.

This review looked at the subjective experience of identity from the perspective of pwMS. Including data from other informants may have offered additional insight. A number of papers have been published that focus on how identity experiences differ between pwMS and their family/carers and this could be a valuable focus of a future literature review.

More needs to be known about what individual characteristics make identity challenges easier or harder to navigate so that support can be targeted to the right people. Across the studies, some people were able to negotiate a positive coherent

self and identity whilst others succumb to a compromised identity and reduced self-worth. Due to reporting within the papers, it was difficult to determine whether MS type had an impact on identity challenges and how they were negotiated. It is possible that people with RRMS regain old identities more easily in between relapses, whereas this may be more challenging for people with PPMS. Future research could pay closer attention to any individual differences effecting identity challenges, including any differences between MS type.

Research to date has focused on personal perceptions of identity and MS. Given the dynamic and evolving nature of identity more process research looking at how people negotiate and construct identity would be beneficial. Using 'small story' research to look at how pwMS negotiate identity dilemmas in everyday conversations could add to the literature (Bamberg, 2011). Longitudinal research exploring how challenges are negotiated in different contexts and over time would also add understanding. Services supporting pwMS could use the knowledge from this review to develop interventions to support pwMS in negotiating identity challenges, and conduct future efficacy research on whether these are helpful.

Conclusion

This qualitative systematic review helps understand what challenges pwMS negotiate in relation to self and identity. In particular challenges around identity coherence and agency were apparent. The findings revealed insight into the ways pwMS negotiate the identity challenges, which seemed to be an ongoing and often conscious process influenced by the wider social and cultural contexts people were in. Findings suggest those supporting pwMS should be aware of the identity

challenges pwMS face and identity could be a focus of psychological support for some.

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Appendices
Appendix A
CASP Scoring

CASP Scoring Key

Criteria	Scoring
Criteria met in depth	3
Criteria mostly met	2
Criteria minimally met	1
No evidence of the criteria being given consideration	0
Studies meeting 75 – 100% of maximum total score ++	
Studies meeting 74 – 50% of maximum total score +	
Studies meeting less than 50% of maximum total score -	

Paper	Clear statement of aims	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship between researcher and participants considered	Ethical issues taken into consideration	Data analysis sufficiently rigorous	Clear statement of findings	How valuable is the research	Total CASP score
#1 Barker et al. (2019)	3	3	1	1	2	0	1	2	2	1	16 +
#2 Boeije et al. (2002)	2	3	3	2	2	0	0	2	1	1	16 +
#3 Finlay, (2003)	1	3	1	1	2	2	1	1	1	2	15 +
#4 Irvine et al. (2009)	2	3	2	2	1	0	1	1	2	1	15 +
#5 Kirk & Hinton (2019)	3	3	2	2	3	3	3	2	2	2	25 ++
#6 Kralik et al. (2003)	2	3	2	1	2	0	1	2	1	1	15 +
#7 Mozo-Dutton et al. (2012)	3	3	3	3	2	0	3	2	3	2	24 ++

#8 Parton & Ussher (2019)	3	2	2	2	2	0	1	2	2	2	18 +
#9 Riessman (2003)	2	2	2	2	1	3	0	1	2	2	17 +
#10 Strickland et al. (2017)	3	2	2	2	2	0	3	2	2	2	20 +
#11 Willson et al. (2018)	2	2	2	2	2	3	2	2	2	2	21 +
#12 Ziakova et al. (2020)	3	2	2	2	2	0	2	2	2	2	19 +

Appendix B

Example of Data Extraction Process

Authors	Data extracted
#1 Barker, Smale, Hunt, Lincoln & das Nair (2019)	<p>“Some participants felt that they should attempt to preserve their prediagnosis identity and to hold on to their established sense of self and identity. They also felt that they should keep their diagnosis private. Rebecca (F 42, RR): “I’ve not gone around announcing that I have MS.” (p238)</p> <p>“Because of their perceptions and worries associated with having MS, participants were unwilling to accept their MS identity due to the implications this has on their idea of their future self. Rosie (F, 59, RR): “It is a bit early days. But as I mentioned before I have avoided certain situations where there are MS meetings, because, you know, it is hard to think that, you know, personally that I might be in that, in a wheelchair so many years down the line.” (p238)</p> <p>“people with MS may not want to identify with or behave in a way that is consistent with the negatively judged MS identity. One pattern of adjusting to the MS identity was to continue to compartmentalize the identity and choose not to incorporate this into the overall self-concept. Alanah (F, 55, NO): “My way of coping is ... if I don’t think it [MS] is happening, then it is not. If I ignore it, it is not there. It is like a tree falling in the forest, does anybody hear it, you pretend it’s not there.” (p240)</p> <p>“To maintain high self-esteem, Rebecca appeared to acknowledge positive aspects of herself as important and unchanging while attaching low importance to aspects of identity related to negative self-beliefs, such as the feared consequences of MS.” (p238)</p> <p>“One participant attempted to preserve a prominent marker of her prediagnosis identity, work, despite increasing symptoms having an effect on this. Kelly (F, 28, RR): “One year when I got ill I was going in [to work], going in, going in and I was pushing through, pushing through, pushing through, and got told off by HR because I shouldn’t have been in in the first place.” Because of the highly valued nature of this (work) identity, Kelly attempted to hold on to this identity despite the increasing symptoms. Kelly downplayed markers of an identity that she saw as unimportant and stigmatized (MS) while acting in accordance with an identity that she saw as highly valued (work).” (p238)</p> <p>“The physical symptoms of MS were perceived as markers of illness progression and changing sense of self. As symptoms became more prominent, participants found that their sense of self was not consistent with markers of their own identity, or how others saw them, and these inconsistent views led to a reevaluation of what the participants viewed as their self. This reevaluation triggered a subjective shift in self-perception. Evelyn (F, 60, SP): “I had to put on an act of being OK, even when I wasn’t.”” (p239)</p> <p>“Over time, participants often began to acknowledge the changed sense of self based on how others responded to them. Leonard (M, 46, DU): “If people see the [walking] stick, they’ve got a completely different attitude towards you.” (p239)</p>

- Turner, Abbie Preserving pre-diagnosis identity
- Turner, Abbie Concealing diagnosis
- Turner, Abbie Rejecting MS from identity
 - Turner, Abbie Fears of self changing
- Turner, Abbie Avoidance of feared future
 - Turner, Abbie Positioning self as ▼
- Turner, Abbie Distancing from stigmatised ▼
 - Turner, Abbie
- Turner, Abbie Compartmentalising MS from ▼
- Turner, Abbie Rejection/avoidance
- Turner, Abbie Prioritising valued identity
 - Turner, Abbie Maintaining sense of ▼
- Turner, Abbie Low importance to MS identity
- Turner, Abbie Avoiding / rejecting MS identity
 - Turner, Abbie Value of work / roles
- Turner, Abbie Valued identity
- Turner, Abbie Prioritising valued identity, ▼
- Turner, Abbie Choosing which identity to ▼
- Turner, Abbie Physical symptoms changing self
- Turner, Abbie Inconsistency between self ▼
- Turner, Abbie Influence of others
- Turner, Abbie Renegotiating self / identity ▼
- Turner, Abbie Shift in perspective
- Turner, Abbie Inconsistencies between felt self
- Turner, Abbie Changed sense of self ▼

Appendix C
Example of Meta-synthesis Process

Focus	Theme	Codes
Challenges faced	Changing self/identity	Preserving pre-diagnosis identity; keeping MS separate; passing as old self; comparing old self and current reality; Inconsistencies between self and identity; incorporating MS into self; disrupted self; identity reconstruction; renewed perspective; changed identity; Loss of valued aspects of self; uncertain futures; unpredictable; illness in foreground/background; loss; integrating MS into identity; fears of self changing; establishing wholeness of self vs fragmented self
	Agency	Regaining agency; negotiating independence/dependence; loss of control over physical body; loss of control over life; engulfment; lost hope; narrowing life; all encompassing
Circumstances	Roles and responsibilities	Roles; loss of roles; new roles; meaning; loss of work; gendered roles
	Body and self	Lost trust; loss of control; mind body split; Physical influence; Physical symptoms impact on self/identity; Changing relationship with the body; Loosing self because of declining physical health and independence; disconnect from body; unpredictable body; stigmatised identity; social connection; social isolation; lost meaningful relationships

	Social influence	Concealing to protect others; Choosing what identity to present to others; view of others; social expectation/comparison; identity seen through the eyes of others; views response from others; perceived judgments; same as others/different than others; treated as unvalued; treated as non-disabled; cultural standards
Ways of negotiating	Shifting identities	Prioritising valued identities; prioritising remaining aspects of self; prioritising old identities; remaining roles; minimising stigmatised identities; rejecting/avoiding; cognitively relocating; performing preferred self; low importance to MS identity; acceptance; reenvisioned life; changed values/perspectives; compartmentalising MS; integrating MS; new roles and identities; adaptations; shifting importance
	Managing social world	Choosing how to present: avoiding others with MS; concealing MS; negotiating support; normalising; social comparison
	Compromised identity	Identity dominated by illness; loss of former identities; patient role; engulfment



SCHOOL OF PSYCHOLOGY

DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

**Shifts in Perspectives Seen Through the Narratives of People with Multiple
Sclerosis Following a Mindfulness Intervention**

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Target Journal: Psychology and Health

Word Count: 8000 words (excluding abstract, references, appendices)

**Submitted in partial fulfilment of requirements for the Doctorate Degree in
Clinical Psychology, University of Exeter**

Abstract

Objective

Within this qualitative study I explored how people with multiple sclerosis (pwMS) described change following a mindfulness intervention to see whether developing awareness of the self in the present moment helped pwMS loosen attachment to a static sense of self and identity supporting them to live well alongside the unpredictable illness.

Design

Eight pwMS were interviewed using a narrative approach. Narrative analysis was used to analyse the data, attention was given to story summaries, turning points and subject positions.

Results

Through narrative analysis I identified three overarching narrative types: growth, tension and simplicity. Mindfulness was constructed as leading to changed perspectives and relationships to self and illness by some. Others found mindfulness more challenging to adopt.

Conclusion

Some pwMS experience a changed perspective towards self and illness following a mindfulness intervention. Increased awareness of the self in the present moment and distance from one's thoughts and feelings may explain this. Mindfulness is not always easy for pwMS and the results indicate that there needs to be better understanding of who and how mindfulness is helpful.

Shifts in Perspectives Seen Through the Narratives of People with Multiple Sclerosis Following a Mindfulness Intervention

People with multiple sclerosis (pwMS) can struggle to adapt to living with the condition, and mindfulness, defined as bringing non-judgmental attention to the present moment, may help by prompting shifts in how people relate to themselves and their experiences (Malpass et al., 2012; Shapiro et al., 2006). Shifts in perspective may arise from learning to step back from one's thoughts, feelings and sensations, and can help people become less attached to the notion of a stable identity and predictable future (Kerr et al., 2011). This might help people manage the unpredictable course of multiple sclerosis (MS). PwMS often respond by trying to establish control and certainty which can be unachievable. Instead, learning to take a more flexible perspective may be beneficial. However, the relationship of mindfulness to existing understandings of how people live with MS is incomplete. Understanding how mindfulness helps pwMS is important so that referring clinicians better understand what mindfulness may or may not help with, and whom it may help. Thus, within this study I analysed the narratives pwMS gave following a mindfulness intervention. I have provided background information about mindfulness and MS in the introduction, to set the scene for the study. The self is used in this paper to refer to one's personal perceptions of who they are at an immediate time point as part of a first order reflexive process. Identity is used to refer to a sense of self-sameness across a longer time point and is determined by the individual but also largely influenced by others (Lichtwarck-Aschoff et al., 2008).

Mindfulness

The meaning of mindfulness can be nuanced and subject to interpretation (Brown et al., 2007). The current research focused on mindfulness as used in

Western psychology, where mindfulness is often integrated with contemporary psychological practice into a standardised mindfulness-based intervention (MBI) such as mindfulness-based stress reduction (MBSR; Kabat-Zinn, 2013). Kabat-Zinn (2003) defines mindfulness as the awareness that is brought about by intentionally paying attention to the present moment without judgment.

Whilst MBSR is typically offered as an eight-week group intervention, mindfulness is about a lifestyle change. MBSR is skills based including experiential learning through in session and home mindfulness practice (Kabat-Zinn, 2003). Research suggests continued practice is needed to create sustained effects. People can find maintaining practice challenging and typically go through a journey moving in and out of practice, however factors influencing this are often neglected in research (Langdon et al., 2011). People's reasons for practicing mindfulness can change over this journey, with more experienced meditators found to move from using mindfulness for self-regulation to self-understanding (Pepping et al., 2016).

Mechanisms of Mindfulness

Research and theories are working towards a coherent framework of the mechanisms of mindfulness. Research is complicated by a lack of consensus around definitions of mindfulness, and what the most important psychological and neurobiological pathways through which change occurs are (Cebolla et al., 2018). Several models agree that the therapeutic processes can lead to a changed perspective over time (Malpass, et al., 2012; Shapiro et al., 2006). This shift in perspective is associated with reduced attachment to internal experiences such as thoughts and emotions, and is thought to lead to a change in self and identity (Malpass, et al., 2012; Shapiro et al., 2006). Shapiro et al. (2006) describes this shift:

“We learn to stand back from and observe our inner commentary about life and the experiences encountered, we begin to stand back from our ‘story’ about who and what we ultimately are. Through this change in perspective, identity begins to shift.” (Shapiro et al., 2006, p. 379)

It is thought the development of this ‘observing self’ may be the mechanism supporting more global changes, such as improved emotion-regulation and mental wellbeing (Shapiro et al., 2006; Kerr et al., 2011).

Two studies analysing diary descriptions of participants’ home-practice experience over an eight-week mindfulness course provide support for mindfulness leading to changes in perspective, prompting a more flexible self and identity (Atkins & Styles, 2015; Kerr et al., 2011). Both found participants developed some degree of an ‘observing stance’ towards their experience by the end of the course. This was demonstrated by instances where participants de-identified from thoughts, feelings and sensations, and times when participants described their minds as ‘the container’ for their experiences. This allowed a more dynamic and flexible self and behaviours to develop. Within these studies data were coded by researchers not blind to the hypotheses and therefore bias in the coding may have occurred. Malpass et al. (2012) completed a meta-ethnography on participants’ experience of MBIs. They found participant described a shift from ‘old’ to ‘new’ self which was linked to the addition of an ‘observing self’.

The development of an ‘observing self’ and loosened attachments to thoughts, feelings and sensations may be particularly salient for people living with chronic illnesses. Chronic illness has been described as a ever-shifting process clouded by uncertainty, which means holding onto ridged ideas of self and identity can be problematic (Paterson et al., 1999). Kerr et al. (2011) proposed that

developing an observing attitude and relationship to illness may be beneficial and warrents exploration.

Multiple Sclerosis

MS is a chronic neurological disease. Different disease courses have been identified but the progression of the disease is often unpredictable (Brownlee et al., 2017). Relapsing-remitting MS (RRMS) is characterised by periods of exacerbated symptoms and return to baseline functioning; this often transitions to secondary-progressive MS (SPMS) where people experience a gradual worsening of symptoms over time. Less common is primary-progressive MS (PPMS) characterised by gradual worsening from first symptom (Mohr & Cox, 2004).

Qualitative research shows pwMS are dissatisfied with the post diagnostic support they receive and want more support with the emotional distress caused by the illness and in finding ways of coping (Dennison et al., 2010; MS Society, 2020). It is therefore important for health professionals to understand what interventions may help, and any individual differences within this. Mindfulness may help pwMS to live well alongside the disease but more needs to be understood about how and who it can benefit (Simpson et al., 2019).

Adjustment to MS continues throughout the disease course and in response to changes in disease status (Dennison et al., 2010). PwMS can experience changes in self and identity throughout the course of illness, along with preoccupations with uncertain futures (Mozo-Dutton et al., 2012). Research has suggested that people have more difficulty adjusting to MS when they keep the illness rigidly in the foreground of self and identity, with limited shifts in perspective to considering other elements of self and identity (Giovannetti et al., 2017). Instead, building in some

psychological flexibility around MS and one's self and identity can have a positive effect on mood and increased acceptance of support (Barker et al., 2019). Learning to take a non-attached perspective towards thoughts, feelings and sensations through mindfulness may help pwMS to develop this psychological flexibility around MS and self-identity. Further research into the relationship between mindfulness and living with MS will help understand whether this is the case.

To date, most of the focus of research into mindfulness for pwMS has been efficacy research and more process research is needed. MBIs have been recommended as a useful intervention for pwMS across a range of symptoms (Simpson et al., 2021a). Whilst studies examining the effectiveness of MBIs in this population group have been mixed and open to bias, recent systematic reviews have found mindfulness is effective at improving mental well-being for pwMS (Carletto, et al., 2020; Simpson et al., 2019). As the aim of mindfulness is not to get rid of symptoms or find relief, traditional efficacy research may not capture the full range of effect (Kerr et al., 2011). In addition, adherence to MBIs for pwMS can be low, and attrition can be high (Simpson et al., 2019), and therefore further understanding of participant experience through qualitative research is needed.

A recent systematic review found no purely qualitative research into the experience of pwMS accessing MBIs (Simpson et al., 2021b). Six mixed-method studies were reviewed including views of pwMS, mindfulness instructors and referring clinicians. These studies mostly focused on feasibility, accessibility and acceptability of MBIs for pwMS, with the exception of one study which looked at the potential treatment mechanisms (Bogosian et al., 2016). Authors of the review synthesised the findings into four main themes: (1) accessing mindfulness, (2) a

sense of belonging, (3) experiencing mindfulness and (4) making mindfulness more relevant and suitable to pwMS. They reported that online and face to face MBIs were acceptable for pwMS and the group aspect provided belonging and shared identity. The development of acceptance and compassion were particularly beneficial for pwMS, and mindfulness was experienced differently by different participants (Simpson et al., 2021b). All studies in the review used focused data collection meaning important views were probably overlooked and the data is prone to social desirability and self-perception biases. All studies employed thematic or content data analyses and any idiosyncrasies of participant experience were lost. The researchers concluded that more needs to be understood about how MBIs work, in particular for those with MS (Simpson et al., 2021b).

Summary

Whilst there is some evidence that mindfulness practice supports people to become less fixed on ideas about the self and their experiences, further research is needed to understand the relationship between mindfulness, the self, and adapting to life with MS. Developing an 'observing self' through mindfulness may help people shift from viewing the self and identity as static to having an awareness of self in the present moment and lead to increased cognitive and behavioural flexibility allowing adaptation to changing illness experiences.

Aim

Within this study I aimed to explore how people with MS who have participated in a mindfulness course describe change, particularly in relation to changes in their experience of self, identity and relationship with illness over time.

Research Questions

1. How do pwMS talk about their experiences of a mindfulness course in the context of living with MS?
2. What are the key turning points for pwMS in their experience through the mindfulness course?
3. How do pwMS construct themselves and their relationship with their illness after the mindfulness course?

Method

Research Approach

This qualitative study was underpinned by a narrative approach which suggests people make sense of their experiences through telling stories (Riessman, 2008). I deemed a narrative approach appropriate for multiple reasons: (1) people often use narratives to add coherence and make sense of their illness experience, (2) in doing so they share their experience of important points in the course of their illness and, (3) people's constructed identities can be understood through the narratives they tell (Bamberg, 1997; Riessman, 2008). I align with postmodern ideas of the incomplete and fragmented nature of narratives representing the self as multi-voiced (Bamberg, 2011), and suggest the data presented represents a single, static, view of dynamically changing identities. Within this research the interview was likely to be influenced by the dominant medical discourse and power differentials of professional and patient. Participants would have likely given a different narrative if talking to a peer for example. Participants' narratives were also told within an individualistic culture that places value on maintaining or getting back to health which

is important in understanding the shape of the narratives and may have biased participants to offer a progressive narrative of overcoming illness (Frank, 2013).

Participants

To be eligible to take part in the study, participants had to be age 18 years or older, have a diagnosis of MS and to have attended a mindfulness course within the last six months. The six-month timeframe was chosen so the experience of the mindfulness course was still fresh in participants minds. Participants were not excluded based on having prior mindfulness experiences because this research was not measuring efficacy and instead was interested in peoples' individual experiences.

I recruited eight participants through a MS charity (Table 1). Recruitment was restricted by the limited frequency of mindfulness courses running for pwMS. All participants were diagnosed with RRMS, four felt this had now developed to SPMS. Participants' ages ranged from 38-65 (M=57). All had participated in a mindfulness course within the past six months, five had completed an eight-week course, three

Table 1

Participant Characteristics

Name	Gender	Age	Years diagnosed	MS type	Ethnicity	Prior mindfulness experience	Course length (weeks)
Samantha	F	62	16	SPMS	Other	None	8
Roy	M	56	7	RRMS	White British	Some	8
Paul	M	50	6	RRMS	British Irish	Some	8

John	M	61	22	SPMS	White British	Extensive	8
Rachel	F	60	16	RRMS	White British	Some	4
Sarah	F	65	9	SPMS	White British	Some	4
Judy	F	63	9	RRMS	White British	Some	4
Ahdia	F	38	19	RRMS	Asian British	Extensive	8

had completed a four-week course. Seven had prior experience of mindfulness, ranging from brief self-directed learning to attending mindfulness retreats and daily practice.

Mindfulness Course

Both mindfulness courses were held online due to the coronavirus pandemic by qualified mindfulness instructors through a MS charity. The eight-week course followed the MBSR protocol whereas the four-week course covered core material from the MBSR condensed (Appendix A). All participants were encouraged to complete personal practice and were given access to guided audio mindfulness practices to support this.

Ethics

I followed the criteria for conducting ethical research online (British Psychological Society, 2021). Ethics approval was granted from the University of Exeter Ethics Committee (Appendix B). The research poster was shared with people who had completed the mindfulness courses (Appendix C). Individuals expressed interest in participating via email. I then sent the information sheet (Appendix D) and

consent form to sign and return via email (Appendix E). I acknowledged that the cognitive difficulties sometimes associated with MS could make informed consent difficult to obtain. I used clinical judgement to consider participants' capacity to provide informed consent, recognising that all participants had recently engaged in a mindfulness course requiring a fair level of cognitive ability. I followed data protection regulations. Zoom meetings were password protected. All data were immediately transferred and stored on a secure server after the interview, with identifiable information stored separately and securely from the data. The interviews were then deleted from Zoom. I removed identifying information from transcripts and all participants have been given pseudonyms.

Narrative Interviews

I used a narrative inducing question (Appendix F) to encourage interviewee led interviews, allowing participants to translate their experience into narratives. The interview question was reviewed by two people living with MS with mindfulness experience. They provided feedback on the structure, content and language of the question adding to its credibility.

After seeking consent, I scheduled a convenient meeting via email and conducted these remotely over Zoom. Participants had space to tell their narrative uninterrupted until they gave clear indication of the end of narration. I asked follow up questions to expand on points within the initial narrative and to gain demographic information. Interviews ended with time for closing comments or questions from participants. Participants tended to use this space for reflection and informal talk. Interviews lasted 45-104 minutes.

Method of Analysis

Interviews were recorded and auto transcribed on Zoom. I listened to the interviews and corrected errors within the transcripts. This gave me a sense of the narrative content and structure. I analysed full verbatim transcripts focusing on three elements of analysis: story summaries, turning points and positioning. Initially, I drew out story summaries using participants' words based on the ideas of McCormack (2004). This gave a sense of structure and sequence within the narratives. I identified key turning points within transcripts, defined as points that changed the direction of the story or led participants to a different sense of themselves in the future (Mishler, 2006). These were inferred from particular forms of speech as put forward by Lieblich et al. (1998) e.g. 'that's when I realised' 'it was the worst experience of my life'. I then examined the transcripts for narrative positions (Bamberg, 1997). Positioning is a discursive practice "whereby selves are located in conversations as observably and intersubjectively coherent participants in jointly produced story lines" (Davies & Harre, 1990, p. 48). Within narratives, positioning is said to take place across three levels (1) characters positioned in relation to one another, (2) positioning of the speaker to the audience, (3) positioning of speaker to themselves (Bamberg, 1997). I paid attention to all three levels, with a particular focus on the latter in line with the research aims. I considered similarities and differences between the stories throughout (Riessman, 2008).

Credibility

Considering credibility, I discussed the data collection and analysis regularly with supervisors with expertise in narrative analysis and mindfulness/MS, within a peer group and a narrative research group at Exeter University. These spaces

provided a critical voice enhancing reflective awareness and credibility. I have provided detailed descriptions and interpretations within context as a way of offering thick descriptions, and have provided participants' own words to enable readers to judge transferability to own cases (Norwell et al., 2017). I have included examples of the process of analysis to offer transparency (Appendix G).

Reflexivity

Approaching this research from a clinical psychology background meant I understood participants' narratives through this lens. My perspective is that psychological interventions can be helpful having seen them alleviate people's distress, and as anticipated this was seen within the data. In an attempt to get closer to participants' experiences I attended a MBSR course before conducting the interviews. This afforded me clearer understanding of the nuanced reactions of participants and specific elements of the course (Berger, 2015). It also meant my own experience of MBSR influenced the research, for example I began the analysis expecting people to have developed a complex understanding of mindfulness, which on reflection was based on my own learning and readings of mindfulness. I was able to notice this and see participants took away different things from the course. I wrote a reflective diary throughout the research process which helped me become more aware of biases (Appendix H). I completed a bracketing interview with my primary supervisor at the start of the analysis process increasing my objectivity and reflexive capacity (Rolls & Relf, 2006).

Analysis

The research question was to examine how pwMS who have participated in a mindfulness course describe change, particularly in relation to changes in their experiences of self, identity and illness. Through narrative analysis I revealed three

differing narrative types— a narrative of growth, tension, and simplicity. Analysis of turning points suggested that those more poignant moments were punctuated by moments of identity change which influenced participants' relationship with the illness. Participants struggled with being in control of their lives – this was demonstrated as participants took up and gave others different subject positions related to control of healthcare and life. For some participants mindfulness was part of constituting a new self, identity and relationship to illness.

Below, I expand on each of these elements by first presenting the narrative structures of the participants' stories, second by elaborating on the turning points identified, and finally by evidencing how participants positioned themselves and others.

Story Summaries

The structure of participants' narratives are illustrated in Table 2. There was considerable homogeneity at the start of participants' narratives, followed by points of divergence leading to three main narrative types being identified (Table 2).

Opening Structure

Participant's narratives began similarly. For example, all except Ahdia started with in-depth descriptions of initial symptoms and experience of being diagnosed with MS (Table 2). Time between first symptoms and receiving a diagnosis was described as a time of uncertainty which acted as a prelude to the dilemmas later faced. At first participants presented a sense of carrying on in the face of illness ($n=7$), describing continuing roles in employment and recreation placing emphasis on aspects holding moral value e.g., work. Beyond this, the narratives differed as elaborated below.

A Story of Growth

Four participants presented growth through their narratives. Roy and Samantha moved from describing experiences of 'carrying on' in the face of illness, to experiences of being overcome by illness. Both described a point of difficulty where worsening symptoms led to a realisation of the impact MS had on their preconceived ideas of life and identities (Table 2). Samantha's narrative was marked by a lack of coherence and narrative order at this point. As she progressed, her narrative gained an element of calmness, perhaps resembling the benefits she gained from mindfulness practice. Roy's dramatic telling of his experiences

Table 2*Story Summaries*

Name	Samantha	Roy	Judy	Ahdia	John	Rachel	Paul	Sarah
Story type	Growth	Growth	Growth	Growth	Simple	Simple	Tension	Tension
Beginning	Road to diagnosis	Road to diagnosis	Road to diagnosis	Looking for a solution	Road to diagnosis	Road to diagnosis	Road to diagnosis	Road to diagnosis
	“It was the first thing I heard of MS”	“I did go from having a brain tumour to cancer to something else horrible that was going to kill me. By the time it came to being MS I was so relieved”	“My Ms journey began in my early 20s. My doctor at that point just dismissed it”	“My MS had become very bad, I’d exhausted all western treatments and was only early 30s. I was like okay I’ve got to find something”	“For years I didn’t have any physical manifestation s”	“It took 2 years to get diagnosed”	“As expected, I’ve got MS” “Life will go on”	“It didn’t interfere with my life” “I almost pushed it to the back of my mind”

Middle	Challenge led to seeking help	Challenge led to seeking help	Coming to terms with MS	Seeking relief	Moving towards mindfulness	Moving towards mindfulness	Seeking relief	Moving towards mindfulness
	<p>“It all came to a head I was walking and fell over” *</p> <p>“Hospital was pretty much the worst experience of my life” *</p> <p>“I thought I’m not going to like this (mindfulness)”</p>	<p>“I suddenly then realise that actually I couldn’t sort it. And I. I rather fell apart” *</p> <p>“Early on it (mindfulness) was mechanical, then it became something I understood”</p>	<p>“It took me a while to tell various people I’ve got MS”</p> <p>“What particularly interested me about the course was it was MS related”</p>	<p>“I went to the retreat, and I could feel my MS getting so much better just through my own thinking”</p> <p>“I signed up with the intention that I want to get back to that condition”</p>	<p>“The overcoming MS is a whole new lifestyle; diet, exercise and meditation is important. That’s a big part of how I live my life now”</p> <p>“I found the course useful to make sure I was doing things right”</p>	<p>“I experience a wide range of symptoms and parcel of MS”</p> <p>“A way of managing it is I keep on top of reading about MS.. which is where I saw mindfulness”</p>	<p>“At times it was like I had my back to a fire, burning fire, I couldn’t walk away from it” *</p> <p>“I thought, I will have to pursue the mindfulness a bit more”</p>	<p>“Don’t worry about what others think, bla bla nonjudgment al. There’s a big gap between the theory and what you feel”</p> <p>“Slowly I’m realising you can only control what you can control”</p>

End	Renewed perspective	Renewed perspective	Renewed perspective	Renewed perspective	Reflection	Reflection	Tension	Tension
	<p>“If it's really going to work it is actually a way of thinking and being that you just stop and take stock rather than constantly rushing to get things done”</p>	<p>“Mindfulness has helped me place things in perspective”</p>	<p>“Actually (MS) was something that came out of the drop-in group and it's been very profound” **</p>	<p>“I'm just more at peace with my illness now. I'm more calm in my mind about the fact that I have less anger and bitterness and more positivity now than before”</p>	<p>“I'm hoping it's just slowing the progression of disease down”</p>	<p>“I have found it very beneficial. It might not make all the symptoms go away completely, but I feel calmer”</p>	<p>“I try and find time, I don't do as much as I should do”</p>	<p>“I haven't quite got it yet. I'm hoping that eventually with practice I'll be able to tune into it (mindfulness) more”</p>

* Turning point relating to worsening symptoms

** Turning point relating to relief from symptoms or renewed direction

presented a sense of being consumed by illness (Table 2), helping set the scene for the later story of overcoming as he reflected on how his illness experience, coupled with insights gained from mindfulness, led him to new meanings and perspectives.

“I can’t stand and look across the valley and all its beauty anymore. But I can look at a blade of grass and see its beauty. And before I wouldn’t have spoken like this. But yeah I’m a different person”. Roy

Ahdia and Judy also described changed perspectives since using mindfulness. Judy’s use of language suggested an initial ambivalence about mindfulness which changed over the course as she “realised it’s a very powerful thing”. She described developing more awareness and self-compassion over the course. Ahdia came to the course with clear intentions which were not met. Yet she described making gains that she wasn’t expecting (Table 2).

All of these narratives demonstrated a depth of understanding of mindfulness which included the idea that mindfulness is a “way of being” (Roy).

A Story of Simplicity

John and Rachel offered a more linear narrative (Table 2) having found their way of coping with MS by controlling what they can, for example through lifestyle changes and researching what helps. They came to mindfulness through this with the hope it would slow the progression of illness (Table 2).

Both narratives finished by stating that mindfulness was helpful, but this was offered as a global description without elaboration on how or what this meant for them in the context of their lives. Mindfulness was presented as one of a range of therapeutic interventions they could draw on.

“It’s just what I’ve got to live with and it’s just finding things that helped me to manage it. And, and so mindfulness isn’t going to make it go away it’s

just going to help me that when I feel I need to find something in my toolbox, whether its medication or whether it's doing other things like mindfulness.

So it's just something else to help." Rachel

A Story of Tension

Two participants presented tensions through their narratives. Paul and Sarah spoke of a desire to find a way of managing MS (Table 2). They described knowing logically what they needed to do and their language suggested a desire to be seen doing the right thing. Mindfulness fell within this category. Alongside this they narrated experiences of challenges and tension in accommodating and committing to practice within their lives for example:

"I couldn't personally say that it's majorly different. But that might be, because I haven't practiced it enough." Sarah

They both described mindfulness 'mechanically' for example using the word "tool". A sense of comparison, expectation and judgment ran through Paul's narrative demonstrated for example by the word "should". Both described knowing mindfulness helped others rather than seeing the direct impact on their own lives, which may suggest they had an extrinsic motivation to practice rather than something intrinsic, as illustrated here:

"It was the people who were there who are following the MS program closely I could see were doing the best. I was definitely towards the bottom end of the table." Paul

Whilst spoken tensions were clear, there was also more subtle evidence of a thoughtfulness, self-awareness and ability to reflect. They both appeared to use their narrative as a way of convincing themselves of the benefits of mindfulness, but ended at a point of tension (Table 2).

Turning Points

Two major turning points were identified (Table 2). Firstly, descriptions of worsening symptoms appeared to precipitate identity shifts either due to a loss of role, for example preceding medical retirement, or because life became 'all-encompassed' by symptoms.

"This neuropathic pain that kind of took over, it was like the year of pain" Paul

Four participants came to mindfulness shortly after times of progressing symptoms.

Secondly, turning points were around points of gaining relief from symptoms and renewed direction with regards to life and coping with MS. These led to shifts in identity associated with meaning and regained sense of control.

"Unlike all my other experiences, she (neuropsychologist) looked me straight in the eye and she went of course you feel like that you are ill you're supposed to feel like this, now we're going to sort it out and she helped me sort it out." Roy

Within this, turning points during the mindfulness course were identified in four participants' narratives. Three in relation to being asked to relate to MS in a new way, leading to a renewed acceptance of MS as a part of one's sense of self and identity (Table 2). The fourth was where Samantha shifted from being sceptical to experiencing benefit from mindfulness:

"At last my mind was completely silent. Yeah, absolutely. We were supposed to be thinking about something, but it was silent. It was finally silent. Yeah. And that's what I've been searching for..." Samantha

Positioning

Participants positioned themselves as sometimes in control and other times, not in control, while grappling with the unpredictable and uncontrollable nature of MS. This was witnessed throughout their journeys as illustrated here. Some showed changes in positioning in self and illness influenced by mindfulness.

Before Mindfulness

Initially, most ($n=7$) positioned themselves as self-reliant and unchanged by illness (Table 2). This ran alongside a desire to maintain control over the MS:

“The MS for the first year or so it wasn’t really getting in the way.” “I can sort this out I’m a man” Roy.

When talking about worsening symptoms, participants ($n=7$) positioned themselves as passive recipients of outside forces (MS or health professionals). Participants’ language demonstrated a lost sense of control and powerlessness over their bodies or decisions over their care:

“All of a sudden, the MS has pulled that apart, I’m now a bloke that can’t” Roy

“I’m sent off to a neuro place.” Samantha

Participants looked to health professionals to provide answers for their symptoms, this was often a lengthy process as participants ($n=4$) struggled to gain medical recognition. As such health professionals were positioned as individuals with power, whilst participants were left in positions of not knowing.

“The neurologist says well you do realise I’m looking at MS. Yes, it was as blunt as that.” Judy

All participants positioned themselves as adhering to the right lifestyle defined by the dominant medical discourse (Table 2). Finding concrete ways of managing

the illness such as the steps of overcoming MS appeared to empower some by giving a sense of control and direction. Mindfulness was included in this.

“I’ve been working towards doing what I think is right which is the MS Program” “I think you can you know take the control yourself and try to do the right thing” Paul

During Mindfulness

Participants ($n=4$) positioned themselves as ambivalent about mindfulness initially. Three of these participants plus another ($n=4$) positioned themselves as logical thinkers with a desire to find something to stop or slow down the disease progression. These participants found mindfulness hard because it challenged their predominant way of thinking. They spoke of not seeing the logic behind mindfulness and having to put their trust in it:

“I’m very much a factual based person..... there are problems and there’s solutions. The link between sitting and trying to calm the mind and seeing what the benefits are, are not that easy.” “I probably had to make a bit of a leap of faith to believe in the benefits” Paul

“It doesn’t come to me, naturally.” Sarah

Others positioned themselves using stereotypes of age ($n=1$) or gender ($n=1$) to demonstrate how mindfulness was challenging for them to adopt.

All participants positioned themselves as helping and being helped through group membership, describing a sense of support and shared learning which helped empathic connections to develop:

“I did enjoy just meeting other people who has MS who we can sort of chop and exchange different things because you know you can meet other

people and they'll never actually know what it's like you can get more from other people's understanding" Paul

Samantha initially positioned herself as different to the group, demonstrating the idea of illness as all-encompassing and a lonely and isolating experience.

"Although they've all got MS... none of them are wheelchair bound and their issues are going to be very different"

Later in the course she moved to a position of feeling connected and as something bigger than MS.

"We have things in common, but we have things that are not in common. And it almost, I mean.. our MS is not really the common factor almost. It's more about you know our children, you know, whether we like cooking." Samantha

The mindfulness tutors were positioned as understanding and non-judgmental. Samantha contrasted this to frequently being told there is a "right and wrong to living with MS". The tutors were also positioned by some ($n=3$) as being role-models through sharing personal experiences of living with MS and their understanding and commitment to mindfulness.

"The best thing was the fact that the person that led the course had MS. Because so often like even when you go when you do physio and stuff you have people leading that know MS but they never really going to know what it's like." Ahdia

After Mindfulness

For most ($n=7$), mindfulness was influential in changes in positioning of self. For example, following the course some ($n=5$) positioned themselves as more

aware, having gained a wider perspective on life and an appreciation of smaller things:

“It had been raining but it stopped when I went outside and then notice the lovely smell of everything. Whereas before probably wouldn’t notice that, so it did heighten awareness of you know, the sort of everyday things.” Sarah

When describing the effects of mindfulness, there were occasions when Roy, Samantha and Judy positioned themselves outside of their thoughts and feelings, demonstrating the development of an ‘observing self’ through their narratives:

“I wouldn’t say I’ve overcome anger, that that bloke in the Audi on the roundabout still winds me up. When he winds me up, I know it, I can see it, I can watch it without it becoming the one and only thing in my life... And yeah that’s important. Because being angry being wound up doesn’t do the MS any good”. Roy

Some demonstrated a shift in perspective and ability to hold a sense of self in a flexible way. For example, near the end of Ahdia’s narrative she was still acknowledging anger and bitterness but was able to hold this alongside other contrasting experiences:

“There is still like anger and bitterness about the fact that it’s taken away so much of my life that I always thought I would have. But there’s less anger and bitterness. I think there’s now there’s definitely more um there’s much more positivity now than there was before.” Ahdia

A number of participants positioned themselves in a more self-compassionate way ($n=4$). This seemed to develop through paying more attention to self and body, thus becoming more self-aware, and allowed participants to prioritise their own needs:

“There’s been one or two little instances of I’m thinking this is just the wrong thing to be doing. And so I’ve worked through it and I’m thinking right, I need to do what is best for me my condition and not over commit myself.”

Judy

Participants positioned themselves more in control as they talked of responding rather than reacting ($n=4$):

“To try and stop yourself from just reacting, and a few breaths, and try and respond to it and trying to think through what the outcome is going to be urm which I can’t say I do all the time, but I do remember that.” Paul

Engaging in mindfulness also changed the way some positioned themselves in relation to MS. For example, some positioned themselves as more accepting of it ($n=4$):

“This mindfulness course was more accepting how I am and realising that it’s not so bad.... I am more at peace with the whole illness” Ahdia

Samantha and Rachel positioned themselves as having gained a greater sense of control of in relation to how they respond to MS:

“I find I can get up off the bed and I just feel calmer it might not make all the symptoms go away completely, but I feel calmer. So that’s a good thing.” Rachel

“so I have no control of my legs, I can’t make my legs work, what I can do is I have control over whether I stay calm” Samantha

John did not suggest significant changes in positioning of self or illness as a result of mindfulness.

“I don’t think it’s made a huge difference because it was it was more. I was doing a lot of it anyway, I wanted it as a as a reminder really.” John

Discussion

I aimed to provide understanding of whether pwMS experienced a changed relationship to self and illness following a mindfulness course. The narratives suggested different experiences of mindfulness in relation to self, identity and illness, including narratives of growth, tension (mindfulness could be helpful and I should do it more) and simplicity (mindfulness being a small part of a selection of useful approaches). Turning points showed the significance of times of worsening symptoms for people's identity as well as finding a new sense of meaning or direction with regards to navigating the illness. There was an overarching tension between physical symptoms of MS and psychological experience of control. Before mindfulness, participants negotiated conflicting positions often related to agency. For some, mindfulness was influential in changing positions in relation to self and illness which included an increased sense of control. I have discussed these findings in relation to existing mindfulness theory and research below.

Some people described a journey of development through the use of mindfulness, fitting the ideas proposed by Shapiro et al. (2006). Within the growth narratives participants constructed a shift in perspective, where they gained capacity for objectivity about their internal and external experiences. Participants' narratives suggested some went from holding static concepts of self, to a more flexible and responsive self as experienced in the present moment. This was not the case for all participants; for some dynamic tensions accompanied self-judgment. This supports the ideas that if attending to experience without bringing attitudinal qualities such as non-judgment, mindfulness may have consequences contrary to one's intention, such as strengthening patterns of judgment (Shapiro et al., 2018). I suggest these

findings support the idea that a shift in perspective may be a possible gain for pwMS from practicing mindfulness but illustrate that developing an observing perspective is not necessarily an easy path.

Developing an observing perspective enabled some participants to regain a sense of power and control. Life with MS posed challenges in which participants felt little agency. The increased self-awareness which came from stepping back from their experiences and responding from a less attached position seemed to offer a sense of empowerment and flexibility over how they responded to the challenges of living with MS, affording a greater sense of agency. Agency has largely been ignored in mindfulness research and acknowledged as a potentially important gap in the literature (Britton et al., 2021). Based on the findings I propose it may be relevant for people living with chronic illness who often experience a reduced sense of agency due to illness.

Through mindfulness, some developed more acceptance of MS which paradoxically meant that illness was less in the forefront and was able to sit alongside other parts of the self. Research suggests integrating MS as part of one's identity is helpful, but keeping illness in the forefront of one's identity without considering other aspects of self and identity is associated with poorer mental health (Barker et al., 2019). The changed relationship to the illness allowed some participants to hold multiple perspectives alongside and afforded more psychological flexibility in relation to MS and self-identity.

Identity could be important in how people approach mindfulness and the ease of one's journey through a mindfulness course. Mindfulness seemed to sit more comfortably alongside some participants' identity and world-view than others.

Descriptions of being solution focused and logical thinkers, and stereotypes of being a man, or older adult seemed to sit uncomfortably alongside mindfulness and meant grasping the teachings of mindfulness and leaning into the practices felt more challenging. Others described mindfulness as aligning easily to their personality. This has some resonance with the findings reported by Bogosian et al. (2016) who suggested some pwMS related more easily to mindfulness, however whereas Bogosian et al. (2016) reported this directly influenced degree of engagement, within the current study misalignment between personality and mindfulness was not necessarily problematic and instead seemed influential in leading to more profound effects for those that were able to adopt a changed world-view.

Motivation to engage with mindfulness seemed to wax and wane alongside MS symptoms. Most participants described previous experiences of doing mindfulness and some were motivated to attend the course at points of worsening symptoms. When symptoms were in remission, MS identities seemed to be more in the background of awareness and mindfulness practice slipped. This supports the theory that people tend to move in and out of mindfulness practice, switching from seeing benefits and feeling motivated, to meeting challenges (often related to the effort and discipline required), which leads to reduced practice and less benefit (Langdon et al., 2011). I suggest for people with chronic health conditions this may relate closely to their physical health, with people moving towards mindfulness at times of progressing symptoms and perhaps slipping out of practice as other aspects of life foreground. Some participants held strong intrinsic motivation to practice mindfulness whilst others had extrinsic motivation and this may also have had relevance.

In listening to the participants' narratives, I was struck by a sense that participants needed their experiences of MS to be heard. Most talked in depth about experience of diagnosis and life with MS. This may reflect gaps in service, where the physical nature of the illness is attended to but no space is given to the psychological impact (Simpson et al., 2021a). It also highlights the fact that mindfulness is only one aspect of someone's life, and MS can be an all-embracing illness (Boeije et al., 2002). The descriptions of people's experiences dominated by having MS could also be read as participants having increased ability to hold and be aware of their MS.

Implications for Clinical Practice

Participants described various psychological effects of living with MS. Services supporting pwMS could better recognise these and consider whether they provide more space to the psychological impact of the illness alongside medical care. This seemed particularly relevant at times of illness progression and associated loss. Professionals supporting pwMS should be aware mindfulness can be a valued intervention for pwMS and can support a journey of development leading to changed relationships with self and illness. A change in perspective and the development of an observer stance may be important within participants' mindfulness journey, and mindfulness teachers could attend more to supporting pwMS to distance from thoughts and emotions, however this may need to be explored further in future research. Attending a mindfulness course specifically for pwMS allowed for deeper consideration and exploration of participants' relationships to their MS. For some this led to greater acceptance and allowed for greater psychological flexibility in relation to MS. Service provision varies geographically and more services could consider running MS specific mindfulness courses.

It is important for professionals to be aware not everyone finds mindfulness a straight forward intervention. All participants wanted to integrate mindfulness into daily life, but some did not find mindfulness intuitive or had difficulties prioritising it in the context of their wider lives. Mindfulness teachers could normalise this and support pwMS in overcoming such challenges. Those with strong intrinsic motivation seemed more able to commit the time and effort needed for sustained practice and this could be one area for mindfulness instructors or referring clinicians to focus on.

Participants' understanding of the core principles of mindfulness varied as seen in common discourse. With the growing popularity of mindfulness comes a risk of incongruity between clinical/academic understandings and lay person understandings including misapplications promoting temporary relief (Choi et al., 2021). Unrealistic expectations may be a barrier to participation and findings from this study support the need for referring clinicians and mindfulness teachers to help pwMS set realistic expectations about what mindfulness can do.

Strengths and Limitations

Within this research I give a unique perspective of how pwMS narrate their experiences of mindfulness in the wider context of their life with MS. Using a qualitative methodology allowed me to provide nuanced information about the diversity of participants' journeys through a MBI which quantitative research misses. Additionally, process research may be better suited to capture the embodied and experiential nature of mindfulness for pwMS. Whilst I have gone some way to characterise participants change experience I have not answer why some pwMS experience growth and others do not. Possible theories raised from the results are differences in intrinsic/extrinsic motivations (intrinsic motivation leading to greater

effects), the degree of challenges leading someone to mindfulness (people with more psychological difficulties experiencing greater relief), the fit of mindfulness with pre-existing identity/world-view (when misaligned to mindfulness people may experience more difficulty but also more opportunity for growth).

At times during the analysis my focus felt far from the mindfulness intervention, and was consumed by participant's illness experience. This may reflect the experiences of pwMS or may have been influenced by my choice of interview question. I reflected on whether to prioritise my perspective and interests as a researcher, or be authentic to the way that participants responded to my research question. This is arguably a helpful reminder of the importance of seeing a person's whole life outside of a singular clinical context which is sometimes forgotten within research.

Most participants had recently finished the mindfulness course, the findings report one snapshot along an evolving journey. Gathering longitudinal data would have allowed a deeper exploration and understanding of how participants' relationship with mindfulness developed over time. Recruiting pwMS who had completed a mindfulness course was challenging due to the limited number of courses running during the coronavirus pandemic. The findings in this study come from narrative interviews with eight people from the UK. Participants' mean age was 58 and all were medically retired. These factors may have increased people's likeliness to have participated in a mindfulness intervention and research. It may also be that illness becomes more prominent in people's lives at later stages of disease, and therefore people seek new ways of coping. Whilst this participant population fills a gap within the qualitative literature on mindfulness for pwMS (Simpson et al.,

2021b), it is not representative of pwMS which is typically diagnosed in early adulthood. The findings are not intended to be generalisable however may have relevance to others in similar settings.

Future Research

The results showed mindfulness was easier and more helpful for some than others. This may reflect the mixed findings of quantitative studies and further research into this area is needed. There were no clear differences between the narratives of participants with RRMS compared to SPMS, but this may be explored in more depth in the future. People's intention and motivation are often neglected within mindfulness research and these factors seemed to influence participants' journey within the current study, and it would be good to understand more about these relationships. Research should focus on the point of participants engaging in mindfulness and what people hope to gain from this.

Conclusion

Through this research I aimed to understand how pwMS experienced change following a mindfulness course to expand on limited qualitative understandings. I have presented findings which suggest mindfulness can help pwMS move from holding strong static concepts of who they are, to a more flexible and responsive self experienced in the present moment. It can also support changes in the relationship pwMS have towards their illness. These changes may not be straight forward and can see people moving away from and back towards mindfulness practices. Some people have more difficulty adopting mindfulness than others, which may relate to whether they hold intrinsic or extrinsic motivations and how aligned mindfulness is to

their pre-existing world view. More research is needed into who mindfulness works best for.

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Appendices

Appendix A

Overview of Mindfulness Courses

Eight-week Mindfulness Course structure

Weeks 1- 3 Beginning to practice and developing awareness

- Mindful awareness
- Looking at things differently
- Awareness of barriers and reactions

Weeks 4-6 Awareness of stress and our reactions

- Awareness of thoughts and emotions
- Responding vs reacting when living with MS
- Working with difficult experiences

Weeks 7- 8 Preparing for the future

- MS Lifestyle modifications
- Identity and taking care of yourself
- Preparing your own meditation practice

Overview of Four-Week Mindfulness Course

The purpose of the four-week course was to offer a more accessible, shorter format for individuals that is more manageable for those with work or other commitments.

Despite being shorter in duration, the course aimed to cover all the fundamentals of the MBSR course, providing an introduction to mindfulness and to begin the individuals' practice of mindfulness for future development.

Appendix B Ethics Approval



CLES – Psychology
Psychology
College of Life and Environmental Sciences
University of Exeter
Washington Singer Building
Perry Road
Exeter
EX4 4QG
Web: www.exeter.ac.uk

CLES – Psychology Ethics Committee

Dear Abbie Turner

Ethics application - eCLESPsy001966

Exploring the narratives of people with multiple sclerosis following a mindfulness-based stress reduction programme.

Your project has been reviewed by the CLES – Psychology Ethics Committee and has received a Favourable opinion.

The Committee has made the following comments about your application:

- Please view your application at <https://eethics.exeter.ac.uk/CLESPsy/> to see comments in full.

If you have received a Favourable with conditions, Provisional or unfavourable outcome you are required to re-submit for full review and/or confirm that committee comments have been addressed before you begin your research.

If you have any further queries, please contact your Ethics Officer.

Yours sincerely

Date: 01/11/2021

CLES – Psychology Ethics Committee

Appendix C

Research Poster

Participants wanted for research on the narratives of people with multiple sclerosis following a mindfulness programme.

Overview

I am a trainee clinical psychologist conducting research into how people with multiple sclerosis (MS) experience a mindfulness programme.

What's involved

You will be given a space to tell your own story over a video call with me. This will be arranged for a mutually convenient time and should take no longer than 1 hour to complete. We can schedule a number of shorter calls if this would work better for you.

Who can take part?

I am interested in hearing from you if you meet the following criteria:

- Age 18 years or older
- Have a diagnosis of multiple sclerosis
- Have attended a mindfulness course
- Speak English

Get in touch

If you are interested in hearing more about this study or would like to be involved, then please email me (Abbie) on at635@exeter.ac.uk

Participants will receive a £15 Amazon eGift voucher for their time participating in this study.

Thank you for your interest in this study.



Appendix D

Participant Information Sheet



Title of Project: Exploring the narratives of people with multiple sclerosis following a mindfulness intervention.

Researcher name: Abbie Turner

My name is Abbie and I am conducting a research project exploring the stories of people living with Multiple Sclerosis (MS) who have completed a mindfulness programme.

I would like to invite you to be involved with this research. Before agreeing to this it is important that you understand what is involved in the research and why the research is being done. Please read the following information sheet carefully. If you have any questions about the information on this sheet or the study in general, then please contact me on the number below. If you would like to take part in the study then I will ask you to sign a consent form which will be emailed to you.

Purpose of the research:

This study is being conducted as part of a doctorate in clinical psychology.

MS is a chronic progressive condition for which there is currently no cure. Being diagnosed with MS can affect people in very different ways and symptoms can be hugely variable, both between different people and for individuals over time. It can change the way people think about themselves and their life – it can change their “narrative”. Mindfulness can be helpful for people living with a chronic illness. Through different exercises, people learn to pay attention to the present moment in a non-judgmental way. Some people report a new relationship with themselves and their illness following attendance of a mindfulness programme. I am interested in learning more about this process.

Why have I been approached?

You have been invited to take part in this study because you are someone who has received a diagnosis of MS, and enrolled or completed a mindfulness programme recently.

What would taking part involve?

If you choose to take part, an appointment will be made for us to talk about your experiences. This will take place after you have completed the mindfulness programme. This conversation will take place over a video conferencing platform such as Zoom.

The first conversation is expected to last around 1 hour. You can take as many breaks as you would like during this, and we can arrange to complete a number of shorter appointments over a few days if this would be best.

You will be invited to be as honest as possible about your experiences. There will be an opportunity at the end of the appointment for you to ask any questions or to say anything that you think is important that has been missed.

You can request to attend a second appointment if you have things that you want to clarify or add following the first appointment.

The interviews will be recorded so that the interviewer can listen without having to take notes. The auto-transcribe function on Zoom will be used to transcribe the interviews as we speak. You can read more about how your information will be stored below.

What are the possible benefits of taking part?

Some people find it helpful to have a space to talk about their experiences with someone who is interested to listen. You would also be helping to add to the growing body of research about living with MS. At the end of the research you will be given the opportunity to read a copy of the research, which you may find interesting.

You will be offered a £15 Amazon eVoucher for your time participating in this study. This will be emailed to you at the end of the interview.

What are the possible disadvantages and risks of taking part?

The personal nature of the interviews can bring up difficult emotions for some people. It is hoped that you feel emotionally contained by the research structure, and it is up to you what information you choose to share. It is hoped that by the end of the interviews you will have returned to your usual mood. The researcher can signpost you towards other support services should you feel you need ongoing support regarding your mental wellbeing.

You will not be deceived in any way during the research.

What will happen if I don't want to carry on with the study?

It is up to you if you would like to take part in this study. The support you receive will not be affected in any way if you choose not to take part.

If you do decide you would like to take part, then you will be asked to electronically sign and email back a consent form. You can change your mind and withdraw your consent at any point before the 24/01/2022 and do not need to provide a reason for this. If you do withdraw, we may use the information that you have provided up until this point unless you tell us otherwise. If you tell us that you would like all of your data removed from the study before the above date, then it will be destroyed and not included.

How will my information be kept confidential?

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

The information that you share will be kept confidential to the research team within the University of Exeter. Each participant will be allocated a pseudonym so that your identity will not be disclosed at any point. A document linking pseudonyms and personal information (e.g. names) will be stored in a separate location to other information (OneDrive folder A). This file will be deleted after the 24/01/2022, as participants are unable to withdraw consent from this point. We may use direct quotations from you within the write-up but these will be anonymised and any identifiable information, such as names or places, will be removed or changed.

Consent forms will be stored on a secure server (OneDrive folder B), in a separate, unlinked folder from the interviews to reduce risk of identification. Interviews will be recorded and automatically transcribed by the video conferencing system (Zoom). They will both be saved encrypted to the Zoom cloud when the meeting ends. They will be immediately downloaded to a secure server (OneDrive folder C) and deleted from Zoom. Both the recording and transcript will be kept on the secure server (OneDrive folder C) during the research period. These recordings and transcripts will only be accessible to the research team. Once the research is submitted the recorded interviews will be deleted (expected to be before 01/05/2022). Transcripts and consent forms will be deleted five years after the study completion (all information expected to be deleted before 01/05/2027).

Your GP does not need to be informed about your participation in this study.

Confidentiality will only be broken in exceptional circumstances for example if you tell us that either you or someone else is at risk of being harmed. If this were the case, it may be necessary for us to share this information with the project supervisor, who may inform your GP or others involved in your care. As far as possible we will do this in discussion with you.

What will happen to the results of this study?

The information gained from this study will be written up as part of the doctorate in clinical psychology training through the University of Exeter. The findings from this study will be shared with MS-UK. It is also hoped that the results will be published in a peer-reviewed journal. Participants will be given the opportunity to read a copy of the written report. In any written report, all identifiable information will be removed and participants identity will remain confidential.

Who has reviewed this study?

This research has been reviewed by the University of Exeter's School of Psychology Ethics Review Panel.

Further information and contact details

If you have any further questions please feel free to talk to the study's principle researcher Abbie Turner at635@exeter.ac.uk

If you are not happy with any aspect of the project and wish to complain you can contact the chairperson of the University of Exeter Department of Psychology Research Ethics Committee - Dr Nick Moberly N.J.Moberly@exeter.ac.uk. You can also contact Gail Seymour, Research Ethics and Governance Manager g.m.seymour@exeter.ac.uk 01392 726621

Thank you for your interest in this project

Appendix E

Participant Consent Form



Participant Identification Number:

CONSENT FORM

Title of Project: Exploring the narratives of people with multiple sclerosis following a mindfulness programme.

Name of Researcher: Abbie Turner

Please initial box

1. I confirm that I have read the information sheet dated 07/05/2020 (version no 1.4) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw from the study before the 24/01/2022 without giving any reason and without my legal rights being affected.
3. I understand that relevant sections of the data collected during the study may be looked at by members of the research team from the University of Exeter. I give permission for these individuals to have access to my records.
4. I consent to the interviews being video recorded and transcribed and understand that these recordings will only be accessed by the research team. I am aware that these recordings will be deleted once the research project is submitted.
5. I understand that anonymised interview transcripts will be stored on a secure sever for up to 5 years. I understand that direct quotations may be used within the write up of the research report, but that identifiable information will be removed.

6. I understand that if I disclose information concerning risk to myself or others then this will be shared with the research supervisor who may pass this on to my GP or other health professionals involved in my care.

7. I agree to take part in the above project.

Name of Participant

Date

Electronic Signature

Appendix F

Narrative Question

Narrative question:

Can you tell me about your experience of living with MS, including your experience of living with MS before, during and after the mindfulness course?

Begin where ever you like and please take the time you need.

Possible prompt questions:

Is there any more story you can tell me?

Are there any other things you remember happening?

How would you have described your life before you attended the MBSR course?

What was your experience like when you were on the MBSR course?

What has life been like since the MBSR course?

If not covered in narrative ask:

Age

Gender

Ethnic background

Year of MS diagnosis

Type of MS

Prior experience of mindfulness

Appendix G

Analysis Examples

Extract from Story Summary - Paul

(AT) Can you tell me about your experience of living with MS, including your experience of living with MS before, during and after the mindfulness course?

(AT) And you can really begin wherever you'd like and just take take as much time as I know, that's a lot to cover.

As expected, I've got MS, I'll read up what that is and work through it, life will go on

I was diagnosed October 2016. years previous I had different symptoms, I couldn't work out what they were. And I was working and I had young children, my wife works as well. It was Friday night, I came back from the seeing the neurologist saying as expected, I've got MS ill read up what that is and work through it was basically life will go on doesn't impact me that much.

I've met people, who say and overnight, I read the book and I changed the way I am. And that's not me. I knew what I had to, it's how I get there.

It would have been February the next year and I've got a book, overcoming multiple sclerosis and I didn't pick it up or read it till April. I thought I done a lot of research on things, but it wasn't until I read the seven steps and the explanation behind it. diet is first, vitamin D is second, exercise is third and mindfulness is fourth. That made a lot of sense. I've met people, who say and overnight, I read the book and I changed the way I am. And that's not me. Because diet was the toughest thing, and everything that I had to change and it's probably been you know, four years since then where I've been working towards doing what I think is right which is the MS Program. One of those steps being mindfulness. So, by the time, then I knew what I had to, it's how I get there.

Shortened Story Summary - Paul

Beginning	Middle	End
I was diagnosed October 2016. Years previous I had different symptoms. I came back from seeing the neurologist saying as expected, I've got MS. I'll read up what that is and work through it. Life will go on.	I went on a MS retreat It was the people who were there who are following the program closely, more closely than I could see were the best. People were saying that mindfulness was the toughest thing they found to do. It was the same for me. At the end of that course I was more convinced of the benefit of mindfulness	I try and find time I don't do as much as I should do. It is the longest I've gone since I've been diagnosed. I wouldn't give mindfulness the credit for that. I think it's an important part of my toolbag.
I thought I done a lot of research on things, but it wasn't until I read the seven steps and the explanation behind it. I've met people, who say and overnight, I read the book and I	my health was deteriorating, it was like the year of pain, it was very difficult going to work, I agreed with work that I would finish up	

<p>changed the way I am. And that's not me. I knew what I had to, it's how I get there.</p>	<p>At times it was like I had my back to a fire, burning fire, I couldn't walk away from it</p> <p>This neuropathic pain, it was somehow connected with stress. So then I thought, you know I will have to pursue the mindfulness a bit more.</p> <p>I was looking forward to it. I did enjoy meeting other people who has MS. I got far more out of the course than the previous one I did.</p>	
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Analysis of Turning Points

Theme	Turning points
Illness progression / loss of control	<p>“Then it all came to a head um one day just I was walking and I fell over.” Samantha</p> <p>“It’s pretty much the worst experience of my life (hospital admission)” Samantha</p> <p>“And then it slightly got worse and then I suddenly then realise that actually I couldn’t sort it. And I. I rather fell apart, to be honest.” Roy</p> <p>“My health was deteriorating... This neuropathic pain was all the way from so that kind of took over, 2019 was like the year of pain” Paul</p> <p>“I did I distinctly remember this numbness in both my legs, that was a real striking thing” John</p> <p>“And it was it was a horrible day is a day I got the actual diagnosis, on the way back from there on the train with my husband coming back out of central London I got the phone call from work to say, we had the meeting today and it has been decided to offer you early retirement. And so, so all on one say so it was a very. very pertinent day.” Rachel</p> <p>“It was just getting so hard and coupled with various other things. It all sort of came together at once, not once but you know to say actually I can retire suddenly not being able to carry two cups of tea, I found I still find really hard and really embarrassing” Sarah</p> <p>“When you’re facing something as as life changing as that (symptoms / diagnosis)” Judy</p> <p>“I noticed my symptoms getting worse again. and I was still doing meditations, but I wasn’t improving anymore and I wasn’t feeling like I was and I kind of lost that passion for it and.....I continue the meditations but more as a burden” Ahdia</p>
Regaining direction / relief	<p>“At last my mind was completely silent. Yeah, absolutely. We were supposed to be thinking about something, but it was silent. It was finally silent. Yeah. And that’s what I’ve been searching for” Samantha</p> <p>“Unlike all my other experiences. She sat me down I whittled on for a bit and she looked me straight in the eye and we went she went Of course you feel like that you are ill you’re supposed to feel like this now we’re going to sort it out. sat down and. She helped me sort it out.” Roy</p> <p>“One of the big lessons that I learned. Is that I shouldn’t be aim to be happy. I should aim to be content. And when there’s days when I can’t do anything. I can be content.” Roy</p>

"I thought I done a lot of research on things, but it wasn't until I read the seven steps and the explanation behind it.That made a lot of sense. I've met people, who say and overnight, I read the book and I changed the way I am. And that's not me. Because diet was the toughest thing, and everything that I had to change and it's probably been you know, four years since then where I've been working towards doing what I think is right which is the MS Program. One of those steps being mindfulness. So, by the time, then I knew what I had to, it's how I get there." Paul

"I don't know almost overnight.... this this neuropathic pain, it was somehow connected with stress. So then I thought, you know the mindfulness I will have to have to pursue it more than like a couple of minutes." Paul

So I was very cynical. And but well while I found Dr Jarack his work I thought this makes a lot of sense, you know. And so, and obviously mindfulness was a part of that." John









"One of the exercises that was really powerful for me was when she asked us in pairs in break out rooms to talk about our MS and then think of your MS being in an empty chair next to you what would you say to it. it required it that required each individual to really search deep." Sarah

"We were asked to write that I want you to imagine MS is sat next to you, and what would you want to say to it. And that was probably the first time, in fact, I was in. It had a very profound emotional reaction in me". Judy

I went to the retreat in January last year it was like really amazing and I could like and there was like an over 1000 other people there and you're all meditating together and Your it was it was just like this really amazing experience, and I could feel like my Ms was getting so much better like just through my own thinking" Ahdia

"during the course we were made to answer the question um. Name something positive that's come out of having MS and we had to actually. share those we shared that those answers with other people and. It forced me to actually address that issue and look at my life and see and really think about all the positive stuff that has come out of my MS". Ahdia

Analysis of Positioning Extract

<p>33 Can you tell me about your experience of living with MS before, during and after the 34 mindfulness course? You can begin anywhere and take as much time as you need. 35</p>		<p>Turner, Abbie Significance of young diagnosis / having to live with MS so long</p>
<p>36 Okay um so my background is that um so I got diagnosed ages ago like when I was 19 and 37 um and that's. for a long time meditation mindfulness that was nothing, nothing, something 38 it wasn't something that I would ever ever consider doing like at all. I think. um I think, as 39 my as I, as my kind of like yeah as I went on, with the illness and stuff I think around two 40 three years back. Well ma around three years back yeah My MS had become very bad and 41 I've now kind of exhausted all the treatments that are available. And I'm still I was still only 42 like. Early 30s, and so I was like okay I've got to find something else to do, now, during the 43 time since 19 to 30 I tried, you know random things like. Changing my diet and all that kind 44 of stuff but it didn't really do anything and so um. Then I thought Okay, let me like I some 45 people mentioned stuff about meditation to me and I kind of just like brushed it off but um, 46 I thought Okay, I thought there's nothing to lose I've got no Western medicine left to try so 47 let me try some other avenues so. I heard about someone called Dr Jodie spencer. (AT: ok) 48 Do you know him. (AT: no) basically hes this American guy that. healed he had a huge car 49 accident, and he was meant to become paralyzed or something but use the power of his 50 own mind. To totally healed himself and he managed like fixes his ribs well I don't know how 51 many broken ribs he had and all sorts of other problems and just through. visualization and 52 meditating he managed to completely fix everything, and so, then he made it kind of like 53 his. job in life to go around the world, helping other people do the same so um theres, like 54 loads of different. testimonials online as well. including lots of people within MS that have</p>	      	<p>Turner, Abbie Positioning self not aligned with mindfulness</p> <p>Turner, Abbie Positioning self as suffering / out of options / hopeless</p> <p>Turner, Abbie Positioning self as victim – Wider cultural narrative that illness shouldn't happen to younger people</p> <p>Turner, Abbie Positioning self with agency / self-reliant</p> <p>Turner, Abbie Positioning self-reliant / someone taking active steps to regain wellness</p> <p>Turner, Abbie Self as uninterested in mindfulness / others help</p> <p>Turner, Abbie Positioning self as lost and regained hope</p>

Appendix H

Section from Reflective Diary

Trying to gain a sense of control and certainty

It has been hard to pin down a research topic - I have limited knowledge in mindfulness and MS and therefore am finding it hard to know where research gaps are. I feel pressured by the deadlines for the presentation and proposal and am finding it hard to sit with the uncertainty and imperfect ideas.

I have spent time thinking about the concept of identity and how to define this. I started by reading identity theories and exploring quantitative methods of measuring identity. There are a few research studies in this area but no agreed definition or measure. I found a lot of the theories made some sense but didn't necessarily capture everything. There was a focus in my reading at this point as identity as something that is fairly fixed. I looked at some qualitative literature and became interested in doing qualitative study as it captures more of the persons experience and I think it fits better with identity as individual and multifaceted. I have been thinking about my own identity and what defines me. Sometimes I don't think I have a good sense of who I am and I can take a passive role and fit in with other people. This is becoming apparent in making research decisions and my lack of confidence in my own ability. I am leaning towards taking a social constructionist approach but anticipate this will be challenging to me as is not my natural way of thinking.

MBSR

I am coming to the end of the MBSR programme. I began by feeling very different to other people on the course. For example, I found their gratitude over the top. The idea of doing 5 x 30 minute practices a week seemed hard at first however during the first week doing the body scan I really valued having set time and space to just stop and be. I felt calmer after the practices and it has been got easier through the week. The informal practices felt more difficult for me. I was really touched by the secondary part section the mindfulness tutor shared. I could really relate to this and notice how much unnecessary suffering comes from my reaction and holding onto things. I am approaching the end of the course and have noticed a number of benefits. I feel my relationship has improved as I am not hold onto things as much, and I am more aware of the impermanent and everchanging nature of things. I have become more aware and kinder to myself. I plan to keep up with regular practices.

Giving up control

I have been reflecting on my position with the research. It is something that I have to do and feel incompetent and resistant towards. I also feel fraudulent coming in with no experience of long-term health condition or MBSR. I feel in an uncomfortable position talking to people with lived experience as they are looking and talking to me as if I am an expert and I feel far from this. I completed my first interviews. I was worried about how I would keep the

interview going without biasing the data. I was really shocked by how much the first person spoke. I found myself feeling preoccupied by what she was talking about and whether it fit my question. I found it hard to give up control and let the interviews be completely guided by her. I didn't feel like they were giving me enough relevant information about mindfulness and instead overwhelmed by the amount of info provided about her experience of living with MS. The second interview was starkly different in terms of where they were at with mindfulness and with MS. I noticed feeling underwhelmed by their description of their response, which mirrored some of my past experiences of trying it.

Getting lost in the data

I am feeling overwhelmed by the data, I'm aware that I want to find evidence that relates to my ideas around identity shifts and flexibility in thinking. I feel distracted by the contextual information which adds complexity. This reminds me that the research is not about my expectations of what's important to them, it's about what's important to them. I find myself wanting to rush ahead and know what the analysis looks like, I need to just sit with the data and immerse myself in it. It is a process that will develop over time. I am noticing themes of losing control and becoming disempowered connected with me and how I'm feeling now. I have also noticed feeling more enthusiastic about the research as I begin to see the humanness behind the stories and the need for this type of research over clinical trials etc. In trying to become familiar with the data I have been struck by the ethical aspects of rewriting people's stories. I am becoming more aware of how truths are often formed through interaction with others. This is holding me back as I'm worried about misrepresenting participants. I have found myself tending to be very descriptive rather than analytic with data, partly because don't feel confident in what I'm doing and partly because I don't want to impose my truth on other people's stories. Struggle between keeping people's individual stories and providing succinct analysis and between keeping the persons voice at the cost of being unanalytical. I've reflected on the difference between analysing data on my own compared to my normal therapeutic positioning of working alongside and coming up with shared understandings. I also found myself wanting to reorder participants stories to fit with my question and how I would have structured it. When I thought about this further, I realised that every time I change something within their stories then I am adding me and taking away from them. I have found myself becoming more aware of LT illness and the massive impact it has on people, and in particular how it is not valued by western society meaning people are left feeling like they become a burden. This is making me more aware of my own vulnerability and health.

Appendix I

Dissemination Statement

The findings from this study will be disseminated through feedback, journal publication and presentation.

Dissemination to participants and mindfulness providers.

Participants were asked if they wanted to be kept informed of the study findings.

Those that opted in will be sent a summary of the findings. The recruitment site and mindfulness course facilitators will be sent a summary of the findings and informed that the study is now complete.

Journal Publication

It is expected that the study will be submitted for publication with Psychology and Health (Impact factor 3.037).

Presentation

The research findings will be presented to an academic audience, for peer review, as part of the Doctorate in Clinical Psychology at the University of Exeter. A verbal presentation of the research findings will be offered to MS-UK.

Appendix J
Copy of Instructions for Authors

<https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=gpsh20>