The Experience of Identity Change in People who Reported Having a Diagnosis of Multiple Sclerosis: A Qualitative Enquiry

Alexander B. Barker[1], Kathryn Smale[1], Nigel Hunt[2], Nadina B. Lincoln[1], and Roshan das Nair[2,3]

[1]: *Division of Rehabilitation and Ageing, University of Nottingham*

[2]: *Division of Psychiatry and Applied Psychology, University of Nottingham*

[3]. *Institute of Mental Health, Nottingham*

Keywords

Multiple Sclerosis (MS), Self, Rehabilitation < Adaptation, Coping, Enduring, Psychology, Psychological Issues

Practice Points

Multiple sclerosis (MS) may cause changes to a person's sense of self. Using a previously held social identity, such as the family identity, can allow a person to acknowledge their changed self-identity and accept social support, which can positively affect their mood. People with MS may be more willing to accept social support from others once they assimilate their MS into their social identity.

Abstract

Background - A diagnosis of multiple sclerosis (MS) can lead to changes to a person's sense of self. The aim of this study was to investigate the subjective experience of identity change and subsequent adjustment to MS.

Methods - Semi-structured interviews were conducted with 16 people who reported having MS. Interviews were analysed using thematic analysis.

Results - In the early stages of the disease progression, participants wished to compartmentalise the disease. Over time, through reflected self-appraisals, brought about by increasing symptoms and changed relationships with others, the disease became a part of participants' self-identity.

Conclusions - For people with MS, incorporating and accepting the disease as part of their self-identity can have positive implications for seeking and receiving support.

Keywords

Multiple Sclerosis**,** Self**,** Rehabilitation**,** Adaptation, Self-identity

Word Count

4039

Introduction

Multiple Sclerosis (MS) is a chronic, progressive, often degenerative condition which affects the central nervous system.[1] MS affects approximately 100,000 people in the UK[2] and 2.5 million people worldwide.[3] The condition can lead to a wide range of symptoms, including cognitive and visual impairment, vertigo, sexual, bowel and bladder dysfunction, fatigue, muscle weakness, ataxia and spasticity.[4] MS can have a devastating impact on a person's sense of self, with body and performance failures leading to feelings of loss of self and changes to identity[5], which can have a negative psychological effect on an individual.[6, 7]

One explanation for how individuals acquire their sense of self is through 'reflected appraisal'. Reflected appraisal refers to the process through which people's self-views are influenced by their perceptions of how others see them.[8] Due to the impact of MS on a person's sense of self and identity,[5] people with MS may perceive that others view them differently because of their MS.

However, people can have multiple identities to represent themselves in different situations.[9] A person can respond to these identities and either incorporate them into their sense of self and think and act accordingly or have a complete lack of interest or motivation in an identity,[10, 11] a person can choose to accept an identity as part of who they are, or to reject it. It is possible that a person could have an identity which they have not internalised to their overall sense of self. As MS is 'imposed' on a person and causes changes to a person's identity and sense of self, it is possible that this MS identity may not be incorporated into a person's sense of self, a person may choose not to accept this identity as part of who they are, this could lead to negative effects of identity change[12] and an unwillingness to seek social support with others who share the MS identity.[10]

The Social Identity Model of Identity Change[12] posits that belonging to a large number of different groups before a life-changing transition, such as a diagnosis of MS, can protect individuals from the effects of this transition by providing them with groups to rely on.[6] These groups form a basis for drawing social support, whilst providing a secure base for people to establish new identities, which are integrated and compatible with previous identities, enhancing a person's identity continuity.[12] This can reduce the negative effects of identity loss on psychological wellbeing.[6]

Whilst research demonstrates that individuals undergo a loss of aspects of identity following a diagnosis of MS,[5] the individual's experience of this change is less well understood. There are also differences in the extent of detrimental effects of having MS that people with MS experience[13,14] and how they live with an unpredictable disease,[15] suggesting that some factors may prevent the negative effects of identity loss, such as psychological factors including perceived stress and emotion focused coping.[16] A person's response to the disease could have an effect on how they manage their illness and may explain why empirical studies evaluating the effectiveness of therapies for depression and anxiety in people with MS, have mixed results.[17,18]

The aim of this study was to investigate the subjective experience of identity change over time to provide insight into this process.

Methods

Participants

Participants were identified from a feasibility randomised controlled trial (RCT) of an adjustment intervention for people who reported a diagnosis of MS.[19] The trial compared individual vs. group delivery of the same adjustment intervention.[20] Participants from both arms of the trial who consented to be interviewed were contacted four months after randomisation. Sixteen participants were interviewed from the 21 participants invited. Ethical approval was granted as part of the feasibility RCT,[19] reference 12/EM/0380.

Table 1 here

Data Collection

Semi-structured interviews were conducted by two researchers, nine by AB and seven by KS, using the same interview schedule (Appendix 1). Open-ended questions were asked which allowed for exploration of participants' thoughts and feelings on their social relationships before and after diagnosis, and changes to social relationships over time, as well as any effect these changes may have had on participants mood. Interviews took place either at the University or at the participant's home, depending on their preference, and lasted between 20 and 60 minutes. Interviews were audio recorded and transcribed verbatim.

Where it facilitated discussion, eco-mapping techniques[21-25] were used to help elicit information about an individual's previous and current social identities. Eco-maps allow a graphical representation of the relationships that people have and their connection to larger social networks.[22] This can provide us with valuable information about a person's social network, including the structure, size and function of the network and individual connections.[26] Eco-maps are useful for mapping and tracking changes to people and their social relations and contacts over time, capturing the participants' own perceptions,[27] in a visual, standardized manner.[28] The use of eco-maps allowed us to gain insight into participants' social lives both before and after the MS diagnosis. A fictitious example of an eco-map can be found in supplementary figure 1.

Data Analysis

To understand and gain further insight into the process of subjective identity change, an interpretive epistemological stance[29] was taken to collect multiple realities from participants.

A thematic analysis was conducted,[30] applying the SIMIC[12] as a lens for understanding and structuring the data. The interview data were examined to identify categories most pertinent to the research question. Once this had been achieved, the process of sense making was used to find connections and relationships in the data. This was achieved by successive reading of the texts, critical reflection and persistent immersion in the text. Following recognition of themes, with the support of quotes, these were discussed and compared and contrasted with within the research team to ensure a consensus.

Results

Overview

Themes identified in the data were: concealing the disease, presenting a more positive identity, effects of increasing symptoms/changing relationships with others, social support, family as a secure base, self-reflected appraisal, and integration or compartmentalisation of the MS identity.

The analysis revealed patterns of adjusting to MS over time, with different factors affecting identity changes at different stages. The patterns of adjustment all began with participants concealing their disease by denying their diagnosis and/or compartmentalising the MS whilst retaining a positive social identity. Due to progressing symptoms which resulted in the MS being more visible to others and subsequent changed relationships, participants began to experience the negative effects of identity change and sought social support, which led to a self-reflected appraisal and an acknowledgement of MS as an identity that they hold.

Following this realisation, participants either incorporated their MS into their self-concept, or did not accept MS as part of their self-concept and kept this identity compartmentalised.

Concealing the disease

Diagnosis was often seen as an identity marker and signalled the start of the adjustment process. However, the time between first acknowledging symptoms and receiving a diagnosis might have made it difficult for some participants to come to terms with their MS.

> Dawn[1] (F, 58, RR[2]) '…I struggled with MS when I was first diagnosed with it, and I struggled with the idea of having it and the fact that I'd had it an awful long time but wasn't diagnosed.'

Some participants felt that they should attempt to preserve their pre-diagnosis 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.'

Some participants felt that they needed to preserve their previous identity due to the perceived stigma they attached to the MS identity. 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.'

---

[1] Pseudonyms are used in these quotations.

[2] Pseudonym, Gender (M = Male, F = Female), Age, Type of MS (RR = Relapsing remitting, SP = Secondary Progressive, B = Benign, DU = Diagnosis Unknown, NO = Neuromyelitis Optica

Some social relationships reinforced the pre-diagnosis identity, which may have led to participants seeing their identity as unchanging.

> Rebecca (F, 42, RR) ‘There’s erm, one or two [friends], that treat the MS as though it’s never happened.’

Being treated in a way in which the MS ‘never happened’ reinforced the pre-diagnosis identity. To maintain high self-esteem, Rebecca appeared to acknowledge positive aspects of herself as important and unchanging whilst attaching low importance to aspects of identity related to negative self-beliefs, such as the feared consequences of MS. In a similar way, participants attempted to regain aspects of their previous identity that may have been lost due to the effects of MS. This externalisation of MS was a way of coping and provided an avenue to vent their frustrations. Another example of the externalisation of MS can be seen in the initial concealment and relative secrecy regarding a diagnosis of MS.

Presenting a more positive identity

In the data, participants articulated numerous identities. One participant attempted to preserve a prominent marker of her pre-diagnosis 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 I 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 stigmatised (MS) whilst acting in accordance to an identity that she saw as highly valued (work). Exchanging a stigmatised negative identity for something that the participant saw as valued was one technique for coming to terms with the diagnosis.

Effects of increasing symptoms/changing relationships with others

The physical symptoms of MS were perceived as markers of the 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 re-evaluation of what the participant viewed as their self. This re-evaluation 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.’

Intrusive symptoms of MS often led to perceived changes in their relationships with other people. This led participants to re-evaluate their sense of self and they began to see the MS as part of who they were.

> William (M, 47, RR) ‘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. I can’t always do the same things that I used to be able to do.’

Social support

Participants saw social relationships as a way of dealing with the problems associated with MS. Participants chose the type of support that they felt they required by actively choosing which identity and reflected appraisal they needed at that moment in time.

> Beth (F, 56, B) ‘[Friends] haven’t really changed, it’s been more about me finding out, which friend can offer me the right support at the right time.’

Social support in general appeared to be closely linked to participants' mood and appeared to help participants come to terms with their diagnosis.

> Dawn (F, 58, RR) 'She [friend] almost brought me back into the fold, so to speak.'

Social relationships also caused negative emotions, due to the conflict they caused between a person's previous identity and their new emerging one, such as struggling to explain to friends that they are tired. A number of relationships were lost or disrupted following the changes to identity due to MS. The loss of social relationships due to identity change had a negative psychological effect on participants' mood.

Receiving social support from other people with MS appeared to normalise the emerging MS identity.

> Kelly (F, 28, RR) 'There's actually people out there that have, are doing, have done, have experienced what I've gone through, have been through.'

Due to the reluctance to accept MS as part of their identity during the early stages of the adjustment process, participants may have been more inclined to seek social support from those who they saw as sharing their pre-diagnosis identity.

Family as a secure base for identity reconstruction

The family provided a source of social support for participants during the identity change. Family members were often the first people to know about participants' diagnosis of MS, and were also seen as useful in providing support for some of the problems that occurred during identity change.

> Kelly (F, 28, RR) 'Immediate family have to spend time with me no matter what…what mood I'm in, and what's going on yeah, that's the best support there is…'

The family can be quite a large social group. One participant, who before diagnosis had expressed strong ties with his wider family group, found that this diminished following diagnosis so that he only remained close to immediate family members. This change was due to the emerging symptoms of MS changing his outlook. Some participants found that not all aspects of their family initially provided a secure base for identity reconstruction.

> Evelyn (F, 60, SP) ‘My ex-partner began to resent me as soon as my disability became really apparent.’

For the family to be an effective secure base for identity reconstruction, all members of the family need to work together to accept and adjust to the diagnosis. This narrative of the family not acting as a secure base suggests how important it is for coping strategies to be aligned between the family and the person with MS.

Self-reflected appraisal

The emergence of symptoms may cause a person with MS to re-examine their identity and sense of self and be more open to self-reflected appraisals. 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.’

Integration of the MS identity into changing sense of self

Over time the MS, which was externalised due to the negative identity connotations, could become integrated into a pre-existing self-concept based on self-reflected appraisals. Participants began to view themselves based on how others reacted to them. Over time, symptoms may become progressively more visible to others, which led participants to re-evaluate their sense of self.

> Leonard (M, 46, DU) ‘I knew for three years before I actually let it [MS] affect my life…And then it got to the point where it does, so you can’t hide it anymore.’

The ability to retain a sense of identity continuity appeared to be associated with positive psychological wellbeing. Indeed, our participants used this as an early coping mechanism until the disease became more prominent, at which point they felt a need to incorporate this identity into their sense of self and engage in activities that were more representative of the MS identity, such as attending MS support groups. This was, however, not universal. Three participants continued to compartmentalise the disease following the recognition of the MS identity. This may reflect differences in willingness or ability to incorporate the MS identity into the overall sense of self.

Compartmentalising the MS identity

The MS identity is one that is forced on to a participant and not an identity developed through motivations or goals. The stigmatised nature of the identity often resulted in a lack of personal value being placed on the MS identity, and people with MS may wish not 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 compartmentalise 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.’

Compartmentalising the MS identity presented a relative absence of internalisation of the MS into the self-concept. Instead, participants presented identities that they considered to be more highly valued.

> Beth (F, 56, B) ‘Because my MS has got worse recently so that’s why I’ve probably got a bit more proactive than I was, because I just didn’t do anything for years because I have been diagnosed, what, 12 years, and I haven’t done…I’ve just got on with it.’

Assimilating the MS identity into self-concept

On acknowledging the MS identity, several participants began to assimilate this identity into their sense of self.

> Dawn (F, 58, RR) ‘Because it [MS] was mine and I wanted to control it. I didn’t understand it, so how can I tell people what I’ve got if I don’t understand it? I didn’t understand it. I did lots of research and reading up, and that, and I still didn’t understand it. I knew all the words, but they just didn’t work for me then. It wasn’t until two years after I was diagnosed, I suppose, that I actually got to grips with it and thought, ‘This is ridiculous, make friends with it and stop worrying about it’, which is what I did.’

A common theme in the data was that after an initial adjustment to the diagnosis of MS, participants acknowledged that they were more willing to talk about their disease. Participants may have been unwilling to talk about their diagnosis without first adjusting to their diagnosis and having incorporated the MS identity into their self-concept. Similarly, whilst social support can help a person adjust to their changing identity, acceptance of a changed identity can have implications for the social support a person seeks and receives in the future.

> Francis (F, 54, RR) ‘No, I probably wasn’t ready [to talk about the MS]. The first year I couldn’t get about anyway. I was quite ill for the very first year and then I... sort of started just getting used to having problems and I probably... No. I think, you know, people say, ‘Oh, there’s this you can phone’ and I had always thought, oh I don’t want to

> speak to other people, it's all the same thing and... You know, I would always have that, sort of, attitude. I think I was just about ready now to have some contact.'

Discussion

Social Identity Theory[31] posits people have multiple identities depending on how they see themselves in the social situation they are in. Whilst, the MS identity may be imposed on an individual due to their diagnosis, the participants in this study articulated multiple identities highlighting a pattern of recognising their MS and choosing to assimilate the MS into their social identity or compartmentalise their MS. In the early stages of the disease progression following diagnosis, participants wished to compartmentalise and conceal the disease and continue with their pre-diagnosis identity, a similar finding to recent research[32] however, over time they came to accept and acknowledge their MS and learned to cope with the everyday problems associated with living with MS. Compartmentalisation of the MS identity could reflect early coping strategies[9] and it appears that individuals can assimilate the MS identity into their self-concept at a later time.

Presenting a more positive identity in social situations appeared to be beneficial for some participants. This exchange of identities can be a stressful process that requires considerable psychological resources[33] and this pattern of compartmentalising thoughts about the self could provide greater resilience in times of stress.[34]

Participants restructured their social resources in an attempt to adapt to the MS. By receiving social support from close family members and friends, participants were able to acknowledge their emerging identity in a supportive environment, consistent with the Social Identity Model of Identity Change.[12] The family was a secure base for identity reconstruction, in line with previous research.[35,36] This suggests that there are stages to adjustment; however, these did not appear to be the same across the sample. However, most participants initially did not acknowledge the MS as part of their identity and instead saw this as a stigmatised identity, which led to an initial concealment of the diagnosis and a period of withdrawal. Presenting a more positive self-image and compartmentalising the disease allowed participants to cope with the early stages of adjustment, allowing them to present an identity that they saw as more highly valued to maintain self-esteem.[31] However, as symptoms became more prevalent, people around the participant began to treat them differently causing a self-reflected appraisal and a changing self-concept. The use of social support during this time appeared to be beneficial for coming to terms with this change in identity. The increasing presence of MS symptoms combined with social support and positive interactions with others appeared to help people recognise the MS as an identity that they hold.

A person's identification with their MS, and therefore assimilation of this identity into their self-concept, appears to be linked to the coping strategies they use. Acting in accordance to an identity that individuals identify with can result in autonomous behaviour in line with this identity, such as increased motivation to communicate with other people who share the MS identity. This has implications for the delivery of interventions for mood problems in people with MS, in that these interventions may be more beneficial once a person has started to come to terms with the diagnosis and incorporate the MS identity into their self-concept.

These findings need to be considered in light of the study's strengths and limitations. To ensure the quality of the research, data were rigorously analyzed. Once the themes were drawn out, with the support of quotes, these were discussed and compared across members of the research team. The participants were a unique group of people at a certain time speaking in a certain context with a particular researcher, and this should be considered in the transferability of results and conclusions. One participant who originally reported having a diagnosis of MS was later found to have a diagnosis of neuromyelitis optica but was retained in the study.

In conclusion, this study has provided us with insight into how people with MS acknowledge and incorporate their MS into their self-concept over time. It appears that people with MS do incorporate their illness into their identity over time and this appeared to have a positive effect on mood. The availability of social support and the coping strategies a person uses may affect the time it takes for a person to come to terms with this change of identity. MS is more readily accepted as part of a person's identity if it is not stigmatised and is seen as only a part of a person's identity. If the diagnosis is stigmatised, people may not readily acknowledge MS as a significant part of their identity, which may restrict their willingness to receive social support, which could then impact on their mood. Using a previous social identity such as the family identity, can allow a person to acknowledge their changed self-identity and accept social support, which can have a positive effect on their mood.

Acknowledgements

No other people were involved in this study.

Conflict of Interest

The authors disclose no conflict of interest.

Funding

Alex B. Barker, PhD studentship was provided by the MS Society (966/12).

Previous presentation

This manuscript has not been previously presented.

References

1. Compston, A. and A. Coles, *Multiple Sclerosis.* Lancet, 2008. **372**(9648): p. 1502-1517.
2. Multiple Sclerosis, S., *What is MS?* 2018.
3. Compston, A. and A. Coles, *Multiple Sclerosis.* Lancet, 2002. **360**(9333): p. 648-648.
4. Goldenberg, M.M., *Multiple sclerosis review.* Pharmacy and Therapeutics, 2012. **37**(175-184).
5. Boeije, H.R., et al., *Encountering the downward phase: biographical work in people with multiple sclerosis living at home.* Social Science & Medicine, 2002. **55**(6): p. 881-893.
6. Haslam, C., et al., *Maintaining group memberships: social identity continuity predicts well-being after stroke.* Neuropsychological Rehabilitation, 2008. **18**(5-6): p. 671-691.
7. Haslam, S.A., et al., *Social identity and well-being: an emerging agenda for applied psychology.* Applied Psychology, 2009. **58**(1): p. 1-23.
8. Wallace, H.M. and D.M. Tice, *Reflected appraisal through a 21st-century looking glass*, in *Handbook of Self and Identity*, M.R. Leary and J.P. Tangney, Editors. 2012, The Guildford Press: New York.
9. Linville, P.W., *Self-complexity theory as a cognitive buffer against stress-related illness and depression.* Journal of Personality and Social Psychology, 1987. **54**(2): p. 663-676.
10. Ryan, M. and E.L. Deci, *Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being.* American Psychologist, 2000. **55**: p. 68-78.
11. Pelletier, L.G., et al., *Why do people fail to adopt environmental behaviours?: Towards a taxonomy of environmental amotivation.* Journal of Applied Social Psychology, 1999. **29**: p. 2481-2504.
12. Jetten, J. and N. Panchana, *not wanting to grow old: a social identity model of identity change (SIMIC) analysis of driving cessation among older adults*, in *The Social Cure: Identity, Health and Well-being*, J. Jetten, A.S. Haslam, and C. Haslam, Editors. 2012, Psychology Press: Hove & New York.
13. Antonak, R.F. and H. Livneh, *Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis.* Social Science and Medicine, 1995. **40**(8): p. 1099-1108.
14. Brooks, N.A. and R.R. Matson, *Social-psychological adjustment to multiple sclerosis: a longitudinal study.* Social Science and Medicine, 1982. **16**(24): p. 2129-2135.

15. Wilkinson, H.R. and R. das Nari, *The psychological impact of the unpredictability of multiple sclerosis: a qualitative literature meta-synthesis.* British Journal of Neuroscience Nursing, 2013. **9**(4): p. 172-178.
16. Dennison, L., R. Moss-Morris, and T. Chalder, *A review of psychological correlates of adjustment in patients with multiple sclerosis.* Clinical Psychology Review, 2009. **29**(2): p. 141-153.
17. Hind, D., et al., *Cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: a systematic review and meta-analysis.* BMC Psychiatry, 2014. **14**(5): p. 1-13.
18. Thomas, P.W., et al., *Psychological interventions for multiple sclerosis.* Cochrane Database of Systematic Reviews, 2006. **1**: p. CD004431.
19. das Nair, R., et al., *Comparing individual and group intervention for psychological adjustment in people with multiple sclerosis: a feasibility randomised controlled trial.* Clinical Rehabilitation, 2016. **30**(12): p. 1156-1164.
20. Lincoln, N.B., et al., *Evaluation of an adjustment group for people with multiple sclerosis and low mood: a randomised controlled trial.* Multiple Sclerosis, 2010. **17**(10): p. 1250-1257.
21. Hartmann, A., *Diagrammatic assessment of family relationships.* Families in Society, 1995. **76**: p. 111.
22. Wright, L.M. and M. Leahey, *Nurses and Families: A Guide to Family Assessment and Intervention*. 2000, Philadelphia, PA.: FA Davis Co.
23. Tracy, E.M., et al., *Support networks of primary caregivers receiving family preservation services: an exploratory study.* Families in Society, 1994. **75**: p. 481-489.
24. McCarty, C. *Structure in personal networks*. Journal of Social Structure 2002 [cited 3; Available from: https://www.cmu.edu/joss/content/articles/volume3/McCarty.html.
25. Barker, A.B. and G. Winship, *Recovery is no laughing matter - or is it?* Mental Health and Social Inclusion, 2016. **20**(3): p. 167-173.
26. Tracy, E.M., et al., *Support networks of primary caregivers receiving family preservation services: an exploratory study.* Families in Society, 1994. **75**(8): p. 481-489.
27. McCarty, C., *Structure in personal networks.* Journal of Social Structure, 2002. **3**.
28. Hartman, A., *Diagrammatic assessment of family relationships.* Families in Society, 1995. **76**(2): p. 111-122.
29. Lincoln, Y. and E. Guba, *Naturalistic Inquiry*. 1985, London: Sage.
30. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative Research in Psychology, 2006. **3**(2): p. 77-101.
31. Abrams, D. and M.A. Hogg, *Social identity theory: Constructive and critical advances*. 1990, Hemel Hempstead, England: Harvester Wheatsheaf.
32. Fallahi-Khoshknab, M., et al., *Confronting the diagnosis of multiple sclerosis: a qualitative study of patient experiences.* Journal of Nursing Research, 2014. **22**(4): p. 275-282.
33. Showers, C.J. and K.C. Kling, *Organisation of self-knowledge: implications for recovery from sad mood.* Journal of Personality and Social Psychology, 1996. **70**(3): p. 578-590.
34. Alloy, L. and L. Abramson, *The Temple-Wisconsin vulnerability to depression project: conceptual background, design and methods.* Journal of Cognitive Psychotherapy: An International Quarterly, 1999. **13**: p. 227-262.
35. Barker, A.B., et al., *Social identity in people with multiple sclerosis: a meta-synthesis of qualitative research.* Social Care and Neurodisability, 2014. **5**(4): p. 256-267.
36. Barker, A.B., et al., *Social Identity in People with Multiple Sclerosis: An Examination of Family Identity and Mood.* International Journal of MS Care, 2017. 20(2): 85-91.

Table 1: Demographic characteristics of the interviewees.

N=16		Mean (SD)
Age (Years)		47.3 (11.9)
Time Since Diagnosis (Years)		8.1 (6.6)
		n
Gender	Men	5
	Women	11
MS disease subtype	Relapsing-Remitting	9
	Primary Progressive	0
	Secondary Progressive	2
	Benign	1
	Neuromyelitis Optica	1
	Unknown	3
Ethnicity	White British	14
	Asian	2
Relationship Status	Married/Partner	10
	Single/Divorced	6

Table 1: Demographic characteristics of the interviewees.

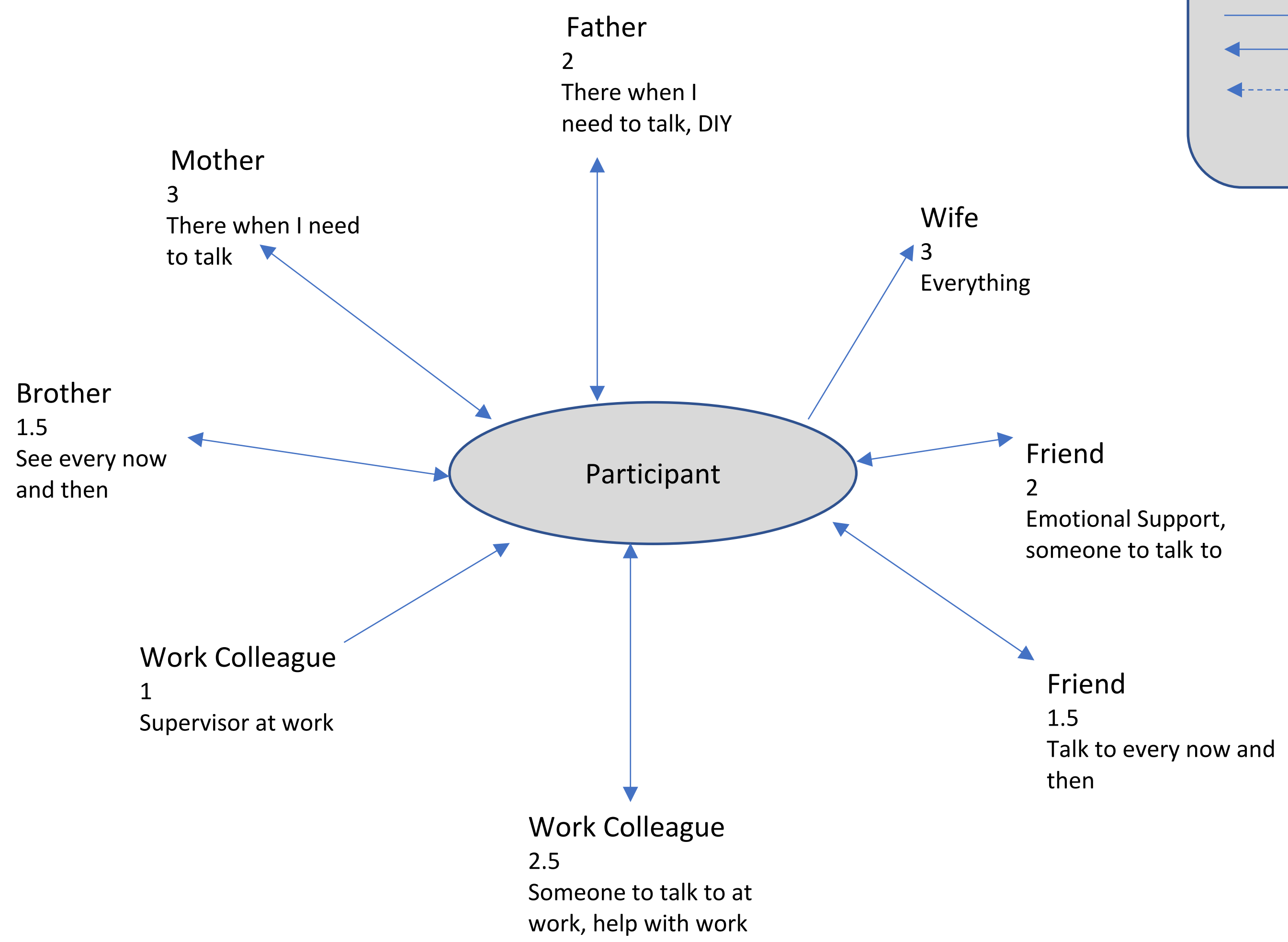
N=16		Mean (SD)
Age (Years)		47.3 (11.9)
Time Since Diagnosis (Years)		8.1 (6.6)
		n
Gender	Men	5
	Women	11
MS disease subtype	Relapsing-Remitting	9
	Primary Progressive	0
	Secondary Progressive	2
	Benign	1
	Neuromyelitis Optica	1
	Unknown	3
Ethnicity	White British	14
	Asian	2
Relationship Status	Married/Partner	10
	Single/Divorced	6

Supplementary Figure 1: Fictional example of an eco-map

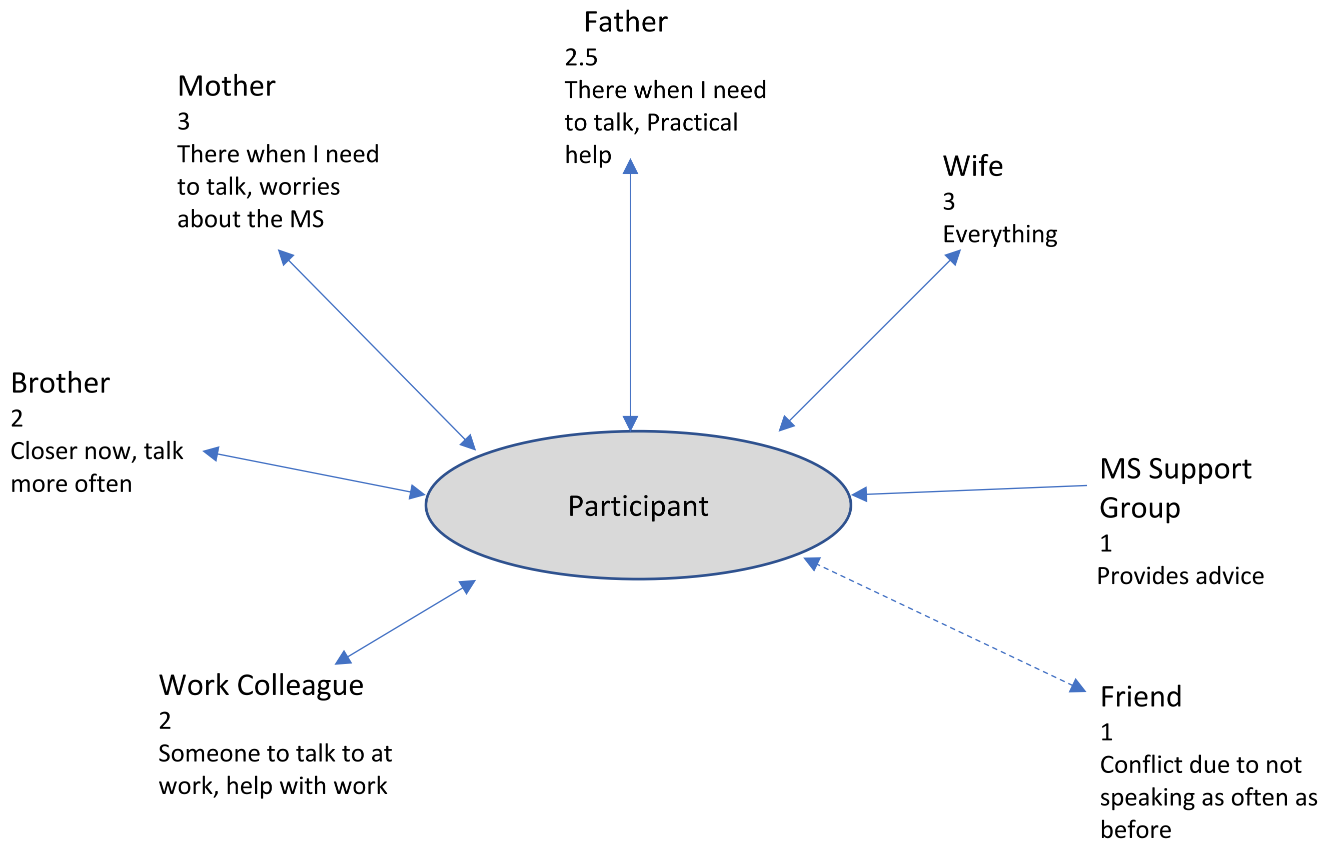
Before diagnosis of MS

Key

1-3 Strength of relationship (1= weak, 3= strong)
→ One-sided relationship
↔ Reciprocal relationship
⇠⇢ Conflicted relationship
Type of support listed underneath each contact



After diagnosis of MS



Supplemental Material Table S1: Interview Guide

Topic	**Example questions/processes**
1) How participants found the intervention (From the feasibility study)	What do you feel you gained from taking part?
	Content/format – relational aspects
	What do you feel were the strengths of being part of a group/individual) intervention?
	Did you have a preference of group or individual intervention beforehand?
2) Eco-mapping	Explain to participant
	Identify social contacts people/groups before diagnosis
	Map relationship type, strength, type of support, direction, frequency, changes for each person/group identified
	Repeat for after diagnosis
	Discuss any changes between the two eco-maps
3) Degree of identification with social groups	Do you identify with and consider yourself to be a part of the groups you have identified?
	Are there any other social groups you consider yourself to be a part of ?
4) Impact of social groups and changes on emotional adjustment/mood	How does being a part of a group affect your mood?
	How have changes to your social groups affected your mood? (Draw back to any changes identified in the eco-mapping if necessary)