PROOF COVER SHEET

Author(s): Abigail Methley, Stephen Campbell, Sudeh Cheraghi-Sohi, and Carolyn Chew-Graham

Article title: Meeting the mental health needs of people with multiple sclerosis: a qualitative study of patients and professionals

Article no: IDRE_A_1180547

Enclosures: 1) Query sheet
2) Article proofs

Dear Author,

1. Please check these proofs carefully. It is the responsibility of the corresponding author to check these and approve or amend them. A second proof is not normally provided. Taylor & Francis cannot be held responsible for uncorrected errors, even if introduced during the production process. Once your corrections have been added to the article, it will be considered ready for publication.

Please limit changes at this stage to the correction of errors. You should not make trivial changes, improve prose style, add new material, or delete existing material at this stage. You may be charged if your corrections are excessive (we would not expect corrections to exceed 30 changes).

For detailed guidance on how to check your proofs, please paste this address into a new browser window: http://journalauthors.tandf.co.uk/production/checkingproofs.asp

---

Your PDF proof file has been enabled so that you can comment on the proof directly using Adobe Acrobat. If you wish to do this, please save the file to your hard disk first. For further information on marking corrections using Acrobat, please paste this address into a new browser window: http://journalauthors.tandf.co.uk/production/acrobat.asp

2. Please review the table of contributors below and confirm that the first and last names are structured correctly and that the authors are listed in the correct order of contribution. This check is to ensure that your name will appear correctly online and when the article is indexed.

Sequence	Prefix	Given name(s)	Surname	Suffix
1		Abigail	Methley	
2		Stephen	Campbell	
3		Sudeh	Cheraghi-Sohi	
4		Carolyn	Chew-Graham	

Queries are marked in the margins of the proofs, and you can also click the hyperlinks below.

General points:

1. **Permissions:** You have warranted that you have secured the necessary written permission from the appropriate copyright owner for the reproduction of any text, illustration, or other material in your article. Please see http://journalauthors.tandf.co.uk/permissions/usingThirdPartyMaterial.asp.

2. **Third-party content:** If there is third-party content in your article, please check that the rightsholder details for re-use are shown correctly.

3. **Affiliation:** The corresponding author is responsible for ensuring that address and email details are correct for all the co-authors. Affiliations given in the article should be the affiliation at the time the research was conducted. Please see http://journalauthors.tandf.co.uk/preparation/writing.asp.

4. **Funding:** Was your research for this article funded by a funding agency? If so, please insert 'This work was supported by <insert the name of the funding agency in full>', followed by the grant number in square brackets '[grant number xxxx]'.
5. **Supplemental data and underlying research materials:** Do you wish to include the location of the underlying research materials (e.g. data, samples or models) for your article? If so, please insert this sentence before the reference section: 'The underlying research materials for this article can be accessed at <full link>/ description of location [author to complete]'. If your article includes supplemental data, the link will also be provided in this paragraph. See <http://journalauthors.tandf.co.uk/preparation/multimedia.asp> for further explanation of supplemental data and underlying research materials.

6. The **PubMed** (http://www.ncbi.nlm.nih.gov/pubmed) and **CrossRef databases** (www.crossref.org/) have been used to validate the references. Changes resulting from mismatches are tracked in red font.

AUTHOR QUERIES

Q1: Please confirm the email address of the corresponding author as set in the proof is correct.
Q2: Please provide the volume number and page range for ref. [4]
Q3: The funding details have been validated against open funder registry. please check and confirm the funding details.

How to make corrections to your proofs using Adobe Acrobat/Reader

Taylor & Francis offers you a choice of options to help you make corrections to your proofs. Your PDF proof file has been enabled so that you can mark up the proof directly using Adobe Acrobat/Reader. This is the simplest and best way for you to ensure that your corrections will be incorporated. If you wish to do this, please follow these instructions:

1. Save the file to your hard disk.

2. Check which version of Adobe Acrobat/Reader you have on your computer. You can do this by clicking on the "Help" tab, and then "About".

If Adobe Reader is not installed, you can get the latest version free from http://get.adobe.com/reader/.

3. If you have Adobe Acrobat/Reader 10 or a later version, click on the "Comment" link at the right-hand side to view the Comments pane.

4. You can then select any text and mark it up for deletion or replacement, or insert new text as needed. Please note that these will clearly be displayed in the Comments pane and secondary annotation is not needed to draw attention to your corrections. If you need to include new sections of text, it is also possible to add a comment to the proofs. To do this, use the Sticky Note tool in the task bar. Please also see our FAQs here: http://journalauthors.tandf.co.uk/production/index.asp.

5. Make sure that you save the file when you close the document before uploading it to CATS using the "Upload File" button on the online correction form. If you have more than one file, please zip them together and then upload the zip file.
If you prefer, you can make your corrections using the CATS online correction form.

Troubleshooting

Acrobat help: http://helpx.adobe.com/acrobat.html
Reader help: http://helpx.adobe.com/reader.html

Please note that full user guides for earlier versions of these programs are available from the Adobe Help pages by clicking on the link "Previous versions" under the "Help and tutorials" heading from the relevant link above. Commenting functionality is available from Adobe Reader 8.0 onwards and from Adobe Acrobat 7.0 onwards.

Firefox users: Firefox's inbuilt PDF Viewer is set to the default; please see the following for instructions on how to use this and download the PDF to your hard drive: http://support.mozilla.org/en-US/kb/view-pdf-files-firefox-without-downloading-them#w_using-a-pdf-reader-plugin

DISABILITY AND REHABILITATION, 2016
http://dx.doi.org/10.1080/09638288.2016.1180547

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

Meeting the mental health needs of people with multiple sclerosis: a qualitative study of patients and professionals

Abigail Methley[a,b], Stephen Campbell[c], Sudeh Cheraghi-Sohi[c] and Carolyn Chew-Graham[d]

[a]Section for Clinical and Health Psychology, School of Psychological Sciences, University of Manchester, Manchester, UK; [b]Manchester Mental Health and Social Care Trust, NHS, Manchester, UK; [c]NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre, Institute of Population Health, University of Manchester, Manchester, UK; [d]Primary Care and Health Sciences, Keele University, Keele, UK

ABSTRACT

Purpose: To explore perspectives and experiences of people with multiple sclerosis (MS) and health care professionals of mental health support for MS in the UK.

Method: 24 people with MS, 13 practice nurses, 12 general practitioners (GPs) and 9 MS specialist nurses were recruited through community groups and primary care practices across North West England. Semi-structured interviews were conducted, and data analyzed thematically using constant comparative analysis within and across the data sets. The theoretical framework of candidacy was used to interrogate data.

Results: Four themes were identified: candidates for care, management choices, defining roles, and permeability and responsiveness.

Discussion: Candidacy for care, and symptom management, depended on the framing of symptoms through a social or medical model of depression. Normalizing symptoms could prevent help-seeking by patients. Reported referral behavior varied by professional group, based on perceived remit, competency and training needs. GPs were perceived by patients and other professionals as central for management of mental health needs in MS, but may not perceive this role themselves, suggesting a need for increased knowledge, training, and improved access to specialist care.

ARTICLE HISTORY
Received 1 October 2015
Revised 11 April 2016
Accepted 16 April 2016
Published online ▮▮▮

KEYWORDS
Health [illegible]ionals; mental health; [illegible]e Sclerosis; patient [illegible]ences; qualitative; staff perspectives

➤ IMPLICATIONS FOR REHABILITATION

- Anxiety and depression are common in people with MS
- Management of mental health needs in people with MS relies on complex decisions made by both people with MS and health care professionals
- General practitioners may play a key role in the ongoing management of mental health needs of people with MS

Introduction

Multiple sclerosis (MS) is a neurological condition in which the nerves in the brain and spinal cord are attacked by the body's immune system.[1] Damage caused by lesions can occur anywhere in the central nervous system, resulting in a wide variety of symptoms, of which incidence and presentation varies by individual. Symptoms may include visual and mobility impairment, paralysis, spasms, pain, incontinence and cognitive dysfunction.[2] MS primarily affects young adults (between 20 and 40 years;[1]), a younger age of onset than many chronic conditions. The estimated prevalence of MS is 285.8/100 000 women and 113.1/100 000 men in the UK.[3] A general practice with a list size of 5000 could expect 17 women and six men with MS on their practice list.

The etiology of MS is unknown, and diagnosis can be difficult, meaning that accurately predicting progression and outcome in individual patients is problematic, (although increasing and progressive disability is common).[1] Variation in the type and severity of symptoms within multiple subtypes of MS, may result in complex and difficult condition management. Uncertainty is associated with emotional distress during diagnosis, relapse and disability progression.[4–6]

Anxiety and depression are common in patients with long-term conditions [7,8] including MS. Major depressive disorder (50% prevalence in community and tertiary care samples;[9]) and clinically significant anxiety (35.7% [illegible]alence;[10]) are common, and ~~still~~ these figures may be high[illegible]subclinical symptoms.

In UK, most people with a[illegible] and depression are managed in primary care,[11,12,8] with increased availability of services since ~~the~~ 2008 due to investment in *Improving Access to Psychological Therapies* (IAPT) services. Clinical guidelines for MS [13] suggest that primary care should play a key role for management of people with MS (PwMS), In a UK sample of PwMS (*n* = 495,[14]), the majority of individuals who consulted their GP for depression were managed within primary care, with few referrals to psychological or psychiatric services (potentially due to system factors such as referral criteria and availability of commissioned services;[12,8]). This study highlights the key role for primary care services in the management of mental health (MH) for PwMS. The quantitative design of this study means that it is not possible to ascertain influences on help-seeking behavior,

---

CONTACT Dr Abigail Methley [illegible]gail.methley@manchester.ac.uk ✉ Section for Clinical and Health Psychology, School of Psychological Sciences, University of Manchester, 2nd Floor Zochonis [illegible]g, Brunswick Street, Manchester, Lancashire M13 9PL, UK

factors impacting on professional referral decisions or patient and professional experiences of primary care based MH management.

Two recent systematic reviews investigating experiences of health care services for MS identified a deficit of studies investigating experiences of support for MH symptoms.[15,16] Although international literature has qualitatively investigated experiences of MH care for MS [17–19] cultural and structural factors (e.g. financial barriers) prevent translation of these findings to a UK health care setting.

Given the high prevalence and detrimental impact of comorbid anxiety and depression in this physical health condition there is a need for research to focus on MH care for MS in a UK health care setting, from the perspective of both professionals and patients. This paper will qualitatively explore perceptions of the availability and acceptability of services, and any discordance in experiences or priorities between professionals and patients.

Methods

This qualitative study, utilizing semi-structured interviews, was conducted in North West England.

Ethical approval was granted by the local Research Ethics Committee (REC: 12/NW/0385).

Data collection

A service-user consultant with MS was involved at all stages of the project. Health professionals in four primary care trusts (commissioning bodies before clinical commissioning groups were established in 2013) and one foundation (hospital) trust participated in the study. Health professionals were recruited through professional networks and direct contact. PwMS were recruited through GP practices, MS charities, online MS forums and community recruitment materials e.g. posters displayed in shops.

Participant's preference dictated the data collection location (telephone interviews or face to face interviews in participants' homes, work place, a university building, or a private quiet space within a public area (e.g. an MS society group). AM conducted semi-structured interviews between October 2012 and September 2013 (PwMS) and October 2013 and April 2014 (health professionals). Interviews lasted 23–150 min for PwMS and 19–53 min for health professionals. All participants provided written consent, and all interviews were recorded (excepting three professionals who did not provide consent for digital-recording, so contemporaneous notes were taken by AM), and transcribed verbatim. Table 1 presents the topic guides which were inductively modified in the light of emerging themes, to investigate topics identified as recurrently important by early participants, including specific encounters with GPs and specialist care services (PwMS) and training needs (health care professionals). Field notes were recorded to incorporate context into analysis.[20]

Table 1. Topic guides for people with MS and health care professionals.

Initial topic guide for people with MS covered:
- Experiences with health care services
- MH symptoms and coping methods

Initial topic guides for health care professionals covered:
- Experiences and perceptions of working with people with MS
- Any problems or challenges in caring for people with MS
- How people with MS present with MH issues such as depression
- How services may be improved

Participants

24 PwMS, 13 practice nurses (PNs), 12 general practitioners (GPs) and 9 MS specialist nurses (SNs) participated in this study. Maximum variation sampling [21] focused on characteristics that have been noted to affect experiences of receiving or providing health care in previous literature. For PwMS these included age, gender, ethnicity (23 were White British, 1 was Iranian), subtype of MS, and level of MS disability (demographic and clinical information is presented in Table 2, clinical information is presented in Table 3).

For professionals, these included time since qualification, teaching/training status of practice, gender and age (demographic information is presented in Tables 4 and 5).

Participants were sought who represented deviant or disconfirming cases.[22] These cases were used to test and refine devised categories and themes by illuminating limitations and boundaries (e.g. people who had disengaged from health care services or were not members of an MS society). This gave a richer insight to the limitations of themes and analysis and allowed exploration of alternative interpretations.[23] Snowball sampling [24] recruited men with MS, and people with progressive MS, who may not commonly respond to community recruitment strategies. Data collection was stopped upon achievement of data saturation, where no information was generated to change or add to existing themes.[25]

Data analysis

A constant comparison approach was used.[26,27] Transcripts were read multiple times whilst listening to the audio-recording to ensure familiarity with the data. A code was defined as a word or phrase characterizing the crux of a segment of data relevant to the research question.[28] Codes were derived from the data (*a posteri*) not imposed upon it *a priori*. During this process, initial codes were made through open coding which was primarily descriptive (including *in vivo* quotes), with analytical codes where possible.[29] Upon completion of open coding, selective coding became more focused on the key research question (experiences of MH care),[29] suggesting potential further sampling needs. Codes were compared both within and across participants,[27] aiming to conceptualize codes into a higher, more encompassing category.[30] This constant comparison allowed the identification of categories and themes across an entire [illegible]set, comprising both health care professionals and people wi[illegible]~~onic conditions~~, as demonstrated previously in health services [illegible]esearch with both patient and professional samples.[31] However, unlike grounded theory this stopped short of creating a novel theory, as the focus of the research was not to create and test new robust theories but to investigate participants' experiences. Contemporaneous data collection and analysis were used.[30]

Theoretical perspective

Analysis comprised both an inductive and a deductive approach. Early inductive constant comparison analysis highlighted that access to mental health care was the overarching theme of the emerging dataset. This incorporated a wide variety of elements of access, including service barriers to access (e.g. waiting times) through to more sociological constructs, such as the role of stigma or lack of knowledge in preventing help-seeking (and thus influencing access). It was therefore decided that (due to the concepts inductively emerging from the data), access needed to be explored in more detail (e.g. deductively, by sampling people with

Table 2. Clinical and demographic characteristics of people with MS.

Participant number	Gender	Age (yrs)	Type of MS	Time since diagnosis (yrs)	Disability	Working	Relationship	Education
1	F	31–40	Relapsing-remitting	0–5	Fully ambulant	FT	Single	Degree
2	F	51–60	Relapsing-remitting	21–30	Fully ambulant	FT	Married	Postgraduate degree
3	F	61–70	Relapsing-remitting	6–10	Mobile with crutches/stick	Retired	Separated	Professional qualification
4	F	61–70	Relapsing-remitting	11–20	Mobile with crutches/stick	Retired	Widowed	5 O levels
5	F	51–60	Secondary Progressive	21–30	Wheelchair user	Retired	Married	NVQ
6	F	41–50	Relapsing-remitting	0–5	Mobile with crutches/stick	FT	Divorced	NVQ
7	F	61–70	Relapsing-remitting	21–30	Mobile with crutches/stick	Retired	Married	Degree
8	F	51–60	Relapsing-remitting	6–10	Fully ambulant	FT	Cohabiting	NVQ
9	M	31–40	Severely Rapidly Evolving MS	6–10	Mobile with crutches/stick	Long-term sick due to MS	Single	Degree
10	F	51–60	Relapsing-remitting	11–20	Fully ambulant.	Long-term sick due to MS	Separated	A Levels
11	M	51–60	Relapsing-remitting	11–20	Fully ambulant.	FT	Married	No qualifications
12	M	61–70	Primar[illegible]essive	21–30	Mobile with crutches/stick	PT	Married	Professional qualification
13	M	61–70	Secondary Progressive	31–40	Wheelchair user	Retired	Married	A Levels
14	F	51–60	Primar[illegible]essive	11–20	Fully ambulant.	Retired	Divorced	O levels
15	M	31–40	Relaps[illegible]itting	6–10	Fully ambulant.	FT	Married	NVQ
16	F	41–50	Benign MS	0–5	Fully ambulant.	FT	Married	5+ O levels
17	F	31–40	Benign MS	6–10	Fully ambulant.	PT	Single	Degree
18	F	51–60	Secondary Progressive	Not provided	Mobile with crutches/stick	Long-term sick due to MS	Married	No qualifications
19	F	71–80	Secondar[illegible]essive	31–40	Wheelchair user	Retired	Married	A Levels
20	F	41–50	Relapsing[illegible]ng	Not provided	Fully ambulant.	FT	Married	Degree
21	M	71–80	Secondary Progressive	31–40	Wheelchair user	Retired	Married	O levels
22	F	61–70	Secondary Progressive	Not provided	Mobile with crutches/stick	Retired	Married	O levels
23	F	61–70	Relapsing-remitting	21–30	Mobile with crutches/stick	Retired	Divorced	No qualifications
24	F	51–60	Relapsing-remitting	6–10	Fully ambulant	FT	Married	Postgraduate degree

Table 3. Demographic characteristics of general practitioners.

Participant number	Age (yrs)	Gender	Ethnicity	Time since qualification (yrs)	Training practice	Teaching practice	FT/PT	Partner/salaried
1	51–60	F	Other	21-30	Yes	Yes	PT	Partner
2	31–40	F	British Chinese	<5	Yes	Yes	PT	Salaried
3	21–30	F	White British	<5	No	Yes	PT	Salaried
4	31–40	F	White British	6-10	Yes	Yes	PT	Partner
5	31–40	F	White British	6-10	Yes	Yes	PT	Salaried
6	21–30	F	White British	<5	No	No	PT	Salaried
7	21–30	M	White British	<5	Yes	Yes	PT	Trainee registrar
8	56–60	M	British Asian	21-30	Yes	Yes	PT	Other
9	31–40	M	British Asian	<5	Yes	No	PT	Salaried
10	51–60	F	White British	21-30	No	Yes	PT	Partner
11	41–50	M	White British	11-20	No	Yes	PT	Partner
12	31–40	M	Arab	6-10	Yes	Yes	FT	Partner

Table 4. Demographic characteristics of practice nurses.

Participant number	Gender	Age (yrs)	Ethnicity	Time since qualification (yrs)	Length of time as practice nurse (yrs)
1	F	51–60	White British	21–30	11–20
2	F	41–50	White British	11–20	6–10
3	F	51–60	White British	31–40	11–20
4	F	41–50	White British	21–30	<5
5	F	41–50	White British	11–20	6–10
6	F	61–70	White British	31–40	<5
7	F	41–50	White British	21–30	11–20
8	F	51–60	White British	31–40	21–30
9	F	51–60	White British	31–40	21–30
10	F	51–60	White British	31–40	21–30
11	F	31–40	White British	11–20	<5
12	F	41–50	White British	21–30	11–20
13	F	31–40	White British	6–10	6–10

disconfirming experiences of access and perceptions of eligibility for services). The theoretical framework of candidacy–[32] was selected as it utilizes a multi-faceted conceptual approach to defining access and it demonstrated a strong fit with the emerging data. This framework explains how use of health care services is based on patient and professional identification of a patient as an appropriate candidate for health care services, and explores experiences of access to health care. It comprises seven stages, outlined in greater detail in Figure 1. Candidacy provided a theoretical framework including both individual and service factors relevant to access, and thus was able to incorporate the experiences of patients and professionals within the concepts identified from the data.

Epistemology

The epistemological position taken was an interactionism approach, including elements of phenomenology and social constructionism, which allowed the linking of experiences and meaning across three levels.[33, p(0).37]

> The microlevel (such as self-awareness, individual action, and interpersonal communication), mesolevel (such as hospitals and medical education), and macrolevel (such as the nation's health status, the structure and political economy of the health care system, and national health policy).

Table 5. Demographic characteristics of specialist nurses.

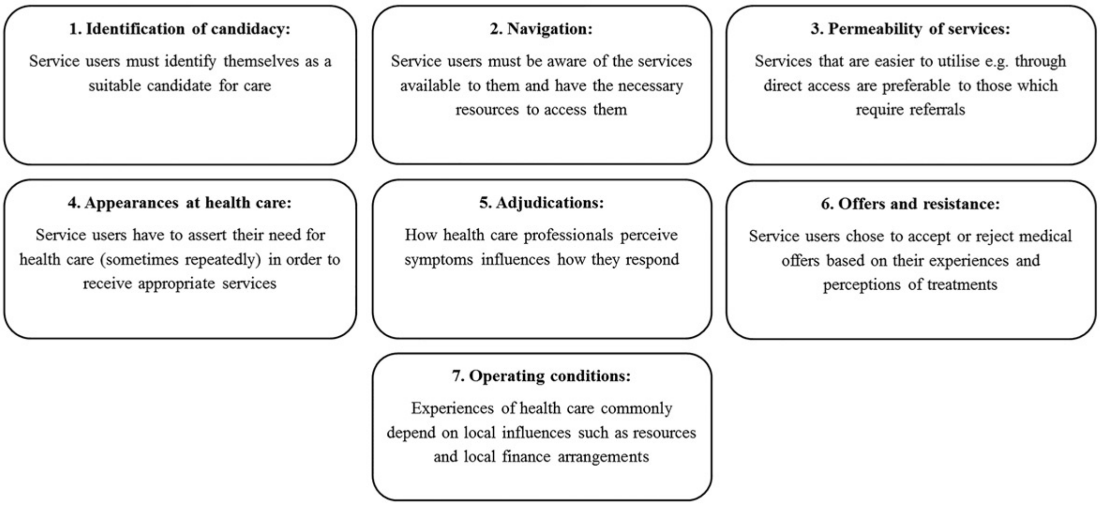
Gender	
Female	8
Male	1
Age	
31–40	1
41–50	4
51–60	4
Ethnicity	
White British	9
Years qualified as a Nurse	
11–20	2
21–30	4
30+	3
Years working as a SN	
<5	1
6–10	2
11–20	6

This epistemology allowed for a subjective interpretation of co-constructed phenomenon (including interpretations of mental health, access to services and experiences of interpersonal interactions within services). The framework of candidacy matched this epistemology by "recognising both the validity of all knowledge and its co-construction and the operation of symbolic power in relationships"[34, p.3] thus incorporating the roles of both professionals and people with MS acting within a health care system and wider socio-political context and influences.

Findings

Analysis of patient and professional datasets identified four inter-related themes (demonstrated in Figure 2) explaining perceptions of MH needs in MS: Candidates for care, management choices, defining roles, and permeability and responsiveness.

Figure 2. The central themes of patients' and professionals' perceptions of meeting the psychological needs of people with MS.



1. Identification of candidacy:
Service users must identify themselves as a suitable candidate for care

2. Navigation:
Service users must be aware of the services available to them and have the necessary resources to access them

3. Permeability of services:
Services that are easier to utilise e.g. through direct access are preferable to those which require referrals

4. Appearances at health care:
Service users have to assert their need for health care (sometimes repeatedly) in order to receive appropriate services

5. Adjudications:
How health care professionals perceive symptoms influences how they respond

6. Offers and resistance:
Service users chose to accept or reject medical offers based on their experiences and perceptions of treatments

7. Operating conditions:
Experiences of health care commonly depend on local influences such as resources and local finance arrangements

Figure 1. The theoretical framework of candidacy.

Candidates for care

Identifying whether an individual was an appropriate candidate for MH services was not clear-cut. PwMS described how they experienced low mood in relation to significant emotional, social and physical changes within their life. They found it difficult to differentiate whether low mood was caused by MS or by the results of disability and of living with MS.

> There was a period of depression because I was such an active person. Really into my sport, worked full time, social life and everything in my life changed at once after my diagnosis. I essentially had to quit my job, split up with my partner, and move back in with my parents. So all the factors that came at once would have had an impact. PwMS1, Female, Relapsing-Remitting MS

The majority of SNs emphasized certain time points at which patients were most likely to experience MH difficulties in relation to physical symptoms, and all professionals discussed the impact of relapses on MH wellbeing.

> There's an understandable element to certain parts of it; when they're just diagnosed you'd expect them to go through the gambit of emotions. If they've not relapsed for quite a few years and they've forgotten they've got MS, when they change from relapsing remitting to a more progressive type and also when they, in their mind, have to make life or death decisions with respect to the treatment. SN2

SNs and GPs commonly resist medicalising or pathologising symptoms of low mood in PwMS, in favor of social explanations of depression onset and maintenance e.g. relationship breakdowns or the stigma attached to physical symptoms such as incontinence. They frequently highlighted the complex interplay of MH and physical wellbeing, in this potentially disabling and unpredictable condition. This could lead to professionals not viewing patients as candidates for care for MH symptoms if their symptoms were not viewed as a discrete MH condition or of a severity requiring MH support.

The majority of SNs referred to research suggesting depression may be a consequence of specific brain pathology in MS or a physiological reaction to disease modifying treatments (DMTs). This suggested a potential contradiction to more social explanations of depression onset.

> A lot of them get very low in mood and we don't know whether that's because they've been diagnosed with a long term condition or whether it's something in the brain, specifically with MS or one of the medications they're on. SN7

All professionals discussed the high levels of depression and anxiety they regularly saw in people with chronic conditions, and SNs particularly highlighted this in MS ("up to 90% of my caseload", SN7). In addition, all SNs and a minority of GPs discussed this within the context of the UK's current financial and socio-economic climate, where financial and employment worries were common.

Professionals expressed frustration and sadness over the difficulties providing MH support when social, environmental and financial factors were perceived as an obvious and understandable cause of low mood.

> When most of your patients are depressed, some have rubbish lives or are down. At what point do you medicalise them or is it just something that we should be trying to improve peoples' lives and quality of life? GP6

Health care professionals interpreted the phrase "mental health needs of PwMS" differently; some discussed conditions such as schizophrenia or bipolar that may require the care of a specialist services, others discussed low mood that could be so mild or intermittent as to not warrant intervention. The threshold at which patients need referral for more intense support was not clearly defined by any professional group. It appeared to be influenced b[illegible]fessional's confidence and experience in managing people w[illegible]H problems.

SNs and GPs felt that, for some PwMS, the MH needs were more pressing than their physical health needs, and that they did not feel able to respond to these needs, and therefore the emphasis of their care should be shifted to mental health services.

> We've got a few patients with mental health issues which can often overshadow the physical symptoms. I'm absolutely rubbish at mental illness. I just haven't got enough knowledge or insight, so I'm really out of my comfort zone and completely out of my depth, so I find that quite traumatizing actually. SN3

Most professionals reported their ability to manage potential risk as a factor in identifying candidacy, requiring the support of MH services to manage people whose MH problems were potentially risky to themselves or others. Both SNs and PNs commonly referred to opening a "can of worms" (SN2), whereby exploring an individual's MH problems revealed more than they had the time or capability to manage without a quick and guaranteed referral to MH services.

> If we open that can of worms and we've got nothing to support them with, are we actually doing them a favour? Yes, it's ignoring them [MH problems] in one sense, because you could actually take away all their boundaries and that concerns me with the lack of back up available. SN2

Due to the perceived risks, some nurses would chose to not address MH issues in their consultations.

Management choices

All professionals (and a minority of patients) described adopting a person-centered approach to the management of patients with MH needs. Management choices therefore relied in part on *knowing about* the patient and *knowing* the patient. Professionals reported using knowledge about the patient gained through continuous long-term relationships to judge differences in body language that may indicate a worsening of MH symptoms. This familiarity included knowledge of patients' physical demeanor such as body language or tone of voice, alongside MH constructs such as personality or mood.

> I mean I think the whole thing about general practice is you work a lot on cues and what people aren't saying and what their body language is saying and their facial expression, and that can be burdened or low in mood. GP5

Whilst this skill was felt to be central to general practice more widely, it was felt to be essential for monitoring change in fluctuating chronic conditions such as MS.

Relational continuity of care also provided patients with the opportunity to feel *known,* that is patients felt listened to and experienced psychological security.

> I would imagine patients probably see the benefit of just having the same person so they're not retelling the same story again and they feel that someone is actually responsible for their care and that someone is listening to what's going on. GP9

Where PwMS reported they felt listened to, and their preferences were respected, they reported feeling more confident about their treatment decisions and their overall relationship with their health care professionals. Healthcare professionals suggested the use of pharmacological interventions (antidepressants) or referral for 'talking treatments' to address symptoms of low mood, or less commonly, anxiety.

The fear of future depressive relapses was commonly reported by PwMS, even where they no longer considered themselves to have depression. Participants reported positive experiences of anti-depressant use where the decision to prescribe had been reached collaboratively, without undue pressure or influence, and in line with their own beliefs about medication use. All participants with MS who reported using anti-depressants felt this had been a positive choice.

> It was a full and frank discussion. He didn't say 'I'm going to put you on [anti-depressants]', he said 'how do you feel about', and I jumped at it, I have no qualms about taking pills at all. PwMS12, Male, Primary Progressive MS

Some participants with MS reported that they monitored and self-managed their mood and emotions, viewing low mood a result of a lack of MH self-management.

> Well since that time at the beginning of the MS I don't allow myself to be low. I can't remember being that low again not since. I've always been a positive person. So I just take on a different task, that's how I work on it. PwMS8, Female, Relapsing-Remitting MS

Social support and social networks were very important for PwMS to identify and manage potential low mood.

> I wouldn't ask for any help with my mood at the moment because I think I've got a really good circle of friends that are really supportive… I feel like they're my counsellors? PwMS2, Female, Relapsing-Remitting MS

For PwMS who lacked social support, there was a need for a supportive listening service that did not incorporate the formality (or perceived stigma) of MH services.

> The GP puts the wheels in motion for a referral for counselling. But then you sort of get labelled as psychiatric in a way and that is terrible, that is dreadful, that is awful. I'm just human and sometimes the whole thing is just too much to bear and you need somebody to talk to or to be empathic. PwMS4, Female, Relapsing-Remitting MS

This was in line with viewing emotional distress as a normal and understandable aspect of the experience of living with MS, which required a compassionate, but not medicalised, approach.

Healthcare professionals were central in helping many PwMS navigate multiple services, including those for MH needs.

> When I moved here my MS nurse said "there's a rehabilitation team which consists of a physio, psychologist, physician, do you want me to put you in touch with them?" And I said "yeah that would be helpful", and it's just gone on from there really. PwMS10, Male, Rapidly Evolving MS

In summary, professionals can help PwMS manage their MH symptoms through monitoring, signposting, pharmacological management and MH management, in line with patient preferences.

Defining roles

All professionals were confident about their abilities to elicit symptoms of depression in PwMS; however, PNs and SNs suggested they would rely on the GP for ongoing psychological and pharmacological management.

> We'd ask the GP to see them, because they are the ones that would do the prescribing in that case. SN1

All PNs and SNs highlighted their lack of training in MH needs, and SNs, and to a lesser extent PNs, felt very strongly that managing MH needs should not be within their remit as they were not knowledgeable or willing to perform the role of a MH professional.

Both PNs and SNs felt that a lack of mental health services for PwMS left them working outside their professional remit. SNs emphasized that both professionals and PwMS expected them to be knowledgeable on MH issues, due to the nature of their role in helping people to adapt and adjust to life with MS. However, they felt untrained and unsupported to manage these needs.

> The patients come to us and expect us to have the knowledge, because we deal with a lot of depression, low mood, as you would with any long term condition but it's really just out of our depth. SN3

Problems caused by unfounded expectations were expounded by the judgement of other [unspecified] health care professionals who overestimated SNs' remit in managing MH symptoms, and their responsibility for managing these.

> The problem lies, sometimes in the community they think well we are MS nurses, this person is low in mood, sort it out and we can only do a certain degree of it, if they really need a course of counselling or something that's a bit more intense it really needs to be done by properly supported counsellors, the ones who are educated in doing it. SN8

All SNs and the majority of PNs reported that their main fear in managing people with MH needs was a risk of a suicide that they could have prevented, or failing to document risk or refer patients on appropriately (thus putting themselves at risk professionally).

Sometimes SNs reported being unsure of the cause of severe MH symptoms e.g. mania or suicidality, which they described as being rare reactions to DMTs or steroids administered to treat relapses. In these instances, SNs wanted support from colleagues trained in MH and viewed this as a reciprocal relationship.

> My role really is to be there for the mental health professionals that deal with her [patient with MS] a lot of the time, because if we can guide them, I've given the staff my name and direct number and said if she gets any more physical issues they know how to ring me for advice. SN3

Limited time in consultations led some PNs to report it was difficult to prioritize MH issues in a 20 min consultation centered on the assessment and measurement of physical symptoms.

> So yeah we ask about depression. But it's difficult because of the time frames we have for appointments. PN1

This was echoed by SNs who felt it would not be possible to address both complex mental and physical needs even in their 30 min consultations.

Permeability and responsiveness of services

Lengthy delays and decreased access to MH services were described by GPs, PNs and SNs and PwMS leaving patients without support when they felt the need for it.

> By the time you get to the counsellor the heat has gone off it because its 12 months later, 18 months. Nothing is instantaneous. You don't get the support and the help when you need it. I had to wait 18 months. PwMS3
>
> Female, Re[illegible]-Remitting MS

These delays in access to services were primarily reported for secondary and community care services. Primary care was viewed as providing more responsive care.

> So I went to the doctor's at five o clock in the evening. I broke down at reception. And I went straight in and that was when the Dr realised that I was having a bit of a do and put me on the anti-depressants. PwMS10, Female, Relapsing-Remitting MS

Whilst a minority of SNs and GPs reported good experiences of accessing MH services for their patients, most suggested that the waiting lists in their local area were prohibitive (up to eight months) and available services were patchy and inequitable across geographical areas. Where GPs' and SNs' reported positive experiences of MH care they described knowledge of their local teams with strong professional relationships, including co-location of services.

> In the practice, once a week, we have a counsellor and they have four or six appointments a week that we can book patients into. GP4

Inequity of services was reported when accessing primary MH care in a community setting, as few PCTs had services for people who required MH support in a home visit format.

> There is a difficulty in accessing psychological services with her obviously with her being housebound, with most of my patients I get them started on medication and I get them seeing psychological services. I can't quite see how that would work because we don't have any community-based, home visiting psychological services. GP9

This could lead to a perceived inequity of care for MH symptoms in the patients wh[illegible]ceived to need it the most, due to isolation or severity of M[illegible]ptoms.

GPs reported facing a conflict between ensuring fast access, but also appropriate service referrals, when the most specialist services had the longest waiting lists. Past experiences of access to services seemed to influence GPs referral decisions.

> The difficulty is that we're trying to manage these patients very often in a timely manner and I'm conscious of the fact that the [secondary care] services have a huge waiting time. If you have someone who has more severe symptoms then asking them to wait for months on end just to see someone seems slightly difficult for me as a GP to say to someone. GP9

When faced with a lack of services or an extensive wait for a service, many GPs took on personal responsibility for patients experiencing MH needs (i.e. booking in regular telephone or face to face consultations) to ensure they received regular follow up in this period.

Both SNs and GPs reported the role of eligibility criteria in facilitating or restricting access to MH services. Apparent differing eligibility for services was felt to cause inequalities and fragmented care.

Discussion

Summary of main findings

This study investigated the role of primary care and specialist care in the management of MH needs in patients with MS, from patient and health professional perspectives. Findings showed that providing and experiencing MH care for PwMS centered around decisions regarding candidacy for care, management choices, how professional roles w~~h~~ere perceived by patients and professionals, and the perceived permeability and responsiveness of services. Decisions regarding candidacy (by both professionals and patients) may influence referral patterns and help-seeking behavior. Where explanations were provided that lessened perceived candidacy (e.g. the normality of low mood), MH needs in MS could be overlooked, potentially leading to under-diagnosis and under-treatment of MH problems. Professionals varied in confidence (and perceived appropriateness of their own role) in managing people with MS and MH problems.

Comparisons with previous literature

This study describes the experiences of GPs and PNs, illuminating the key role of primary care professionals in the identification and (in the case of GPs) ongoing management of MH needs of PwMS. It also highlights the stress experienced by nurses who feel pressurized to provide care outside of their professional role, due to poor access to services. The experiences of PNs resonates with other studies where lack of knowledge and insufficient training limits PNs' wishes to expand their role to incorporate ongoing management of patients with complex problems.[35]

Previous research suggests many PwMS experience depressive symptoms that are undiagnosed and therefore untreated.[36,14] Our study suggests one potential reason, i.e. PwMS are aware of their low mood but 'normalise' their depression within a narrative of loss and change (e.g. unemployment and relationship breakdowns). Where participants did not relate this low mood to their perception and understanding of depression,[37] a potential barrier to help seeking and diagnosis of depression was formed.[38]

Participants with MS in this study reported help-seeking when their symptoms left them feeling unable to continue with the demands of daily life, similarly to research into depression suggesting identification of candidacy occurs when symptoms start to interfere with everyday roles or family relationships.[39] These crisis periods may be a key point for intervention, if a health care professional is aware of this situation and adjudicates accordingly.

Referral thresholds for MH symptoms were demonstrated in this study. Previous research,[40] reports that GPs emphasized the value of being able to contact a named individual for specialist knowledge, and how this was now nearly impossible due to limited service configuration. They highlighted their concerns about the sustainability of current MH services, and the negative impact poor responsiveness had on PwMS in need of care. PwMS also detailed the responsiveness and timeliness required to address their needs, without their MH wellbeing deteriorating unnecessarily.

The concept of 'knowing the patient' was important to PwMS and health care professionals. Fairhurst and May (2001)[41] described two types of *knowing the patient* which were both relevant to this data: developing biomedical and biographical knowledge, and knowledge of their behavior and cognitions.

Strengths and limitations

The strength of this exploratory study was its focus on primary care professionals, who are often neglected in MS research. This study also reports findings of a relatively large group of participants, in comparison to previous studies of this rare condition. Data saturation was reached in this exploratory study; however, the sample represents the views of a reasonably small number of professionals from a defined geographical area. Broader quantitative research utilizing larger nationwide samples is required to establish the prevalence of the needs identified for commissioning purposes.

Data were collected through semi-structured interviews; a method to expand these findings would be to use real-time interactional data with patient-professional dyads to investigate how identification of candidacy and treatment decisions are made.[42]

Previous research has criticized the paucity of studies~~,~~ allowing individuals who described low mood to define what the experience and definition of depression meant to them.[39] A strength of this study is that PwMS and professionals were asked to explain their own perceptions of MH need in MS, highlighting inconsistencies and discrepancies in perceptions of MH need. For example, a potential disconnect was demonstrated between how PwMS viewed themselves as a candidate for care (not experiencing depression), and how they acted as a candidate for care (utilizing medication and medication reviews for depression), requiring further empirical investigation.

Implications for clinical practice

These findings highlight the key role for primary care in management of MH needs in PwMS. Currently, the importance of this role is underplayed in both research and policy.[13] The concept of "knowing" a patient appears to be strongly related to continuity of care in this chronic relapsing condition. A central clinical implication is therefore to preserve these continuous professional-patient relationships, with potential implications for psychological patient safety.[43]

Our findings suggest professionals to have well-defined roles in which they feel confident and competent, suggesting additional training to broaden their remit would not be perceived as feasible. More integrated models of care, with joint working between primary care, specialist MS services and mental health services may help ensure appropriate access to services and support for both patients and professionals. A good practice example demonstrated that incorporating a mental health nurse within a specialist MS team decreased the need for community mental health teams and increased MS Nurses' perceived ability to manage mental health symptoms after discharge from psychological services.[44]

Finally, educating PwMS on the risk of MH problems and their candidacy for MH care (both primary care and MH services) and increasing signposting of potential services to both PwMS and professionals may challenge assumptions about a lack of candidacy for MH support for PwMS.

Conclusion

Both professionals and patients describe a continuum of MH needs in MS from 'normal' responses to difficult circumstances, through to distinct symptoms requiring specialist support. GPs were identified as a central figure in the management of MH needs in MS, due to their continuing close relationships with patients, and their ability to manage pharmacological treatments. PNs and SNs reported a lack of confidence in their capability and remit of managing MH needs. These findings have implications for service provision, highlighting the need for increased joint working to share expertise and continuity of GP-patient care for accessible mental health support in MS.

Acknowledgements

We are grateful to all our participants for sharing their experiences. We thar[illegible]n Brady and Shoba Dawson for their feedback on this mar[illegible]t.

Disclosure statement

The authors report no declarations of interest.

Funding information

We are grateful to Carole [illegible]t for her support in her role as service-user consultant and to Janice Howard, Jessica Drinkwater and Karen Vernon for their support with recruitment.

This project was fully funded by a National Institute of Health Research (NIHR) School for Primary Care Research (SPCR) PhD studentship. The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The National Institute for Health Research School for Primary Care Research (NIHR SPCR) is a partnership between the Universities of Bristol, Cambridge, Keele, Manchester, Newcastle, Nottingham, Oxford, Southampton and University College London.

References

[1] Compston A, Coles A. Multiple sclerosis. The Lancet. 2008;372:1502–1517.
[2] Compston A, McDonald IR, Noseworthy J, et al. McAlpine's multiple sclerosis. London: Churchill Livingstone; 2006.
[3] Mackenzie IS, Morant SV, Bloomfield GA, et al. Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the general practice research database. J Neurol Neurosurg Psychiatry. 2014;85:76–84.
[4] Davies F, Edwards A, Brain K, et al. 'You are just left to get on with it': qualitative study of patient and carer experiences of the transition tc[illegible]ndary progressive multiple sclerosis. BMJ Open. 2015. [illegible]
[5] Thorne S, Con A, McGu[illegible]ss L, et al. Health care communication issues in multiple sclerosis: an interpretive description. Qualitative Health Res. 2004;14:5–22.
[6] White CP, White M, Russell CS. Multiple sclerosis patients talking with healthcare providers about emotions. J Neurosci Nurs 2007;39:89–101.
[7] Naylor C, Parsonage M, McDaid D, et al. Long term conditions and mental health: the cost of comorbidity. London: The King's Fund; 2012.
[8] National Institute for Health and Clinical Excellence. Depression in adults with a chronic physical health problem: treatment and management, NICE clinical guideline 91. London: National Institute for Health and Clinical Excellence; 2009.
[9] Feinstein A. Multiple sclerosis and depression. Mult Scler. 2011;17:1276–1281.
[10] Korostil M, Feinstein A. Anxiety disorders and their clinical correlates in multiple sclerosis patients. Mult Scler. 2007;13:67–72.
[11] Bower P, Gilbody S. Managing common mental health disorders in primary care: conceptual models and evidence base. BMJ. 2005;330:839–842.
[12] National Institute for Health and Clinical Excellence. Depression in adults: the treatment and management of depression in adults, NICE clinical guideline 90. London: National Institute for Health and Clinical Excellence; 2009.
[13] National Institute for Health and Care Excellence. Multiple sclerosis: management of multiple sclerosis in primary and secondary care, NICE clinical guideline 186. London: National Clinical Guideline Centre; 2014.
[14] Sollom AC, Kneebone II. Treatment of depression in people who have multiple sclerosis. Mult Scler. 2007;13:632–635.
[15] Methley AM, Campbell S, Chew-Graham C, et al. Experiences of health care services for people with multiple sclerosis: a systematic narrative review. Health Expect. 2014;18:1844–1855.
[16] Methley AM, Campbell S, Chew-Graham C, et al. PICO, PICOS and SPIDER: a comparison study of sensitivity and specificity in three search tools for qualitative systematic reviews. BMC Health Serv Res. 2014;14:579.
[17] Mazaheri M, Fanian N, Zargham-Boroujeni A. Experiences of patients with multiple sclerosis from group counseling. Iran J Nurs Midwifery Res. 2011;16:181–190.
[18] Minden SL, Ding L, Cleary PD, et al. Improving the quality of mental health care in multiple sclerosis. J Neurol Sci. 2013;335:42–47.

[19] Rintell DJ, Frankel D, Minden SL, et al. Patients' perspectives on quality of mental health care for people with MS. Gen Hosp Psychiatry. 2012;34:604–610.

[20] Wiener C. Making teams work in conducting grounded theory. In: Bryant A, Charmaz K, editors. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007. p. 293–310.

[21] Sandelowski M. Sample size in qualitative research. Res Nurs Health. 1995;18:179–183.

[22] Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ. 2000;320:114–116.

[23] Booth A, Carroll C, Ilott I, et al. Desperately seeking dissonance: identifying the disconfirming case in qualitative evidence synthesis. Qual Health Res. 2013;23:126–141.

[24] Sadler GR, Lee HC, Lim RS-H, et al. Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. Nurs Health Sci. 2010;12:369–374.

[25] Guest G, Bunce A, Johnson L. How many interviews are enough?: an experiment with data saturation and variability. Field Methods. 2006;18:59–82.

[26] Glaser B, Strauss A. The discovery of grounded theory: strategies for qualitative research. New York: Aldine Publishing Company; 1967.

[27] Lincoln, YS, Guba EG. Naturalistic inquiry. California: SAGE Publications; 1985.

[28] Saldana J. The coding manual for qualitative researchers. New York: Sage Publications; 2009.

[29] Urquhart C. Grounded theory for qualitative research: a practical guide. London: SAGE Publications; 2013.

[30] Bryant A., Charmaz, K. The SAGE handbook of grounded theory. London: SAGE Publications; 2007.

[31] Burroughs H, Lovell K, Morley M, et al. 'Justifiable depression': how primary care professionals and patients view late-life depression? A qualitative study. Family Pract. 2006;23:369–377.

[32] Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC Med Res Methodol. 2006;6:35.

[33] Brown P. Naming and framing: the social construction of diagnosis and illness. J Health Soc Behav. 1995;35:34–52.

[34] Koehn S. Negotiating candidacy: ethnic minority seniors' access to care. Ageing Soc. 2009;29:585–608.

[35] Chew-Graham CA, Dixon R, Shaw JW, et al. Practice Nurses' views of their role in the management of chronic fatigue syndrome/myalagic encephalitis: a qualitative study. BMC Nurs. 2009;8:2.

[36] Marrie RA, Horwitz R, Cutter G, et al. The burden of mental comorbidity in multiple sclerosis: frequent, underdiagnosed, and undertreated. Mult Scler. 2009;15:385–392.

[37] Alderson SL, Foy R, Glidewell L, et al. Patients understanding of depression associated with chronic physical illness: a qualitative study. BMC Family Pract. 2014;15:37.

[38] Coventry P, Hays R, Dickens C, et al. Talking about depression: a qualitative study of barriers to managing depression in people with long term conditions in primary care. BMC Family Pract. 2011;12:10.

[39] Maxwell M. Women's and doctors' accounts of their experiences of depression in primary care: the influence of social and moral reasoning on patients' and doctors' decisions. Chronic Illness. 2005;1:61–71.

[40] Chew-Graham C, Slade M, Montana C, et al. A qualitative study of referral to community mental health teams in the UK: exploring the rhetoric and the reality. BMC Health Serv Res. 2007;7:117.

[41] Fairhurst K, May C. Knowing patients and knowledge about patients: evidence of modes of reasoning in the consultation? Family Pract. 2001;18:501–505.

[42] Karasz A, Dowrick C, Byng R, et al. What we talk about when we talk about depression: doctor-patient conversations and treatment decision outcomes. Br J Gen Pract. 2012;62:e55–e63.

[43] Rhodes P, Campbell SM, Sanders C. Relationship continuity: when and why do primary care patients think it is safer? Br J Gen Pract. 2014;64:e758–e764.

[44] Askey-Jones S, Shaw P, Silber E. Working together: multiple sclerosis and mental health nurses. Br J Neurosci Nurs. 2011;7:696–706.