

A qualitative study of patient and professional perspectives of health care services for multiple sclerosis: implications for service development and policy

Multiple Sclerosis (MS) is a chronic degenerative condition, with heterogeneous symptoms, and an unpredictable prognosis. Previous literature suggests patients' experiences of health care are **dissatisfactory**. Primary care may play a key role in the management of people with MS, however provision of services for people with MS has received little focus in the primary care literature. This study aimed to explore perspectives and experiences of people with Multiple Sclerosis (PwMS) and health care professionals of UK health care services for MS.

Semi-structured interviews were conducted with 24 PwMS, 13 Practice Nurses, 12 General Practitioners and 9 MS Specialist Nurses in northern England, between October 2012 and April 2014. Participants were purposively selected. Data were analysed thematically using constant comparative analysis. The theoretical framework of candidacy was used to interrogate data, with themes mapping onto MS NICE guideline 186.

How PwMS interpreted symptoms as leading to candidacy for care dictated help-seeking. PwMS required additional support in identifying symptoms due to MS. Participants reported poor experiences of care including poor access to services, poor continuity of care and poor interpersonal interactions with perceptions of limited person-centredness. PwMS and professionals identified that MS-related disability and progression of symptoms required responsive care. Relational continuity enabled PwMS to feel understood, and professionals to holistically appraise symptoms and progression.

In conclusion, continuity and patient-centredness of care are central to positive health care experiences for people with MS and professionals. Services need to be more accessible to ensure responsive and effective MS management. This study provides unique findings on the role of primary care for people with MS, and the relationship between findings and MS NICE guideline recommendations with implications for service delivery in the community.

What is known about this topic

1. Multiple Sclerosis (MS) is a chronic degenerative condition of increasing prevalence, presenting with highly varied symptoms and an unpredictable prognosis.
2. Research suggests experiences of UK health care for MS are **unsatisfactory**, despite policy initiatives created to improve patient experiences of neurological health care services.
3. **Primary care is under researched in MS, despite its potential to provide multiple elements of required health care for MS.**

What this paper adds

1. Primary care may provide timely access to services, continuity with one professional and person-centred interactions, addressing previous areas of dissatisfaction in MS care.
2. Moving MS care into the community is in line with recent policy initiatives such as 'closer to home'.

Introduction

Multiple Sclerosis (MS) is the most prevalent cause of neurological disability in young adults in Europe and North America (Alonso *et al.* 2007). It affects 127,000 people in the UK, with an increasing prevalence (Mackenzie *et al.* 2013). Where the estimated prevalence of MS is 285.8/100,000 for women and 113.1/100,000 for men (Mackenzie *et al.* 2013), a practice with the North West average list size of 5,000 (Health and Social Care Information Centre, 2014) could expect to have 17 women and 6 men with MS registered with their practice.

MS has an unpredictable disease course with a changing trajectory, causing difficulties in symptom management for both people with MS and clinicians (Deibel, Edwards & Edwards, 2013; Davies *et al.*, 2015; Wilkinson & Das Nair, 2013). Historically, services for MS have been provided in hospital-based specialist clinics, and correspondingly the majority of research has focussed on patients' experiences of secondary care and the role of neurologists and MS specialist nurses. However, UK policy is increasingly focussed on moving services from secondary care to primary care (outlined in the NHS Five Year Forward View; NHS England, 2014), with an increasing awareness of the role for primary care in care planning and coordination for clients with complex needs (Department of Health, 2014). Previous research into experiences of symptom management in MS (Deibel, Edwards & Edwards, 2013; Methley *et al.*, 2014) identified unmet health care needs and highlighted the necessity of coordinated, proactive care to support people with MS and their carers.

Patients are likely to present at the onset of symptoms to the GP and people with MS have a higher than average number of consultations at their general practice both before

and after diagnosis (Marrie et al., 2012). Whilst diagnosis is traditionally made in specialist care, on-going care is provided within primary care. Practice Nurses (PNs) are key members of the primary care health care team in the UK. They play a key role in the management of patients with chronic conditions through their role in delivering the Quality Outcomes Framework (QOF), an aspect of the NHS General Medical Services Contract (Department of Health, 2005) which offers financial incentives for the diagnosis and treatment of certain high prevalence conditions (Campbell & Lester, 2010).

Data from Scotland suggests consultations with Practice Nurses comprise approximately 17.39% of all primary care consultations for people with MS (approximately 2770 consultations in 2012-2013; Information Services Division Scotland, 2014). People with MS display negative health behaviours traditionally within the remit of PNs, including smoking, alcohol abuse, obesity and lowered exercise levels (Marrie *et al.*, 2009). Practice Nurses may also provide emotional support and information on MS and relevant local services to people with MS and their families and assist with symptom management (Litchfield & Thomas, 2010).

Previous research into UK GPs' and PNs' roles and experiences of providing care for MS, particularly using in-depth qualitative methodologies, is lacking. In 2003 Defriez et al. explored GPs' and PNs' experiences of MS care through focus groups and questionnaires, and identified that GPs perceived difficulties in providing MS care due to its low prevalence, clinical heterogeneity and complexity of management. However, multiple policy changes and role changes within primary care, may potentially have resulted in changes in health care professional perceptions.

This paper addresses the gap in evidence regarding current patient and professional experiences of UK health care services for MS, by presenting findings from a qualitative study with GPs, PNs, MS Specialist Nurses (SNs) and people with MS. The research aims were therefore to investigate what are the health care experiences of people with MS in the UK, and what are the experiences of primary and secondary care professionals of providing health care services to people with MS. These findings expand knowledge on the role of primary care for MS, crucial to moving services from a hospital-based to a primary care based model of provision.

Method

Study design

A qualitative study was undertaken within Northern England (four Primary Care Trusts and five Foundation Trusts). Ethical approval was granted by the local Research Ethics Committee (REC: 12/NW/0385).

Recruitment and sampling

A list of GP surgeries within three PCTs was obtained from PCT websites. A sample was selected purposively to represent a variety of practice sizes, training vs. non-training practices and rural vs. urban practices.

Ten GPs agreed to be interviewed after information sheets were sent to 265 GPs, direct emails sent to eight GPs, and two GPs recruited through snowballing. Fourteen Practice Nurses were recruited through written or emailed invitations (154 information sheets sent) and snowballing (n = 2). Nine Specialist Nurses were recruited through written or emailed direct invitations (18 sent). Patients were recruited through contact by their GP (n = 1) or community recruitment methods including the MS Society (n = 23).

Responders were contact by email/telephone initially to obtain verbal preliminary consent and then interviews were conducted with written consent. Consent was obtained by the first author.

Data collection and analysis

Participants were interviewed between October 2012 and April 2014 at their preferred venue, primarily work for professionals and home for patients. Interviews lasted between 23-150 minutes for people with MS and 19-53 minutes for health professionals. Interview topic guides were developed from relevant literature, and discussion within the research team, and the use of semi-structured interviews enabled interviews to begin with areas relevant to health care experience, whilst being responsive to individual's unique experiences. The professional interview topic guides covered experiences of working with people with MS and potential service improvements, iteratively evolving to cover training needs. The patient interview topic guide explored the experience of living with MS and experiences of health care services, and iteratively evolved to cover specific examples of health care consultations. Interviews were audio-recorded and transcribed verbatim before anonymisation. Prompts were used to further lines of enquiry. Data collection and analysis were contemporaneous to ensure an iterative process.

Constant comparison analysis was used to code, categorise and analyse data from transcribed interviews (Lincoln & Guba, 1985). The lead author conducted all interviews and re-read the transcripts to ensure familiarity with the data. Codes were derived from the data *a posteriori*, starting with descriptive codes and moving to analytical codes. Selective coding was used to focus analysis on the key research question and

identify factors relevant for further, more purposeful sampling (Urquhart, 2013). Comparing codes within and between transcripts enabled the creation of a broader, more conceptual category and codes were compared both within and across patient and professional datasets (Lincoln & Guba, 1985). Analysis was iterative and inductive; after coding was completed suggesting access was the most salient topic; the theoretical framework of candidacy was used to further interrogate the data (Dixon-Woods *et al.* 2006). **Once category saturation had been achieved, recruitment was closed.**

A service-user with MS consulted at all stages of the project. Findings were disseminated through oral presentation to an MS society group and newsletters to participants, gatekeepers and commissioners.

Findings

Twelve GPs, 14 PNs, 9 SNs and 24 people with MS were interviewed. Demographics are reported in tables 1 and 2. Three overall themes identified in the data analysis are reported here: Access, interpersonal interactions and continuity of care (figure 1 displays a diagrammatic representation of the identified themes and how they map on to the MS 2014 NICE clinical guideline; National Institute for Health and Care Excellence, 2014). Quotes were selected which best represented the theme or sub-theme; illustrative data are identified by GP, PN, SN and PwMS and interview number.

1. Access

Access to primary care

How patients and professionals interpreted symptoms as leading to candidacy for care dictated their help-seeking and referrals.

“My GP retired part way through and the GP that replaced him wasn’t as aware of my situation and my symptoms and when they changed they said “oh no you must have always been like this.” (PwMS1)

MS symptoms could be difficult to correctly identify due to varied and fluctuating presentations, with many differential diagnoses and an uncertain and unpredictable prognosis.

“All three of my patients with MS tend to blame a lot of the other things that are going on all down to the MS. So it's trying to make sure that we're not missing that, you know, the lady's tiredness isn't because she's got some other medical problem going on and going over the basics as we do for patients that didn't have MS.” (GP2)

Where symptoms were incorrectly attributed to MS, or conversely not correctly identified as MS, this could result in missed referral opportunities, decreasing access to secondary and community services and lessening the responsiveness of care.

“At A & E it was “it’s all in your head, stupid little girl”, it literally was, “go home, read a magazine and put your foot up and make a cup of tea, there’s nothing wrong with you!” And I thought, no, that’s not good enough, you don’t wake up one morning and suddenly you find that you can’t move your lower arms, you know, so that’s why I went back to my GP.” (PwMS18)

GPs reported a key role in providing treatment and service coordination for people with MS. This role could provide the flexibility needed for the changing needs of MS over time, supporting the patient from their initial symptoms through emergency relapse treatment, through to the provision of palliative care.

“I see myself primarily, as treat what you can that’s acute, treat what you can medication-wise, and then move on to coordinate the rest of the services.” GP3

“This young man had multiple sclerosis and died at home, I used to see him quite a lot. At that point there was nothing more that anyone in secondary care could do, so it was really making sure he had all the help at home, trying to liaise with social workers, making sure his family got the respite care.” GP8

Some GPs (primarily more junior clinicians) expressed difficulties in providing care for people with MS. These difficulties centred around managing such complex needs in a restricted amount of time, and having the required knowledge for treatment options.

“You want to make a difference and you’re not sure whether you’ll be able to really. Time is always a factor and you’re aware that there are so many different bits that need looking at. It’s also about education; you’re not quite sure which particular interventions would be helpful for certain people. So you think should you be referring to an OT? Can an OT actually do anything here?”(GP5)

Increased training about MS was not viewed as a feasible option by the majority of GPs and PNs in this study, as the small number of patients with MS seen, and its status as a non-QOF condition, meant it was not a priority for training.

“Well things like diabetes, hypertension, because that is linked to QOF I think we’re all up to date and knowledgeable of the chronic diseases. But I suppose like MS we don’t see a lot of patients, it’s quite a speciality so it’s an area we don’t have training in.” (PN12)

Navigation of services (defined as a central tenet of access to healthcare by the Dixon-Woods candidacy theoretical framework; Dixon-Woods *et al.* 2006) relied on awareness of relevant services, by both people with MS and professionals. Finding out which additional services were available, and how to access them, could be difficult and lengthy process for both people with MS and professionals. Once PwMS felt they had a well-defined support network of professionals, their confidence in accessing them improved and their experiences of care were more positive.

“I know exactly where to go now. I’m under the care of [neurologist] at [local district hospital]. I’ve got the MS nurse’s number which [neurologist] gave me and I’ve got the [MS society] yoga, I’ve got my GP who’s wonderful, so I know exactly where I’m going, it was just very confusing in the beginning.” (PwMS10)

Increasing awareness of services helped people with MS and professionals to assess candidacy for available care. All participants with MS were aware of GPs and their

geographical closeness, making them a highly utilised service, perceived as relatively easy to access.

“It’s easier sometimes to just go to my GP, because it’s just down the road. And since I’ve come down with MS they’ve put me down as ‘urgent’.” (PwMS6)

Access to secondary care

Many participants discussed delays in access to secondary and community services including diagnostic testing, SN services, neurologist services and physiotherapy which limited their perceived permeability.

“The only thing I would like is to always be able to access the MS specialist when I want to access her. Not that minute, but knowing that they’d get back to you within a reasonable [time period], within 24 hours would be really good.” (GP10)

Reported lengthy waits and frequent rearrangement of appointments in secondary care caused frustration. The fast onset and severe disability caused by MS relapses meant that services needed to be highly responsive to prevent avoidable disability and distress. Participants with MS reported the need to stay “*in the loop*” (PwMS4) by maintaining contact with services, to increase access to information and emergency treatment. SNs also expressed concerns regarding patients who disengaged with services.

“Patients may not just have MS and from a general health view point they’re not being reviewed and that is a real big concern, because if they fall out of primary care and they don’t come to see us for whatever they’ve actually got no input. Every now and again you find someone who’s not seen anyone for years, and if someone had got in there earlier you might have made a bit of a difference.” (SN2)

Data from PwMS suggested potential reasons for disengagement from services. Views on follow up appointments in secondary care varied amongst people with MS, with some participants reporting they felt “*abandoned*” (PwMS14, female, Secondary Progressive MS) without regular follow up. However, people with progressive MS

reported that the lack of information and treatment for their subtype meant that staying in the loop by attending annual appointments was not worth the perceived effort. In addition, people with mild MS symptoms reported that they did not feel regular intervention was required, although some felt it was beneficial to monitor any possible progression.

“If you’re in the loop, providing you keep seeing these neurologists, then if anything comes up you’re in the loop. Well we aren’t in the loop, we’re okay, they’ve got nothing for primary progressing MS, there’s nothing at all.”
(PwMS13)

People with MS therefore felt it was key that services were flexible and able to vary according to type of MS, thus patient, need.

2. Interpersonal interactions

Participants with MS described varied experiences of interactions with health care professionals. Negative interactions (reported most frequently with GPs and neurologists) were highly emotive, even years or decades later and could have an impact on future engagement with services. Negative interactions frequently centred on perceived poor interpersonal skills and a lack of empathy, politeness, respect and active listening skills. These interactions challenged participants with MS’ sense of personhood, devaluing them to a number.

“I just found the consultants half the time don’t listen, you’re a number not a person, you’re occupying a bed that they wanted free and you’ve got an allocated time and it’s time to go.” (PwMS1)

Positive experiences with health care professionals (most commonly GPs and nurses) were perceived as those where the participant with MS felt they were taken seriously, treated as someone with a credible and legitimate concern and offered reassurance.

Positive descriptions of professionals included someone who took interest in the person with MS and their life, and took responsibility for the responsiveness of care. This description was mirrored by professional participants who viewed their role in MS as providing person-centred and holistic care.

“[My role is] making sure they’ve got the support in place either from their families or other people. I suppose more so in the community we sort of try to support the carers as well, the whole family approach rather than just individuals. When I worked in hospital it was more about focusing on the patient.” (SN9)

PNs reported that they struggled to provide person-centred care for PwMS due to infrequent contact, which limited the extent that care was ‘personalised’ (The Health Foundation, 2014), and limited their role in coordinating care.

“She turns up every three months for vitamin B12 injections. So yeah, she’s doing fine but I don’t know what other treatments she’s on. I don’t know much about them, about their life or anything. That’s all I know, that she comes to us for her B12 injections.” (PN10)

People with MS, GPs and SNs reported that a good quality health care professional would explore all potential symptom causes, without focussing solely on MS or limiting further intervention due to nihilistic beliefs about MS.

“He [GP]’s always said to me “don’t put what’s the matter with you in the MS bag, we have to separate it and make sure that it’s not MS before we pile it into that group.” (PwMS19)

Where participants with MS felt appreciated and listened to they reported feeling more satisfied with their treatment decisions and their overall use of health care services.

3. Continuity of care

Relational continuity (defined as continued services from one professional for a prolonged length of time; Freeman & Hughes, 2014) was reported to be highly valued by all groups of participants. In primary and secondary care, long term relational

continuity allowed professionals to learn patients' medical histories and psychosocial context, allowing them to holistically appraise new or progressed symptoms.

"I would say that I feel quite safe with him [GP]. I think it makes me feel safe that I don't actually have to remember to say what year this happened, can you remember when, so I don't have to have the explanations because he's got it all there and he knows." (PwMS19)

It was thought to allow easier discussion of potentially sensitive topics.

"They often come back to the same person because they like that continuity, and it often takes a long time for people to trust you and to get to know you, and to feel comfortable with telling you this information. And often patients with MS might have urinary incontinence or something, and they might not want to tell the person that they've just met for the first time." (GP4)

The majority of PNs reported limited continuity of care with PwMS, unless they had other physical comorbidities (particularly those in QOF).

"For a practice nurse, MS patients wouldn't see us, that would be the doctor. Because we're only going to see them for vaccinations and smears really. If they have any other conditions like asthma or heart disease then we're going to see them for that so we're going to get to know them from that perspective." (PN1)

The majority of participants reported poor relational continuity with neurologists, causing confusion and frustration. People with MS' experiences of relational continuity varied by geographical area, whilst most reported long term continuity, others saw varying SNs at scheduled reviews. Two participants travelled long distances to stay with their original SN, despite moving out of the official catchment area.

"I've been with [MS nurse] since it first started and years ago I moved out of [catchment area] and I went actually I'd like to stay with you so I see [MS Nurse] once every 12 months just for a check-up and like I say if I need steroids." (PwMS20)

This long term continuity provided reassurance and ensured easy navigation and access to services, as patients reported they knew there was a trusted and knowledgeable health care professional to go to with an exacerbation of their symptoms.

Discussion

Summary

Assessing candidacy for care requires both people with MS and professionals to be able to correctly identify symptoms and act on them accordingly. Furthermore, decision making is influenced by knowledge and awareness of local health care and community services. Primary care was viewed as easily accessible by people with MS, whilst specialist and community services were harder to access. The presentation of MS relapses and disability progression required responsive care to prevent avoidable disability and distress (as identified by Deibel, Edwards & Edwards, 2013). Assisting patients to 'stay in the loop' with meaningful follow-up and communication was important for high quality care. Where this may not be provided by hospital based provision (i.e. in research into the experiences of people with secondary progressive MS such as Davies et al., 2015), this suggests the need to consider other models of care. Negative interactions with health care professionals focussed on poor interpersonal skills and continuity, which lessened the person-centredness and responsiveness of care. The desire for person-centred care was central to the experiences of PwMS, facilitating greater personal and professional satisfaction. Relational continuity improved the experiences of PwMS feeling understood and developing trust, and improved professionals' experiences of holistically appraising symptoms and progression (potentially aiding the flexibility needed to support self-mangement identified in Deibel,

Edwards & Edwards, 2013). As identified in Davies et al. (2015), relational continuity improved navigation and access, and provided psychological reassurance for a condition which may be highly anxiety-provoking.

Strengths and limitations

A strength of this study is its focus on the role of primary care **in relation to MS management and services**, which is often neglected in MS research (Methley *et al.* 2014). The low response rates of GPs and PNs in this study are not unusual, as previous qualitative studies investigating MS state many professionals declined to participate due to a lack of involvement with people with MS, lack of financial remuneration or a lack of time (Golla *et al.* 2012). Low GP response rates influenced the number of participants with MS recruited through primary care. It is possible that people with MS recently using primary care have a better recollection of their last primary care consultation, or may experience more comorbidities resulting in more frequent use of primary care, than people recruited from community samples whose MS was long term and relatively stable. Innovative recruitment will be needed in future research to address this and ensure participation of younger people with MS, people from ethnic minority backgrounds and people experiencing more severe MS disability.

Data were collected through one off interviews. Completing multiple longitudinal interviews may be an effective method of investigating changing experiences and priorities for care over time with the fluctuating and progressive nature of MS.

Comparison with existing literature

Overall, the themes identified in this study suggest that person-centred care, prompt treatment, and access to community and specialist support are still central issues (Royal College of Physicians, 2011) **in health care experiences for people with MS**. This paper expands on this knowledge by using the theoretical framework of candidacy to develop a deeper understanding of how these issues fit within the context of primary care services (not simply specialist services, as has previously been the focus; Methley *et al.* 2014). Figure 1 outlines how aspects of the candidacy theoretical framework correspond with the NICE guideline and the study themes.

The findings suggest there is a key role for primary care in the management of MS symptoms. Differences in financial procedures and authorisation for treatments and services, with a subsequent impact on access to care and ease of navigation, were reported between the different PCTs and Foundation Trusts in which this study was conducted. Edwards (2014) identified that changes to infrastructure and financing are crucial to support moving services to the community, and it is likely that this has not been successfully addressed in the case of MS. Implications for Clinical Commissioning Groups are therefore to aim to ensure parity of care and continuous access across geographical and service boundaries, through structural, clinician and patient factors, whilst also developing services responsive to local need.

Moving services from specialist hospital-based services into the community is in line with the shift in investment from acute to primary and community services (Department of Health, 2014). In the 'Closer to home' initiative aiming to substitute community services for hospital care, it was suggested that increased community services may decrease waiting times in comparison to hospital based services, however the

demonstration sites used did not include neurology (Sibbald *et al.* 2008) so further investigation is required. Nonetheless, increased community management of people with MS, potentially through clinics run in a CCG by a GPs with a Specialist Interest (GPwSI) in MS and a MS SN, could address the reported difficulties in access to secondary care. This is increasingly important as the caseloads of MS SNs continue to rise and an increasing proportion of MS Nurse time is spent managing disease modifying treatments (MS Trust, 2015), potentially influencing access.

The importance of good interpersonal communication and a person-centred focus in health care consultations is well-established in the MS (Royal College of Physicians, 2011) and broader long-term conditions literature (Eaton, Roberts & Turner, 2015). The dignity, compassion and respect embedded within person-centred care (The Health Foundation, 2014) were missing from the reported negative interactions with health care professionals reported in this study. This focus on the importance of communication and interaction between two people ('micro-level'), supports Dixon-Woods *et al.*'s (2005) observation that understanding micro-level interactions is central to understanding referral and retention patterns, as it recursively influences future use of services.

However, (as displayed in figure 1), this aspect has not been fully addressed within the 2014 NICE guideline (National Institute for Health and Care Excellence, 2014), thus not addressing the significance of interpersonal aspects in effective care for people with MS.

The relational continuity and therapeutic relationship GPs have with their patients have been described as central to the work of primary care, and policy developments such as 48 hour access targets and the development of 'polyclinics' (focusing on diseases and

technical care) have been suggested to fragment care, prohibiting relational continuity (Royal College of General Practitioners, 2007). The 2014 NICE guideline recommends a “single point of access” for people with MS, to improve coordination of services, and the interpersonal and psychological benefits of a continuous relationship are not expounded (Rhodes, Campbell & Sanders, 2014). The guideline does not recommend where this single point of access should be based, and therefore potentially primary care could act as a gateway to all services, as in stepped care mental health services.

This study identified that continuity of care was important on a personal level to both people with MS and professionals, but was increasingly threatened by political and socio-demographic changes. Relational continuity with one professional was valued highly by all participants, as in previous research investigating other chronic conditions (Waibel *et al.* 2012) and may be of greater importance in a fluctuating condition such as MS where a highly responsive relationship is required. People with MS reported they felt unable to trust advice from professionals who lacked ‘personalised’ knowledge of their preferences and needs, and GPs reported that where they lacked clinical knowledge on MS this could be built up during multiple consultations with someone with MS, and liaison with specialist care. A lack of continuity may therefore prevent the aggregation of this knowledge, thus resulting in professionals who are less responsive and less knowledgeable, causing difficulties for both professionals and patients (as discussed in Rhodes *et al.* 2014).

Participants with MS discussed the conflict between ensuring relational continuity and ensuring fast access to care, which has been suggested in previous research on chronic conditions (Waibel *et al.* 2012, Rhodes, Campbell & Sanders, 2014). Whilst relational

continuity of care was viewed by people with MS and professionals as improving access to ongoing care services, in emergency situations people with MS reported preferring faster access to care (e.g. Accident and Emergency departments) to routine relational care (such as GPs). In these situations the perceived risks of slower access to treatment, outweighed the perceived benefits of relational continuity. This corresponds with current recommended practice where access is provided through outpatient relapse clinics; increasing the use of a single point of access could provide both continuity and access.

Implications for research and/or practice

Correct assessment of candidacy for services relies on adequate knowledge of potential MS symptoms. However, symptoms due to MS can be difficult to correctly identify, relying on GPs and patients to decide whether symptoms are likely to be due to MS and then negotiate a management plan (potentially involving onward referral). An implication for practice is that GPs are competent in the management of neurological conditions (including neurological emergencies) outlined in the 2014 RCGP curriculum. This study suggests this may require further education or training, to expand the role for MS in primary care more broadly, including differential diagnosis, coordinating care, and health promotion (as recommended in the 2014 NICE guideline, National Institute for Health and Care Excellence, 2014).

There are a small number of GPwSI in MS in the UK whose knowledge and interest could be used to inform commissioning and education. Furthermore, there may also be a remit for training practitioners with special interests such as pharmacists (as outlined by the Department of Health, 2007), to improve access to specialist knowledge on

symptom management, disease modifying treatments or relapse treatment in community settings (identified as a priority in prior research; Heesen *et al.* 2011).

Greater collaboration with specialist services may increase access to specialist knowledge without intensive additional training. One example outlined by a specialist nurse in this study is to embed MS specialist nurse clinics into a primary care setting (i.e. GP surgeries), thus increasing inter-professional communication and improving access for patients (as recommended in the ‘Closer to home’ initiative (Department of Health, 2007) and the Five Year Forward View (NHS England, 2014)).

Conclusions

Multiple sclerosis is a heterogeneous condition, with an unpredictable prognosis, requiring flexible and responsive health care services. Qualitative evidence from this study suggests that timely access to services, relational continuity of care and person-centred interactions are central to positive experiences of health care. Moving aspects of MS care into the community, particularly primary care, may increase patients’ satisfaction of services, improve experiences for health care professionals and adhere to recent health care policy initiatives.

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Figure

Figure 1. Identified themes and their relationship to the theoretical framework of candidacy and MS NICE guideline 186 (2014) recommendations.

Tables

Table 1. Sample characteristics for Health Care Professionals

Table 2. Sample characteristics for people with MS