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# Let's talk about sex(ual) wellbeing! Staff perceptions of implementing a novel service for people with Multiple Sclerosis

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## Abstract

**Background:** In people with multiple sclerosis (PwMS), a complex interplay of neurological dysfunction, polypharmacy and psychological issues, contrive to impair their sexual and reproductive wellbeing. Realising an unmet need, the Tayside MS service in collaboration with a sexual health clinician (LJ), established a 'Pelvic Health Clinic' to improve quality of life for PwMS.

**Objective:** To explore clinician's perceptions of implementing an MS Pelvic Health service with a view to establishing future outcomes for health care professionals about the utility in such a service.

**Method:** In this small-scale qualitative case study, we explored clinician's perceptions of such a clinic adjunct. Semi-structured interviews were conducted, transcribed, and thematically analysed in a reflexive manner.

**Results:** Five participants consented. Ten sub-themes emerged, which were organised into three main themes: service tensions, patient needs and practitioner feelings.

**Conclusion:** Clinicians highly valued the new MS 'pelvic health clinic'. Knowing that there was a service available empowered clinicians to ask patients about sexual health needs. Specific referral criteria may help further develop the service and improve patient care. Staff welcome training and support in this area or the option to signpost onwards; either mechanism lends itself to enhancing MS patient needs.

**Keywords:** Multiple sclerosis, quality of life, symptomatic treatment

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## Introduction

Tayside has a high prevalence of Multiple Sclerosis (MS), with one of the peak rates of incidence of MS nationally and two thirds of the cohort being female.<sup>1</sup> The UK average age of onset of MS is 42 years, thus many patients receive a diagnosis and disease modifying therapy during (DMT) their reproductive lifetime.<sup>1</sup> Some of the drugs used to treat MS are teratogenic and so highly effective contraception is important. Additionally, hormonal effects during the menstrual cycle and menopause may exacerbate symptoms of MS or viceversa.<sup>2</sup>

As a result of a complex interplay between neurological dysfunction, polypharmacy and psychological issues, patients with MS (PwMS) experience problems with their sexual and reproductive wellbeing.<sup>3–5</sup>

Whilst urinary and bowel dysfunction are often discussed and managed, problems with sexual dysfunction, although common, are often overlooked during clinical reviews.<sup>6,7</sup> It has been estimated that 69.8% of women report sexual difficulties<sup>4</sup> and 62.9% of men.<sup>8</sup> Patients may be reluctant to disclose these issues and many health care professionals lack the skills to address such problems.<sup>6,9</sup> This is an issue that can also extend beyond the realm of the MS clinical neurological environment.<sup>10–13</sup>

Although recognised in the NICE<sup>14</sup> guidance, evidence suggests sexual health concerns are not regularly discussed during an MS patient's annual review.<sup>6,9</sup> In Tayside, a service needs assessment in 2017 highlighted that the majority of PwMS had pelvic and sexual health concerns, e.g., contraceptive,

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menopause and sexual problems, or erectile dysfunction. This service needs assessment was performed in collaboration with a consultant neurologist, GP with a specialist interest in MS and MS specialist nurses. Thus, an MS neurology outpatient service, collaborations were established with a sexual health clinician to provide a 'Pelvic Health Clinic' to address such PwMS issues of quality of life.<sup>6</sup> This clinic commenced in August 2018 by a single clinician Dr L Jarvis, a specialist sexual health clinician, who ran a parallel clinic within the MS team. She provided a monthly service to see patients who had been identified by the MS team as having 'pelvic health' needs. She provided advice and counselling to patients on contraception, menopause and sexual problems. These patients were from the whole spectrum of the condition and included those initially diagnosed with minimal disability to patients with severe symptoms and those in between.

Previously we had looked at patients' views of the clinic. A random review demonstrated a positive response.

In response to the question -"Do you feel that your attendance at the MS pelvic health service has improved your quality of life?"

Patient No.1 "it was difficult to disclose my insecurities about lack of intimacy, but I am so glad that I did as Dr Jarvis made a potentially difficult discussion, much easier than I feared. She has helped me to understand devoting time and effort to protect one's relationship, even in the face of coping with the demands of MS is essential to intimacy."

Patient No. 2 "I got on really well with the specialist doctor. She made me feel really comfortable and suggested a medication. I'm not embarrassed to say that erectile dysfunction caused a significant impact on quality of life. I felt able to express my difficulties. Otherwise, I would most likely have gone to my GP, eventually, at some point. If I'm truthful I kept putting off a visit to the GP!"

Patient No. 3 "MS is difficult, I didn't expect it to cause me sexual problems too! I was able to explain to Dr Jarvis that MS has changed me as person. I'm a completely different person from whom I was! She explained that my low mood can play a big part. I shared all of this with my partner and now we are devoting more time to resolve my issues. We just need to make the effort to make more time for each other."

This qualitative case study aimed to assess clinicians' perceptions of this novel, holistic patient care

approach with a view to establishing future learning outcomes for health care professionals and students about the utility in such a service.

## Methods

This research was conducted as a qualitative case study<sup>15</sup> within NHS Tayside, Ninewells Hospital and Dundee Medical School in Scotland during December 2020. Approval was granted from the University of Dundee's School of Medicine Research Ethics Committee.

### *Clinician recruitment*

Participants were all staff who work in the Tayside and NE Fife Multiple Sclerosis team. This team is a subsection of the neurology service as a whole: Two doctors (one consultant neurologist and one GP with a special interest in MS) and three MS specialist nurses. The MS Pelvic Health Clinic was already established for some 28 months prior to the study.

Participants were recruited by the departmental secretary acting as an administrative gate-keeper to send out an invitation to partake in this research. Any staff involved in the delivery of annual MS reviews were eligible. Clinicians who volunteered were contacted, and an interview was undertaken either face-to-face or via phone. No clinician declined participation.

### *Data collection*

To protect anonymity, only the role of the clinician was collected. Semi-structured interviews with clinicians were conducted by one of the authors (LJ) in December 2020 facilitated by an interview schedule (Supplemental Appendix 1). Interviews were audio-recorded and transcribed verbatim.

### *Analysis*

Data were analysed via an inductive thematic analysis<sup>16</sup> by two of the researchers (LJ, KM). Transcripts were read, re-read and coded by one researcher (KM), then discussed and reconciled by the other (LJ). For an example of the coding process see Supplemental Appendix 2. The analysis allowed for generating predominant themes and subthemes clustered together, taking into account data saturation.<sup>17</sup> As the primary researcher (LJ) also worked within the neurology department, consideration was given to the importance of reflexivity throughout this process<sup>18</sup> to take into account any subjective biases that might emerge.

## Results

Five interviews were conducted in total, i.e., the entirety of the MS team consented to participate. Three MS specialist nurses [N] (all female) and two MS specialist doctors [D] (one female, one male) were interviewed. Ten sub-themes emerged, which were organised into three main themes: service tensions, patient needs and practitioner feelings (Figure 1). In the following section we present examples of these themes and sub-themes with selected quotations to contextualise the perspectives of the clinicians and their service provision to patients with MS. All those interviewed had referred patients to the specialist clinic.

### *Service tensions – unmet needs and time pressures*

All of the interviewees expressed that sexual health was often previously neglected during MS clinical review due to lack of time, knowledge, and availability of appropriate opportunities for further clinical management.

N1: ... recognise that this is an area we have perhaps neglected in the past..

N2: ... truthfully this is a very time-consuming activity rather than one to one discussion with patients which is more valuable...

### *Service tensions – clinic purpose and future developments*

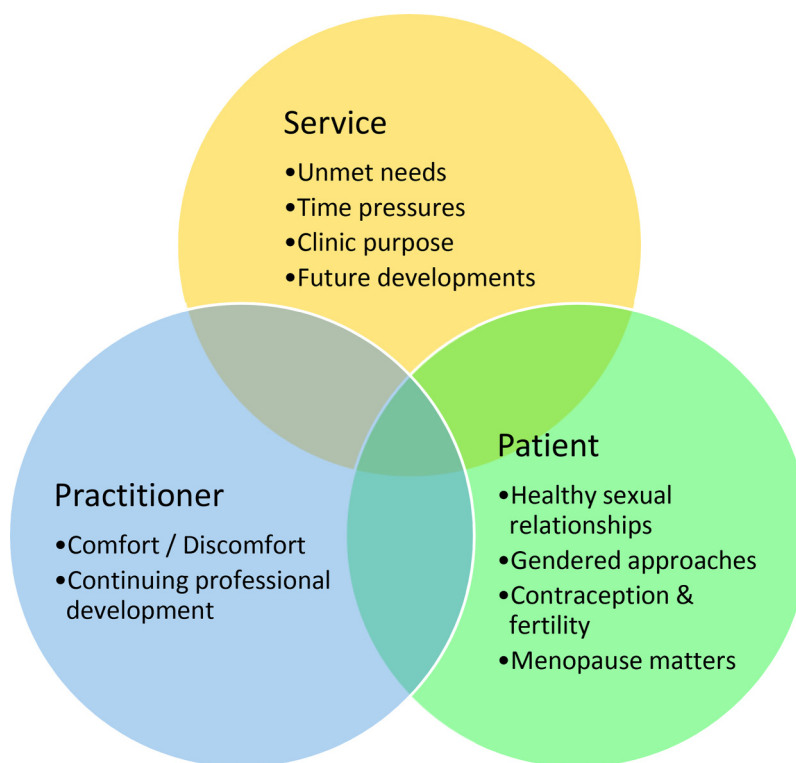
When asked about the purpose of the 'pelvic health clinic,' respondents requested a clearer definition about the role of the clinic. Some interviewees advocated incorporating sexual health questions into future annual review appointments.

N2: ... I anticipate that it provides a protected space for patients to disclose any problems that they may have in terms of sexual health and pelvic floor health...

D2: So, I think it's probably important that we have a good way of making sure that we note down...in their annual review...and we refer them...

### *Patient needs – healthy relationships and gender approaches*

Participants recognised that sexual health can be a significant concern for PwMS.



**Figure 1.** Themes and sub-themes.

N2: ...something to improve patient's welfare or sense of wellbeing to be able to talk about sexual health...

Two clinicians commented that they found it difficult to discuss sexual health with a patient of the opposite sex.

D1: (I) refer male patients, more than, than female patients...

N2: I think as a nurse we don't engage enough with in getting to the nitty gritty aspect of discussion particularly with a male

#### *Patient needs- contraception, fertility and menopause*

It was acknowledged that patients on DMT for MS may require contraceptive advice, or on the contrary, may be planning a pregnancy creating an imperative that contraception and DMT management is discussed, particularly for DMT medications with potential teratogenic side effects.

D2: ...having a documented and robust conversation about contraception for patients on DMT...

Interviewees felt that menopause symptoms might exacerbate MS symptoms. Although it was good to have an understanding of this, the potential inequity of MS patients having unique access to a menopause specialist was mentioned.

N1: ...It is recognising that menopause exacerbates MS symptoms and it is good to have an understanding there...

D2: ...I think that is quite a difficult area...patients that discuss menopause symptoms at their MS review get a different level of care than if they weren't attending the MS clinic...

#### *Practitioner feelings of comfort or discomfort and continuing professional development (CPD)*

It was noted that several practitioners felt uncomfortable discussing sexual health issues with their patients.

D1: Not comfortable...so I don't tend to go there.

However, there was a desire, particularly from the nursing staff, for further education and support to give them the confidence to raise these topics during a consultation.

N2: ...from a nursing perspective a wee bit of a session on things that patients could experience with MS pelvic health. To give us the confidence to address these things...

#### **Discussion**

Three major themes have emerged from introducing a 'pelvic health clinic' within an MS service for patients. Analysis of the interviews suggests that all health care professionals interviewed considered the MS pelvic health clinic to provide valuable, additional holistic patient care.

In the past, whilst clinicians might recognise that there existed disparities regarding MS patients' sexual and reproductive wellbeing,<sup>3-5</sup> they have been inclined to cite pressures of time as one barrier towards avoiding such topics. However, the creation of the service would appear to enable clinicians to ask about their patients' sexual health issues, knowing that time and expertise was available to redress such challenges.

Whilst in the early stages of the 'pelvic health clinic' evolving there existed some lack of clarity about the purpose of the clinic; longitudinally, staff began to recognise and suggest how such a provision aligns with evidence suggestive of tackling issues of MS patients who have sexual function problems.<sup>6,9</sup> Indeed staff began to have future aspirational plans in monitoring and addressing MS patients' needs that align with advanced pathways of care.<sup>6</sup> Such an approach reinforces evidence seen elsewhere regarding staff empowerment to set an agenda that focuses on patients' sexual health needs.<sup>19</sup>

Our results indicate that interdisciplinary collaborations (e.g. neurology and sexual/reproductive health services) can create a safe space in which MS patients concerns, like those cohorts with other conditions,<sup>10-13</sup> can be remediated. The availability of the 'pelvic health clinic' allows staff to support enquiries about sexual wellbeing, including contraceptive methods, menopausal matters, sexual dysfunction and healthy relationships, as part of the MS clinical review.

This study highlights a need for staff training and education to allow more confidence to raise the topic of sexual health with patients, particularly when it involves the opposite gender. This could be done through tutorials or clinic teaching sessions. In doing so, we recognise that having additional support from external services such as sexual health, empowers staff who might feel less comfortable in

addressing such issues given that they can still have a facilitative role.<sup>6,12</sup>

### Limitations

This was a study aimed at clinician's perspective and as such did not explore patients perceptions. We have previously performed a random audit of the clinic and while the results are favourable it is clear that a more extensive audit is required. This is ongoing and the subject of further study.

### Conclusion

We explored the clinician's perceptions of introducing a 'pelvic health clinic' within an MS neurological service. We acknowledge that this is a small scale, qualitative case study which requires the reader to consider the transferability of our results to their setting.<sup>20</sup>

MS service staff highly valued the new MS 'pelvic health clinic'. Knowing that there was a service available empowered clinician to ask patients about sexual health needs. Specific referral criteria may help further develop the service and improve patient care. Staff welcome training and support in this area or the option to signpost onwards; either mechanism lends itself to enhancing MS patient needs. Implications for the extension of such interservice collaborations out with the realm of PwMS might also be considered. Future research could focus on this latter area and patient perspectives of such service delivery.

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### Declaration of conflicting interests

Laura Jarvis - Paid by Bayer to deliver teaching to a practice nurse

Kevin McConville - Nil to declare


Sonia Devereux - Paid by Biogen to deliver a lecture and workshop


Professor O'Riordan - I have been a principal investigator in clinical trials sponsored by TEVA, Biogen, Novartis and Sanofi Genzyme. I have participated in advisory boards with Biogen, TEVA and Roche. I have been a guest of Biogen, TEVA and Novartis to attend conferences.

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### Supplemental material

Supplemental material for this article is available online

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The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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