

Navigating Uncertainty and Mental Health in Pregnancy in Patients with Multiple Sclerosis: A Qualitative Study

Vivian Chen, MS3¹, Suma Shah, MD²

¹Duke University School of Medicine, ²Department of Neurology, Duke University Medical Center, Durham, NC, USA

INTRODUCTION

- Multiple sclerosis (MS) is more prevalent in female patients and is frequently diagnosed during reproductive years¹.
- There are few prior qualitative studies examining patients with multiple sclerosis (PwMS) in pregnancy and motherhood²⁻⁶.
- Living with uncertainty is a daily experience⁷ and is a known driver of anxiety and depression for PwMS^{8,9}.
- We aimed to explore PwMS' pregnancy experience to identify opportunities to improve care.

METHODS

- Conducted semi-structured interviews with PwMS who have been pregnant and treated at the Duke MS clinic.
- The interview guide queried participants' lived experiences and resource needs.
- Thematic analysis was conducted inductively to identify main themes and subthemes.

Table 1. Characteristics of participants

Characteristic	Participants (n = 10)
Mean age (range)	35 (26-40)
Mean no. years since diagnosis (range)	6 (1-12)
Mean no. pregnancies	2
Mean no. children	1.3

Insufficient research

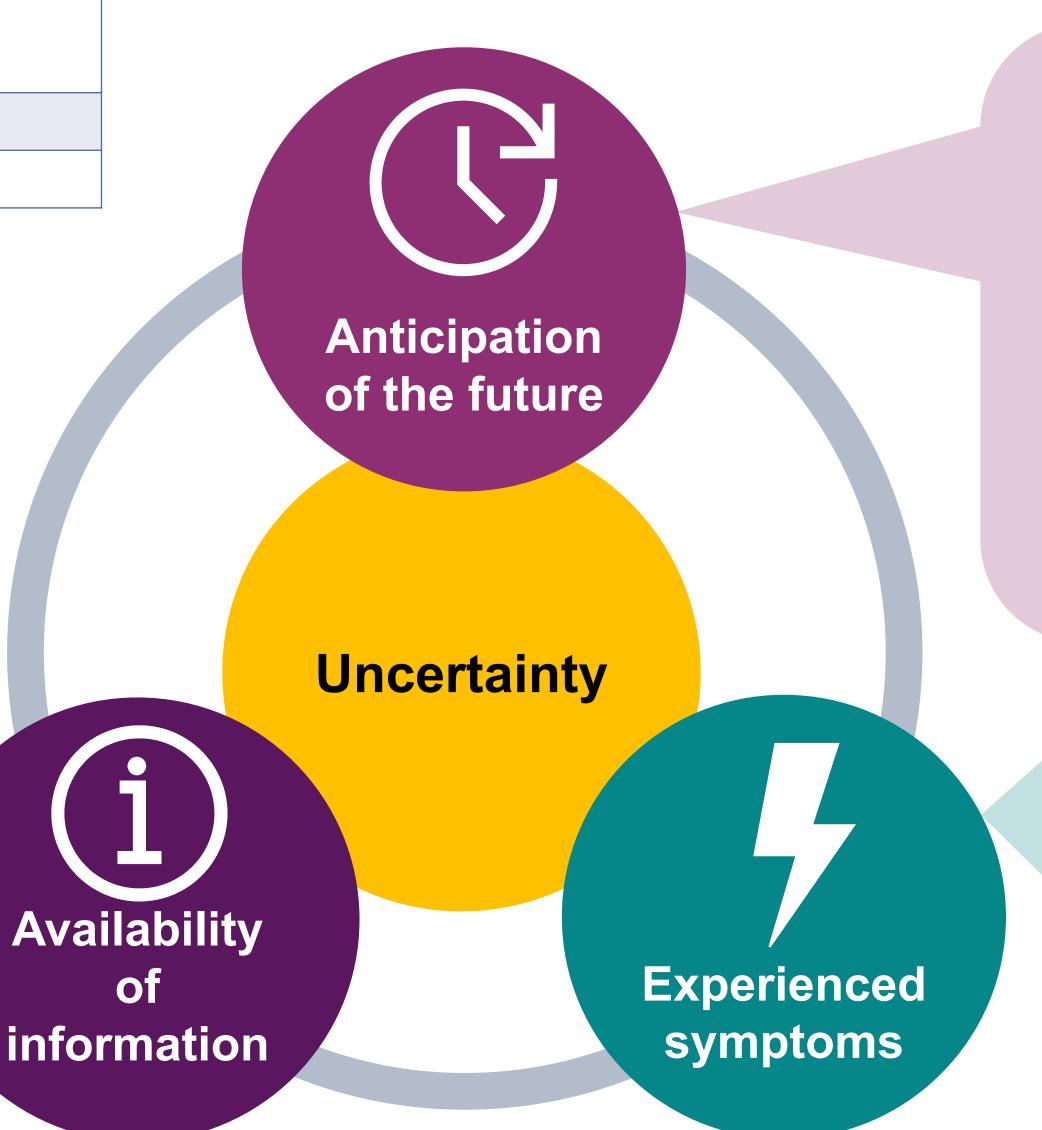
"The guidelines change so frequently because there's still just not a whole lot of research... What distance do we need to keep between like my infusion and when we start trying? And how long can we try before I need to get reinfused?"

External support/communities

"Two women that commented like their neurologist told them, 'Don't. That's not fair to kids.' ... It's just such conflicting information that we're being given."

RESULTS

- All participants (n=10, 100%) discussed dealing with uncertainty during pregnancy or postpartum.
- A majority personally experienced mental health challenges (n=7, 70%) or discussed utilizing mental health resources (n=8, 80%).



Relapses

"It kind of was like a ticking clock in my head of like, okay, you're not on medicine yet... Am I gonna start like getting a new lesion?"

Impact of MS on motherhood

"And new lesions. What would that look like?... The scariest thing for me too was like, will I be able to take care of him?"

Healthcare-associated factors

"I'm very nervous that I'm not going to be able to continue after this year is up because I can't pay 100,000 a year and have two kids"

Differentiating MS from pregnancy

"My arms started to go numb... well, this is your MS and here's a drug for it. Well, the frustrating part is the anxiety part of it. You can't pinpoint like the baby could be on a nerve."

Role of MS in peripartum challenges

"Is the medicine what's creating this infertility?... Is it the fact that I have an autoimmune disease?"

Fig 1. Dimensions of uncertainty in pregnancy

CONCLUSION

- PwMS experience unique dimensions of uncertainty during and around pregnancy.
- Providers may aim to decrease uncertainty by addressing patient information gaps surrounding safety and timing of disease modifying therapies (DMTs), risk counseling, establishing clear plans, coordinating care across the patient's reproductive health team, and providing anticipatory guidance on when to seek care.
- Uncertainty may negatively impact PwMS' mental health and pregnancy experiences necessitating more screening for detection of mental health changes and provision of more social and mental health support.

REFERENCES

- . Orton SM, Herrera BM, Yee IM, et al. Sex ratio of multiple sclerosis in Canada: a longitudinal study. Lancet Neurol.
- Colaceci S, Zambri F, Marchetti F, et al. 'A sleeping volcano that could erupt sooner or later'. Lived experiences of women with multiple sclerosis during childbearing age and motherhood: A phenomenological qualitative study. Mult Scler Relat Disord.
- Fragkoudi A, Rumbold AR, Grzeskowiak LE. Family planning and multiple sclerosis: A qualitative study of patient experiences to understand information needs and promote informed decision-making. Patient Educ Couns. 2023;110:107673.

 Kosmala-Anderson J, Wallace LM. A qualitative study of the childbearing experience of women living with multiple sclerosis.
- Disabil Rehabil. 2013;35(12):976-981.

 Payne D, McPherson KM. Becoming mothers. Multiple sclerosis and motherhood: A qualitative study. Disability and
- Rehabilitation. 2010;32(8):629-638.

 6. Ghafoori F, Dehghan-Nayeri N, Khakbazan Z, et al. Pregnancy and Motherhood Concerns Surrounding Women with Multiple
- Sclerosis: A Qualitative Content Analysis. Int J Community Based Nurs Midwifery. 2020;8(1):2-11.

 7. Nissen N, Lemche J, Reestorff CM, et al. The lived experience of uncertainty in everyday life with MS. Disabil Rehabil.
- Hanna M, Strober LB. Anxiety and depression in Multiple Sclerosis (MS): Antecedents, consequences, and differential im
- 9. Siegert RJ, Abernethy DA. Depression in multiple sclerosis: a review. J Neurol Neurosurg Psychiatry. 2005;76(4):469-47