

## **Navigating uncertainty and mental health in pregnancy in patients with multiple sclerosis: a qualitative study**

Vivian Chen<sup>1</sup>, Suma Shah, MD<sup>2</sup>

<sup>1</sup>Duke University School of Medicine, <sup>2</sup>Department of Neurology, Duke University Medical Center, Durham, NC, USA

### **Background:**

Multiple sclerosis (MS) is more prevalent in female patients and is frequently diagnosed during reproductive years. Patients with multiple sclerosis (PwMS) have a decreased risk of relapse during pregnancy and this risk increases postpartum. In prior studies, PwMS reported feeling inadequately informed about pregnancy and reported that MS has affected their family planning. Further exploration into MS and pregnancy is needed to provide optimal and safe care to PwMS in pregnancy. The purpose of this study is to explore PwMS' pregnancy experience to identify opportunities for interventions to improve care.

### **Methods:**

PwMS who have had current or prior pregnancies and who received medical care from an MS specialist at Duke University Medical Center were identified. We conducted semi-structured in-depth interviews using videoconferencing software to record and transcribe the interviews. Thematic analysis was conducted inductively with an emphasis on lived experiences and resource needs of PwMS. All transcripts were independently coded in NVivo 12 and 14 by two researchers and coding discrepancies were resolved by consensus. Main themes and subthemes were identified and presented below.

### **Results:**

A total of ten participants were interviewed. The mean age of participants was 35 years (range 26-40) and mean number of years since diagnosis was 6 (range 1-12). A dominant theme that emerged was navigating uncertainty and its relationship with mental health. 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%). Uncertainty was characterized in three main ways with several subthemes: (1) Anticipation of the future (relapses, impact of MS on motherhood, and healthcare-associated factors); (2) Experienced symptoms (differentiating MS from pregnancy, role of MS in peripartum challenges); (3) Availability of information (insufficient research, provider counseling, external support / communities). These subthemes emerged in the context of a negative impact on mental health, including postpartum depression, anxiety, and feelings of guilt, responsibility, and isolation. Participants reported several mental health resources as helpful: talk therapy, psychiatric medications, nurse phone lines, MS support groups, and other support systems (family, friends, hired childcare).

### **Conclusions:**

This study identifies the need for enhanced mental health support to help PwMS navigate uncertainty during pregnancy and postpartum. Participants described three main dimensions of uncertainty related to their future, experienced symptoms, and information available. Our work demonstrates that opportunities exist to improve patient care. Interventions to address patient mental health and informational resource needs are likely to be beneficial in this setting.