# Role of the Specialist Nurse at the Time of MS Diagnosis: Canadian Survey Results

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### BACKGROUND

A large proportion of MS patients do not start treatment with a disease-modifying therapy (DMT) or delay their decision to initiate treatment (1). There is a need to understand patients' perceptions about MS and its management at the time of diagnosis, and how to enhance the effectiveness of MS nurses in their education and counselling of MS patients.

#### **OBJECTIVES**

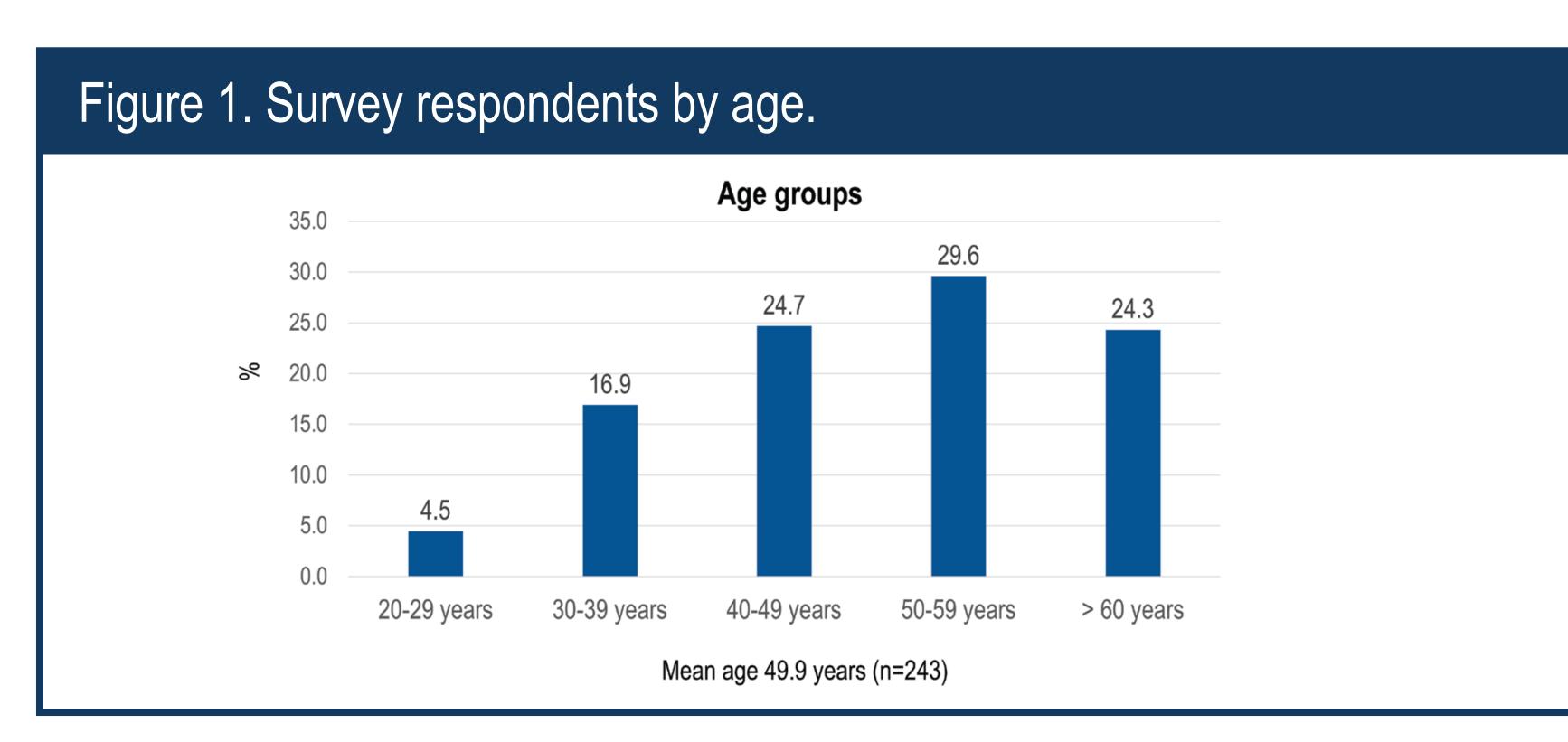
To survey Canadian MS patients' experience at the time of diagnosis, including their knowledge of MS and their access to services and community resources. Nursing and other factors that may contribute to a patient's decision to initiate treatment with a disease-modifying therapy were also investigated.

#### METHODS

MS patients were invited to complete a 20-item questionnaire on MSology.com, a website that provides news and information to approximately 40,000 MS patients per year. The survey period was December 2018 to March 2019. The survey was provided in English and French and promoted to subscribers and through social media.

### RESULTS

There were 251 Canadian respondents (English 138, French tres or MS specialist nurses. 113). Most were female (89.8%, n=244); mean age was 49.9 At the first visit, most of the discussion time was spent on education years (range 20-80 years, n=243) (Figure 1). The largest about DMTs, general education on MS and symptom management cohort was diagnosed in the periods 2015-2018 (34.7%) and (Figure 3). Mean satisfaction score, as rated on a 5-point scale 2010-2014 (19.9%). Mean age at diagnosis was 39.7 years. (0=Dissatisfied, 4=Very satisfied), was 2.3. Satisfaction scores were Mean duration of MS was 10.5 years. Patients received their MS diagnosis from a neurologist at a hospital/MS clinic higher for topics addressed at greater length, such as education about DMTs and about MS (Figure 4). Topics that received the least (59.8%), a community neurologist (17.4%), a family physician (12.9%) or other healthcare professional (9.9%). amount of time (< 10% of nurse visit) received the lowest scores.



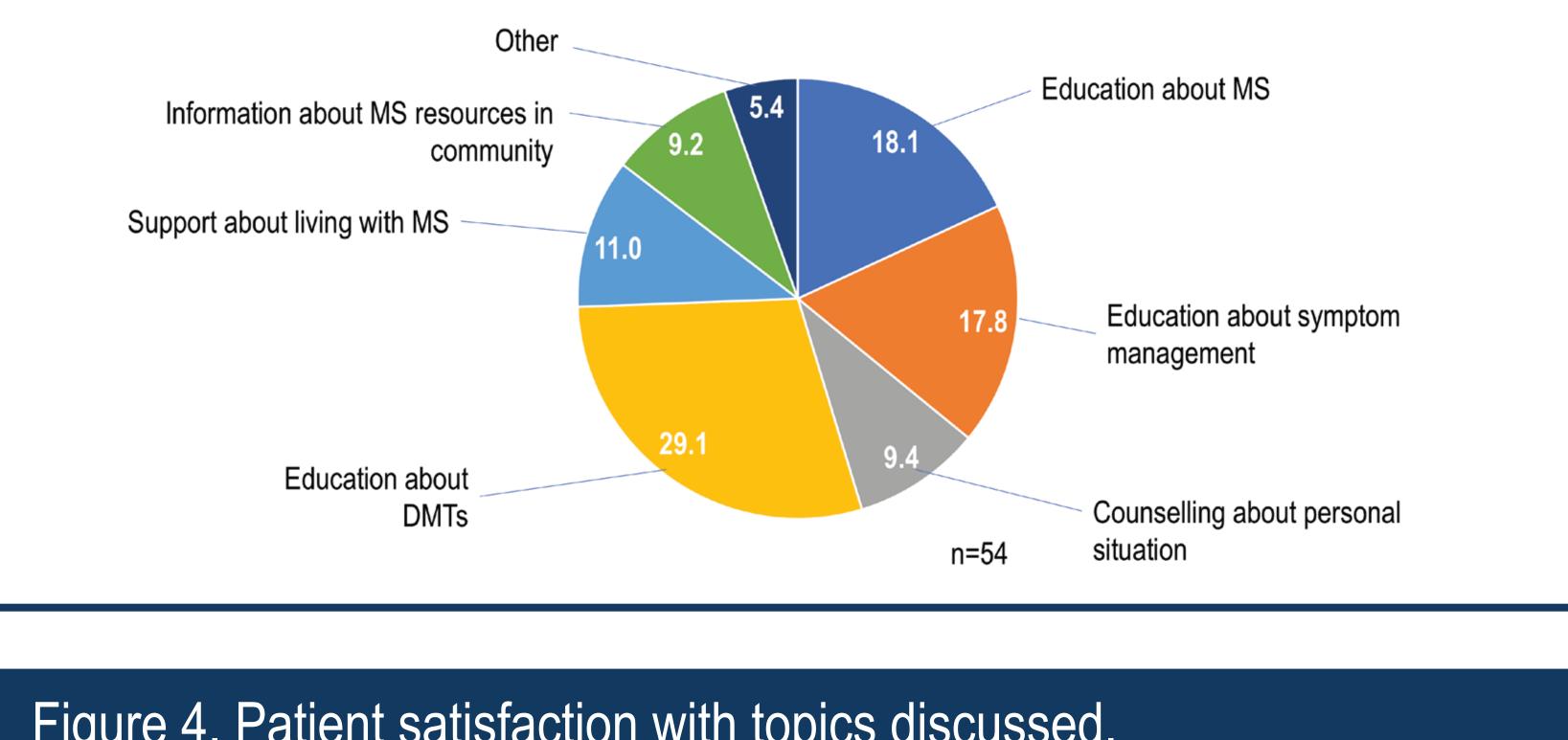
### **AT DIAGNOSIS**

Patients rated their knowledge of MS at the time of diagnosis (0= none, 10=excellent) as low (mean 2.81, n=244). A minority reported having a friend (24.0%) or family member with MS (23.6%). Francophones were more likely to have a family member with MS compared to anglophones (33.6% vs. 15.0%). Most said that family members (82.6%) and employers/school (52.7%) were supportive at the time of diagnosis.

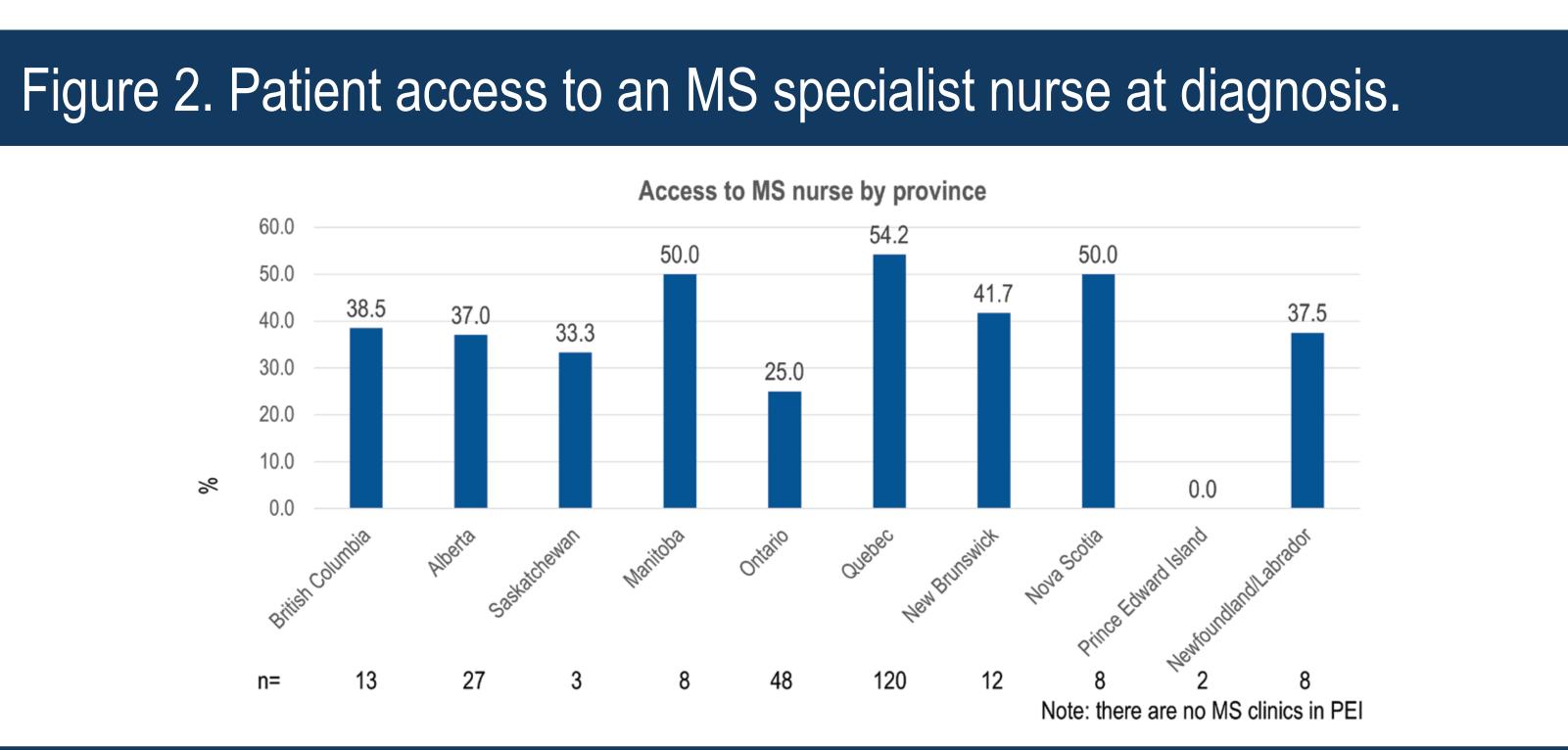
#### **MS NURSE INTERACTIONS**

A minority of respondents stated they had access to an MS specialist nurse at the time of diagnosis (43.8%, n=249). Access to an MS nurse was lower for male (28.0%) versus female patients (46.1%). MS nurse access was highest in the province of Quebec and lowest in Prince Edward Island (Figure 2); PEI does not have any MS cen-



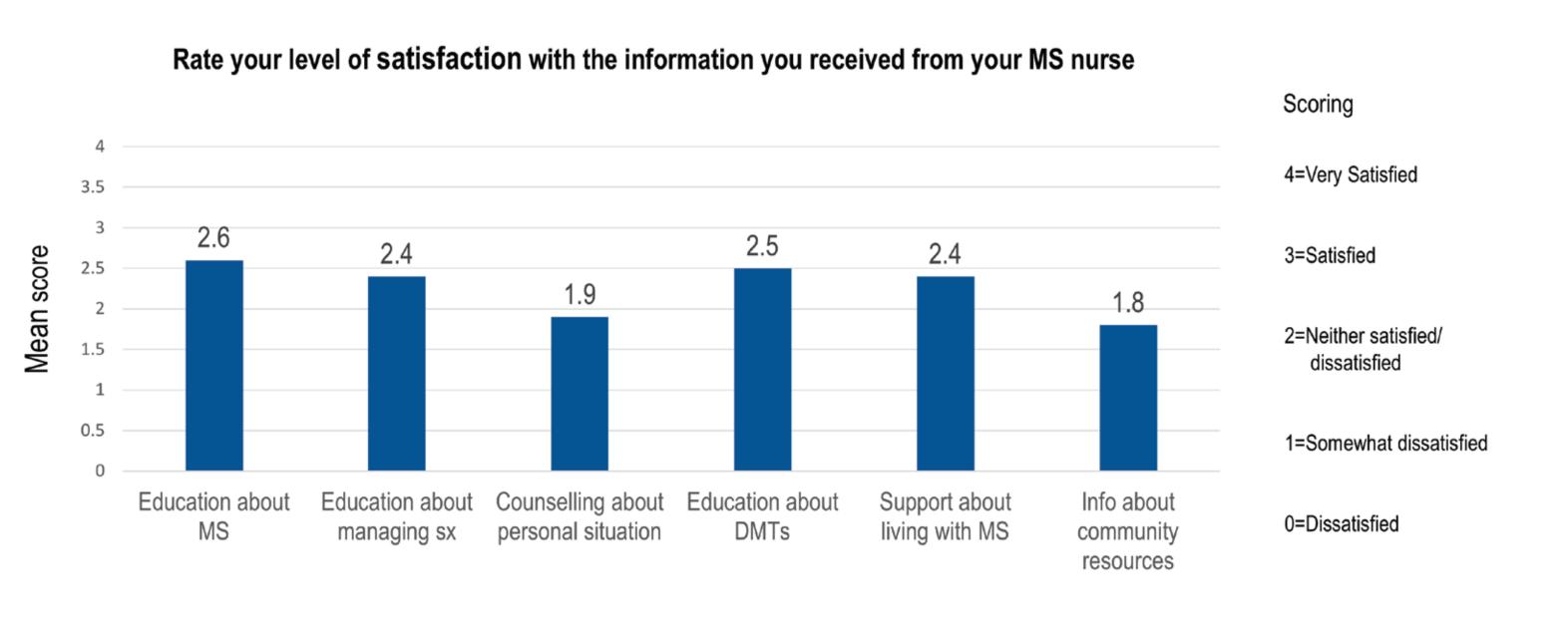


Among patients diagnosed after 1995 when DMTs became available in Canada (n=153), most (71.2%) were advised to start a treatment around the time of their diagnosis. The proportion advised to start a DMT was low in 1996-1999 (12.5%), increased in 2000-2004 (50%) and 2005-2009 (76.2%), with further increases in 2010-2014



#### Figure 3. Proportion of time spent discussing with the MS nurse.

#### Figure 4. Patient satisfaction with topics discussed.



### DMT USE

(91.4%) and 2015-2018 (98.3%). The likelihood of being offered a DMT was higher among patients with access to an MS specialist nurse compared to those with no nurse access (81.9% vs. 63.7%).

Among patients diagnosed after 1995, 57.1% were receiving a DMT at the time of the survey, 24.0% had never received treatment, 12.3% had discontinued treatment and 6.5% were untreated but planned to start a DMT. In the group initially offered a DMT, 77.7% are currently on treatment; among those not offered a DMT, 79.5% have remained untreated. Current DMT use was higher among patients seen by an MS nurse (71.7%) compared to those with no nurse access (47.3%).

## CONCLUSIONS

The present survey found that many MS patients in Canada do not have access to an MS specialist nurse, similar to previous findings by the authors (2). In Canada, MS nurses are affiliated with specialized clinics, and DMTs can only be prescribed through a clinic in some provinces. This suggests that many patients with limited access to an MS clinic may not be offered a DMT early and will remain untreated. Patients who reported access to an MS nurse (43.8%) were more likely to have been offered a DMT at the first visit (81.9%), and to be currently on treatment (71.7%). Study limitations were that survey responses were obtained from patients seeking information on an MS news website which may have biased the sample; patients ineligible for treatment due to progressive MS were not identified; and patients' interactions with nurses were rated according to "satisfaction" which may not have been the optimal term for evaluating the quality of the interaction.

The nurse's role in educating patients about DMTs has become increasingly complex (3). Counselling must address the potential benefits and risks of more potent treatments and the need to adhere to long-term safety monitoring. A consequence is that there is less time spent on other important areas, such as the availability of community resources and patients' emotional well-being, so nurse visits may not meet the full spectrum of patients' often complex needs (4-6). Greater efforts are needed to ensure that patients' evolving requirements are met by health care teams throughout the clinical course.