

The CORE TM/AFM Registry

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Outcomes studies of idiopathic transverse myelitis

- Challenging, due to:
 - Relatively uncommon condition.
 - Outdated definitions (last updated in 2004).
 - Inconsistent data collection.
- Rough measures of outcome (such as the modified Rankin scale) often used in literature, but patient reported outcomes rarely utilized.

Table 2: Modified Rankin Scale for Measuring the Degree of Disability or Dependence in the Daily Activities of People who experience a Stroke

Level	Description
0	No symptoms
1	No significant disability, despite symptoms; able to perform all usual duties and activities
2	Slight disability; unable to perform all previous activities but able to look after own affairs without assistance
3	Moderate disability; requires some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requires nursing care and attention

Adapted from Rankin, 1957¹ and van Swieten et al., 1988²

CORE TM hopes to gain a large understanding of TM/AFM outcomes.

- Large study, compiling records on diagnosis, treatment, and long term outcomes of TM and AFM.
- Anyone with diagnosis of idiopathic TM/AFM, access to MRI scan and records (in English) may participate. There is no age or time cutoff.

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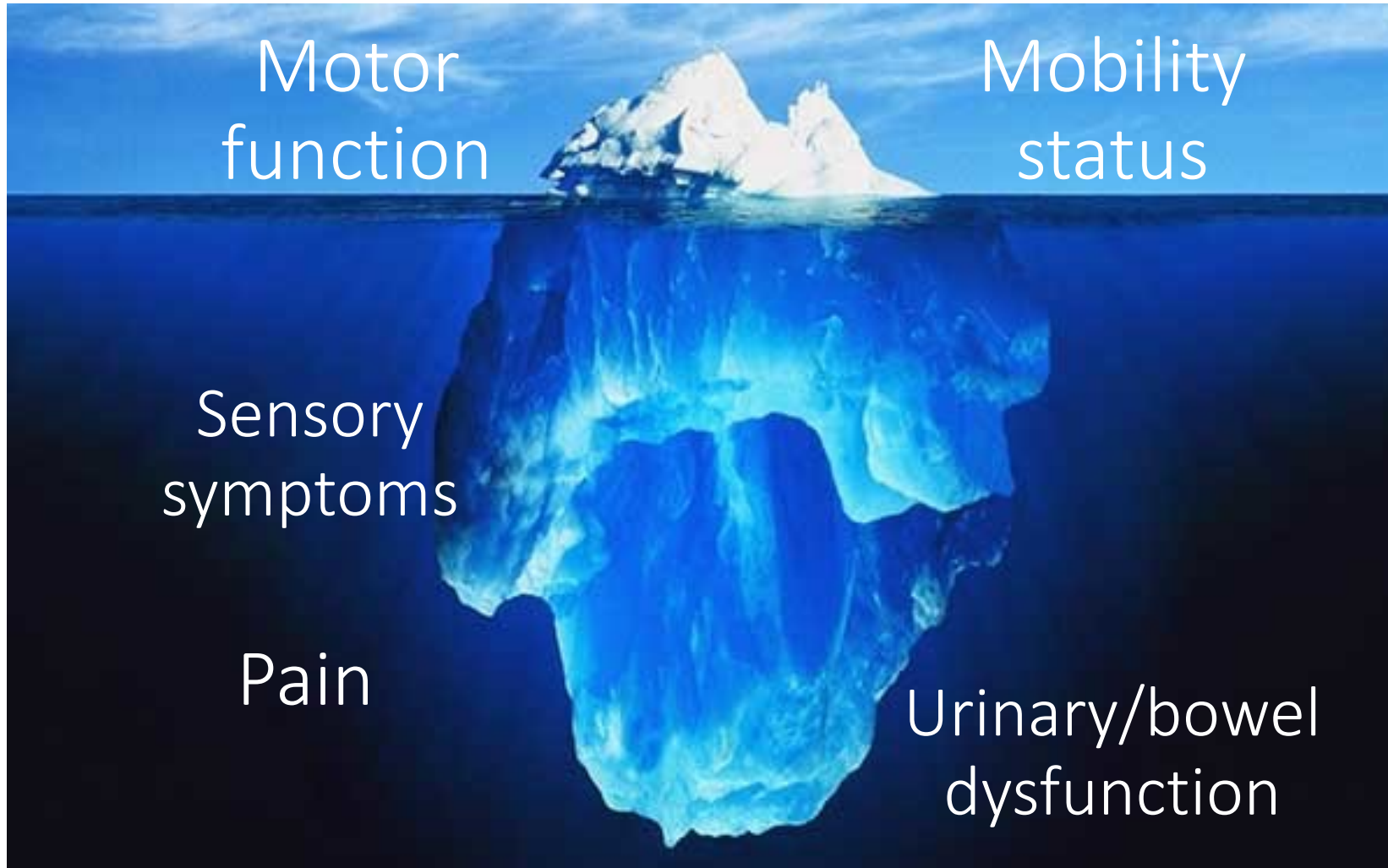
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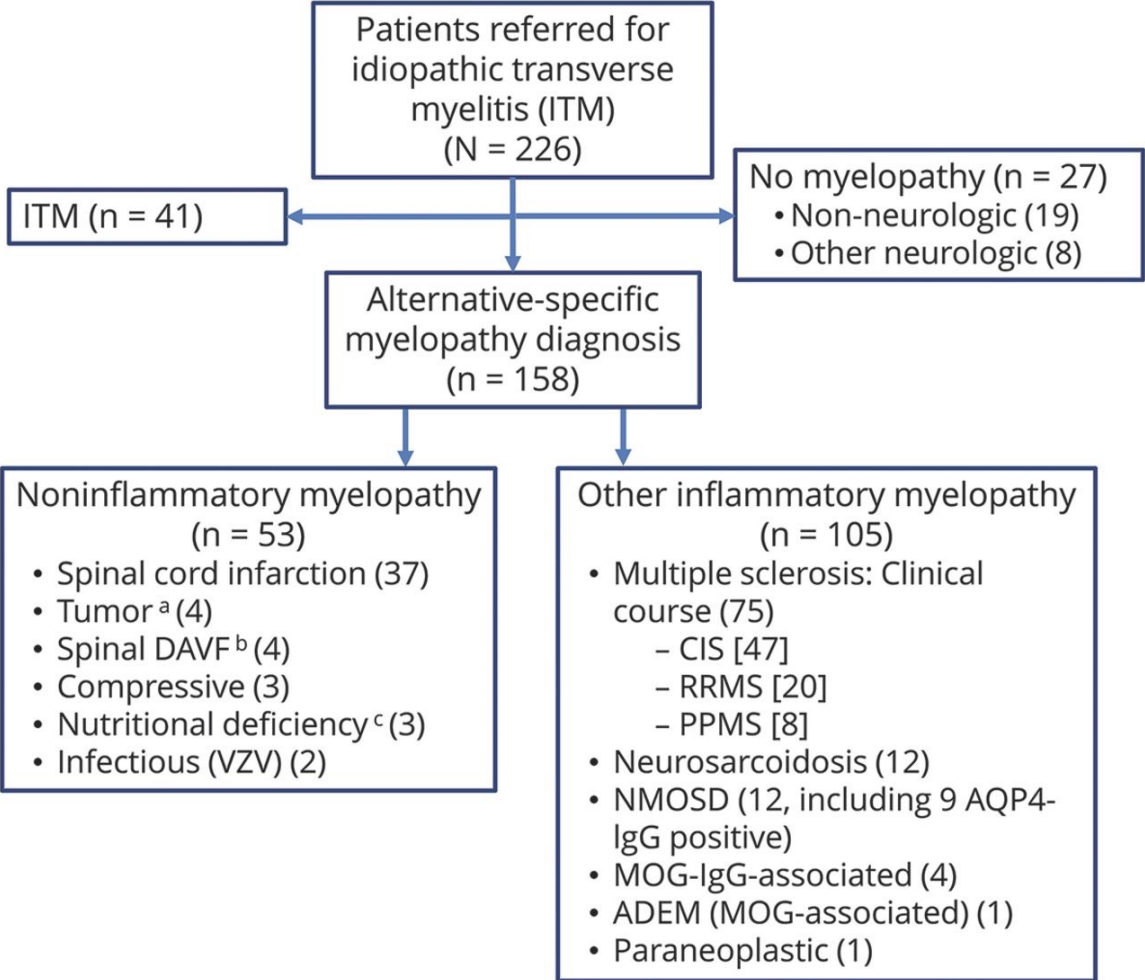
T
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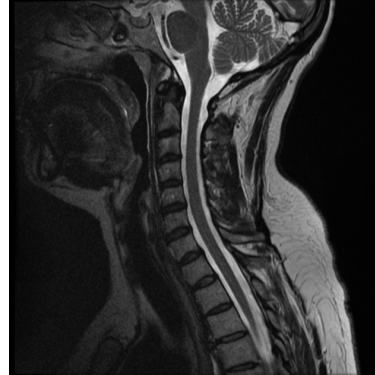
Aim 1: Gain a better understanding of the ‘full’
impact of myelitis to guide needs in the
community



Aim 2: Assess diagnostic accuracy. It's not always TM...



Study details: greater than 2 years from onset



1. Express interest and submit informed consent

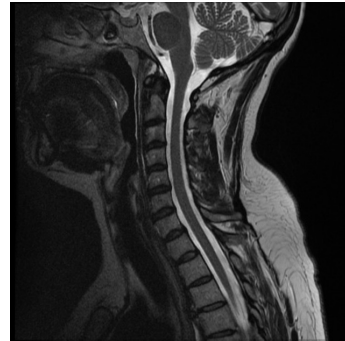
2. Submit MRI images from onset on a CD.
Submit medical records from diagnosis.

3. Complete surveys

Study details: less than 2 years from onset



1. Express interest and submit informed consent



2. Submit MRIs on CD and medical records



3. Complete initial surveys

2 years later



4. Complete Follow-up surveys

Surveys include information about

- Name, information about diagnosis and treatment.
- Measure of mobility status (Patient Derived Disease Steps).
- Depression, Anxiety.
- Pain
- Bladder Function.



Materials to gather prior to participation

- Medical records from diagnosis:
 - CSF studies.
 - Blood work done at time of diagnosis.
 - Comprehensive hospital record from admission (if applicable).
- MRI scan (must be able to provide images from diagnosis on CD).
- It is recommended these are sent via a service that will allow for tracking.

To participate:

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