

Norwegian Narcolepsy Registry finds low use of Sodium oxybate in post-H1N1 (Pandemrix-vaccinated) Narcolepsy Type 1

Ragnhild Berling Grande¹, Rannveig Viste^{1,2}, Martin Aker¹, Stine Knudsen Heier¹

¹Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnias (NevSom), Department of Rare Disorders, Oslo University Hospital, Norway. ²Institute of Clinical medicine, University of Oslo, Norway.

INTRODUCTION

The Norwegian Narcolepsy Registry is a medical quality registry established by request of the Norwegian health authorities.

Main aims are to survey the quality of diagnostics and treatment of CNS-hypersomnias in Norway, with special priority of post-H1N1 (Pandemrix)-vaccinated Narcolepsy Type 1 (NT1).

METHOD

Patients were included at the Norwegian Centre of Expertise for Hypersomnias: NevSom, Oslo University Hospital 2015-2020.

Data collected via semi-structured interview, validated questionnaires and patient journals. All diagnoses according to International Classification of Sleep Disorders (ICSD-3). Written informed consent.

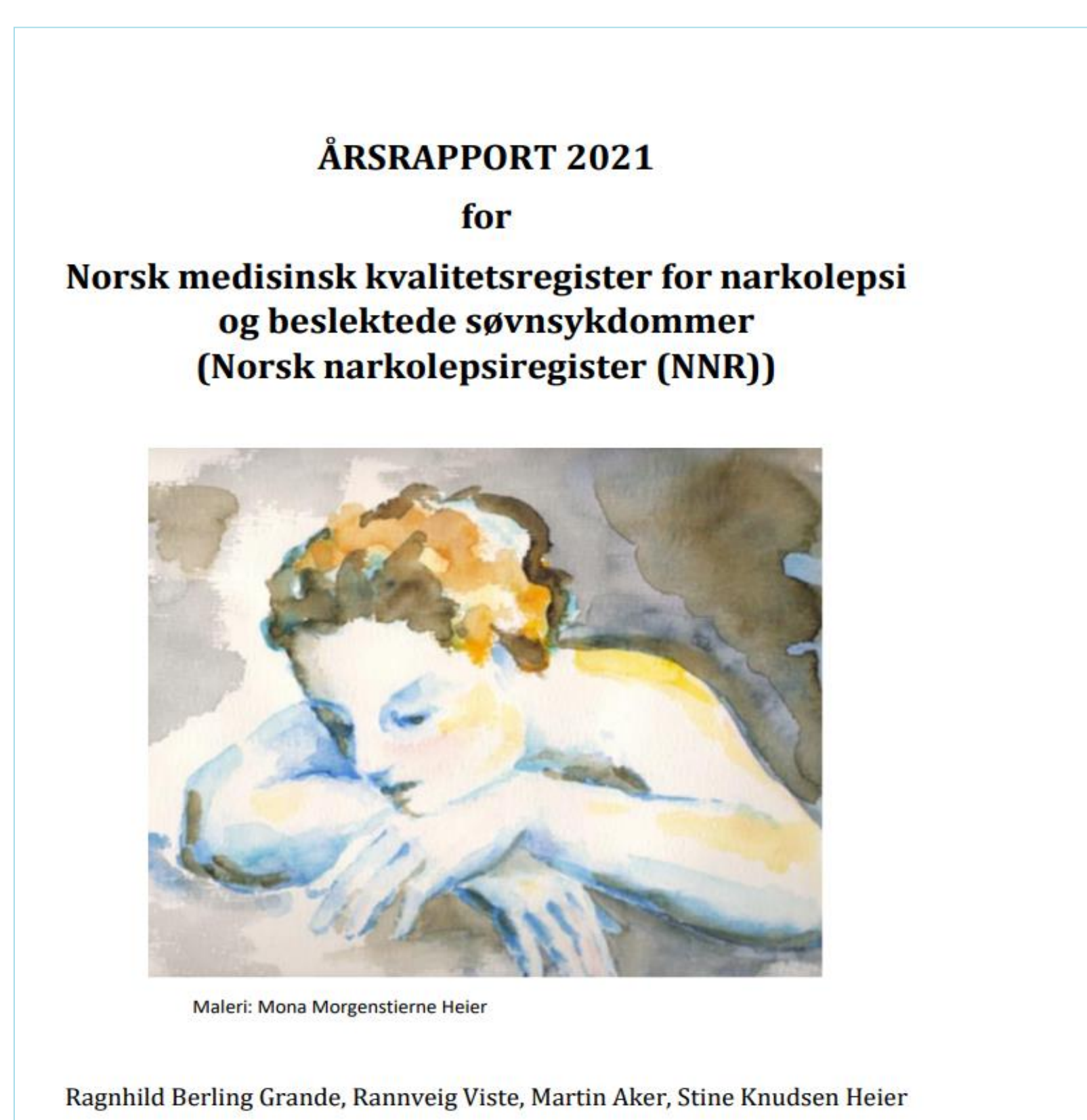
CONCLUSIONS

The typical Norwegian post-H1N1 (Pandemrix)-vaccinated NT1-patient has cataplexy and severe excessive daytime sleepiness.

It is therefore notable that >50% of patients are on monotherapy with stimulants.

A limited use of anticataplectic treatment is notable, especially the use of sodium oxybate.

Sodium oxybate has been shown to improve several phenotypic aspects of NT1 as well as patients quality of life, we therefore need to further investigate reasons for and consequences of the limited use of sodium oxybate in Norway.



Registry-report in norwegian language at www.nevsom.no

RESULTS

Included: 80 NT1 patients (61% women) were included. Median age at inclusion: 21 years (range 8.3-62).

Disease onset: Median age at disease onset: 14 years (range 4,5-54).

Age at diagnosis: Median age at time of diagnosis: 18 years.

Diagnostic Delay: 4 years (range 0-9).

Hypocretin: CSF-hypocretin was measured in 76/80. Low CSF-hypocretin-1 levels were found in all 76.

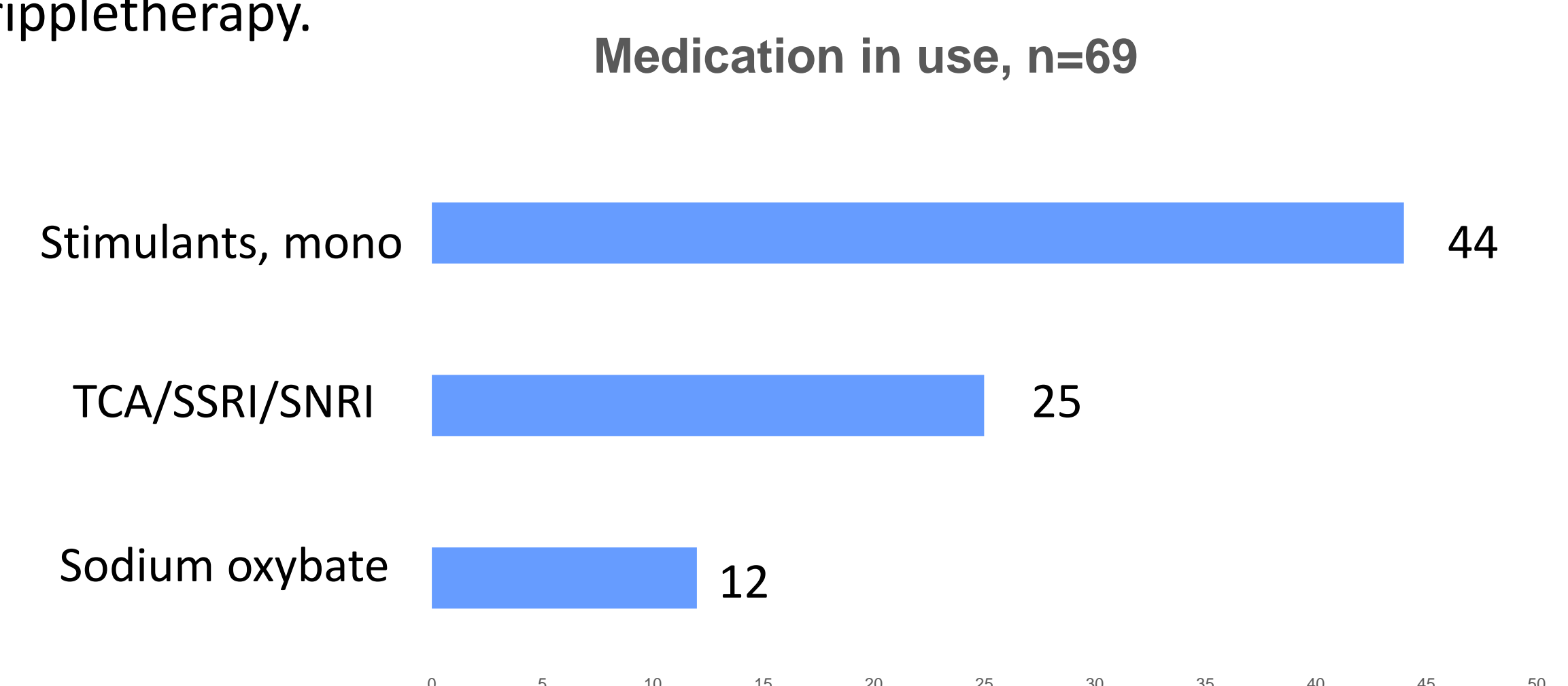
Narcolepsy symptoms:

Epworth Sleepiness Score: 18/24.

78/80 had cataplexy, 68/80 had hypnagogic hallucinations, 64/80 had sleep paralysis.

RESULTS

Treatment with medication: 11/80 patients were unmedicated, 69/80 were medicated: 68/69 on stimulants (44/68 on monotherapy stimulants), 25/69 on TCA/SSRI/SNRI, and 12/69 on sodium oxybate. 21/69 had duotherapy and 4/69 trippletherapy.



RESULTS

Occupation: 45 were students, 10 worked full time and 25 had sick-leave, sick-pension or similar.

