NARCOLEPSY IN SWEDEN
- a nationwide register study

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Introduction

Narcolepsy is a neurological disorder characterized by daytime sleepiness, disrupted sleep and in some cases associated with episodes of cataplexy (partial or total loss of muscle tone, often triggered by a strong emotion, as laughter, excitement or anger (1).

To date, much is unknown about the narcolepsy population in Sweden. The narcolepsy population is estimated to range between prevalence estimations of 3,500 and 4,500 (2,3). However, no register-based study has been conducted. Hence, the aim of this study is to map the narcolepsy population, how many they are, their characteristics and what kind of treatment they receive.

Methods

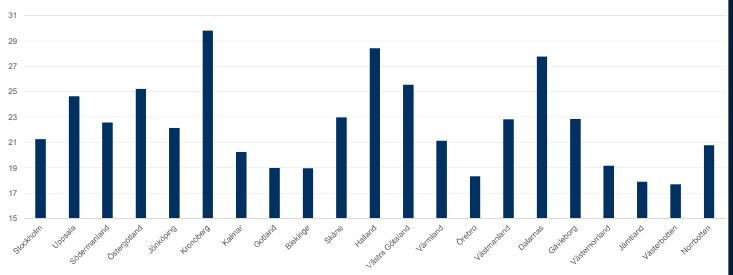
Using the nationwide patient register, all Swedish inhabitants with a narcolepsy diagnose (ICD-10: G474, including subgroups) were included in the study. The Swedish patient register includes all hospital visits, both inpatient (from 1997) and outpatient (from 2001). Besides information from the patient register, data from the information death register and prescription register was also included. This latter ensures that we have complete information regarding redeemed prescriptions.

Results

From the start of the patient register, through 2016, 2,508 individuals have at least one diagnose of narcolepsy. Of the diagnosed 1,422 or 56.7% were females.

Turning to regional difference, figure 1 shows the prevalence rate in the Swedish regions.

Figure 1



Note: Prevalence rate by region. The unit is number of narcolepsy patients by 100,000 inhabitants

The number of patients with narcolepsy diagnosis per 100,000 individuals differs from 17.68 in Västerbotten county to 29.8 in Kronoberg, where the difference is statistically significant according to the Chi2 test (P=0.07).

After removing those that had either emigrated or were deceased, the number of narcolepsy patients was 2,173 patients in Sweden on December 31st 2016, giving a prevalence of 21.7 per 100,000 inhabitants.

Take home message:

- **2,173 narcolepsy patients (Dec 31st 2016)**
  - **Prevalence rate: 21,7 per 100,000**
  - **Prevalence rates differ between regions**
- **Heterogenous pharmaceutical treatment**

Turning to pharmaceutical treatments, this paper also maps the different pharmaceutical treatments for narcolepsy (table 1).

Table 1

Drug	Initiating treatments		
	n (%)	Men, n (%)	Women, n (%)
Total	2,508 (100)	1,086 (100)	1,422 (100)
Sodium oxybate (N07XX04)	271 (10.8)	128 (11.8)	143 (10.1)
Modafinil (N06BA07)	1202 (47.9)	485 (44.1)	717 (50.4)
Methylphenidate (N06BA04)	848 (33.8)	345 (31.8)	503 (35.4)
Amphetamine (N06BA01)	657 (26.2)	262 (24.1)	395 (27.8)
Dexamphetamine (N06BA02) and Lisdexamphetamine (N06BA12)	171 (6.8)	72 (6.6)	99 (7.0)
Atomoxetin (N06BA09)	74 (3.0)	33 (3.0)	41 (2.9)
Antidepressants*	594 (23.7)	206 (19.0)	388 (27.3)
no or other pharmaceutical treatment	415 (16.5)	220 (20.3)	195 (13.8)

Note: *Antidepressants defined as venlafaxine (N06AX16), klomipramin (N06AA04), sertraline (N06AB06), citalopram (N06AB04), escitalopram (N06AB10) and amitriptyline (N06AA09).

The mapping of the pharmaceutical treatments shows that narcolepsy patients receive different types of treatments. It should be noted that narcolepsy is a multifaceted disease and hence patients often receive one treatment for cataplexy and one for daytime sleepiness. For instance, modafinil and venlafaxine is a common combination treatment (4).

Sodium oxybate is a relatively new drug (introduced in 2012 in Sweden) and is the first drug to both treat cataplexy and daytime sleepiness. It is also worth noting that 220 men and 195 women with narcolepsy diagnosis do not appear to receive any pharmaceutical treatment.

Discussion

This study showed that by December 21st, 2016, 2,173 individuals had a narcolepsy diagnosis in Sweden. This could indicate that the earlier estimations (3,500-4,500 individuals) are to high.

The difference in prevalence rate between the Swedish regions could indicate different awareness of narcolepsy in different parts of Sweden. It could also indicate underreporting in regions with a relatively low prevalence rate.

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