

# The socio-economical burden of hypersomnia

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**Objectives** – In the absence of socio-economical consequences of hypersomnia this study addresses the factual indirect and direct costs. **Methods** – Two thousand two hundred and eight patients with a hypersomnia diagnosis from 1998 to 2005 were identified in the Danish national patient registry (NPR), each compared with 4 age and gender adjusted, randomly chosen citizens selected from the Civil Registration System Statistics. The health cost was decomposed in direct and indirect yearly costs, including labor supply and social transfer payments. Direct costs included frequencies and costs of discharges and outpatient use by cost weights according to diagnosis related groups and specific outpatient prices based on data from The Danish Ministry of Health. The use of and costs of drugs was based on data from the Danish Medicines Agency. The frequencies and costs from primary sectors were based on data from The National Health Security. Indirect costs were based on income data from the coherent social statistics (CSS). **Results** – Patients with hypersomnia presented significant higher health related contact rate, expenses and medication use. No differences were identified in employment and income. The yearly sum of direct and indirect costs were yearly €3402 vs. €1212 in controls ( $P < 0.001$ ), corresponding to a yearly excess costs €2190. The patients presented higher transfer income, total €889. **Conclusion** – Hypersomnia patient present higher health and medication uses, and social transfer income and thus represent a significant socio-economical burden.

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## Introduction

Hypersomnia is a common complaint related to sleep, neurological, medical and psychiatric disorders, but often is a sole complaint without obvious contemporary diseases. Hypersomnia is part of the international sleep disorders classification related to sleep disordered breathing or of non-respiratory causes like narcolepsy and other hypersomnias of central origins. Former studies have presented evidence that sleep disorders like insomnia, narcolepsy, restless legs and sleep apnea influence quality of life, social or economical aspects (1–23). These studies were carried out in out-patient clinic in selected patients using questionnaire or telephone based information, and the economical burden was extracted from this

information. There are however limited or no information regarding the impact of hypersomnia on the socio-economical burden, including the factual indirect and direct costs. In order to evaluate the health related consequences for patients with hypersomnia the current study were conducted in order to evaluate the socio-economical consequences evaluated in a population-based study.

## Methods

In Denmark, all patient contacts are recorded by time of contact with the main diagnose in the Danish national patient registry (NPR). The NPR includes administrative aspects, diagnose, diagnostic and treatment procedures using several

international classification systems including the International Classification of Diseases (ICD-10). Thus the NPR is a time-based national database including all patient contacts related to public and private hospitals and clinics in the secondary and primary sector. The patients that are included thus represent all national patients who have received a diagnosis in the primary and secondary sector in public and private hospitals, independent of diagnostic evaluation.

The economic consequence of narcolepsy was estimated by the yearly cost of illness per patients diagnosed with hypersomnia (ICD code DG471) compared to a matched control group. In the same period 462 patients were diagnosed with a diagnose of narcolepsy (ICD code DG 474, 24). The health cost was decomposed in direct yearly health care costs and indirect yearly costs, i.e. cost due to reduced labor supply. We also included social transfer payments. Costs were measured from the perspective of the society.

Direct costs included frequencies and costs of discharges and outpatient use by cost weights according to diagnosis related groups and specific outpatient prices – all based on data from The Danish Ministry of Health. The use of and costs of drugs was based on data from the National Danish Medicine Agency that is which includes the selling price of the drug (including charge of dispensary) combined by the number of transactions. The frequencies and costs of consultations with general practitioner and other practicing specialists were based on data from The National Health Security. Indirect costs were based on income data from data from the Coherent social statistics (CSS).

Cost of illness studies measure the economic burden resulting from disease and illness across a defined population, including both direct and indirect costs. Direct costs are the value of resources used in the treatment, care, and rehabilitation of persons with the condition under study. Indirect costs represent the value of economic resources lost because of disease-related work disability or premature mortality. It is important to distinguish costs from monetary transfer payments such as disability and welfare payments. Such payments represent a transfer of purchasing power to the recipients from the general taxpayers, but do not represent net increases in the use of resources, and are therefore not included in the total cost estimate.

All patients with a hypersomnia diagnosis from 1998 to 2005 were identified in the NPR. Based on the Civil Registration System Statistics Denmark matched each patient with four randomly chosen citizens with the same age and gender but no

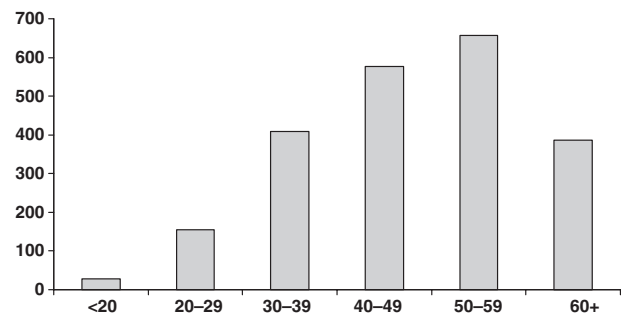
hypersomnia nor hypersomnia diagnosis. The reason for the choice of four controls was to ensure adequate statistical power and to level out variations in control subjects. Patients and matched controls were followed from diagnosis year until 2005. Patient and matched controls that could not be identified in the CSS database were excluded from the sample (more than 99% of the observations in both groups were successfully matched). Costs were measured on a yearly basis, and adjusted to 2005 prices using the health sector price index for health sector costs (Ref: Ministry's of Finance, Jens Gordon Clausen, The Central County Health Insurance) and the general price index was applied to non-medical costs. All cost were measured in DKK and converted into Euros (€1: DKK 7.45).

The study was approved by the Danish Data Protection Agency. As the data handling was anonymous individual or ethical approval were not statutory. Statistical analysis was performed in SAS 9.1.3. Statistical significance of the cost estimates were generated using nonparametric bootstrap analysis (25)

## Results

In total 2211 patients were identified. Complete data for cross-tabulations were identified in 2208 (1732 male and 476 female) patients and the number of controls was 4:1, in total 8832 corresponding with 9139 and 36452 observation-years, respectively. The age distribution of the patients is shown in Fig. 1. As can be seen the age distribution was relatively mature, most patients being above 30 years of age.

More patients than controls were treated in out-hospital clinics (28% vs. 25%, NS), hospitalized (24% vs. 10%,  $P < 0.0001$ ), total use of medication (78% vs. 68%), medication with public support (57% vs. 42%,  $P < 0.001$ ), presenting contact with the primary care system (98% versus



**Figure 1.** Number and gender distribution of patients receiving the diagnose hypersomnia, 1998–2005.

93%, NS), receiving social service (47% vs. 35%,  $P < 0.001$ ). No differences were observed in employment/receipt of employment income (71% v. 73%, n.s.) (Fig. 2).

There were no significantly difference between the number of patients and controls regarding employment, number on leave, and pension benefits/ (Table 1).

The direct health costs (GP services, hospital services, medication) and indirect costs (loss of labor market income), sum of direct and indirect costs was 2190 Euros. Furthermore, hypersomnia patients presented higher social transfer payments. Interestingly, it is observed that the labor market income is only slightly lower in hypersomnia patients, which is compensated in the social welfare system. The direct and indirect costs are shown in Table 2.

**Discussion**

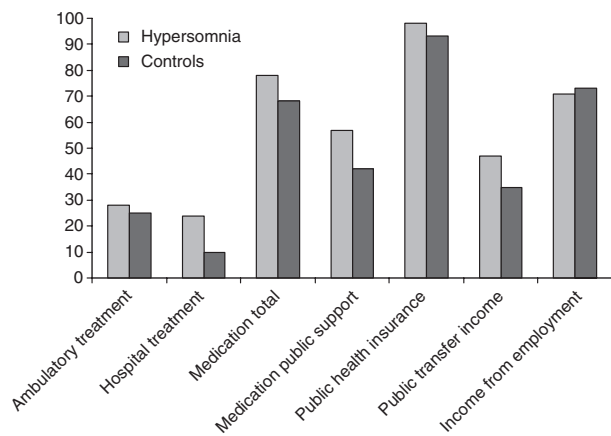
This is the first study evaluating the factual socio-economical impact of hypersomnia. The study is a population based study including all national patients with a diagnosis of hypersomnia. Patients with hypersomnia presented significant higher

contact with the health care system. The health care uses were significantly higher in all health care sectors: general practice, outpatient treatment and in hospital services. The patients present higher medication use, including public supported medication. The public expenses are higher in the group of hypersomnia patients. Hypersomnia patients were more commonly on transfer income, but the employment rate and the income level was comparable to control subjects. This suggests a full compensation or an overcompensation in the social system (e.g. the patients receive social transfer income despite a comparable labor market income).

The study shows that patients with hypersomnia present higher morbidity in terms of primary and secondary health care expenditures, increased use and expenditure of medication, higher unemployment rate, higher social expenditure and those who employed present lower income as compared to employed controls subjects. Thus hypersomnia presents a significant socio-economical impact. As hypersomnia is a chronic complaint with varying onset, the economical impact of the disease is considerable. The impact of hypersomnia is however less compared to patients with narcolepsy, in which we have estimated the yearly cost is estimated to 10.303 Euros per year in Denmark. Furthermore narcoleptic patients present a significant lower employment rate (24).

We used the diagnosis based on reports from different clinics or hospitals registered in the NPR, thus representing a concrete and complete national patient sample. Consequently the patients given the hypersomnia diagnose is based on clinical information with or without the use of polysomnography (PSG) or multiple sleep latency test (MSLT). The diagnosis of hypersomnia involves a wide range of conditions; patients with neurological, rheumatic, psychiatric and sleep disorders. The majority of this group is likely not to suffer from other major disorders. We only included patients with the diagnosis of hypersomnia and excluded narcoleptic patients. In the same observational period approximately 19,000 patients had a diagnosis of sleep apnea. Cross-tabulation to sleep related breathing disorder showed almost no overlap (data not shown). The strength of the use of NPR data is important to evaluate the factual national socio-economical disease burden, but the weakness is that detailed information regarding diagnostic criteria and clinical information is weaker.

The ciphers are extracted from the period 1998 to 2005, and calculated for 2005 prizing. The control subjects were randomly selected from the



**Figure 2.** Percentage of hypersomniacs and controls receiving any of the services (public or income).

**Table 1** Occurrences of unemployment, transfer income and pension/retirement in hypersomniacs and controls

	Hypersomnia (%)	Controls (%)	P-value*
Employed <sup>†</sup> , on leave	70	72	NS
Transfer income	15	12	NS
Pension benefits payable between early retirement and normal retirement pension	13	13	NS
Other	3	3	NS

\*Bootstrap.

<sup>†</sup>Includes self-employed persons, salary earners, students.

**Table 2** Sources of information and the average annual health cost per person year by cost categories in Denmark, Euros

Category of data	Sources	Annual costs hypersomnia	Annual costs controls	P-value*
Direct health costs				
The primary sector	The National Health	264	169	<0.0001
Inpatient cost	Insurance Security System	1415	664	<0.0001
Outpatient cost	Danish Ministry of Health	437	168	<0.0001
Drugs	Danish Ministry of Health	364	211	<0.0001
Total direct health costs	Danish Medicines Agency	2480	1212	
Labor market Income	Coherent Social Statistics	27,214	28,136	0.001
Indirect cost of hypersomnia		922		
Sum of direct and indirect costs		3402	1212	<0.0001
Net yearly costs of hypersomnia		<b>2190</b>		
Social transfer payments	Coherent Social Statistics	5358	4469	<0.0001

\*Bootstrap.

background population without the hypersomnia which includes healthy and non-healthy subjects in order to evaluate the additional socio-economical impact of the hypersomnia diagnose. The reason for the selection of four controls per case is to reduce the variation among controls and to ensure a representative control population. Statistical analyses prior to the study initiation have shown that at least four equalize variations in the sample population and increase the statistical power.

Hypersomnia patients may present a higher risk of automobile accidents (26–31). Traffic accidents have not been extracted but as the analysis include all contacts, income and social contacts, the health and occupational consequences are included in the analysis (which includes all primary and secondary health related and occupational costs). However the consequence to secondary parts of such accidents (e.g. traffic victims, material), effect on family etc. is not included. Consequently the economical estimates represent a conservative, concrete, and realistic economical estimate of the consequence of hypersomnia.

Former studies have studied the influence of sleep complaints as insomnia, restless legs syndrome and narcolepsy on quality of life (14, 18, 32–49) all using questionnaire information mostly SF-36 and correlated this information to the socio-economical burden. The advantage with this method is the involvement of quality of life estimates e.g. including the patient perspective, but the disadvantages is that a selected and limited number of patients are included, the factual estimates of health related contacts, medication, health economical estimates, employment and income estimates are not included, which create a significant bias, especially in diseases with high diagnostic and treatment cost or where the social factor deviate significantly. The model used in this study compensates for this and is the first study

which shows that patients with hypersomnia present a health related burden.

During the past few years the insight into the mechanism, diagnosis and treatment of hypersomnias of central origin has increased. The validity of the diagnostic criteria and the electrophysiological methods of narcolepsy and other hypersomnias of central origin have been evaluated (50–52). There is significant improvement to the understanding of narcolepsy and the use of cerebrospinal hypocretin-1 (CSV-Hct-1) and HLA typing (53–58) may further add information to the diagnosis of hypersomnias of central origin and other neurological disorders (59, 60). This is important as subtypes of hypersomnia are under-diagnosed and potentially treatable. Despite these progresses, there is a need for improved understanding of central hypersomnias and the relation to other conditions. Although several lines of treatment are suggested, controlled studies only applies for few treatments (61). A limited number of studies suggests that treatment may improve quality of life in narcoleptic and hypersomnia patients (62–65), but there is no current evidence whether early diagnosing, medical treatment, information, educational and professional advices to these patients have any influence on the consequences of the disease. Furthermore none of the current studies have presented evidence that management and medical treatment cause influence on health, social aspects, educational level or employment and as such present socio-economical impact. The results of this study strongly suggest that such interventions are most relevant.

In conclusion, the current study including all national patients diagnosed with hypersomnia during a 6 year period present a higher health-related and social transfer costs. Interestingly the study also showed that the income level was only slightly lower as compared to the control group

and they were fully compensated. The current study shows that the health related impact and socio-economical aspect of the disease is significant, why there is a need to further address the relevance of diagnosing and treatment effect. There is a need for focusing on management and the effect on quality of life, socio-economical aspect, work capabilities and traffic accidents, in order to reduce these costs for the patients and the society.

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