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The Swedish sleep apnea registry (SESAR) cohort – "Real world data" on a national level

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A R T I C L E I N F O

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A B S T R A C T

Introduction: The Swedish Sleep Apnea Registry (SESAR) collects clinical data from individual obstructive sleep apnea (OSA) patients since 2010. SESAR has recently been integrated with additional national healthcare data. The current analysis presents the SESAR structure and representative clinical data of a national sleep apnea cohort.

Methods: Clinical data from unselected patients with a diagnosis of OSA are submitted to the SESAR registry. 48 sleep centers report data from diagnosis, treatment starts with Continuous Positive Airway Pressure (CPAP), oral devices (OD), and Upper Airway Surgery (UAS). Data from follow-up are included. SESAR is linked to mandatory national healthcare data (mortality, comorbidities, procedures, prescriptions) and diagnosis-specific quality registries (e.g. stroke, heart failure, diabetes) within the DISCOVERY project.

Results: 83,404 OSA patients have been reported during the diagnostic workup (age 55.4 ± 14.1 years, BMI 30.8 ± 6.5 kg/m^2, AHI 25.8 ± 21.6n/h, respectively). At least one cardiometabolic and respiratory comorbidity is recognized in 57 % of female and 53 % of male OSA patients with a linear increase across OSA severity. In 54,468, 7,797, and 390 patients, start of CPAP, OD or UAS treatment is reported, respectively. OD patients have 4 units lower BMI and 10 units lower AHI compared to patients started on CPAP. UAS patients are characterized by 10 years lower age. The degree of daytime sleepiness is comparable between treatment groups with mean Epworth Sleepiness Scale Scores between 9 and 10.

Conclusion: SESAR is introduced as a large national registry of OSA patients. SESAR provides a useful tool to highlight OSA management and to perform relevant outcome research.

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1. Introduction

Obstructive Sleep Apnea (OSA) represents a significant public health concern [1]. The condition is characterized by repetitive cessation or reduction of airflow during sleep [2]. OSA contributes to cardiometabolic disease and cognitive impairment. Traditional approaches to OSA research and management have often been limited by studies with small sample sizes and short observation periods; pathways towards comprehensive data integration and Big Data have been discussed [3].

The diagnosis of OSA is based on a patient history, a physical examination and overnight sleep testing to confirm symptom burden, obstructive respiratory events during sleep, and the degree of nocturnal hypoxia. The most frequently used treatment options include continuous positive airway pressure (CPAP) ventilation, mandibular advancement therapy by oral devices (OD), upper airway surgery (UAS), weight reduction therapy in overweight/obese OSA patients, and positional therapy [4].

The management of OSA differs significantly between sleep centers and health care systems. A recent study in Europe highlights the diversity of diagnostic algorithms by using polygraphy or polysomnography in the primary diagnosis [5]. Another aspect is the decision to treat in OSA. In many cases, the Apnea Hypopnea index is used as the main criterion [6]. However, more recent guiding documents like the Baveno classification or the national Swedish treatment guidelines, recommend symptoms, comorbidities, and age as important determinants for the decision to treat OSA [7,8]. This diversity of clinical practice may in part be related to the lack of clear guidance by outcome data in the sleep apnea field.

Swedish health care quality registries are used to longitudinally monitor and improve the quality of care provided in national healthcare [10]. To date, approximately 100 registries have been established and collect data continuously [9]. Examples for these quality registries include diagnoses and procedures in patients with stroke, heart failure, diabetes, and hip replacement [10]. Registry data can be used to identify knowledge gaps and areas of clinical practice in need of improvement. They can also serve to track progress of clinical parameters over time [11]. The information obtained in those registries is made publicly available for patients, health care professionals, and health care policy makers. Additionally, the data can be used by researchers to better understand the effectiveness of procedures, treatments, and interventions to generate data-driven practice guidelines or to develop new therapies. Registry-based randomized clinical trials have also been performed [12,13].

Amongst above mentioned registries, the Swedish Sleep Apnea Registry (SESAR) has assembled clinical data from individual OSA patients since 2010. Data from SESAR have recently been integrated with national health care databases and national quality registries in the Swedish CPAP Oxygen and VEntilator RegistrY (DISCOVERY) cohort [14]. The SESAR and DISCOVERY represent national, population-based longitudinal cohorts available as important sources for research in patients with OSA.

The aim of this paper is to describe in detail the SESAR data structure and to provide key clinical data of this large, representative, national OSA patient cohort. The paper also introduces the recently established link of SESAR to additional sources of health care and socio-economic data within the DISCOVERY cohort.

2. Materials and methods

2.1. Patient selection

Clinical data from unselected patients with a physician-based diagnosis of OSA (ICD-10 code G47.3) are reported to the SESAR registry. Data are entered manually by heath care personnel or by automated transfer from Electronic Medical Records (one center so far) to SESAR.

Sleep centers reporting into SESAR are mainly located at regional hospitals or specialist care centers associated with pulmonary medicine or otorhinolaryngology. In rare cases, SESAR centers are free standing sleep clinics or associated with departments for clinical neurophysiology. For OD treatment, SESAR centers are associated with public or private dental care units and hospital dentists. The majority of OSA care is provided by tax-funded public health care with no obligation to report into quality registries.

All patients receive oral and written information to consider a voluntary participation in the quality registry. However, according to Swedish law, no specific signed informed consent is necessary for registration in the registry. Patient data is highly protected according to Swedish law. Participation in the SESAR registry is voluntary, and patients may opt out at any time.

2.2. Type of visit in SESAR

SESAR follows the patient during the procedures in all aspects of OSA management. This includes the initial diagnosis and the treatment of CPAP, OD, UAS, and/or weight reduction therapy. In addition, follow-up of all treatment modalities can be registered in SESAR. Patients may change caregiver in the process of OSA management.

2.3. Type of data in the registry

The reported information into the SESAR registry is summarized in Table 1. Data differ between the type of visit and include clinical data, information about procedures, and treatment outcome. Examples for those data are age, Body Mass Index (BMI), as well as cardiovascular, metabolic, pulmonary and psychiatric comorbidities. Sleep related information comprises the apnea hypopnea index (AHI), oxygen desaturation index (ODI), mean overnight saturation and self-reported daytime sleepiness (Epworth Sleepiness Scale (ESS) score). Procedural data describe how the diagnostic process is organized, how patients are trained to start CPAP or how long waiting times are at the different sleep centers. Outcome data include the choice of primary treatment, the change in AHI or ESS score with treatment, or the occurrence of adverse events. Individual adherence with CPAP or OD treatment is also addressed in SESAR.

2.4. Diagnosis of sleep apnea

Patients with a confirmed diagnosis of sleep apnea are reported into the database. The diagnosis is provided by the sleep expert at the respective center after patient interview, physical examination, and an overnight sleep test. According to data collected in 2010–2015, most patients were investigated with polygraphy (99.7 %) and only a small fraction with polysomnography (0.3 %). Subsequently, this parameter is no longer captured in the registry. Respiratory events are scored according to local routines. In 2014 SESAR recognized the need for national consensus in scoring polygraphies and national guidelines for the diagnosis of OSA were published subsequently [16]. Those state that apneas are scored with a 90 % reduction in flow of at least 10 s without any desaturation criteria. Hypopneas are recommended to be scored with at least a 30 % reduction in flow over 10 s combined with ≥3%-desaturation criteria. ODI is based on the ≥4%-desaturation cut-off. Several data entries in SESAR are linked to the quality assessment of the diagnostic process (Table 1).

2.5. Start of treatment in SESAR

SESAR receives data for the start of different treatment modalities (CPAP, OD, UAS, weight reduction). During those visits, clinical data as well as procedures are recorded (Table 1). Between 2015 and 2021, all CPAP treatment start data in SESAR (N = 38,242 patients) were automatically transferred to the parallel treatment-based CPAP registry in

Table 1
Structure of data reported to SESAR. A detailed variable list and variable statistics are publicly available on SESAR's webpage (www.sesar.se). Abbreviations: OSA = obstructive sleep apnea, CPAP = continuous positive airway pressure, OD = oral device, UAS = upper airway surgery, BMI = body mass index, ESS = Epworth sleepiness scale, AHI = apnea hypopnea index; ODI = oxygen desaturation index.

	Time points of registration		
Type of data	Diagnostic test	Start of treatment (CPAP, OD, UAS)	Treatment follow-up (all treatments)
Clinical data	Anthropometric data (age, BMI, gender) and symptoms (ESS score)	Anthropometric data (age, BMI, gender) and symptoms (ESS score)	Anthropometric data (age, BMI, gender) and symptoms (ESS score)
	Diagnostic sleep test (AHI, ODI, mean saturation)	Diagnostic sleep test (AHI, ODI)	Sleep test on treatment (AHI, ODI, mean saturation)
	Comorbidities listed as: Hypertension, ischemic heart disease, atrial fibrillation, heart failure, cerebrovascular disease, diabetes mellitus, obstructive pulmonary disease, depression, smoking	Hypertension diagnosis yes/no	
Procedural data	Time from referral to diagnosis	Time from diagnosis to treatment start	Time from start of treatment to follow-up
	AHI-ODI difference per center (scoring tradition)	Type of CPAP education, physical visit versus distance contact	Physical visit versus distance contact
	Proportion of personal meeting with sleep physician/caregiver	Humidifier from start and type of mask	Type of mask (CPAP)
	Manual scoring of sleep test	Type of oral device and dental procedures prior treatment start with OD	Advancement of mandible (OD treatment)
		Type of surgical procedure (for data reported from 2010 to 2021)	
Outcome data	Recommendations for primary OSA treatment at the end of the diagnostic process	Proportion of individuals with severe OSA receiving lifestyle interventions	Treatment efficacy (AHI) and change in symptoms (ESS)
	Gender difference in OSA severity and degree of daytime sleepiness	Proportion of obese patients receiving weight loss therapy	Adverse events
			Adherence with treatment (not UAS)

the National Registry of Respiratory Failure (SWEDEVOX). SESAR can capture patients using different OSA treatment options sequentially or even in parallel. In addition, several start-visits on the same type of therapy can also be reported in the registry.

2.6. Organisation

SESAR is hosted by the Centre of Registers Västra Götaland (RCV) which also supports the web-based platform [15]. Västra Götaland Region serves as the legal authority for data handling and data security.

SESAR has a steering committee (author list) which is responsible for maintenance and development of the registry. Reporting of results to the medical profession, OSA patients, the general public as well as to health care decision-makers is very important in this context. For that purpose, SESAR maintains a public homepage with an extensive presentation of information related to SESAR and OSA in general (www.sesar.se). More data analyses are presented in annual reports. SESAR has published the first national guideline for the diagnosis of sleep apnea in Sweden, partly influenced by the analysis of current practice derived from data in SESAR [16]. The registry recieves annual funding from the Swedish Association of Local Authorities and Regions (SALAR) for costs related to the data platform, statistical support, and part-time salaries for two coordinators. The Swedish Heart and Lung Foundation supported SESAR in 2024.

2.7. Data evaluation and statistics

The current data analysis is based on SESAR data in the context of the DISCOVERY study and was approved by the Ethics Committee at the Medical Faculty at Lund University (Dnr 2018/519) and the Swedish Ethical Review Authority (Dnr 2022-02012-02). Analysis is performed on data recorded in SESAR from 2010 to 2022. Detailed analysis of clinical characteristics has been performed in the cohort for the most recent years 2020–2022. Data quality is monitored by data coverage assessment for several key data in the database (Date of Diagnosis, Apnea Hypopnea Index, Epworth Sleepiness Scale Score and Body Mass Index). Statistical analysis was performed using the IBM/SPSS Statistics statistical program (version 29.0).

3. Results

3.1. Recruitment of patient into the register over time

In 2010, 7 sleep centers started the reporting in SESAR and this number has increased to 48 centers in 2022 (Fig. 1). Accordingly, the annual number of reported diagnostic visits increased from 95 in 2010 to 15,365 in 2022. The corresponding number for treatment starts (from 7 to 12,430), and follow-up recordings (from 1 to 12,186) showed a parallel annual growth over time. The total number of visits exceeded 40,000 in 2021 (Fig. 1). By 2022, SESAR is represented in 18 out of 21 regions in Sweden including the three main cities Stockholm, Gothenburg, and Malmö.

The national coverage of OSA-related medical procedures in 2022, estimated by comparison with national and regional production numbers, is 65–70 % for the initial diagnosis of OSA, 85–90 % for the start of CPAP treatment and 10–15 % for the start of oral device treatment. Coverage for UAS with OSA indication is unknown and expected to be below 10 %. Follow-up data is captured in approximately half of the CPAP patients but to a lesser extent in patients treated with OD.

Data coverage for key variables in the registry is as follows: "AHI at diagnosis" between 99.3 and 99.8 %, "ODI at diagnosis" between 97.2 and 99.1 %, "BMI at diagnosis" between 92.1 and 97.6 %, "ESS score at diagnosis" between 89.5 and 91.4 %, and "Date of Diagnosis" in 100 % for the years 2015–22, respectively.

3.2. Patient cohorts in the SESAR

Four subcohorts can be identified in SESAR (Fig. 2). 83,404 patients have been reported during the diagnostic workup between 2010 and 2022. In 54,468 and 7797 patients, the start of CPAP and oral device treatment is documented, respectively. Of those, 34,567 CPAP treatment starts were reported into the Swedevox CPAP arm during 2015–2021. 390 patients comprise the group with upper airway surgery as a treatment for OSA. Patients can be reported in only one of those sub-cohorts,

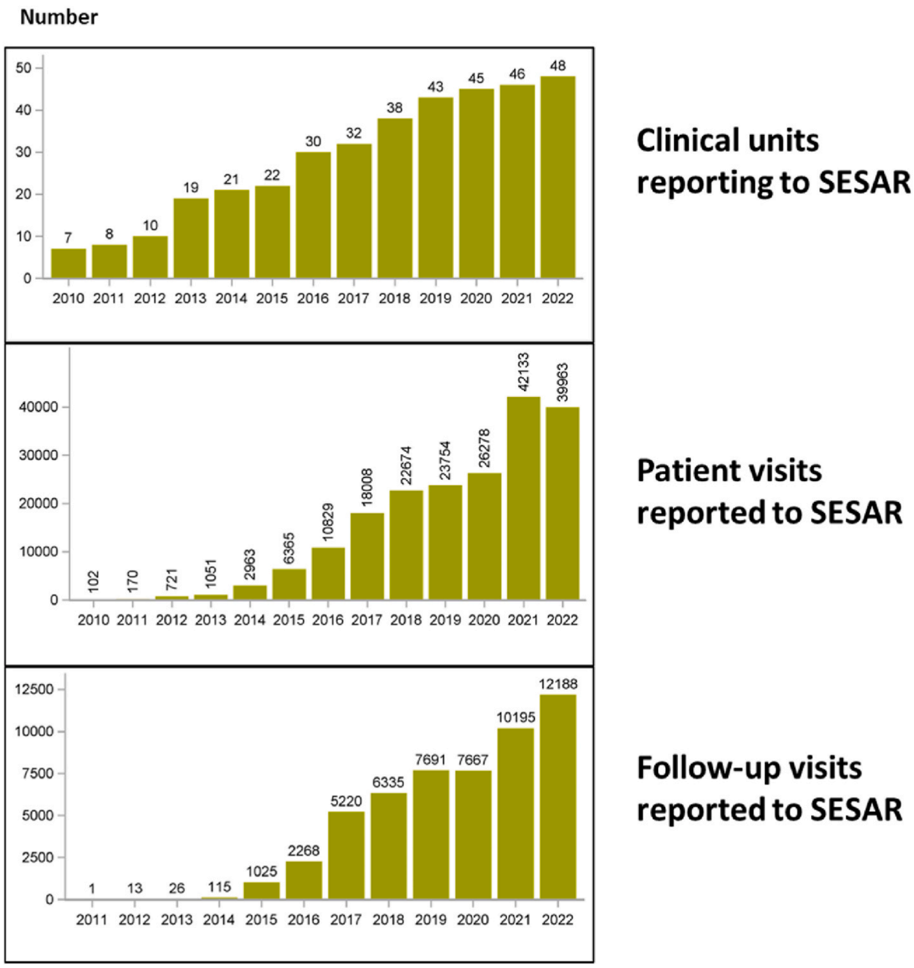

Fig. 1. Annual growth of the SESAR registry from the start in 2010 and the following 12 years until 2022. Shown are number of centers and included patients per year.

the majority is reported both for the diagnostic process as well as for any treatment start. In addition, patient visits are reported during treatment follow up (Fig. 2).

3.3. Clinical data at the time of diagnosis and treatment start

As exemplified for data from 2021 to 2022, the OSA patient population in Sweden is middle aged (55.4 ± 14.1 years), obese (BMI 30.8 ± 6.5 kg/m^2), and showed a mean AHI and ODI in the moderate range (25.8 ± 21.6/h and 23.1 ± 21.1/h, respectively), Table 2. The male/female ratio is approximately 2:1. The number of comorbidities increase with AHI severity in both male and female OSA patients (Fig. 3).

Compared to males, female OSA patients are approximately 3 years older, 1 BMI unit more obese, and slightly sleepier. AHI and ODI are more than 5 units/hour lower in female when compared with male OSA patients (Table 2). Females have higher prevalence of diabetes, respiratory and psychiatric comorbidity whereas cardiovascular comorbidity was higher in males (Table 2). Total comorbidity load in severe OSA is approximately 10 % higher in female compared to male OSA patients (Fig. 3).

3.4. Patients starting therapy with CPAP, oral device and upper airway surgery

SESAR provides clinical data for the comparison of the patient cohorts treated with CPAP, OD and UAS (Fig. 4). In detail, the age did not differ clinically significant between patients starting CPAP or OD treatment whereas patients registered for UAS were approximately 10 years younger than those for CPAP and OD treatment. Obesity was most prominent in patients starting CPAP treatment whereas patients on OD treatment were approximately 4 BMI units less obese. Patients treated with Upper Airway Surgery ranked in between these numbers. OSA frequency was substantially lower in patients treated with OD (AHI around 20/h) when compared to those treated with surgery (AHI around 30/h) and CPAP (AHI around 35/h). The degree of daytime sleepiness was comparable between the treatment groups with mean values varying between 9 and 10 (Fig. 4).

3.5. Integration of SESAR with the CPAP registry Swedevox in the DISCOVERY project

Altogether, the combination of data from the SESAR registry and the CPAP arm of the Swedevox registry created a cohort of 164,422 individual patients. With respect to AHI frequency, 7.5 % (N = 12,313) had an AHI<5n/h (classified as non-apneic snorers), 19.9 % had mild OSA (N = 32,679), 30.6 % (N = 50,342) had moderate OSA, and 38.7 % (N = 69,088) had severe OSA. The patient data have been linked to data from 16 registries (Fig. 5).

A control group sourced from Statistics Sweden's Living Conditions Surveys (ULF/SILC) was established. This group comprises around 6000 individuals aged between 16 and 74, randomly selected annually since 1987. The control cohort spans a comparable timeframe as the study

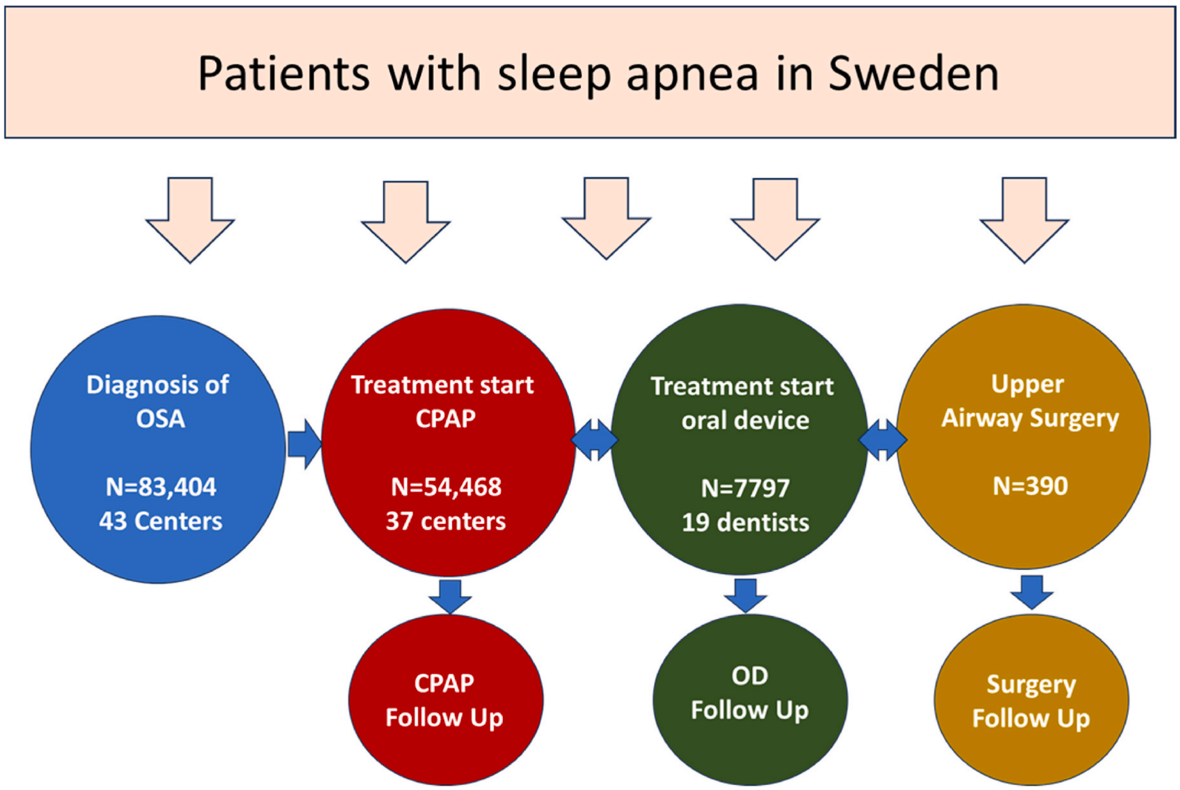

Fig. 2. Flow chart of the SESAR registry. Patients can enter the registry at any time and may generate data at multiple visits. CPAP =Continuous Positive Airway Pressure, OD=Oral Device, OSA=Obstructive Sleep Apnea.

Table 2
Clinical data for patients in the SESAR registry (dataset 2021–2022). Shown are mean and standard deviation for continuous data and percentages for categorical data.

Variable	Total	Women	Men	p_value
Number of OSA patients	25144	8612 (34 %)	16532 (66 %)	
Age (years)	55.4 (14.1)	57.8 (13.6)	54.1 (14.1)	<0.001
BMI (kg/m^2)	30.8 (6.5)	31.3 (7.1)	30.5 (6.1)	<0.001
Height (cm)	174.5 (9.8)	164.9 (6.7)	179.4 (7.2)	<0.001
Weight (kg)	96.1 (21.5)	87.6 (20.6)	100.5 (20.7)	<0.001
AHI (h^{-1})	25.8 (21.6)	22.2 (20.2)	27.7 (22)	<0.001
ODI (h^{-1})	23.1 (21.1)	19.7 (19.6)	24.9 (21.6)	<0.001
ESS	9.1 (5.1)	9.4 (5.1)	9.0 (5.1)	<0.001
Average Saturation (%)	92.4 (2.5)	92.6 (2.5)	92.4 (2.5)	<0.001
Arterial hypertension (%)	39.7	39.4	39.8	0.5
Coronary artery disease (%)	4.0	2.8	4.7	<0.001
Stroke (%)	2.1	1.9	2.1	0.2
Atrial fibrillation (%)	6.6	5.4	7.2	<0.001
Depression (%)	7.6	10.8	5.9	<0.001
Obstructive pulmonary disease (COPD/asthma) (%)	10.1	13.6	8.3	<0.001
At least one comorbidity (%)	54.6	56.8	53.4	<0.001

population. Information from ULF/SILC including age, gender, height, weight, smoking habits, housing type, locality, marital status, and year of survey is gathered for analysis (N = 145,244, 48.3 % males, mean age 49.9 ± 20.4y, mean BMI 24.9 ± 4.0 kg/m^2).

4. Discussion

In this report we present the structure and clinical data of the large SESAR OSA patient cohort as one example for a real-world clinical cohort in one of the most prevalent sleep disorders. We demonstrate gender differences in the clinical picture of OSA and diverse phenotypes selected for treatment modalities used in OSA. With the DISCOVERY cohort we exemplified on how SESAR data can be used for more detailed phenotyping and outcome research. Thereby, SESAR offers unique opportunities for future research and collaboration in the field.

4.1. Reference to other large scale OSA patient registries

Several international, national and regional databases have been described in the sleep apnea field. All of them have an individual profile. The European Sleep Apnea Database (ESADA) started in 2007 and assembled data from more than 40,000 patients in almost 40 sleep centers in 20 European countries [17]. Like the SESAR registry, patient data are collected at diagnosis, treatment start and follow-up and the ESADA network has published more than 40 research articles based on those registry data. Another important database has been generated by the Sleep Apnea Global Interdisciplinary Consortium (SAGIC) which includes sleep centers from several continents [18]. Although the current cohort is limited in size, the global aspect is important to consider when studying OSA as a major international health problem.

National databases for regular OSA patients have been established, for example in Türkiye, Greece, and France, with a very similar structure and concept as that of SESAR [19–21]. However, only few of those have established a linkage to national health care and socioeconomic databases. Each of these national databases contain variable levels of detailed and validated information about anthropometrics, comorbidities, the sleep diagnostic test results (sleep stages, hypoxic burden, AHI, ODI), as well as data on follow up and adherence with treatment.

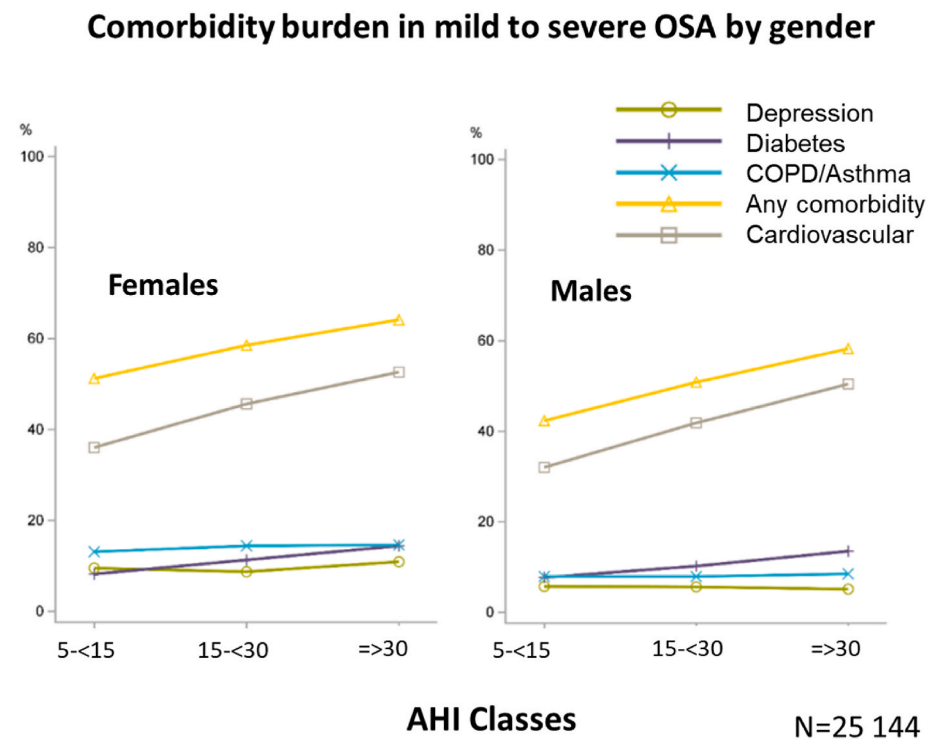

Fig. 3. Comorbidity prevalence in male and female patients with different degrees of OSA severity assessed as AHI classes. AHI = Apnea Hypopnea Index, Any comorbidity = at least one comorbidity, COPD=Chronic Obstructive Pulmonary Disease.

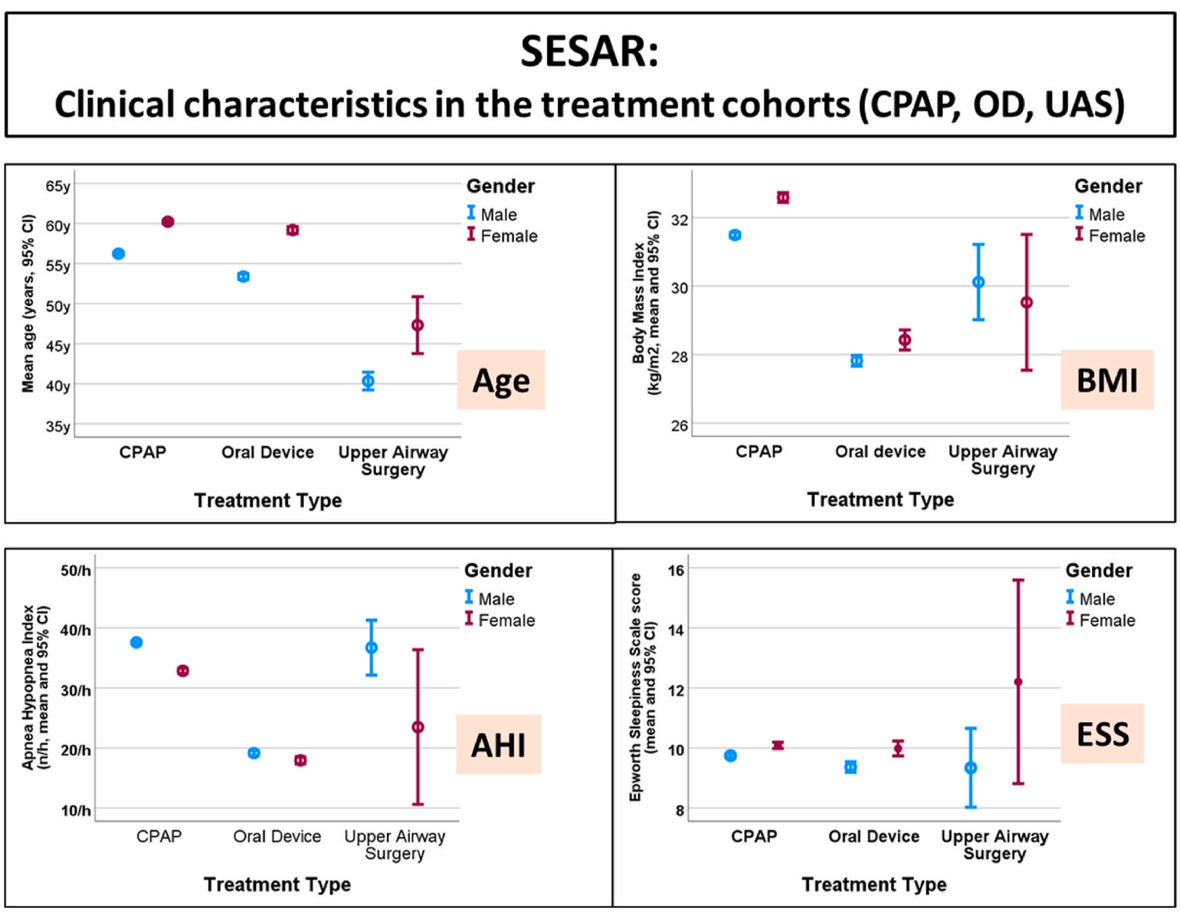

Fig. 4. Age, Body Mass Index (BMI), Apnea Hypopnea Index (AHI), and Epworth Sleepiness Scale (ESS) score in patients treated with CPAP, Oral Device and Upper Airway Surgery from the SESAR cohort 2010-22.

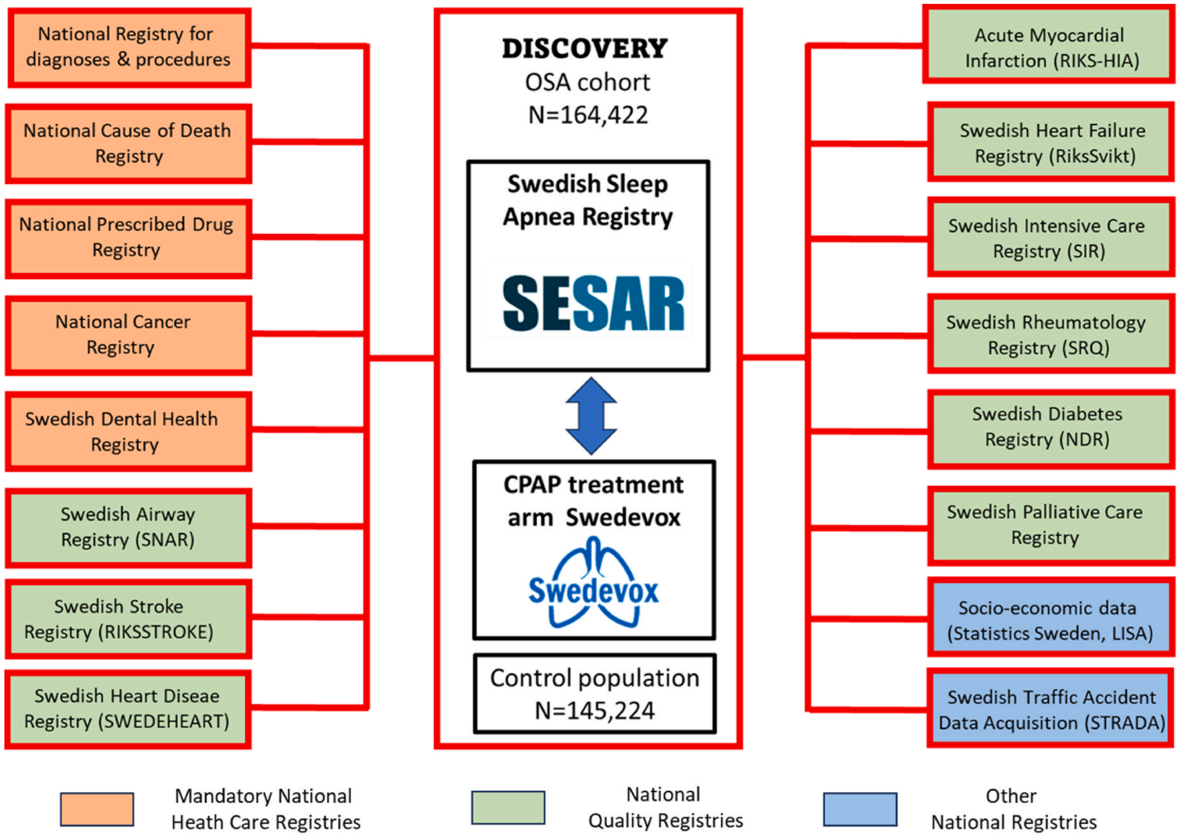

Fig. 5. The DISCOVERY OSA cohort: Data from the SESAR OSA patient cohort (2010-22) and the Swedevox CPAP treated patient cohort (2010–2021) are linked with several mandatory national health care registries, national quality registries related to medical diagnoses, and national registries for socioeconomic and traffic accident data.

As an example of a regional cohort, the French Pays-de-la-Loire Sleep cohort has generated very important knowledge about OSA [22]. By linking the clinical data mentioned above with general medical registry data, sleep test recordings and detailed information about CPAP use by telemetric CPAP data, the French database has a comprehensive data structure relevant for the study of typical OSA patients in this region of Europe. In this setting, detailed phenotypic information about sleep signals like the pulse wave during sleep have been analysed and linked to OSA treatment effects on cardiovascular outcome data [23].

Several countries like USA, Finland, Denmark, United Kingdom, France, and Korea have national databases capturing diagnoses and health care procedures. Patients with an OSA diagnosis can be linked to other diagnose codes, medical procedures, and health care outcomes. OSA patients can be compared with individuals without known OSA [24–26]. However, evaluation of those databases may be significantly limited by the lack of OSA severity characterization (mild/moderate/severe) as well as OSA symptom description (symptomatic versus asymptomatic OSA). Reporting of diagnosis codes may also vary within those countries leading to incomplete data.

4.2. Clinical presentation of the OSA patient population in SESAR

Patients reported to SESAR are comparable in the clinical phenotype to those reported to the ESADA studied by a polygraphic sleep test [27]. In ESADA compared to SESAR, patients were 3 years younger (age 51.9 $\pm$ 13.1 versus 55.4 $\pm$ 14.1) years, BMI was comparable (31.2 $\pm$ 6.8 versus 30.8 $\pm$ 6.5 kg/m$^{2)}$) as was the ESS score (9.9 $\pm$ 5.2 versus 9.1 $\pm$ 5.1) and the frequency of comorbid arterial hypertension (38.8 % versus 39.7 %, respectively). The severity of sleep disordered breathing was slightly lower in ESADA compared to SESAR (AHI 22.0 $\pm$ 23.5 versus 25.8 $\pm$ 2.6 n/h and ODI 18.4 $\pm$ 21.7 versus 23.1 $\pm$ 21.1).

To our knowledge, the direct comparison of national treatment cohorts for CPAP, OD and UAS therapies is unique for our current registry. In particular, the large group of patients on OD treatment is relevant to the field as OD treatment cohorts are less available today. OSA patients started on OD have lower AHI and BMI, whereas clinical symptoms as assessed by the ESS are similar with patients started with CPAP. For patients undergoing UAS, the younger age is characteristic whereas the degree of AHI frequency and symptomatology is not very different to other frequently applied therapy options in OSA. This result is in line with current recommendations for non-CPAP therapies [28].

4.3. Strength and limitations

Strength of the SESAR cohort include the large cohort size, the multicentric design, and the high national coverage of both diagnostic and CPAP treatment procedures. Data submitted to SESAR have previously been validated together with the Swedevox registry against the entries in the medical records. In that study, between 98.2 % and 95.7 % of data entries in the registry were congruent with the clinical records for key variables like AHI, BMI, and ESS score [29]. Together with the high coverage of data as reported above, the validity of data is very high. Further, inclusion of patients in the registry is not biased towards OSA severity, anthropometric characteristics, comorbidity spectrum, or health-insurance claims. Finally, SESAR offers unique research possibilities by its integration with several national quality registries for comorbid diseases relevant for OSA. Specific phenotypic characteristics and information from bio-samples are available for OSA comorbidities like heart failure, stroke, diabetes mellitus, and COPD.

A few limitations need to be mentioned as well. First, estimates for patient coverage in SESAR contain a certain degree of uncertainty as no national statistics cover the entire care provided to OSA patients.

However, SESAR probably contains one of the largest clinical cohorts of OSA patients, in particular for OSA treated with OD. Second, SESAR does not capture all OSA patients in Sweden and a potential reporting bias relates to the lack of resources to report patient related data from all sleep clinics. However, the bias is not driven by selection due to medical reasons. Third, in Sweden like in several European countries, only polygraphy is routinely used to identify OSA. The AHI assessed by polygraphy in our cohort is expected to be lower than the AHI determined by polysomnography in other cohorts [27]. Fourth, SESAR does not contain all clinical data, symptom evaluations, or biosignal data assessed during the diagnostic work-up. This strategy was chosen to increase the coverage of patients by keeping the reporting feasible for sleep centers. To overcome the current limited capture of patient related outcome data (PROM), SESAR collaborates within a national initiative to include more generalised PROM's in national quality registries. To summarize the discussion above, all larger cohorts have specific strengths and limitations.

4.4. Current clinical application and future developments

SESAR provides a source of data for patients, health care professionals, and health care politicians who seek information on a publicly and readily available webpage (www.sesar.se). Waiting times, typical procedures and treatment outcomes are presented on the region/county level as well as by sleep unit spread over the entire country. This homepage is visited approximately 3500 times/month and approximately 100 users download national documents each month (national diagnostic and treatment guidelines, management program, annual SESAR reports). Thereby, SESAR contributes to OSA management in Sweden. Alignment with guidelines and the changes in care over time are closely monitored on a national level by means of SESAR data [8].

Despite this contribution to national care, SESAR aims to be part of high level epidemiological and outcome research in the OSA patient population [30,31]. For example, ongoing and future research projects using SESAR data are related to the analysis of waiting times, outcomes of CPAP therapy in cardiometabolic diseases like hypertension and diabetes mellitus, and cancer incidence in untreated versus treated OSA. In particular, the between center variability in the diagnostic process is addressed in several ongoing studies.

To further facilitate research, SESAR is integrated in the Register Utility Tool Meta-database of the Swedish Research Council (RUT). RUT allows researchers to identify information on specific patient groups including OSA. Integration of data from disease specific registries like SESAR and Swedevox with several national registries into the DISCOVERY OSA cohort is an important example on how to facilitate multidisciplinary research in the field of OSA [32–34].

5. Conclusion

SESAR is a national registry that continuously collects and stores data from patients with OSA. The goal of SESAR is to improve the quality of care provided to OSA patients by delivery of information on treatment outcomes and patient experience. The registry also provides important data for research initiatives, as well as public health policies related to OSA.

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Institutional review board statement

Ethics Committee at the Medical Faculty at Lund university (Dnr 2018/519) and the Swedish Ethical Review Authority (Dnr 2022-02012-02).

Informed consent statement

According to Swedish Law, patients entering the national quality registries are informed but do not give written consent for participation. Patients can, at any time, request withdrawal of their data from the registries.

Data availability statement

SESAR data are available on request when all legal requirements according to Swedish Law are fulfilled. In general, a study protocol, an ethical approval, and a data transfer agreement between institutions are required.

CRediT authorship contribution statement

Ludger Grote: Writing – original draft, Visualization, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Yvonne Asp Jonzon:** Writing – review & editing, Supervision, Project administration. **Peter Barta:** Writing – review & editing, Validation, Project administration. **Tarmo Murto:** Writing – review & editing, Validation, Project administration. **Zarita Nilsson:** Writing – review & editing, Supervision, Project administration. **Anna Nygren:** Writing – review & editing, Supervision, Project administration, Methodology. **Jenny Theorell-Haglöw:** Writing – review & editing, Supervision, Project administration. **Ola Sunnergren:** Writing – review & editing, Validation, Supervision, Project administration. **Martin Ulander:** Writing – review & editing, Validation, Project administration. **Magnus Ekström:** Writing – review & editing, Supervision, Resources, Methodology, Funding acquisition. **Andreas Palm:** Writing – review & editing, Resources, Project administration, Methodology. **Jan Hedner:** Writing – review & editing, Validation, Resources, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization.

Declaration of competing interest

The authors declare participation in the steering committees for the SESAR and/or the Swedevox registries. Outside the submitted work, LG has received unrestricted institutional grants for the ESADA collaboration from RESMED; RESPIRONICS and BAYER AG. LG has lectured for Itamar, Lundbeck, Astra Zeneca, Resmed, and Respironics. LG owns shares of a company which has licensed a patent for pharmacological OSA therapy to Desitin GMBH. Outside the submitted work, ME has received a research grant from ResMed and personal fees from AstraZeneca, Boehringer Ingelheim, Novartis, and Roche. Outside the submitted work, JH has received unrestricted institutional grants for maintenance of the ESADA collaboration from RESMED; RESPIRONICS and BAYER AG. JH has lectured for Itamar, Astra Zeneca, Resmed, and Somnomed. JH is part owner of a company which has licensed a patent for pharmacological OSA therapy to Desitin GMBH.

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