Paediatric obesity treatment during 14 years in Sweden: Lessons from the Swedish Childhood Obesity Treatment Register—BORIS

Emilia Hagman | Pernilla Danielsson | Louise Lindberg | Claude Marcus | on behalf of the BORIS Steering Committee

Division of Pediatrics, Department of Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

Correspondence
Emilia Hagman, Karolinska Institutet, Blickagången 6A Novum, S-141 57 Huddinge, Sweden.
Email: emilia.hagman@ki.se

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Abstract

Background: Treatment of paediatric obesity has been offered customarily and free of charge for more than 15 years in Sweden. The Swedish Childhood Obesity Treatment Register (BORIS) is a prospective register of children and adolescents undergoing obesity treatment.

Objectives: To investigate how patient characteristics and treatment efficacy has changed over 14 years on a national scale.

Methods: All subjects in BORIS with data from 2004 until 2017 were included, n = 21 499. Outcomes were age and BMI SDS at treatment initiation, dropout rates and treatment outcome up to 3 years after treatment initiation.

Results: Age and BMI SDS at treatment initiation have decreased during the years (both \( P < .0001 \)). Of the patients who started treatment before 2009, more than 80% had at least 1-year follow-up. This number has decreased to about 60% in 2017. Since 2004, no trend in improvement of treatment results was observed when evaluating change in either BMI SDS or proportion of obesity remission. There was no difference between the sexes.

Conclusion: Although children in Sweden receive treatment at an earlier age, which is a major determinant of treatment success, and at a lower degree of obesity at treatment initiation, the effect of childhood obesity treatment on standard anthropometric measures has not improved over the investigated years.

KEYWORDS
behavioural treatment, childhood obesity treatment, epidemiology

1 | INTRODUCTION

1.1 | Paediatric obesity treatment in Sweden

The prevalence of childhood obesity in Sweden is estimated to 4% to 9%.\(^1\) However, a complete survey across the country and across ages is not available. Treatment of paediatric obesity (up to 18 years of age) has been offered for more than 15 years in Sweden and is comprised mainly of behavioural lifestyle modification. The treatment is generally offered at paediatric outpatient clinics. Guidelines for obesity treatment are evidence-based and include that treatment should be initiated at an early age and before a severe obesity is
manifested. A Swedish study has shown that as many as 90% of the 6-year-old children can achieve a clinical relevant treatment effect whereas only 10% of the adolescents reach the same effect after 3 years of treatment. Recommendations regarding clinical check-ups are provided by the Swedish Pediatric Society and the local county councils and examinations involve investigation of cardio-metabolic health. All health care, including treatment of obesity, is free of charge for children and adolescents up to 18 years of age. Generally, treatment is aimed to be tailored towards the families’ needs and abilities to adhere to specific programmes. Treatment may therefore be delivered differently, that is, individual and/or group treatment; hence, the rate of visits and type of examinations are not uniform. However, annual visits are recommended, regardless if treatment is successful or not. In accordance with recommendations, the treatment centres are striving to create multi-disciplinary teams with paediatricians, paediatric nurses, dietitians, and physiotherapists, but it is often the paediatric nurse who is providing majority of the behavioural support. As often reported, the fairly large drop-out rate among patients with obesity is prevalent also among paediatric patients. Despite that obesity is considered a disease, the availability of treatment facilities varies over the country and in combination with that not all families are interested in treatment, only a minority of children with obesity receive behavioural support. Pharmacological treatment of paediatric obesity in Sweden is only allowed in clinical trials and bariatric surgery is only performed in carefully selected adolescent patients. It is recommended that the patients are registered in The Swedish Childhood Obesity Treatment Register—BORIS which is a register for treatment follow-up.

2 | AIM

To study if and how patient characteristics at treatment initiation of paediatric obesity treatment and treatment efficacy have changed over 14 years on a national scale.

3 | METHODS

3.1 | The Swedish Childhood Obesity Treatment Register—BORIS

3.1.1 | History and structure

A prospective documentation of children and adolescents with obesity was initiated in 2005 for long-term monitoring of childhood obesity treatment in Sweden. Retrospective data on 1513 individuals, who started obesity treatment between 1994 and 2005, were also entered. The register contained in 2019 about 28 000 unique individuals from 109 different paediatric clinics across Sweden. Six out of seven university hospitals report to BORIS as well as 19 paediatric clinics on a county council level, 64 local paediatric open ward clinics and two primary health care units. The Swedish health care system is in detail described by Wettergren et al.

3.1.2 | At the clinic

BORIS is integrated into clinical workflows and generates data in real time. Data from the register can be used in the meeting with the patient. Dynamic charts can show how the patient’s weight, height and blood pressure (BP) have changed over time.

Apart from the patient’s personal summary, each treating clinic can view and retrieve statistics, both graphically and in numbers, of the clinic’s patients (age, body mass index standard deviation score [BMI SDS], sex, etc.) and the overall treatment progress (change in BMI SDS). In addition, each clinic can compare their data on an aggregated level with other reporting units in the same county or nationwide. The results can be divided by sex, age category, parental BMI and more.

3.1.3 | A source for research

Except for quality assurance of the paediatric obesity care and a tool for the treating health care staff, BORIS has also been widely used for research purpose. Several studies regarding paediatric obesity treatment, including lifestyle behavioural modification and surgical interventions have been published. Other areas of research include cardiac, endocrine and psychosocial aspects of obesity in childhood and adolescence. More research using data from BORIS in combination with other Swedish registers are currently conducted.

3.1.4 | Operation, data safety and confidentiality

Leadership of BORIS consists of a registry director, a coordinator, who oversees the day-to-day operations and a steering committee, which provides support for the direction and implementation of registry efforts. The steering group is the decision-making authority, broadly deciding about the function and development of the register. The coordinator’s work includes user support and quality improvement, extracting data from the register and compiling statistics. The electronic database system, which collects and holds the data, is outsourced. Authorized paediatric health care staff treat obesity log into the system online by a two-step authentication. The head of BORIS is Karolinska University Hospital, Stockholm, Sweden.
Thanks to a unique individual personal identification number (PIN) assigned to each individual born or living in Sweden, duplicates of patients will not occur. The PIN has a built-in control function, making it impossible to enter an invalid number. The possibilities and potential pitfalls of the Swedish PIN in health care and medical research have been described previously.22

Patients and guardians are informed about the register, and approval of registration is documented in the patient’s electronic medical file. An opt-out approval is the current law and regulation in Sweden.

### 3.1.5 Variables collected and data quality

Since obesity in childhood and adolescents is associated with a variety of both somatic18,23 and psychosocial21 consequences, health outcomes and determinants are collected. Data from clinical examination include anthropometric measures such as height, weight, waist circumference and BP. Laboratory analyses of blood samples include among others fasting glucose, insulin, HbA1c, lipid profile, and liver status. A summary of the clinical visit can be viewed by the clinical staff as regard to degree of obesity (BMI SDS), weight status classification (overweight, obesity degree I and degree II),24 normal or hypertensive BP,25 normal or pre-diabetic fasting glycaemic levels, etc. A notice appears if the patient has hypertensive BP levels or has impaired fasting glycaemia. In addition to data from treatment visits, personal information regarding prenatal history, physical activity, present or past medical history, quality of life (PedsQL), family history of disease, psychosocial information and more may be collected. Basic registration information (eg, PIN and approval of registration) and anthropometrical measurements at clinical visits are mandatory, while other variables are voluntary and are used upon the clinics’ routines and needs. A full list of variables is provided as Data S1.

The data quality is assured in several steps: Implausible values are identified and flagged to the user when entered into the system. By randomisation, site visits are regularly performed for data monitoring. In addition to comparisons between register data and medical files, it is also checked whether there are patients who are treated but not registered. The quality of registered data has been shown to be in accordance to medical files, and selection bias of registered patients has not been identified. In the future, data will be imported directly from medical files, which will eliminate potential errors caused by manual data handling. When exported for scientific use, data are validated before analyses.

### 3.2 Subjects

In this study, all subjects in BORIS with data from January 2004 until December 31, 2017 were included in the analyses. No exclusion criteria were applied. Data were extracted in July 2018. The regional ethical committee in Stockholm approved extracting data and performing analyses, file no 2014/381-31/5.

### 3.3 Definitions

Degree of obesity, measured with BMI SDS, was based on the reference recommended by the International Obesity Task Force.24

Yearly intervals were defined as 1, 2 and 3 years, respectively, −3 months and +6 months, in order to grasp the clinical situation. In other words, 2 years are defined as 21 to 30 months.

In order to give a profile of key cardio-metabolic investigations, we present proportion of individuals with measured BP, glucose homeostasis (fasting glucose and/or HbA1c), lipid profile (triglycerides, total cholesterol, high-density lipoprotein cholesterol and/or low-density lipoprotein cholesterol) and liver status (alanine aminotransferase and/or aspartate aminotransferase).

### 3.4 Statistics

Descriptive data are presented as mean and SD or 95% confidence limits, or with median and interquartile range. Obesity treatment results are presented by year of treatment initiation and are measured as change in BMI SDS (Δ BMI SDS), proportion of patients reaching a clinical relevant change in BMI SDS of 0.25 units26,27 and proportion in obesity remission (overweight or normal weight). These three measures are evaluated 1, 2 and 3 years after treatment initiation and complete cases are reported, that is, no data were imputed. In order to investigate trends over time for analyses of treatment outcomes, year of treatment initiation was handled as a continuous variable in a generalized linear model (change in BMI SDS), logistic regression (reduction of 0.25 BMI SDS units) or ANOVA.

Cardio-metabolic profile within 1 year of treatment initiation is defined as no later than 12 months from the initial visit. All analyses were performed in SAS statistical software (version 9.4, Cary, North Carolina).

### 4 RESULTS

#### 4.1 Profile of new referrals

##### 4.1.1 Number of patients

Number of new patients referred annually to paediatric obesity treatment has increased from about 330 in 2004 to more than 2500 in 2017 (Figure 1). In total did 21 499 patients start paediatric obesity treatment between January 2004 and December 2017. Complete descriptive statistics are provided in Data S2.

##### 4.1.2 Age

The average age at treatment initiation has decreased from 11.3 ± 3.3 years in 2004 to 9.7 ± 3.6 years in 2017 (P < .0001). This was more pronounced among girls than boys, P < .0001. Since 2010, boys have been older than girls at treatment initiation (Figure 2A).
4.1.3 | BMI SDS

The average BMI at treatment initiation has decreased by 3.28 kg/m² ($P < .0001$) to 2017, corresponding to a decrease in degree of obesity from 3.05 ± 0.51 BMI SDS units to 2.81 ± 0.55 units ($P < .0001$). This was more evident in girls than boys ($P < .0001$). In 2017, the average BMI SDS was 2.87 units for boys and 2.74 units for girls, $P < .0001$. However, the cut-off for the definition of obesity is $\approx 0.1$ BMI SDS units higher in boys. After considering that difference into account, the difference in BMI SDS between boys and girls was no longer statistically significant, $P = .11$ (Figure 2B).

4.1.4 | Cardio-metabolic profile

In conjunction with the initial treatment visit, a majority of children had their blood lipids, glucose homeostasis, liver enzymes and BP measured. For example, approximately 75% of all new referrals since 2009 have had their BP measured. The proportion of children with measured comorbidity profile has remained similar between 2007 and 2016 (Figure 3).

4.1.5 | Dropout rates

In the beginning of the era of more generalised childhood obesity treatment in Sweden, the proportion of patients discontinuing obesity treatment was fairly low. Of those patients who started their treatment before 2009, more than 80% had at least 1-year follow-up and more than 40% remained in treatment after 3 years. These numbers have, however, decreased during the last decade, and now a stabilisation of about 60% remain in treatment after 1 year (Figure 4).

4.2 | Treatment results

4.2.1 | Response analyses

Patients without follow-up data (47.5%) were of similar sex distribution ($P = .29$), were $5.6 \pm 42.1$ months older ($P < .0001$), had $0.23 \pm 0.08$ kg/m² higher BMI and had $0.06 \pm 0.54$ lower BMI SDS units ($P < .0001$).

4.2.2 | Change in BMI SDS

Overall since 2004, no trend in improvement of treatment results was observed, but rather the opposite. For every year since 2004, the reduction in BMI SDS has become smaller by 0.005 BMI SDS units ($P < .0001$) after 1 year in treatment, 0.007 after 2 years in treatment ($P < .0001$) and 0.01 after 3 years in treatment ($P = .0002$). There was no difference between the sexes as regard to 1-year ($P = .16$), 2-year ($P = .28$) and 3-year ($P = .09$) treatment results (Figure 5).

4.2.3 | Clinically relevant change in BMI SDS

The proportion who achieved a clinically relevant change in BMI SDS of 0.25 units after one and 2 years of treatment has declined over the
investigated years. The odds of achieving a reduction in BMI SDS of 0.25 are lower after 1 year in treatment (OR = 0.98, 95% confidence limits 0.97-0.996), and 2 years in treatment (OR = 0.97, 95% confidence limits 0.69-0.99), whereas the proportion has remained similar after 3 years of treatment over the investigated years. One year after treatment initiation, approximately 30% lost 0.25 BMI SDS units or more. After 2 and 3 years, the proportions were 40% to 45% and 45% to 50%, respectively (illustrated in Figure S1).

4.2.4 Obesity remission

The proportion of children in obesity remission has not increased after 2 and 3 years in treatment. Over the investigated years, approximately 15% of those who had obesity at baseline went into obese remission after 1 year of treatment. The corresponding proportions after 2 and 3 years were approximately 18% and 19%. No statistically significant trends were detected, and no difference between the sexes in obesity remission was observed after 3 years in treatment (boys 19.8%, girls 19.4%, P = .80) (Figure 6).

5 DISCUSSION

The Swedish Childhood Obesity Treatment Register—BORIS—provides useful tools for health care providers. BORIS’ approach is a national network for systematic evaluation, enabling quality improvement of treatment care delivery, engaging patients and professional providers, clinical trials and clinical research. In similarity to other pediatric obesity treatment registers/initiatives,28-30 patient data, including degree of obesity and cardio-metabolic profile, is collected among many other variables.

The number of patients who receive paediatric obesity treatment has increased during the last 14 years in Sweden. The patients receive treatment at an earlier age and with a lower BMI SDS at treatment initiation, factors known to be of importance for successful weight loss.2 However, the effect of treatment shows a tendency to have deteriorated during the last years. This is also mirrored in the stable proportion of obesity remission despite the lower degree of obesity at the start of the treatment.

In addition, the number of families not coming back for follow-up visits has increased. It is an important question whether the dropout rates are higher due to differences in the type of treatment offered. The number of treating centres has increased, but so has also the number of patients. There are no signs indicating that the experience of obesity treatment is of major importance for the outcome. Our hypothesis is that the demand for obesity treatment has increased, whereas the treatment resources is on the same level; thus, it is most probably a less intensive treatment today compared to 5 to 10 years ago and this is causing declining outcome and more dropouts.

The health care providers are aware of the cardio-metabolic risk and check for essential regularly comorbidities. However, more than 20% do not get their cardio-metabolic profile measured. The reasons for this are probably multifactorial; the current Swedish guidelines recommend routine blood testing from 9 years of age, perhaps logistical problem or not entering the data might contribute. However, the proportion of patients who were investigated for cardio-metabolic comorbidities was much larger than previously reported from a childhood obesity treatment register in Germany,28 where 43% had their BP checked between the years 2000 and 2003.

The effectiveness of obesity treatment is delicate to define. Most studies use change in BMI SDS as a continuum. However, a statistically significant decrease does not always result in a clinically relevant change. Therefore, a pre-specified change (eg, −0.25 BMI SDS units), that has previously shown to be associated with improved metabolic profile,26,27 is sometimes used. A third way is to estimate how many patients who go in remission from obesity—the optimal but rarely used long-term goal for obesity treatment.31 As the possibility to reach this goal depends on the degree of obesity at treatment initiation, a robust evaluation of childhood obesity treatment outcome requires that several outcome indicators are presented.31
From a gender equality perspective, it is concerning that boys are registered in BORIS at an older age than girls. The reasons for this might include the parental view of boys' and girls' needs of obesity treatment or perhaps it is due to health care system considerations. However, even though obesity treatment in boys is initiated when they are older, and at a somewhat higher degree of obesity than girls, boys still reached the same decrease in degree of obesity over time.

A study by Danielsson et al showed that 92% of children, who started treatment at age 14 to 16 had, obesity already before the age of seven, an age group where we know that obesity treatment is more successful. Thus, it is positive that treatment is initiated at a younger age in Sweden, but unfortunately, the overall treatment result has not improved simultaneously.

We can only speculate in the reasons, but it is likely that the treatment quality has been negatively affected when the limited health care resources have been shared between an increasing number of patients. The ability to keep patients in treatment has drastically decreased, for example, in 2004 70% remained in treatment, whereas the corresponding proportion in 2015 was 40%. Other factors that may contribute to lack of improvements of treatment results include inadequate number of visits or increasing challenges with family function. Paediatric obesity behavioural treatment must be intensive in order to succeed, why resources are crucial in order to
generate satisfying treatment results. There might be a limited willingness in many countries to allocate sufficient economic support for treatment of a "self-induced" disease such as childhood obesity despite that an effective childhood obesity treatment should reduce the long-term health care costs. The direct costs, such as excess hospital costs, and indirect costs of obesity in childhood and adolescence are difficult to estimate. In 2003, the annual direct cost of overweight and obesity in adults was estimated to 3.6 billion SEK (€390 million) in Sweden.33 More recent (2017) estimates, including both direct and indirect costs, reached 70 billion SEK (€6.7 billion)/year.34 In summary, given the moderate effect of current obesity treatment and the large costs associated with obesity, intensified paediatric obesity treatment may be beneficial for both individual health and societal economy.

5.1 | BORIS Pitfalls

Data registered in BORIS have so far been entered manually. Even though biological implausible values are flagged, it is impossible to guarantee an accurate and fully covered data entering. However, data accuracy is regularly checked in a random sub-sample of the reporting units. Further, even though BORIS provides the health care staff with important tools and education on how to register data, a potential bias in what patients that are registered cannot be excluded. This is, however, evaluated in randomly selected treatment providers and annual questionnaires. Those clinics that register in BORIS report that they register “all of their patients” and our random visits have confirmed this statement. Despite potential pitfalls, the clinical and scientific value of the register is invaluable.

5.2 | Possibilities

The future plans and improvements of BORIS involve tools to determine treatment progression, predictors of treatment outcome and dropout, as well as better age- and sex-specific cut-offs for biomarkers and degree of obesity. Long-term register outcome data where different treatment strategies have been used in combination with clinical trials will together help to clarify how behavioural
treatment can be optimised. Further, international collaborations, for example, with other paediatric obesity registers,28-30 could potentially generate great research.

6 | CONCLUSION

Treatment of paediatric obesity has increased with more than 900% in Sweden from 2004 to 2017. Over the last 14 years, we have seen a positive change with treatment initiation at a younger age and with a lower BMI SDS. Cardio-metabolic investigations are performed to a large extent. Even though patients receive treatment for obesity at an earlier stage, the treatment results have not improved, which may indicate lack of resources or adapting to increasing challenges in families. We therefore conclude that the present treatment strategies of paediatric obesity in Sweden need to be enhanced.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

E.H. conceptualised the study, carried out the data management and statistical analysis. All authors were involved in the interpretation of the results. E.H. drafted the manuscript, and all other authors edited the manuscript. All authors approved the final version for submission and agree to be responsible for its contents.

ORCID

Emilia Hagman https://orcid.org/0000-0003-1433-2295
Louise Lindberg https://orcid.org/0000-0002-9517-5000

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Additional supporting information may be found online in the Supporting Information section at the end of this article.

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