Tita Kirkinen

Dental health and dental care in children in out-of-home care
DENTAL HEALTH AND DENTAL CARE IN CHILDREN IN OUT-OF-HOME CARE
Dental health and dental care in children in out-of-home care
Thesis for Doctoral Degree (Ph.D)
By Tita Kirkinen

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DENTAL HEALTH AND DENTAL CARE IN CHILDREN IN OUT-OF-HOME CARE

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To my children
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Preface

With this thesis I hope to engender change...

My experience as a dentist, both in general dentistry and as a paediatric dentist is that children in out-of-home care (OHC) do not always receive the dental care they are entitled to. A child is often moved to accommodation in another county or region and consequently we are no longer able to treat the child. For example, one of my patients moved seven (!) times in one year. Under these circumstances, when the child is moved, Social Services should ensure that health and dental care will be available in the new setting. To try to ensure this, I used to send a referral to the nearest paediatric dentistry clinic. However, because of the high frequency of moves, I am still concerned that these children will not receive necessary ongoing dental care.

During the years 2017-2018, while working on a project with The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU), I interviewed Social Service managers around Sweden about their routines for children being placed in care. The aim was to determine whether these children in fact received general medical and dental examinations before, during and after placement in out-of-home care. I found that, while many municipalities had such procedures in place, these routines were surprisingly often not adhered to.

For a paediatric dentist, children’s welfare is of high priority. In this context it is particularly important that children receive the dental care they are entitled to, that there is equality of access to care for all children, including those most vulnerable. This does not mean that all children should receive the same care, but all children should have the right to access the care they need. Unfortunately, children in OHC seem to “fall between the cracks”. That is the hypothesis to be investigated in my thesis. If my research confirms that this is the case, then routines guidelines and policies must change, at the highest level.

So now with this thesis, I hope to engender a change for children in out-of-home care.
Thesis at a glance

<table>
<thead>
<tr>
<th>Paper</th>
<th>Aim</th>
<th>Study design</th>
<th>Sample</th>
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<th>Main findings</th>
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<tr>
<td>I</td>
<td>To analyse dental health care among young adults with childhood experience of out-of-home care (OHC), by combining available selected registries.</td>
<td>Registry-based cohort study</td>
<td>Swedish residents born in 1980–1994; 1,667,660 individuals in total, of whom 565,261 had entered OHC at some point during childhood</td>
<td>Check-up visits or preventive care</td>
<td>Young adults who had been in OHC during childhood had more emergency visits, more extracted teeth and did not visit the dentist for check-ups and preventive care to the same extent as their peers in the majority population</td>
</tr>
<tr>
<td>II</td>
<td>To evaluate the effects of organisational models intended to ensure that OHC children receive health and dental care.</td>
<td>Systematic review/HTA</td>
<td>14,576 abstracts from 10 databases and nine additional studies identified by hand search</td>
<td>Access to health- and dental care</td>
<td>Of the total of 14,585 studies, 271 were read in full text. Despite the high volume of published papers, critical analysis failed to identify any study with low or moderate risk of bias. When organisational models are implemented, well-conducted follow-up studies should be done to evaluate their effects</td>
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<tr>
<td>III</td>
<td>Evaluate the reliability and accuracy of output data from the Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa) regarding dental caries in 6- and 12-year-old children</td>
<td>Diagnostic accuracy study: clinic/patient record/SKaPa</td>
<td>170 children: 84 boys (40 6-year-olds, 44 12-year-olds) and 86 girls (43 6-year-olds, 43 12-year-olds)</td>
<td>dft/DFT</td>
<td>Good agreements were ascertained between the dental examinations, data registered in the dental records and data retrieved from the SKaPa registry</td>
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<td>IV</td>
<td>Evaluate the reliability and accuracy of output data from SKaPa in 6- and 12-year-old children of data on caries and preventive dental treatments</td>
<td>Diagnostic accuracy study: patient record/SKaPa</td>
<td>A random sample of 500 6- and 12-year-old children (250 per age group)</td>
<td>dft/DFT, deft/DMFT, e/M and preventive dental treatments</td>
<td>Agreement for preventive measures and dft/DFT were very high, whereas the agreement for deft/DMFT values were considerably lower, due to problems in e/M respectively</td>
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<td>V</td>
<td>Investigate whether children in OHC have similar dental health and dental care as other children</td>
<td>Registry-based cohort study</td>
<td>409,638 individuals, of whom 68,273 had been placed in OHC at some point during the period 2010-2018</td>
<td>Check-up visits Emergency visits Dental caries Extracted teeth: number of extracted teeth Trauma to jaws/teeth</td>
<td>Children in OHC received fewer regular dental examinations, they had more dental caries (dft/DFT), more extracted teeth, more emergency dental visits and more traumatic injuries to teeth and jaws than children who had never been placed in OHC</td>
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</table>
List of papers

This thesis is based on the following five studies, referred to in the text by the Roman numerals I–V.


V. Kirkinen T, Naimi-Akbar A, Cederlund A, Tranæus S, Klingberg G. The Swedish Out-of-Home Care Children Cohort (SweOHC) - evaluation of dental health and dental care. In manuscript.

All papers are reprinted with the kind permission from the copyright holders and are appended to the end of this thesis.
Definitions and abbreviations

Definitions

Accuracy  How close or correct a measurement is to the true value.
Agreement  Agreement between measurements refers to the degree of concordance between two (or more) sets of measurements.
Index test  The test that is being evaluated against a reference standard.
Reference standard  A reference standard is the best test currently available.
Region  A self-governing unit with a geographical area of responsibility equivalent to a county.
Reliability  The consistency a measure, the quality of being able to be trusted.
Sensitivity  Proportion of those with the target condition who test positive with the index test.
Specificity  Proportion of those without the target condition who test negative with the index test.
Systematic review  Systematic search for and compilation of all relevant literature addressing a specific research question.
Validity  How accurately a method measures what it is intended to measure.

Abbreviations

ADAD  Adolescent Drug Abuse Diagnosis
AMSTAR  A measurement tool to assess the methodological quality of systematic reviews
BBIC  Children's needs in the centre (In Swedish: Barns behov i centrum)
CHS  Child health services
CRC  United Nations Convention on the Rights of the Child
deft  decayed, extracted, filled teeth (primary teeth)
dft  decayed, filled teeth (primary teeth)
DFT  Decayed, Filled Teeth (permanent teeth)
DHR  Dental Health Register (In Swedish: Tandhälsoregistret)
DMFS  Decayed, Missing, Filled Surfaces (permanent teeth)
DMFT  Decayed, Missing, Filled Teeth (permanent teeth)
<table>
<thead>
<tr>
<th>Abbreviation</th>
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<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
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<tr>
<td>HTA</td>
<td>Health technology assessment</td>
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<td>ICDAS</td>
<td>International Caries Detection and Assessment system</td>
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<td>LISA</td>
<td>Longitudinal Integration Database for Health Insurance and Labour Market Studies (In Swedish: Longitudinell integrationsdatabas för Sjukförsäkrings- och Arbetsmarknadsstudier)</td>
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<td>LVU</td>
<td>Care of Young Persons (Special Provisions) Act (In Swedish: Lag (1990:52) med särskilda bestämmelser om vård av unga)</td>
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<td>MIH</td>
<td>Molar Incisor Hypomineralization</td>
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<tr>
<td>OHC</td>
<td>Out-of-home care</td>
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<td>PECO</td>
<td>Population, Exposure, Control, Outcome</td>
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<tr>
<td>PICO</td>
<td>Population, Intervention, Comparison, Outcome</td>
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<tr>
<td>PIN</td>
<td>Personal identity number</td>
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<tr>
<td>PIRO</td>
<td>Population, Index test, Reference standard, Outcome</td>
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<tr>
<td>SBU</td>
<td>Swedish Agency for Health Technology Assessment and Assessment of Social Services (In Swedish: Statens beredning för medicinsk och social utvärdering)</td>
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<tr>
<td>SCB</td>
<td>Statistics Sweden (In Swedish: Statistiska centralbyråns Statistikmyndigheten)</td>
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<tr>
<td>SiC</td>
<td>Significant Caries Index</td>
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<td>SIP</td>
<td>Coordinated individual plan (In Swedish: Samordnad individuell plan)</td>
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<td>SiS</td>
<td>The National Board of Institutional Care (In Swedish: Statens institutionsstyrelse)</td>
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<td>SKaPa</td>
<td>The Swedish Quality Registry for Caries and Periodontal Diseases (In Swedish: Svenskt Kvalitetsregister för Karies och Parodontit)</td>
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<tr>
<td>SoL</td>
<td>The Social Services Act (In Swedish: Socialtjänstlag (2001:453)</td>
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<tr>
<td>SR</td>
<td>Systematic review</td>
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<td>SweOHC</td>
<td>Swedish Out-of-Home Care Children cohort</td>
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<tr>
<td>TLV</td>
<td>Dental and Pharmaceutical Benefits Agency (In Swedish: Tandvårds- och Läkemedelsförmånsverket)</td>
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Abstract

More than 26,000 children and young people are placed in out-of-home care in Sweden every year. Several studies show that children placed in out of home care have poorer health during childhood and are generally in poorer physical condition later in life.

The overall aim of this thesis was to study dental health and dental care in children in out-of-home care (OHC), through registry-based research.

Paper I was a registry-based study of dental health care utilisation among young adults who as children had been placed in societal out-of-home care. These young adults had more emergency dental visits and more extractions and fewer regular scheduled dental check-ups than their peers who had never experienced OHC.

Paper II was a systematic review/HTA to evaluate organisational models intended to ensure that children and young people in out-of-home care will receive health and dental care. We were unable to identify any study, of low or medium risk of bias, which examined the effects of organisational models on provision of health and dental care for children and young people in foster care and in institutions.

Papers III and IV were validation studies of the Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa), undertaken to determine the accuracy of the registry and whether it was appropriate for application in the next study (Paper V) and for other research purposes. For dft/DFT, the validation studies showed high agreement between the data in the patient records and the SKaPa registry. However, e/M in deft/DMFT was shown to be uncertain.

Paper V was a registry-based study linking different registries, to investigate dental health and dental care in children in OHC. This study showed that children in OHC have more caries and undergo fewer dental health assessments than those who have never been placed in OHC. There was a difference in dental health examinations before and after the year 2017, with higher frequencies of assessments after the legislative amendment in 2017. However, differences remain.
Conclusions

- Young adults who have been placed in OHC at some point during their childhood have poorer dental health, with more emergency dental visits and more tooth extractions. The dental health of those who had been placed in OHC for most of their childhood was no better than that of those who had been in OHC only for a shorter period. Thereby, adults who have been placed in OHC during childhood don't have the same opportunities to achieve good dental health as other young adults.

- There are no studies of sufficient quality assessing the effects of organisational models on accessibility of health and dental care for children placed in OHC. Therefore, when such models are planned and introduced, high quality follow-up studies are needed.

- With reference to caries data dft/DFT and treatment measures, SKaPa is a quality register, which can be used for research. However, as agreement was substantially lower for e/M, especially in 12-year-olds, at present the use of SKaPa output data on deft or DMFT for research purposes is not advised.

- Children in OHC have poorer dental health and receive less dental care than other children. They have, for example, more caries, more emergency dental treatment, and more tooth extractions. Higher frequencies of dental health examinations were found after the legislative amendment in 2017. There is a need for efficient procedures and models to ensure that children placed in OHC receive appropriate and timely dental care.
Populärvetenskaplig sammanfattning

Drygt 26 000 barn och unga placeras varje år i Sverige. Placeringen kan ske i familjehem, jourhem, stödboende eller hem för vård eller boende med stöd av Socialtjänstlagen, SoL, eller Lagen med särskilda bestämmelser om vård av unga, LVU. Hälsoproblem är överrepresenterade hos placerade barn. Det finns bland annat brister i vaccinationsskydd och uppföljning av barnets fysiska och psykiska hälsa. Att tillgodose samhällsvårdade barns och ungas hälsa- och sjukvård är sedan april 2017 reglerad i ”Lag om hälsoundersökning av barn och unga som vårdas utanför det egna hemmet”. Av denna lag framgår att regionerna ska, på initiativ av socialnämnden, erbjuda en hälsoundersökning i anslutning till att vård inleds utanför det egna hemmet av ett barn eller en ung person i åldern 18–20 år.

De register, inklusive register inom tandvården, som finns idag ger nya möjligheter att utvärdera och följa upp munhälso hos grupper av barn i behov av särskilt stöd på grund av exempelvis sociala omständigheter, funktionsnedsättningar och medicinska problem. Genom att utvärdera tandhälso och den tandvård placerade barn får, finns möjlighet att utveckla strategier för att påverka beslutsfattare, så att nya organisatoriska modeller kan utarbetas och på så sätt särskilda att dessa barn verkligen får den tandvård de har rätt till.

Konklusioner

- Unga vuxna som har placerats någon gång under sin barndom har sämre tandhälsa, med fler akuta tandvårdsbesök och fler tandutdragningar. Tandhälsan hos unga vuxna som hade placerats under större delen av sin barndom var inte bättre än hos de som hade varit placerade en kortare period. Unga vuxna som varit placerade under barndomen har inte samma möjligheter att uppnå likvärdig tandhälsa som andra unga vuxna.

- Det går det inte att bedöma effekterna av organisatoriska modeller för att barn och unga som placeras i samhällelig dygnsvård (familjehems- eller institutionsvård) ska få hälso- och sjukvård och tandvård eftersom det saknas studier av tillräcklig kvalitet. Därför behövs välgjorda uppföljande studier när sådana modeller planeras och introduceras.

- SKaPa är ett kvalitetsregister som kan användas för forskning, avseende karierade/fyllda tänder (dft/DFT) och behandlingsåtgärder. Variabeln extraherad/saknad (e/M) i kariesindex karierade/fyllda/extraherade tänder (deft/DMFT) är dock osäkra data och bör i nuläget inte användas i forskning.

- Placerede barn har sämre tandhälsa och får mindre tandvård än andra barn. De har bland annat mer karies, fler akuta tandvårdsbesök och fler tandutdragningar. Fler placerede barn fick tandhälsoundersökningar efter lagändringen 2017 men fortfarande färre än barn som inte var placerade. Det finns ett behov av ändamålsenliga rutiner och modeller som gör det möjligt för placerede barn att få sin tandvård.
INTRODUCTION

Background
In Sweden, all children are entitled to free health and dental care. Nevertheless, children placed in out-of-home care do not benefit from these entitlements to the same extent as other children. Many studies show that from the start, the health of these children is poorer: hence in terms of health they risk being marginalized during childhood and in adulthood (1-7).

The child’s right in Sweden
In recent decades, the rights of the child have gradually been incorporated into Swedish legislation. As from January 1st, 2020, The United Nations Convention on the Rights of the Child (CRC) has been fully incorporated into Swedish law (Act (2018:1197)) (8). The CRC consists of 54 articles with four central principles, Articles 2, 3, 6 and 12 (Figure1):
In the CRC, the right of the child to health on equal terms is fundamental. The right of all children to healthcare shall be ensured in accordance with Articles 24 and 25. Article 26 stipulates that every child shall be entitled to social security and in accordance with Article 27, every child is entitled to the standard of living required for the physical, mental, spiritual, moral, and social development of the child. Individuals are counted as children up to their 18th birthday (9).

What is health?
Health has long been regarded as the absence of disease: if or when the disease is treated, the outcome is health (10, 11). Today, this view of health has broadened and spans several areas. The WHO defines health as "a state of complete physical, mental and social well-being, not merely the absence of disease and infirmity" (12).

In the UN's Agenda 2030, the global goals include health and well-being, where the goal of health has several sub-goals, such as reducing child mortality and making healthcare accessible to all (13). The global goals are also intended to reduce inequality within and between countries (13).

Equality in health is one of the Swedish government's overarching goals of public health policy, to create societal conditions which promote good and equal health throughout the population and close the avoidable health gaps (14).

Health and dental care for children in Sweden
Swedish healthcare is the responsibility of the 21 regions and is funded primarily by taxes. The Swedish healthcare system is required to be socially responsible and equally accessible to all. All citizens have the right to healthcare and medical treatment, with priority to those in greatest need.

Children’s health is monitored from the start in Sweden. During pregnancy, maternal health is monitored at midwife-led maternity care centres. After the child is born, its health is supervised at nurse-led child healthcare centres (CHC). Once the child starts school, there are nurse-led school healthcare settings. This preventive care is an important platform for children’s health and reaches almost everyone (99%). All children and adolescents are entitled to comprehensive health and medical care and prescription drugs, free of charge, up to the age of 18 (15).

It is the overall responsibility of the regional (county) councils to ensure that dental care, including specialist dental care, is available for people living in the region and particularly to ensure the provision of dental care to children and young adults (16). Dental care in Sweden is free of charge for all children and
young people up to and including 23 years of age and is available from either the Public Dental Service (responsible for about 86% of dental care for children and young adults) or private practitioners (17). About 95% of Swedish children and adolescents receive regular dental examinations and dental care over a period of one to three years (18).

**Dental caries**

Dental caries is one of the most common non-communicable chronic diseases in the world and causes suffering, impairs people's quality of life and is a major economic burden for both affected individuals and society. This is a major public health problem. At the same time, dental caries is largely preventable.

Dental caries can develop when cariogenic bacteria in the dental biofilm produce acids, which dissolve calcium from the enamel on the tooth surface. Factors which influence caries progression include the presence of cariogenic bacteria, poor oral hygiene, lack of saliva, and behavioural factors such as frequent intake of sugar and lack of protective factors such as fluoride.

Clinically, dental caries is often defined as visible tooth substance loss without the signs of a developmental defect, or in pits and fissures when the point of the probe “caught” upon with gentle pressure. On radiographs, manifest dental caries is defined as a lesion extending beyond the dentin-enamel junction (19).

**Caries registration and indices**

Caries diagnosis is complex. Lesions can be detected clinically through visual inspection, by probing and with the aid of auxiliary methods such as radiography, fiber optics and laser fluorescence (20). A combination of visual, tactile and radiographic examination is more reliable than any of the methods alone, and to date there is insufficient scientific support for other complementary diagnostic methods (21).

ICDAS II (International Caries Detection and Assessment System) is a standardized visual system for encoding caries. ICDAS encodes six different stages of caries lesions, where scores 3-6 are classified as manifest caries. ICDAS allows detection of the caries process at each stage and characterization of activity status in the caries lesion (22-25). The first stage of the ICDAS process was adopted at a convention in Scotland in 2002 and was developed for clinical research and practice and for epidemiological investigations, as there was no consensus as to how caries should be diagnosed and recorded. There is a need for a uniform international system which allows comparison of data collected in various surveys. The ICDAS provides e-learning on their website (26). This training was previously free but is now subject to a fee.
To obtain a measure and describe caries prevalence, the caries indices DMFT and DMFS are most widely applied, expressing the number of Decayed, Missing, and Filled Teeth or Surfaces, respectively (27). Decayed, Missing (due to caries) and Filled Teeth and tooth Surfaces (DMFT/DMFS) apply to the permanent dentition. The corresponding terms for the primary dentition are d (decayed), e (extracted due to caries) and f (filled) teeth/tooth surfaces (deft/defs). The data refer to the occurrence and prevalence of dentin caries. Data are often recorded as dft/DFT, i.e. excluding the e/M component of the index (e=tooth extracted due to caries/M=tooth missing due to caries). The component decayed (d/D) of the dft/DFT represents only caries that penetrates the dentin. This definition is used in epidemiological data reported to the Swedish National Board of Health and Welfare. Moreover, only dft/DFT, not deft/DMFT, are used in epidemiological data by the National Board of Health and Welfare.

Dental caries in Swedish children

The dental health of Swedish children is generally considered to be good. However, WHO’s vision for 2021 for children's dental health in Europe, with a goal of 80% caries-free 6-year-olds, has not yet been achieved in Sweden: in 2021 75% of 6-year-olds were caries-free (28).

There are major social differences and the pattern of dental caries in children and adolescents is skewed. While most are relatively healthy, a group of children has persistently poorer dental health (29). Some of the strongest non-behavioural risk factors for poor dental health are immigrant parents from outside Western Europe, receiving financial social-welfare benefits, parents with only basic education, young parents, and parents who themselves have poor dental health (29-31).

The National Board of Health and Welfare has been collecting regional data on caries in children and adolescents at indicator ages 3, 6, 12 and 19 years. Since 2019, data on 23-year-olds have also been included (32). The 2013 report by The National Board of Health and Welfare's showed major social differences in dental health among children and adolescents in Sweden (29). In the period 2009-2019, The National Board of Health and Welfare reported an increase in manifest caries and fillings in the primary dentition in 6-year-old children (33). Between 2011–2018, the Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa) also reported an increase in caries incidence in the primary dentition for children aged from three to seven years (34). However, the trend seems now to be broken: for the year 2022, almost all regions reported a marked increase in the proportion of caries-free 6-year-olds (32). In their report for the year 2022, SKaPa also showed that for 3-9-year-old children, the increase in caries incidence in the primary dentition was broken (35) (Figure 2). The Significant Caries Index (SiC), which represents the one-third of individuals with the highest DFT/DMFT values
in a population (36), has decreased for 12-year-old children in Sweden: from 2.09 in 2017 (37) to 1.84 in 2022 (32).

![Figure 2. Decayed and filled primary teeth (mean dft) 2013-2022 (35). By permission from SKaPa.](image)

**The Swedish child welfare system**

If a child is at risk of harm, the child welfare services in Sweden may be alerted in various ways. School personnel or neighbours may report their concerns. Personnel employed for example by the police, the dental and healthcare services are obliged to report if children are at risk of harm (38). In 2021, there were 422,000 reports of child maltreatment or suspected harm to Social Services. The reports concerned approximately 216,000 children, representing almost 10% of all children in Sweden aged from 0-17: 54% were boys, 46% were girls and over 60% were aged 12 years or younger. The reports of concern came from - among others - the police (24%), health services (16%) and 1% from dental services. Of the reports to the Social Services, 19% were related to violence in close relationships (39). Parents, or the children or adolescents themselves, can also apply for an intervention.

Several studies indicate that at some point during childhood, approximately 10% of children in Sweden have experienced violence between close adults, i.e. around 210,000 children (40, 41). In July 2021, a new penal provision was incorporated into the Swedish legal system, declaring that children who witness domestic violence are to be considered victims of crime (42).
When Social Services learn that a child may be in need of support or protection, they are obliged to investigate. The Social Welfare Board must then initiate an investigation without delay. A decision on this investigation must be made within 14 days and investigation must be completed within four months (38, 43).

Many actions within the child welfare system are based on volunteerism from the parents and built on supportive measures. A placement based on the Social Services Act (SoL) is voluntary, which means that parents have a say and in practice can cancel it at any time. A placement in OHC can also be based on Care of Young Persons (Special Provisions) Act (LVU) (44): Social Services then assume responsibility for care of the child. The key difference between these forms of placement is the issue of consent. If the assessment by Social Services is that the parents do not consent or if, for various reasons, the consent is questionable, Social Services can apply for LVU. LVU supplements the Social Services Act when voluntary interventions are not possible. Ultimately, the Administrative Court decides whether the child is to be placed under the LVU. In all cases, decisions about care are to be made, as far as possible, in agreement with the parents. However, in LVU, Social Services have the final say. Moreover, when children reach the age of 15, they need to consent to care. If the child refuses, Social Services may apply for care under LVU from the Administrative Court. In urgent cases, the Social Welfare Board can decide that a child shall be taken into care immediately. Such a decision is sent to the court for approval.

The National Board of Health and Welfare has developed a national support strategy, a management and documentation system called “Children's needs at the centre” (BBIC, Barns behov i centrum) (45, 46), adapted to the Social Services regulations, to help administrators work with Social Services' child welfare in a structured way, focusing on the child and its needs. The basic principles of the BBIC and the BBIC triangle support the process of investigating the child's needs. The BBIC triangle highlights the children’s needs, the parents’ capabilities, and the children’s environment (Figure 3).
BBIC is a way to ensure that children have access to the support and protection they need to be able to grow up in safe conditions. BBIC’s purpose is to provide the Social Services with structure and systematics so that the work is based on the unique child's situation, has the child’s needs in focus, maintains good quality and is conducted in accordance with the legal certainty and regulations (46). BBIC is based on seven basic principles (Figure 4). The work should:

1. be based on the rights of the child
2. let the best interests of the child be vital
3. strive for equal opportunities for every child
4. involve the child and the parents
5. be in collaboration with other professions
6. address difficulties and strengthen resources
7. have a holistic perspective on the child and their situation

Figure 3. The BBIC triangle highlights the children’s needs, the parents’ capabilities, and the children’s environment (46). By permission of The National Board of Health and Welfare (Socialstyrelsen).

Figure 4. BBIC presents seven basic principles for Social Services’ child welfare work (46).
Children in OHC

At some point during childhood, around 4-5% of all children in Sweden are placed in out-of-home care: around 26,500 children in 2022. Half were under the age of 15 and most (53%) were boys (Figure 5). The statistics for the year 2022 include 2,410 unaccompanied minors, mostly aged 15-21, of whom 1,749 were boys (47).

![Figure 5. Number of children and young persons placed in OHC sometime during 2022. By permission of The National Board of Health and Welfare (Socialstyrelsen) (47).](image)

Placement can vary: in family homes (foster homes), in assisted living or homes for care or housing. Family homes are the most common form of placement (Figure 6) (47).

![Figure 6. Number of children and young persons placed in OHC sometime during 2022. By permission of The National Board of Health and Welfare (Socialstyrelsen) (47).](image)
There is also another form of placement, special supervisory homes, run by The State Board of Institutional Care (SiS), for young people with psychosocial problems, substance abuse and/or criminality. The care is provided under the terms of the Care of Young Persons (Special Provisions) Act (LVU) (44). At some of these special supervisory homes, care is also provided for young people who have committed serious criminal offences and who have been sentenced to secure youth care under the Secure Youth Care Act (LSU) (48). SiS undertakes individually adapted compulsory care and administers inpatient youth care. In collaboration with Social Services, their function is to help children, mostly adolescents, with serious and extensive psychosocial problems achieve better conditions for a socially functioning life without addiction and crime. Today the agency has 21 special youth homes located across Sweden and receives just over 1,000 children a year. For the year 2022, the average age of children placed in SiS was 16 years (49).

The majority of the children and young people placed in OHC sometime during 2022 were committed under SoL (Figure 7) (47). Placements are made not only to protect the child, but also to enhance future opportunities and to compensate for adverse childhood factors (50). There are various reasons why children are placed in OHC. There may be parents with diverse problems, parental health issues, parental alcohol or drug abuse, parental mental health problems, and/or child physical abuse and/or neglect or other reasons why parents are unable to care for a child (51).

Figure 7. Number of children and young persons placed in OHC sometime during 2022. By permission of The National Board of Health and Welfare (Socialstyrelsen) (47).
Neglect

In 1999, WHO issued the following definition of neglect: "Neglect is the failure to provide for the development of the child in all spheres: health, education, emotional development, nutrition, shelter, and safe living conditions, in the context of resources reasonably available to the family or caretakers and causes or has a high probability of causing harm to the child’s health or physical, mental, spiritual, moral or social development" (52). Neglect also occurs when organisations such as schools and healthcare services, or society, such as the local authorities or municipalities, fail to observe children's basic needs and do not support children who need help because of neglect (53). Unlike other types of abuse, neglect is an act of omission, i.e. failure to provide something which the child needs (53, 54, 55).

The dental team has a unique opportunity to detect abuse or neglect in children, as they encounter so many children in the dental setting. Indications of physical abuse can be observed as signs often manifests in the head, neck and orofacial region (56). When dental staff treat children with poor dental health and high treatment needs, they must consider that these are signs of neglect and report their concerns, as the parents should have sought dental care for the child earlier, for example cases where parents have not taken their parental responsibility and not helped their children with tooth brushing, permitted frequent snacking which had led to dental caries and/or failed to seek dental care or missed dental care appointments even though the child was in pain (57). With reference to missed appointments, it is preferable to record “was not brought” in the patient records rather than “did not attend”, emphasising that failure to keep a dental appointment is not the child’s fault (58). In many such cases there is a reason to respond by submitting a report of concern to Social Services. According to the Social Services Act, it is mandatory for all dental professionals to report any suspicion of child maltreatment (38). The law declares that mere suspicion of abuse is enough to warrant filing a report (59). Compared with other children, those investigated by the Swedish Social Services have a higher prevalence of dental caries and high levels of non-attendance and dental avoidance (57).

Health and dental health examinations for children in OHC

According to SoL, the Social Welfare Board shall, in the case of children who are placed in OHC, contribute to their good care, upbringing and favourable growing conditions and promote the provision of any necessary health care. Children in OHC shall have their healthcare and dental care needs met (60).

When a child is placed in OHC, whether under LVU or SoL, a care plan is established, setting out the child’s needs during placement (45). Social services have ultimate responsibility for ensuring that the child receives the care and healthcare they need. Furthermore, Social Services are also required to monitor
the child’s progress in OHC and maintain regular contact with the child. When the child is placed in OHC under SoL, the parents/legal guardians and Social Services must agree on the child’s care and healthcare, whereas when placement is made under LVU, the Social Welfare Board assumes this responsibility (43).

On 1 January 2013, the Swedish Social Services Act declared that the Social Welfare Board shall work to ensure that children in OHC receive the healthcare they need and are entitled to and that the Social Welfare Board must specifically monitor the child's health during placement. Since April 2017, the healthcare of children and young people in OHC have been regulated by the Act (2017:209) on Health Examinations of Children and Young People who are Cared for Outside Their Own Home (61), which states that the county councils shall, on the initiative of the Social Welfare Board, offer children or young person’s entering OHC a health examination, unless it is considered unnecessary. In principle, the procedure is unnecessary only if the child has undergone such an examination within the past year (62).

When the child needs interventions from both Social Services and the health services, a coordinated individual plan (SIP), must be established (38, 63). The purpose of the SIP is to ensure cooperation between the authorities so that the overall needs of individuals for health care and Social Services are met. The region must, on the initiative of the Social Welfare Board, offer a health examination in conjunction with entry into OHC of a child or young person aged 18–20. The purpose of the health examination is to assess the child's need for medical and dental care, how the Social Welfare Board should work to ensure that the child receives medical and dental care and to facilitate continued contact between the child and the health and dental services (64).

Oral health assessment of the child or young person should include the following observations: whether the child has extraoral abnormalities, oral diseases, risk factors for oral diseases, and malocclusion (64).

The national support strategy BBIC includes a health examination of children in OHC. A study by Randsalu and Laurell of children in OHC in the southern Swedish region of Skåne showed that of 11,413 such children in the region, only 409 (6%) had undergone a health examination according to the BBIC routine (5). The Swedish Association of Local Authorities and Regions has investigated how many children in OHC undergo medical and dental examinations. Children who were placed under LVU had a higher rate of medical examinations than those who were placed with the support of SoL (68 and 32 percent respectively). Only 12 percent had undergone dental examinations and in around 40% of these children, the examination disclosed the need for further dental care (65). The report "Foster children's health" showed that in Malmö, only 60 percent of children in OHC attended a dental clinic (66).

In a survey of Swedish practice conducted by SBU, several municipalities received an electronic questionnaire about the routines or methods used to ensure
that children undergo general health and dental examinations before and during placement. The survey was followed up with telephone interviews, questioning whether these examinations are in fact carried out in practice. Overall, the results showed that just under half the municipalities have established routines to ensure that the health and dental health of children and young people is assessed before, during and after placement in OHC; however, only a few municipalities ensure that all such children actually undergo initial and follow-up medical and dental examinations. Only 6% undertook an oral health assessment and none of the local authorities had routines for assessing mental health (67). Although the Nordic countries are among the best in the world at promoting children's well-being and health, the Nordic welfare models have failed to prevent inequality among children in OHC (68).

Health of Children in OHC

Although children in OHC in Sweden are included in the general healthcare system and health and dental care are free of charge, several studies have shown that with respect to children in OHC, the support provided under this system is poor (5, 69, 70).

Health problems are overrepresented in children placed in out-of-home care (OHC). There are shortcomings in vaccination protection and follow-up of the child's physical and mental health. A study of 91 adolescents placed in SiS institutions, showed that 53% of the girls and 40% of the boys had recently diagnosed somatic health problems (6). Another study showed that of children placed in OHC, 39% had failed to present at child health services (CHS), 36% had incomplete vaccination coverage and 20% had newly diagnosed visual impairment (5). Köhler et al. showed that 31% of children in foster care lacked a documented 4-week check-up by the CHS nurse, compared to 7% of those children living with their parents; 26% had not undergone an annual medical examination by a CHS physician, compared to 4% of children living with their parents. Moreover, according to the Swedish national vaccination program, vaccination was incomplete in 13% of children in OHC, compared to 3% of children who lived with their parents. On average, children in foster care had missed four visits to CHS, compared to an average of one missed visit for children in the care of their parents (51).

It has been shown that children who have been in OHC have in general a less favourable start in life than other children. Children in OHC grow up at much higher risk of health problems and poorer school results than others; they enter adulthood with poorer health and poorer prospects for continued development and work opportunities. There are reports of more abuse, with negative long-term outcomes related to occupational performance, addiction, socio-economic status and criminality (71). A substantial volume of international research, including
Swedish studies, shows that a large proportion of young people who have been placed in OHC also exhibit poor school performance and low educational attainment (50, 68).

Oral health of children in OHC

The WHO definition of oral health is the absence of orofacial pain or diseases such as mouth and throat cancer, oral infections and ulcers, periodontal disease, tooth decay, tooth loss and other diseases and disorders that limit an individual's ability to bite, chew, smile, speak and experience psychosocial well-being (12).

There are some reports about the oral health of Swedish children in OHC, mainly based on limited samples, but all show unequivocally that these children have poorer oral health than other children. The report by The National Board of Health and Welfare's "The Health of Vulnerable Children" showed profound neglect of preventive dental care among children placed in OHC and about half of those who were school-aged, needed treatment for tooth decay (72).

In a compilation of Adolescent Drug Abuse Diagnosis (ADAD), enrolment interviews conducted with children and young adults aged 10-20 who were admitted to The Swedish National Board of Institutional Care special supervisory homes for young people (SiS homes) in the year 2018, 29% stated that they had dental problems (73). A report from 2020 by The National Board of Health and Welfare showed that children in OHC have poorer oral health and less frequent dental attendance than other children (74).

In 2018, the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) highlighted the need for research into the health of children in OHC (67). In this context, Swedish researchers have a unique opportunity to contribute, thanks to the availability of high-quality Swedish population registries (50).

Registry-based research

Registry-based research processes data from registries maintained by authorities or other organisations. Data covering large parts of the population, stored in different registries, can be linked. This is possible because of Sweden’s unique personal identity number (PIN), a twelve-digit number combination, allotted by the Swedish Tax Agency for every person registered in the Swedish population register (75). The PIN provides the date of birth and gender. The date of birth is shown in the first eight numbers, determined by the year, month, and day of birth. Gender is shown in the 11th digit of the PIN: an odd number if the legal gender is male and an even number for females. The PIN makes it possible to link the data on a particular individual, sourced from different registries (76).
There are over a hundred individual-based national quality registries in health care in Sweden. The registries have been developed in order to achieve health equity and are used for follow-up, learning, quality development, improvement, research and management (77). While several of the registries include specific groups of patients, there are also complete population and health data registries, such as the National Prescribed Drug Register, National Cause of Death Register, the National Medical Birth Register, and the National Patient Register, etc. Population-based registry data have been used to study several areas where other study designs may be unethical or difficult to use (78). The quality of the data in population registries data is generally regarded as high (79).

The advantages of registry-based research are that it is cost-effective, it allows research on large populations and is less time-consuming than, for example, clinical studies. Further, interventions and evaluation of implementations can be analysed with great statistical power. The limitations are the risk of missing or incomplete data in the registries, uneven quality of data, and a lack of detail in the collected data (80).

The quality of registries

Data and results from quality registers are increasingly used in healthcare quality assurance, in management and control and in research. It has become increasingly important that the data in the registers are complete and correct. Validation of accuracy in a registry compared to source data is time-consuming and is therefore usually undertaken on a sample of individuals. This means that the registry data are compared with the source data, usually at patient level, in most cases the patient’s medical record. These data are regarded as the reference standard (81, 82). Each National Quality Register must have systems for validation and a system for reporting data (83).

It is also important to know how many individuals the register contains, in relation to the whole population, i.e. the completeness rate of the registry. The completeness rate is a measure of the proportion of the intended population contained in the register. The degree of completeness is crucial to the credibility of a register's output, and it affects how different types of indicators can and should be interpreted (82).

The Swedish Association of Local Authorities and Regions has a four-level scale for certification of the registries, where level 1 is the highest. This level requires a completeness rate of more than 85% and the registry should also contribute with data for open comparisons. Further, information about the registry and its results should be publicly available for patients to access and understand and the registry should actively enable and facilitate research (84).
National dental registries in Sweden

In Sweden, patient’s dental records are all electronic and use PIN as well as a national system for documentation of diagnoses and treatment procedures from the Dental and Pharmaceutical Benefits Agency (TLV) (85). Thus, registry-based data of dental care are easily accessible for studies. There are two national dental registries, the Dental Health Register, comprising data on individuals aged from 24 years and The Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa).

The Dental Health Register

The Dental Health Register (DHR) started in 2008. It is managed by the National Board of Health and Welfare and contains information about dental care for the adult population (24 years and older), reimbursed by the State. Until 2016, individuals were included in the registry from the year they turned 20. The age at which data on an individual are included in the registry has gradually increased: from 22 years in 2017, to 23 years in 2018. From 2019, the register covers adults from the year they turn 24. The data include information about dental diagnoses, the number of remaining teeth, the number of intact teeth and the type of dental care. DHR also contains information on citizenship, marital status, and country of birth. Maxillofacial surgery and special care dentistry are not included in dental procedures reimbursed by the State and are therefore not included in the registry, nor is dental care for children and young adults (86). The register is updated on a monthly basis (87, 88).

The Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa)

The Swedish Quality Registry for Caries and Periodontal Diseases (SKaPa) is a national registry of dental care, intended to promote high quality of care and good oral health, primarily with reference to tooth decay and periodontitis. The register was officially launched in 2007 and the first annual report was for the year 2009. In 2018, all Public Dental Services (PDS) were included. In 2013, all major dental data systems used in Sweden were included (personal communication with SKaPa). SKaPa has the highest level of certification on the four-level scale for certification of the registries according to the Swedish Association of Local Authorities and Regions. The registry currently has detailed dental information on more than 8 million individuals. The report for 2022 includes 12.2 million coded dental procedures and 77.2 million status observations (35). Data from the patients’ electronic dental records are captured daily and entirely automatically. Dental care is reported according to the national coding system for dental diagnoses/conditions and treatments from TLV (85), at tooth and tooth surface
levels and for primary and permanent dentitions respectively (18). In total, more than 400 variables are transferred to the registry. The information collected on children and young people concerns primarily caries (35).

About 95% of all Swedish children and adolescents are regular dental attenders and of these, about 90% are included in SKaPa (18). As SKaPa includes so many individuals, the registry should contain a wealth of information about dental care of children and young people. Fourteen annual SKaPa reports have been published on oral health and quality of dental care, but to date the registry has not been widely used for research.

When data are analysed for research, it is important to know the degree of completeness and the number of individuals included (Figure 8). SKaPa's annual reports do not always disclose the number of children included under the different variables. Moreover, the data provided are cross-sectional and no analyses are provided for individuals over time e.g. we do not know how many of the 4-year-olds in, for example, 2017 are included as 5-year-olds in 2018. The issue of the completeness ratio can be even more complicated. What should be the denominator? Sweden's population or the proportion of the population who go to the dentist?

![Figure 8. Calculating completeness rate in SKaPa: calculated number of individuals in SKaPa/total population of Sweden](image)

The calculated completeness rate in SKaPa, for the years 2014 and 2019 varies from 58% to 78%. This calculation is based on the total number of individuals and does not correspond with the number of individuals who receive dental care in those years (Table 1).
Table 1. Number of individuals (N) according to population statistics from Statistics Sweden (SCB) and number of individuals and completeness rate (%) in the SKaPa registry for 3-, 6-, 12-, and 19-year-old children for the years 2014 and 2019.

<table>
<thead>
<tr>
<th>AGE</th>
<th>SCB 2014</th>
<th>SCB 2019</th>
<th>SCaPa 2014</th>
<th>SCaPa 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>N (%)</td>
<td>N</td>
<td>N (%)</td>
</tr>
<tr>
<td>3 years</td>
<td>115 824</td>
<td>86 207 (74.43)</td>
<td>124 681</td>
<td>97 582 (76.27)</td>
</tr>
<tr>
<td>6 years</td>
<td>115 815</td>
<td>67 091 (57.93)</td>
<td>123 335</td>
<td>72 182 (58.53)</td>
</tr>
<tr>
<td>12 years</td>
<td>105 408</td>
<td>67 085 (63.64)</td>
<td>121 905</td>
<td>78 674 (64.54)</td>
</tr>
<tr>
<td>19 years</td>
<td>115 849</td>
<td>81 224 (70.11)</td>
<td>112 896</td>
<td>88 843 (60.98)</td>
</tr>
</tbody>
</table>

**Systematic review and health technology assessment**

A systematic review is a literature study of a research topic, undertaken in order to identify, evaluate, select and compile all relevant high-quality research evidence. The difference between a systematic review (SR) and a Health Technology Assessment (HTA) is that an HTA typically includes systematic reviews, with additional analyses of economic, political, social, ethical and legal aspects and is often used as a basis for policy recommendations (89). Moreover, HTA is a global term for evaluating healthcare methods, procedures, and related technology, with the aim of ensuring good quality and cost efficiency (89, 90).

The work of a systematic review/HTA begins with a written protocol, to describe the purpose of the review and the questions to be answered. The research question must be structured: an unstructured question leads to problems throughout the process, e.g. difficulties in creating search strategies and assessing which studies are relevant for inclusion. The next step in the process is to specify the aims as a PICO, to determine inclusion and exclusion criteria. The abbreviation PICO stands for Population, Intervention, Comparison and Outcome. In this context, several questions should be specified: for which patients or individuals is the effect of the intervention relevant? What is the intervention? What is the control measure? What positive or negative outcomes of the intervention are of interest and how should they be measured/defined? The included studies must be relevant and comply with the PICO.
In diagnostic research, a PIRO format (Population, Index test, Reference standard, Outcome) is used, while a PECO format (Population, Exposure, Control, Outcome) is used for exposure studies (91).

To ensure the quality of the literature search and the strength of the systematic review the input of an informatician/information specialist is of great importance. The information specialist should preferably also be included in the research group. The search should cover at least two electronic data bases.

The evaluation of the identified papers starts with two readers independently reading abstracts: on the basis of information from the title and the abstract, irrelevant studies are deleted. Articles which on the basis of title and abstract appear to meet the inclusion criteria, are read in full text by the two readers, in order to assess the studies independently. They then make a combined final assessment of whether or not a study should be included. A list is made of the excluded studies, along with the reasons for exclusion. In the next step, the risk of bias of the included studies is assessed, according to a fixed protocol. Examples of bias are selection, performance, detection, attrition, reporting and conflict of interest. The overall risk of bias is assessed as high, low or moderate. In the ensuing steps, studies with a high risk of bias are often excluded. Studies with a low and moderate risk of bias are used in qualitative and quantitative analyses. Data are extracted from the studies and tabulated, to give an overview of the characteristics of the studies. At the end of the project, an updated literature search is undertaken, to ensure that the most recent publications or papers accepted for publication can be included in the analyses. Such newly identified studies are evaluated using the same steps as described above (91).
ETHICAL CONSIDERATIONS

Ethics in research

Research ethics were developed following disclosure of the medical experiments in the concentration camps during World War II. This led to creation of the Nuremberg Code in 1947. It stated, among other things, that informed consent is required from research participants, that the risks to research participants should be minimized, that each participant has the right to terminate their participation in research at any time, and that research should be of benefit to society. The Declaration of Helsinki was adopted by the World Medical Association (WMA) in 1964, as a statement of ethical principles for medical research involving human participants, including research on identifiable human material and data. The Declaration of Helsinki is not legally binding but has had a major impact on national legislations (92). The Declaration of Helsinki has been revised several times over the years. Some of the fundamental principles of good research practice are reliability in ensuring the quality of the research, honesty in developing and implementing the research and reporting the research in a transparent, complete and objective way. Respect for research participants, and liability for research from idea to publication are also fundamental (93).

Ethical approval is required for research that involves physical interventions on humans, uses human tissue, or includes handling sensitive personal data. The Swedish Ethical Review Authority determines ethical approval of research, according to the ethical review legislation (94). Until 31st December 2018, ethical reviews in Sweden were the responsibility of six regional ethical review boards, located in Gothenburg, Linköping, Lund, Stockholm, Umeå and Uppsala. Since 1st January 2019, the Ethical Review Authority with headquarters in Uppsala, is responsible for organising the ethical reviews (95). The Ethical Review Authority complies with the Ethical Review Act (94). This act is intended
to safeguard individuals and the respect for human dignity in research. In the analyses, the possible risks are weighed against the expected gain in knowledge. Furthermore, in 2019 a new law was enacted in Sweden, setting out the responsibility of researchers and research principals to ensure that research is carried out in accordance with good research practice (96).

For registry-based research, personal consent from the study participants is not usually a requirement for approval by the Ethical Review Authority, as most registry-based research does not deviate from clinical routine or involve contact with the study participants (78).

Research involving children

For research that has the potential to benefit children, the risks must be minimized and outweighed by the prospect of potential benefit. Specific protection is necessary to safeguard children’s rights and welfare in research. Research involving children demands high ethical levels and knowledge of children, so that information can be adapted to the age groups concerned. The child must be given age-appropriate information about the research project and the role of the participant and must be involved in the actual decision-making process.

According to law, informed consent is essential. Up to the age 18 years, both legal guardians and the child are involved in obtaining consent. For children under the age of 15 the parents/legal guardians must consent. Both parents/legal guardians must consent. However, the researcher must also provide age-appropriate information to younger children. This must be in writing for children who are able to read and thereby able to assent to participation. If the researcher considers that the child seems unwilling to participate, the child should not be enrolled in research, regardless of the opinions of the parents/legal guardians. From age 15, the child him/herself has the mandate to consent and to participate or otherwise, regardless of the legal guardians’ opinions but the process of obtaining consent must consider their individual circumstances, intellectual capacities, and psychological maturity. When the individual is 18 years or older, he/she gives his/her own consent (97, 98).

Ensuring the integrity of the research participants is of great importance. Basic protection of individuals can be expressed in four main ethical requirements: information, consent, confidentiality and the requirement of use (99).

To ensure equal treatment in the child and adolescent population and to achieve the goal of equal health, it is important to study groups within society who for social and/or medical reasons, are at risk of being marginalized in terms of health. With respect to disadvantaged children in society, there is, unfortunately, very little research into the health of those who, for social and/or medical reasons, are at risk of being marginalised.
Aims

The main purpose of this thesis was to evaluate dental health and dental care in children in OHC through registry research. The specific aims were:

1. to explore dental health and dental care in young adults placed in OHC in childhood, by combining available selected registries. This explorative study was guided by the following research questions:
   - To what extent do young adults (age 20–29) who have been in OHC during childhood visit a dentist for dental examinations and preventive care, compared with their majority-population peers?
   - To what extent do they present for dental emergencies or tooth extractions, compared with their majority population peers?
   - Are there any differences in dental healthcare utilisation among different groups of young adults with OHC experience, in relation to age at entry into care and length of stay?

2. to evaluate the effects of organisational models intended to ensure that OHC children receive health and dental care by means of a systematic literature review/HTA.

3. to study how reliable and accurate the SKaPa registry’s information is on dental caries in children and adolescents, registered as dft/DFT.

4. to evaluate the agreement of data on dental caries between electronic dental records and data retrieved from the SKaPa registry, with special reference to e/M in deft/DMFT.
5. to compare the oral health and dental care needs of children in OHC with those of other children in Sweden, by merging data from different Swedish registries, addressing the following questions:
   - Are there differences between children in OHC and other children with respect to the dental care they receive (dental examinations, emergency appointments, extractions) and their oral health (dft, DFT, fractures of teeth or jaws)?
   - Has implementation of the new law in 2017 resulted in any differences in the frequency of dental examinations in close relation to placement?

**Hypotheses**

The following hypotheses were formulated:

- Comparison of clinical registrations in 6 and 12-year-old children with those in the electronic dental records and with data retrieved from the SKaPa registry, differ minimally with respect to the number of decayed and filled teeth (dft in the primary dentition and DFT in the permanent dentition (Paper III).
- The data in the electronic dental records for 6- and 12-year-old children, with respect to dft/DFT, deft/DMFT and preventive dental treatments differ minimally from data extracted from the SKaPa registry (Paper IV).
- Children placed in OHC have poorer dental health and receive less regular dental care than other children (Paper V).
MATERIAL AND METHODS

Three different methods were used in this thesis. The first and fifth papers were registry-based cohort studies, in which registry data were used to evaluate dental health and dental care in children in OHC and in young adults who had been placed in OHC during childhood. In order to evaluate organisational models intended to ensure that children placed in OHC receive health and dental care, a systematic review/Health Technology Assessment (HTA) was undertaken. Before linking the SKaPa registry with other registries, two diagnostic accuracy studies were conducted to validate the accuracy of the registry, to ensure the trustworthiness of the data as a basis for the research.

Study population

Dental health and dental care in young adults with experience of OHC (Paper I)

The first paper included all Swedish residents born between 1980 and 1994 and who, according to data in the Total Population Register, were alive and residing in Sweden at age 20. The study includes more than 1.7 million individuals in total, of whom around 4% (n=565,261) had entered OHC at some point during their childhood or adolescence (age 0–19); the controls comprised 1,667,660 who had never been placed in OHC (Paper I).

Organisational models of health services for children and adolescents in out-of-home care (Paper II)

The study population for the systematic review/HTA was specified as PICO (participants, intervention, control, outcome). Children 0-17 years of age who are about to enter OHC or are already in OHC were included (Paper II).
Validation of the SKaPa registry in two steps (Paper III and IV)

In the first validation study, 177 children (83 6-year-olds, 94 12-year-olds) from twelve PDS dental clinics were invited to undergo clinical examination in conjunction with their annual check-up. Of these, 171 children presented for examination and one declined to participate. A total of 170 children underwent a clinical dental examination: 84 boys (40 6-year-olds, 44 12-year-olds) and 86 girls (43 6-year-olds, 43 12-year-olds). The sample size was calculated and inclusion of 75 children in each age group was found to be sufficient. To ensure inclusion of children with different caries incidence, differences in socioeconomic status and rural as well as urban residents, twelve out of 25 dental clinics were identified and children due for their annual dental examinations at the clinics were invited to participate (Paper III).

In the next step, the PDS (Public Dental Service) administration in Värmland identified a random sample of 500 6- and 12-year-old children (250 per age group) who had received dental care in 2014. The children had not been included in the preceding study. To ensure representative inclusion of the background population, it was decided to include 250 children from each age group, i.e. approximately 10% of the total background population per age group (Paper IV).

Dental health and dental care in children in OHC (Paper V)

The other registry study is based on the Swedish Out of Home Care Children cohort (SweOHC). It includes all children and adolescents 0-19 years of age, who had been placed in OHC sometime during the period 2010-2018 (n=68,273). Further, SweOHC includes an unexposed cohort of individuals who were not part of the exposed cohort, matched 1:5 to the exposed cohort with respect to gender, age and county of residence (n=409,638) (Paper V). The workflow and registries for identifying the cohorts are shown in Figure 9.
Figure 9. Workflow: retrieving the data from the registries.
NBHW= National Board of Health and Welfare, SCB=Statistics Sweden, SKaPa=Swedish Quality Registry for Caries and Periodontal disease, PIN=Personal Identification Number, OHC=children in Out-of-Home Care, NRMCY=National Register of Measures for Children and Young persons, TPR= Total Population Register, MGR= Multi-Generation Register, LISA= Longitudinal integrated database for health insurance and labour market studies, NPR=National Patient Register, NPDR=National Prescribed Drug Register; NCDR=National Cause of Death Register, NRCSA=National Register for Care of Substance Abuse. *=data from registry not used in Paper V.
METHODS

Dental health and dental care in young adults with experience of OHC (Paper I)

The following registries held by the Swedish Board of Health and Welfare were used: The Swedish Dental Health Register, the Child welfare Intervention Register, the Swedish Cause of Death Register. From Statistics Sweden the Swedish Register of Education and the Total Population Register were used.

The population was classified into four groups:

- Short OHC: first placement in OHC before age 13 and placement for fewer than five years
- Long OHC: first placement in OHC before age 13 and placement for five years or more
- Teen placements: first placement after 13th birthday, regardless of total time spent in OHC
- Majority population: never been placed in OHC (controls)

The cohort individuals were followed in the Swedish Dental Health Register from age 20 to 29, during the period 2009–2014. The following variables were used for the study period:

- Check-up visits, preventive care
- Emergency visits only
- Number of extracted teeth other than wisdom teeth
Organisational models of health services for children and adolescents in out-of-home care (Paper II)

The study population for the systematic review/HTA was specified as PICO (Participants, Intervention, Control, Outcome). Children 0-17 years of age who are about to enter OHC or are already in OHC were included (Paper II). In the HTA (Paper II) a PICO was created to define the population, intervention, control intervention and outcome (Table 2). The inclusion/exclusion criteria are presented in Table 3.

Table 2. PICO defining the Population, Intervention, Control intervention and Outcome.

<table>
<thead>
<tr>
<th>P</th>
<th>Population</th>
<th>Children/adolescents to age 17 who are about to enter OHC or are already in OHC</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Intervention</td>
<td>Organisational models for delivery of health and dental care to children and adolescents in OHC</td>
</tr>
<tr>
<td>C</td>
<td>Control intervention</td>
<td>No restriction</td>
</tr>
<tr>
<td>O</td>
<td>Outcome</td>
<td>Access to health and dental care</td>
</tr>
</tbody>
</table>

Table 3. The inclusion and exclusion criteria.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Types of Studies</strong>: Systematic reviews, randomised controlled trials (RCT) and non-randomised studies with pre-and post-measurement of outcome.</td>
<td>Studies without a control group and without pre-and post-measurement of outcome.</td>
</tr>
<tr>
<td><strong>Follow-up time</strong>: Not specified.</td>
<td></td>
</tr>
<tr>
<td><strong>Study size</strong>: Not specified.</td>
<td></td>
</tr>
<tr>
<td><strong>Languages</strong>: Swedish, Norwegian, Danish, English, Spanish, French and German.</td>
<td></td>
</tr>
<tr>
<td><strong>Search period</strong>: From 1990 to March 2018.</td>
<td></td>
</tr>
</tbody>
</table>

Literature searches of the following databases were conducted: Cochrane Library, Campbell Library, EBSCO, Embase, Medline (OVID), PsycInfo, PubMed, Proquest Health and Medicine, Science Direct and SocIndex. The search period was from 1990 to March 2018. There was special emphasis on designing a broad search strategy. The systematic search strategies were designed and implemented by an information specialist. Two pairs of authors screened the search results (title and abstract) independently, matching the defined inclusion and exclusion criteria. If at least one reviewer considered an abstract relevant, the paper was included and read in full text. The full-text articles were also reviewed in pairs and independently of each other. The systematic review process followed the general concepts covered by PRISMA (100).
Validation of the SKaPa registry in two steps (Paper III and IV)

A clinical caries examination, using the ICDAS II caries system, was carried out in 170 children aged 6 and 12 years. The registrations were compared with data in the patients’ dental records and with data extracted from SKaPa. All registrations were transferred to an Excel® protocol where each individual in the dataset received a unique serial number. The outcome measures were number of teeth and caries incidence expressed as dft and DFT respectively, in the two age groups. Cohen’s Kappa, Intraclass Correlation Coefficient (ICC), exact agreement, sensitivity and specificity were calculated (Paper III).

In the second validation study (Paper IV) two dentists independently reviewed dental records for the year 2014 in a random sample of 500 individuals (250 6- and 12-year-olds respectively). For the same individuals and year, comparisons were made with data retrieved from the SKaPa registry. Outcome measures were the number of teeth and caries incidence expressed as dft/DFT, deft/DMFT, e/M, and the number of preventive treatments undertaken in the two age groups, respectively. Output data from the SKaPa registry were used as an index test while data from the electronic dental records served as the reference standard (Paper IV).

Dental health and dental care in children in OHC (Paper V)

For the second registry study (Paper V) all available information about the included subjects was retrieved from the following registries (Figure 9.):

- National Register of Measures for Children and Young Persons
- National Patient Register
- Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA)
- SKaPa

The population was classified into four study groups based on placement 2010-2018:

- 1 = total time in OHC less than one year
- 2 = total time in OHC 1-3 years,
- 3 = total time in OHC more than 3 years.
- 0 = never placed in OHC (controls)
The following variables were collected:

- ICD-10 codes for several medical diagnoses and for tooth and jaw fractures
- Parents’ education level
- Children’s country of birth
- Dental health and dental treatment
- Dental examinations and emergency visits
- Dental caries (dft/DFT)
- Number of extracted teeth

**Ethical considerations for this thesis**

For the clinical validation study (Paper III), the four research ethical requirements apply: the requirements of information, consent, confidentiality, and requirement of use. All requirements were complied with when the participants were informed in writing and participation was voluntary. All children received age-appropriate information. After oral and written information, the guardians signed an informed consent form. There is a risk that the children may have felt compelled to participate. Through careful information, we tried to reduce this risk.

There is always a small risk of perceived violation of integrity when individuals are asked to participate in a study, but with accurate information, good treatment and accuracy in handling the data and privacy, the risk can be minimized. The registrations concern aspects of routine dental care and not information about the person. For the patient, the benefit was assessed as greater than the possible risk of perceived violation of privacy. For the patient examined, the dental appointment took a maximum of 10 minutes longer than a routine appointment. At the same time, for a young patient, this can be perceived as positive, implying special attention, and receiving some extra care during the dental appointment. The risk of injury may be considered minimal - it was a routine examination with mirror and probe. Participation in the study did not involve taking any additional radiographs. The radiographs taken during the regular examination were assessed by the child’s regular clinician, based on individual indications and in consultation with the patient and guardians. With respect to the dental clinic routines, the study examination involved some disruption of the clinics’ agenda for the day, as it took time that could otherwise have been spent with other patients, thereby implying also a small financial loss for the dental clinic. At the same time, dental care needs self-assessment and quality assurance, which the study contributed to. The benefit thus outweighed possible risks.
The dentists, dental hygienists, and dental nurses responsible for the patients included in the study may have felt that they were being assessed or questioned. At the same time, in their professional life, they have an obligation to promote good and patient-safe care. This includes working with quality assurance and analysis of one's own work. The results of the study can help in this work. In order to reduce the risk of perceived violation of integrity, all staff were informed about the study.

For society, the study posed a small problem in the form of the time consumed: other patients were denied access to dental clinic resources/personnel during this time. At the same time, society has a great responsibility to ensure that as far as possible, the right care is provided on equal terms. It is also in society's interest that different registries are available to improve and develop care. The study offers this potential. From a societal perspective, the benefits of the project outweigh the risks.

With respect to the validation study (Paper IV), reviewing the electronic dental records of 500 patients, it is impossible to know for certain whether they would have perceived the study as a violation of integrity. To minimize this risk, all data were pseudonymised in all analyses. The Swedish Public Dental Service has information boards in every dental clinic informing the public about the SKaPa registry. It is in the patient's interest that the healthcare provider ensures the quality of the registrations. To reduce the risk of error, a high awareness of this in the research group and accuracy in data management were important. The assessment was that the benefits outweighed risks. Overall, the benefits of the validation studies are considered to outweigh possible risks.

Regarding Paper V, an ethical analysis could be made from three different perspectives: the patient, dental care and society. The project does not offer benefits to the individual patient or the individual child in OHC, but it may greatly benefit the dental health of this group of children in the future. For dental care, the project can provide a deeper knowledge of the dental health of children and young people placed in OHC and ultimately contribute to more appropriate and improved dental care.

From a societal perspective, both democracy and the Convention on the Rights of the Child are highlighted, because all children have the right to care and health. With reference to the linking of registries, no patients were contacted or asked for consent. As this was a registry study, all extracted information was provided with serial numbers, without any information that could identify an individual person. Data were processed and reported at group level. The privacy breaches associated with retrieval of data from the different registries must be balanced against the expected benefit and the fact that the research focus itself (caries occurrence in children in OHC) requires that the researcher is able to gather information without the patient's consent. When the study is published, a certain risk of stigmatizing children placed in OHC cannot be excluded. However, this
risk is offset by the assumption that a deeper knowledge of the dental health of children placed in OHC will ultimately contribute to more appropriate dental care and an improved relationship between clinicians and children and young people who need special support.

Registration of studies

Registration of studies in open registries like ClinicalTrials.gov and PROSPERO is important for transparency. The information is accessible to other researchers: this gives them the opportunity to identify ongoing studies within their field of interest, to read and review, to avoid undertaking research very similar to that being conducted elsewhere and for networking. It also enables reviewers to double check that a pre-decided design is followed. The protocol for the HTA/systematic review (Paper II) was registered in PROSPERO CRD42016049484, available at https://www.crd.york.ac.uk/prospero/. The studies in Paper III and IV were registered in ClinicalTrials.gov NCT03039010, available at https://clinicaltrials.gov.

Ethical approvals

Paper III and IV were approved by the Regional Ethics Review Board in Uppsala, Sweden (#2016/051). Paper V was approved by The Swedish Ethical Review Authority (# 2020-01699 and 2020-06957).

Statistical analyses

In Paper I, the life table method and Cox proportional hazards models were used for statistical analyses. The frequencies and yearly percentage of dental attendances were calculated. The life table method was used to estimate accumulated experiences of tooth extraction over time (2009–2014) and to calculate the percentage of the population who had undergone at least one check-up/preventive dental care appointment or emergency visit at the end of the follow-up period. Cox proportional hazards models were also used to calculate adjusted hazard ratios of dental healthcare visits and tooth extractions. This was done in two steps. In the first step, the model included sex, year of birth and study group. In the second step, maternal education was added. The SAS software package (SAS Institute Inc) was used for statistical analyses.

In paper III, to test the agreement for dft/DFT between the researcher’s dental examination, the data registered in the electronic dental record and the SKaPa registry, the Intraclass Correlation Coefficient (ICC) was calculated. To test the accuracy of caries diagnosis at tooth level, the following calculations were made: sensitivity, specificity, predictive value of positive test (PV+) and predictive
value of negative test (PV−) with 95% confidence intervals. Moreover, Cohen’s Kappa was calculated for level of agreement on tooth position. P-values less than 0.05 were considered statistically significant.

For paper IV the proportions of registrations with exact agreement were calculated. We also included Cohen’s Kappa and Intraclass Correlation Coefficient (ICC), which is presented with the test statistic and 95% confidence interval.

For Paper V the two-sample t-test was applied to analyse differences between exposed subjects (children in OHC) and unexposed controls, with reference to the number of examinations and emergency appointments, dft/DFT and extractions. In addition, linear regression analyses were used to compare subgroups of OHC with controls, with reference to dental examinations, emergency appointments and dft/DFT. The Chi-square test was applied to compare the number of ICD-10 diagnoses, emergency appointments, examinations at the time of placement in OHC for individuals in OHC and the controls, and the proportion of caries-free children in OHC and controls. To adjust for potential confounding factors when analysing the association between OHC and dft/DFT, a multiple linear regression analysis was applied. P-values less than 0.05 were considered statistically significant. In Papers III-V, STATA SE 15 software (Stata Corporation LLC, College Station, U.S.A) was used for statistical analyses.
RESULTS

Dental health and dental care in young adults with experience of OHC (Paper I)

Young adults who had been placed in OHC during childhood did not visit the dentist for check-ups and preventive care to the same extent as their peers in the majority population. The prevalence of check-up visits in the OHC groups at the end of the follow-up period were 77% among the females and 61–64% among the males compared with 87% among the females and 80% among the males in the majority-population group (controls) (Table 4). The proportion who had not had any check-ups at all during 2009–2014 was nearly double in the OHC groups, compared with the majority-population group. Instead, they had more emergency visits than young adults who never had been placed in OHC, with around a doubled risk for the OHC groups of having to make an emergency visit (Table 4 and Table 5).

Table 4. Percentage (life-table method) and numbers of the population subgroups who have made any check-ups and emergency visits during follow-up (2009–2014), by sex and study group.

<table>
<thead>
<tr>
<th></th>
<th>Majority population</th>
<th>Short OHC</th>
<th>Long OHC</th>
<th>Teen care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Check-up</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>577,586</td>
<td>89</td>
<td>4,475</td>
<td>64</td>
</tr>
<tr>
<td>Women</td>
<td>607,374</td>
<td>87</td>
<td>4,830</td>
<td>77</td>
</tr>
<tr>
<td>Emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>52,725</td>
<td>9</td>
<td>912</td>
<td>17</td>
</tr>
<tr>
<td>Women</td>
<td>55,194</td>
<td>10</td>
<td>836</td>
<td>18</td>
</tr>
</tbody>
</table>

Note: Swedish residents born in 1980–1994 who were residing in Sweden at age 20.
The young adults who had been placed in OHC during childhood had three to four times higher risk of having a tooth extracted compared with majority-population peers (Table 5).

**Table 5.** Risk of dental visits (check-ups and emergency visits) and extracted teeth other than wisdom tooth during follow-up period (2009–2014), by subgroup.

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Check-up HR (95% CI)</th>
<th>Emergency HR (95% CI)</th>
<th>Extraction HR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Majority population</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
</tr>
<tr>
<td>Short OHC</td>
<td>0.72 (0.70–0.74)</td>
<td>1.76 (1.68–1.85)</td>
<td>2.89 (2.71–3.06)</td>
</tr>
<tr>
<td>Long OHC</td>
<td>0.70 (0.68–0.72)</td>
<td>1.80 (1.70–1.90)</td>
<td>2.90 (2.70–3.12)</td>
</tr>
<tr>
<td>Teen care</td>
<td>0.71 (0.70–0.72)</td>
<td>2.23 (2.17–2.29)</td>
<td>3.83 (3.70–3.98)</td>
</tr>
</tbody>
</table>

Model 1. Adjusted for gender and year of birth

Model 2. Adjusted for gender, year of birth, and maternal education (as in Table 4)

Notes: CI = Confidence interval. OHC = Out-of-home care. Ref. = Reference group (HR = 1).

The male young adults had lower hazard risks compared with females for check-ups, emergency visits and tooth extractions. There was also an association between maternal education and emergency visits and tooth extraction reflecting a social gradient. (Table 6).

**Table 6.** Risk of dental visits (check-up and emergency) and extracted teeth other than wisdom tooth during follow-up (2009–2014), by study group and background variables.

<table>
<thead>
<tr>
<th>Subgroup</th>
<th>Check-up HR (95% CI)</th>
<th>Emergency HR (95% CI)</th>
<th>Extraction HR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
</tr>
<tr>
<td>Men</td>
<td>0.84 (0.84–0.84)</td>
<td>0.85 (0.87–0.89)</td>
<td>0.95 (0.98–1.02)</td>
</tr>
<tr>
<td>Year of birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuous</td>
<td>0.999 (0.998–0.999)</td>
<td>1.01 (1.01–1.01)</td>
<td>1.00 (0.99–1.00)</td>
</tr>
<tr>
<td>Study group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Majority population</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
</tr>
<tr>
<td>Short OHC</td>
<td>0.76 (0.74–0.78)</td>
<td>1.63 (1.52–1.67)</td>
<td>2.33 (2.19–2.47)</td>
</tr>
<tr>
<td>Long OHC</td>
<td>0.78 (0.76–0.80)</td>
<td>1.55 (1.46–1.63)</td>
<td>2.08 (1.94–2.24)</td>
</tr>
<tr>
<td>Teen care</td>
<td>0.76 (0.75–0.77)</td>
<td>2.02 (1.97–2.08)</td>
<td>3.13 (3.02–3.25)</td>
</tr>
<tr>
<td>Maternal education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>0.65 (0.65–0.66)</td>
<td>1.08 (1.25–1.30)</td>
<td>1.31 (1.17–1.47)</td>
</tr>
<tr>
<td>Short (&lt; 9 years)</td>
<td>0.87 (0.87–0.88)</td>
<td>1.21 (1.29–1.23)</td>
<td>1.35 (1.54–1.92)</td>
</tr>
<tr>
<td>Medium (10–12 years)</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
</tr>
<tr>
<td>Long (≥ 13 years)</td>
<td>1.06 (1.05–1.06)</td>
<td>0.87 (0.83–0.95)</td>
<td>0.64 (0.56–0.79)</td>
</tr>
</tbody>
</table>

Notes: CI = Confidence interval. OHC = Out-of-home care. Ref. = Reference group (HR = 1).

Organisational models of health services for children and adolescents in out-of-home care (Paper II)

The database searches identified 14,576 abstracts and nine additional studies were identified by hand search. 271 full-text articles were read, but no study of low or medium risk of bias could be identified that examined the effects of organisational models for placing children and young people in family homes and institutions receiving healthcare and dental care (Figure 10). Thus, the result shows an empty systematic review. As we did not identify any study of low or medium risk of bias, we could not assess the quality with GRADE, which is a tool for grading the quality of evidence nor AMSTAR, also a measurement tool, to assess the methodological quality of systematic reviews, as planned.

![Flowchart showing the literature review process for the SR/HTA.](image-url)
Validation of the SKaPa registry in two steps (Paper III and IV)

In the first accuracy study (Paper III), good agreements were ascertained between the dental examinations, data registered in the dental records and data retrieved from the SKaPa registry. Calculated Cohen’s Kappa dft/DFT on tooth level was 0.91 between the researcher and the patient record, 0.93 between patient dental record and SKaPa, and 0.87 between the researcher and SKaPa. Cohens’ Kappa, and ICC for dft/DFT were generally good (Table 7), as were specificity and sensitivity values (Table 8).

Table 7. Cohen’s Kappa, exact agreement and Intraclass Correlation Coefficient (ICC) for reported dft/DFT-value in total population and 6- and 12-year-old children between the researcher, the patient dental records and the SKaPa registry.

<table>
<thead>
<tr>
<th></th>
<th>Total (n=170)</th>
<th>6-year olds (n=83)</th>
<th>12-year olds (n=87)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Kappa (S.E.)</td>
<td>Agreement (%)</td>
<td>Kappa (S.E.)</td>
</tr>
<tr>
<td>Researcher/patient dental record</td>
<td>0.79 (0.05)</td>
<td>90.0</td>
<td>0.75 (0.06)</td>
</tr>
<tr>
<td>Patient dental record/ SKaPa</td>
<td>0.95 (0.05)</td>
<td>97.6</td>
<td>0.92 (0.06)</td>
</tr>
<tr>
<td>Researcher/ SKaPa</td>
<td>0.76 (0.05)</td>
<td>88.8</td>
<td>0.72 (0.06)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Total (n=170)</th>
<th>6-year olds (n=83)</th>
<th>12-year olds (n=87)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ICC</td>
<td>95% C.I.</td>
<td>ICC</td>
</tr>
<tr>
<td>Researcher/patient dental record</td>
<td>0.96</td>
<td>0.94-0.97</td>
<td>0.96</td>
</tr>
<tr>
<td>Patient dental record/ SKaPa</td>
<td>0.99</td>
<td>0.98-0.99</td>
<td>0.99</td>
</tr>
<tr>
<td>Researcher/ SKaPa</td>
<td>0.95</td>
<td>0.93-0.96</td>
<td>0.96</td>
</tr>
</tbody>
</table>

Table 8. Accuracy of caries diagnostics. Comparisons between researcher, patient dental record and SKaPa registry. Values for sensitivity, specificity, predictive value of positive test (PV+), predictive value of negative test (PV−) and 95% confidence intervals.

<table>
<thead>
<tr>
<th></th>
<th>Sensitivity</th>
<th>Specificity</th>
<th>PV+</th>
<th>PV−</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>95 % CI</td>
<td>95 % CI</td>
<td>95 % CI</td>
<td>95 % CI</td>
</tr>
<tr>
<td>Researcher/patient dental record</td>
<td>0.93</td>
<td>0.87-0.97</td>
<td>1.00</td>
<td>0.99-1.00</td>
</tr>
<tr>
<td>Patient dental record/ SKaPa</td>
<td>0.97</td>
<td>0.93-0.99</td>
<td>1.00</td>
<td>0.99-1.00</td>
</tr>
<tr>
<td>Researcher/ SKaPa</td>
<td>0.93</td>
<td>0.87-0.97</td>
<td>0.99-1.00</td>
<td>0.83-0.89</td>
</tr>
</tbody>
</table>
In the second validation study (Paper IV), comparisons of dental records to data retrieved from SKaPa revealed that Cohen’s Kappa and ICC values were higher for dft/DFT than for deft/DMFT. When individuals without caries were excluded, there was a clear decrease of outcomes in Cohen’s Kappa, exact agreement (Table 9), and ICC, most pronounced in the DMFT-values for the 12-year-olds (Table 10).

Table 9. Agreement between data on dental caries from patients’ electronic dental records and the SKaPa registry shown as Cohen’s Kappa-values with standard error (SE), and exact agreement in percent. on dft, deft and et provided for primary teeth in 6-year-olds, and DFT, DMFT, and MT for permanent teeth in 12-year-olds. For the total group dft/DMFT, deft/DMFT and et/MT are combined. For dft/>1 only, deft/DMFT >1 only and et/MT >1 only the analyses include cases where the value for dft/DFT/deft/DMFT/et/MT exceeds 0 in the dental record.

<table>
<thead>
<tr>
<th></th>
<th>Total (6- and 12-year-olds)</th>
<th>6-year-olds</th>
<th>12-year-olds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Kappa</td>
<td>Exact agreement (%)</td>
</tr>
<tr>
<td>dft/DFT</td>
<td>560</td>
<td>0.95 (0.03)</td>
<td>98.0</td>
</tr>
<tr>
<td>dft/DFT ≥1 only</td>
<td>126</td>
<td>0.91 (0.04)</td>
<td>92.9</td>
</tr>
<tr>
<td>deft/DMFT</td>
<td>560</td>
<td>0.80 (0.03)</td>
<td>90.8</td>
</tr>
<tr>
<td>deft/DMFT ≥1 only</td>
<td>144</td>
<td>0.63 (0.03)</td>
<td>70.1</td>
</tr>
<tr>
<td>et/MT</td>
<td>560</td>
<td>0.38 (0.03)</td>
<td>91.8</td>
</tr>
<tr>
<td>et/MT ≥1 only</td>
<td>45</td>
<td>0.13 (0.04)</td>
<td>26.7</td>
</tr>
</tbody>
</table>

Table 10. Intraclass Correlation Coefficient (ICC) and 95 % confidence interval (CI) of dental caries in 6- and 12-year-old children recorded in electronic patient dental records and SKaPa. on dft, deft and et provided for primary teeth in 6-year-olds, and DFT, DMFT, and MT for permanent teeth in 12-year-olds. For the total group dft/DMFT, deft/DMFT and et/MT are combined. For dft/DFT >1 only, deft/>1 only and et/MT >1 only the analyses include cases where the value for dft/DFT/deft/DMFT/et/MT exceeds 0 in the dental record.

<table>
<thead>
<tr>
<th></th>
<th>Total (6- and 12-year-olds)</th>
<th>6-year-olds</th>
<th>12-year-olds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>ICC</td>
<td>95% CI</td>
</tr>
<tr>
<td>dft/DFT</td>
<td>500</td>
<td>0.98</td>
<td>0.98</td>
</tr>
<tr>
<td>dft/DFT ≥1 only</td>
<td>126</td>
<td>0.97</td>
<td>0.96</td>
</tr>
<tr>
<td>deft/DMFT</td>
<td>500</td>
<td>0.96</td>
<td>0.96</td>
</tr>
<tr>
<td>deft/DMFT ≥1 only</td>
<td>144</td>
<td>0.94</td>
<td>0.90</td>
</tr>
<tr>
<td>et/MT</td>
<td>500</td>
<td>0.36</td>
<td>0.29</td>
</tr>
<tr>
<td>et/MT ≥1 only</td>
<td>45</td>
<td>0.05</td>
<td>-0.17</td>
</tr>
</tbody>
</table>
The data in the SKaPa registry showed satisfactory reliability and accuracy regarding dft/DFT and preventive treatment codes in 6- and 12-year-old children. However, the accuracy of deft/DMFT was considerably lower than for dft/DFT.

**Dental health and dental care in children in OHC (Paper V)**

The second registry study (Paper V) comprised of 409,638 individuals as the total population, of whom 68,273 had been placed in OHC at some point during the period 2010-2018. Of these, 8,925 were unaccompanied minors: of whom 88% were boys. As unaccompanied minors, this group was considered not to have had access to dental health care on the same premises as others, and so they and their controls were excluded: 8,925 exposed children and 44,625 controls (a total of 53,550 individuals). Also, 10 controls were excluded because they had the status of unaccompanied minors. Thus, the final study population included 59,348 children in OHC and 296,730 controls (Table 11).

**Table 11.** Characteristics of the study population. Control group and children placed in out-of-home care (OHC).

<table>
<thead>
<tr>
<th></th>
<th>Controls N=296,730 (%)</th>
<th>Total OHC N=59,348 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>129,384 (43.60)</td>
<td>25,877 (43.60)</td>
</tr>
<tr>
<td>Male</td>
<td>167,346 (56.40)</td>
<td>33,471 (56.40)</td>
</tr>
<tr>
<td>Parents’ educational level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mothers/Fathers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary/secondary school</td>
<td>83,727 (28.22)/116,361 (39.21)</td>
<td>28,170 (47.47)/ 26,595 (44.81)</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>68,074 (22.94)/58,238 (19.63)</td>
<td>7,140 (12.03)/5,781 (9.74)</td>
</tr>
<tr>
<td>Post-secondary school</td>
<td>134,665 (45.38)/102,474 (34.53)</td>
<td>6,828 (11.51)/5,858 (9.87)</td>
</tr>
<tr>
<td>Data unavailable</td>
<td>10,264 (3.46)</td>
<td>17,210 (29.00)</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>268,166 (90.37)</td>
<td>38,101 (64.20)</td>
</tr>
<tr>
<td>Other Nordic countries</td>
<td>1,652 (0.56)</td>
<td>329 (0.55)</td>
</tr>
<tr>
<td>Other European countries</td>
<td>7,061 (2.38)</td>
<td>1,533 (2.58)</td>
</tr>
<tr>
<td>Non-European countries</td>
<td>19,826 (6.68)</td>
<td>19,349 (32.60)</td>
</tr>
<tr>
<td>Data unavailable</td>
<td>25 (&lt;0.00)</td>
<td>36 (&lt;0.00)</td>
</tr>
</tbody>
</table>
The children in OHC were divided in three subgroups, according to total time in placement: less than 1 year, 1-to-3 years, more than 3 years (Table 12). The frequency of placements varied within the subgroups: children placed in out-of-home care (OHC) for less than 1 year had a mean number of placements 1.67 with a variation of 1-12 placements. Children placed 1-to-3 years had a mean of 3.31 (1-29 placements), and children placed in OHC more than 3 years had a mean 4.16 (1-36 placements).

Table 12. Study population by year of birth. Control group and children in out-of-home care (OHC), stratified according to duration of placement: less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC.

<table>
<thead>
<tr>
<th>Birth yr</th>
<th>No OHC</th>
<th>Total OHC</th>
<th>OHC &lt;1yr</th>
<th>OHC 1-3 yrs</th>
<th>OHC &gt;3yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>26 085</td>
<td>5 217</td>
<td>1 350</td>
<td>1 263</td>
<td>2 564</td>
</tr>
<tr>
<td>1997</td>
<td>26 925</td>
<td>5 385</td>
<td>1 504</td>
<td>1 284</td>
<td>2 597</td>
</tr>
<tr>
<td>1998</td>
<td>28 485</td>
<td>5 697</td>
<td>1 549</td>
<td>1 444</td>
<td>2 704</td>
</tr>
<tr>
<td>1999</td>
<td>28 488</td>
<td>5 698</td>
<td>1 415</td>
<td>1 413</td>
<td>2 870</td>
</tr>
<tr>
<td>2000</td>
<td>25 774</td>
<td>5 156</td>
<td>1 321</td>
<td>1 308</td>
<td>2 527</td>
</tr>
<tr>
<td>2001</td>
<td>21 144</td>
<td>4 229</td>
<td>1 071</td>
<td>1 014</td>
<td>2 144</td>
</tr>
<tr>
<td>2002</td>
<td>17 389</td>
<td>3 476</td>
<td>933</td>
<td>811</td>
<td>1 734</td>
</tr>
<tr>
<td>2003</td>
<td>14 465</td>
<td>2 893</td>
<td>888</td>
<td>595</td>
<td>1 410</td>
</tr>
<tr>
<td>2004</td>
<td>12 435</td>
<td>2 487</td>
<td>852</td>
<td>440</td>
<td>1 195</td>
</tr>
<tr>
<td>2005</td>
<td>10 515</td>
<td>2 103</td>
<td>650</td>
<td>342</td>
<td>1 111</td>
</tr>
<tr>
<td>2006</td>
<td>10 205</td>
<td>2 041</td>
<td>726</td>
<td>299</td>
<td>1 016</td>
</tr>
<tr>
<td>2007</td>
<td>9 610</td>
<td>1 922</td>
<td>707</td>
<td>282</td>
<td>933</td>
</tr>
<tr>
<td>2008</td>
<td>9 575</td>
<td>1 915</td>
<td>726</td>
<td>269</td>
<td>920</td>
</tr>
<tr>
<td>2009</td>
<td>9 280</td>
<td>1 856</td>
<td>727</td>
<td>260</td>
<td>869</td>
</tr>
<tr>
<td>2010</td>
<td>9 335</td>
<td>1 867</td>
<td>817</td>
<td>224</td>
<td>826</td>
</tr>
<tr>
<td>2011</td>
<td>8 090</td>
<td>1 618</td>
<td>700</td>
<td>182</td>
<td>736</td>
</tr>
<tr>
<td>2012</td>
<td>8 035</td>
<td>1 607</td>
<td>671</td>
<td>204</td>
<td>732</td>
</tr>
<tr>
<td>2013</td>
<td>6 670</td>
<td>1 334</td>
<td>575</td>
<td>168</td>
<td>591</td>
</tr>
<tr>
<td>2014</td>
<td>5 670</td>
<td>1 334</td>
<td>489</td>
<td>142</td>
<td>503</td>
</tr>
<tr>
<td>2015</td>
<td>4 850</td>
<td>972</td>
<td>412</td>
<td>112</td>
<td>448</td>
</tr>
<tr>
<td>2016</td>
<td>3 895</td>
<td>739</td>
<td>300</td>
<td>86</td>
<td>253</td>
</tr>
<tr>
<td>Total</td>
<td>296 730</td>
<td>59 348</td>
<td>18 423</td>
<td>12 142</td>
<td>28 783</td>
</tr>
</tbody>
</table>

Children in OHC had fewer dental examinations than controls during the study period (mean 4.94 (sd 2.04) vs. mean 4.35 (sd 2.21), respectively; p=0.000). They also had more emergency visits than controls (mean 0.27 (sd 0.67) vs. mean 0.20 (sd 0.56) respectively; p=0.000). When the new law on mandatory health examinations was implemented in 2017, more children in OHC underwent dental examinations (Table 13).
Table 13. Numbers and frequencies of children in out-of-home care (OHC) and their controls undergoing dental examinations during the year of placement or the following year. Placements in 2016, 2017 and 2018 and for control group and children placed in OHC for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Chi-square tests comparing controls and total OHC group.

<table>
<thead>
<tr>
<th>Year of placement</th>
<th>Examination</th>
<th>Controls</th>
<th>Total OHC</th>
<th>OHC &lt;1yr</th>
<th>OHC 1-3yrs</th>
<th>OHC &gt;3yrs</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes/No</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>Yes</td>
<td>26,503 (71.43)</td>
<td>4,956 (66.78)</td>
<td>1,471 (66.68)</td>
<td>860 (64.76)</td>
<td>2,625 (66.53)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10,601 (28.57)</td>
<td>2,465 (33.22)</td>
<td>735 (33.32)</td>
<td>468 (35.24)</td>
<td>1,262 (32.47)</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>Yes</td>
<td>18,847 (75.18)</td>
<td>3,388 (67.56)</td>
<td>781 (69.30)</td>
<td>1,330 (65.39)</td>
<td>1,277 (68.88)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>6,222 (24.82)</td>
<td>1,627 (32.44)</td>
<td>346 (30.70)</td>
<td>704 (34.61)</td>
<td>577 (31.12)</td>
<td></td>
</tr>
<tr>
<td>2018</td>
<td>Yes</td>
<td>24,200 (77.47)</td>
<td>4,552 (72.86)</td>
<td>2,195 (74.28)</td>
<td>1,223 (68.59)</td>
<td>1,134 (75.10)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7,038 (22.53)</td>
<td>1,696 (27.14)</td>
<td>760 (25.72)</td>
<td>560 (31.41)</td>
<td>376 (24.90)</td>
<td></td>
</tr>
</tbody>
</table>

Dental caries was studied separately at the ages of 3-, 6-, 12-, and 19-years. In all age groups, children in OHC had statistically significantly higher mean dft/DFT values than those who have never been in OHC (Table 14).

Table 14. Dental caries expressed as dft or DFT (decayed and filled teeth in the primary and permanent dentitions, respectively) for children aged 3-, 6-, 12- and 19 years of age. Comparisons within age groups between control group and children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Linear regression analyses comparing different OHC groups with controls, Two-sample t-tests for comparisons between controls and total OHC groups.
Children in OHC had experienced more extractions than the controls. This applied to both the primary and permanent dentitions (primary dentition 0.79 (sd 1.6) vs. 0.55 (sd 1.2), and permanent dentition 0.26 (sd 0.78) vs. 0.22 (sd 0.77); p=0.000). Furthermore, traumatic injuries to teeth and jaws, diagnosed within medical care, were more common in the OHC group. Overall, 0.53% of the children in the OHC group had experienced tooth or jaw fractures compared with 0.30% in the controls (p=0.000). The differences applied to all diagnoses for boys and for the total group. With respect to girls, differences were seen in fractures of mandibular bones (0.11, compared with 0.06 in the controls; p=0.001).

ICD-10 diagnoses from the medical system, retrieved from the National Patient Register, showed that the children in OHC had more mental and behavioural disorders than their peers (44.55% vs. 18.97%; p=0.000).
DISCUSSION

The purpose of this thesis was all along to evaluate dental health and dental care in children in OHC. A starting point was the poor dental health in young adults who had previously been placed in OHC. This gave rise to the question how the organisational support of dental care for children in OHC is. In order to study dental health and adolescents in OHC a registry study was planned. However, to ensure the quality in such study the validity of SKaPa registry had to be evaluated first. Finally, after investigating the registry’s accuracy, the registry study could be carried out.

Main findings

This thesis shows several important findings. Firstly, it clearly shows that children in OHC have a considerably poorer dental health and do not receive dental care on the same premise as other children. Typically, being placed in OHC comes with fewer regular dental visits and more emergency treatments. At the same time children in OHC have more dental caries and more tooth extractions than others. These problems continue into adulthood and the same patterns can be seen in young adults with a history of OHC in childhood or adolescence.

Secondly, it shows that there is a lack of knowledge concerning organisational models intended to ensure adequate health and dental care for children in OHC. Further, this thesis shows that data from the SKaPa registry is safe and correct concerning dft/DFT and preventive measures, while the variables e/M and deft/DMFT are not. Thus, the SKaPa registry can be used for health monitoring and research purposes regarding foremost caries in children.
Methodological aspects of the five papers

Dental health and dental care in young adults with experience of OHC (Paper I)

As the Dental Health Register (DHR) does not provide information about children it was not possible to analyse dental care or dental health during childhood which is a limitation. While young adults previously placed in OHC as children had more tooth extractions than others, it was not possible to fully evaluate the differences as reasons for the extractions could not be provided from the DHR. Reasons for extracting a tooth could be severe dental caries, endodontic or periodontal problems, orthodontic treatment or abnormalities in enamel or tooth formation. Since the young adults in this study were 20–29 years old, it is reasonable to believe that most extractions were done because of dental caries, periodontal disease or pathology of the pulp.

Further, there was no information about country of birth in controls, paternal educational level, or previous status as unaccompanied asylum-seeking minors and therefore the impact of these factors was not investigated.

Organisational models of health services for children and adolescents in out-of-home care (Paper II)

A strength of this HTA was that we had an information specialist in both the planning of the search, for the search itself, and in the research group. To reduce the risk that any relevant studies or literature were missed, a very broad search strategy was chosen. The search identified a lot of irrelevant studies that could be excluded already when reading the abstracts. This is expected when using this approach.

A SR/HTA places very high demands on the methodology of the primary studies that are reviewed. The methodology of how to make a SR/HTA as well as stringent study design have developed and been refined for a long time in the medical field. The tradition might be different within the field of social sciences which could be reflected in the lack of identified studies in Paper II.

One can debate if it is worth to publish an empty systematic review/HTA. However, publishing a blank HTA is also an important result as it shows that there is a knowledge gap that requires well-designed studies (101).

This HTA was registered in PROSPERO, which is a strength. Still there were deviations from the original protocol where it was stated to include young adults. After discussions it was decided to only include children (0–17-year-olds), and unfortunately the protocol in PROSPERO was not changed accordingly.
Validation of the SKaPa registry in two steps (Paper III and IV)

In the first validation study (Paper III) there were a few individuals where data for dft/DFT differed between the patient dental record and the output from SKaPa. This affected Cohen’s Kappa, ICC and calculations of specificity and sensitivity etc. When reviewing the dental records of the patients in question it was discovered that they had developed new dental caries lesions during the calendar year but after the dental examination. As SKaPa reports information for the full calendar year, i.e. by December 31, there was not a perfect match.

It is a shortcoming that calibration of clinical examiners was only carried out on 10 and not 25 children. WHO recommends at least 25 children for epidemiological studies. However, none of the examined children were caries free and there was a perfect agreement on the caries scoring.

Studies III and IV were registered in ClinicalTrials.gov database, which is a strength. However, the use of ICDAS II was not mentioned in the registration, and it was stated that the outcome measures deft/DMFT would be used (including e=extracted, M=missing due to caries). Originally, it was intended to use DMFT but there was a problem to retrieve information for this variable from SKaPa. Regrettably, the information about using ICDAS II and the fact of not using deft/DMFT was not updated in ClinicalTrials.gov.

Many of the included children were caries free which of course is good from an oral health perspective. At the same time, this causes a floor effect that is likely to impact on both ICC and Cohen’s Kappa values as accuracy in excluding the presence of caries is greater than in confirming its presence; it’s easier to identify a caries free tooth compared to diagnose caries (102). To address this, stratified analyses were added for individuals with caries (where the values of dft/DFT, deft/DMFT and et/MT, exceeded 0 in the dental records). By doing so, this revealed a clear decrease in accuracy of the variable e/M, most pronounced in the 12-year-olds.

No socioeconomic factors were examined since this data is not included in SKaPa. However, as this study uses a random sample of 10% of the background population it should mirror its socioeconomic status.

None of the children in Paper III were included in Paper IV. Thus, the evaluations of SKaPa were based on two different study populations which is a strength.

Dental health and dental care in children in OHC (Paper V)

One major strength with the fifth study is the inclusion of ALL children placed in OHC during the study period. Further, to ensure statistical power five matched controls were identified to each OHC child.

It is problematic that approximately 11% of the study population could not be found in the SKaPa registry. The reasons are not fully known but can probably
be attributed to the child being treated by a private dental practitioner not affiliated with SKaPa, or that the child has not visited dental care at all during the study period (2010–2020). The proportions of missing individuals were comparable in the control and the OHC group and as the total number of individuals included was high it is reasonable to assume that the results are reliable. The proportion of missing individuals is similar to that reported in national epidemiological data (32). Still, it is possible that the reasons may differ between controls and OHC group. More controls may actively have chosen to go to PP, whereas the placement instabilities and many moves in the OHC group as well as avoiding dental care prior to OHC in case of child abuse/neglect could explain why some individuals in this group are not in SKaPa. At the same time, it should be borne in mind that 16–19-year-olds miss as many as 13% of their booked dental appointments (103).

There is a risk that the registry study (Paper V) has not included all placed children as the National Register of Measures for Children and Young persons is dependent on the degree of reporting from municipalities. It is reported that there have been problems with the interface of reporting from the municipalities into the registry during some periods (104). However, the study includes a long follow-up period, why the risk that same child it affected every year is very small.

**Discussion of results**

**Dental health and dental care in young adults with experience of OHC (Paper I)**

Compared with the controls, young adults, who had experienced OHC during childhood, had fewer dental appointments for check-ups and preventive care. However, this is probably not because their dental health was better: at the same time, they had presented for more emergency treatment and had more tooth extractions. Poor dental health status (measured as the need for emergency treatment and extractions) accumulates over time, hence the higher risks disclosed in young adults with experience of OHC are likely to have originated in childhood. This is supported by the fact that differences between the study groups were already emerging in the first year studied, when the individuals were in their early twenties. In several cases, their dental health was probably already poor when they were first placed in OHC, as reported from smaller study populations in Sweden (5, 6).

The known link between socioeconomic status and dental health supports the problems in the OHC group. Several studies have shown that caries in childhood is also a major risk factor for further caries later in life (102, 105). Thus, in terms of dental health, children in OHC are affected in more ways than other children.
Their dental health is probably poorer when they enter OHC and the dental care system does not support them well during their placement, so their dental health deteriorates. By the time they reach adulthood their dental health is worse than that of others. For a variety of reasons – (financial constraints, social problems, illness, etc.) the habit of regular dental care has never been established. It is likely that because of their poor dental health they are reluctant to seek dental care, reluctant to reveal their poor oral health, of which they are ashamed. This avoidance can lead to a vicious cycle, leading to exacerbation of oral problems and pain. Poor dental health can lead to both aesthetic and functional problems, which in turn can lead to a deterioration in quality of life. Poor dental status is stigmatizing, it affects social life and probably even prospects for employment (106). A Norwegian register study showed that many young adults, previously placed in OHC, were receiving financial support from the Norwegian social welfare (107).

A possible explanation that the young adult males with experience of OHC had lower rates for check-ups, emergency visits and extractions may be that women tend to seek care more often than men (108).

It is of interest to note that the dental health of those who had been placed in OHC for most of their childhood was no better than that of those who had been in OHC only for a shorter period: society had assumed responsibility for the welfare of the children in long-term care and should have monitored and met their overall needs for care. A probable explanation is the high risk within the group for adverse outcomes such as alcohol and drug abuse and criminality, which are risk factors associated with poor health (109). Another possible explanation is the instability of placements and repeated moves within OHC (110) which makes it difficult for dental services to locate the child for regular dental appointments.

There are limitations in registry-based studies, as they provide an ‘aerial view’ of a complex reality. Detailed important information about behavioural risk factors for developing dental caries, such as oral hygiene habits or diet are not available, nor information as to why the children were placed in OHC. Reasons for placement in OHC could be e.g., parental drug abuse, domestic violence, death of parents, acute illness of parents, or factors related to the child (such as criminal activity or drug abuse). Thus, it is not unlikely that the reason for placement could have some impact on dental health. It is clear that the dental care of the young adults with experience of OHC has been different from that of other young adults.
Organisational models of health services for children and adolescents in out-of-home care (Paper II)

The lack of studies meeting the inclusion and quality criteria is problematic, especially as available studies on the health of children in OHC are very discouraging. Many organisations propose interventions and models which they think will help, without presenting any evidence. A recently published study of interventions in social work involving children in Sweden showed that only a quarter of the interventions had scientific support (111). It is important that organisational interventions and models are evaluated in well-designed studies, so that for example, evidence-based guidelines can be developed, the effects can be evaluated, and resources can then be invested in methods most likely to benefit as many children as possible. Despite the existence and use of the BBIC tool, there is uncertainty as to whether it works, and its effects may need to be evaluated. There is a great need for research as to the kind of organisational models which would strengthen the health status of this group of children.

Validation of the SKaPa registry in two steps (Paper III and IV)

The SKaPa registry works well and it is safe to use some variables for research, such as dft/DFT and preventive treatment measures. However, there is a problem with an important variable, namely e/M. As these are the first systematic evaluations of the accuracy of SKaPa, this issue has not previously emerged. The low accuracy for e/M is problematic, as extraction is the most serious outcome of neglected caries. Looking at the two validation studies in parallel, it becomes clear that registration and transfer of information about teeth extracted or missing due to caries constitute a major problem for SKaPa. The caries epidemiology in SKaPa cannot fully be utilized as it stands today, as e/M cannot be included in the output data. It is important to try to resolve this problem in order to be able to make full use of the registry. The transfer is automatic and correct – the registry receives information about a missing tooth but cannot determine why the tooth is missing.

There are several different possible causes of the problem, such as errors in registration in the dental record (e.g. a missing tooth is marked as extracted instead of exfoliated) or in the compilation of output data, or combinations of the two. It is important that researchers are aware of this issue when selecting variables in SKaPa for inclusion in registry-based research. Exclusion of these data from research, because of the uncertainty about the variable e/M in SKaPa, is a major disadvantage: there is a high risk of excluding children who have undergone multiple extractions and this gives a misleading, more positive impression of children’s dental health. Using dft/DFT alone will overestimate health, i.e. dental health will appear to be better than it actually is. For example:
a 6-year-old child who has had all primary teeth extracted due to rampant caries will have a dft=0, and if e (extracted) teeth are included, the deft score will be 20! Thus, excluding the extracted/missing component gives a skewed impression of the child’s dental health. Tooth extractions are likely to be more common in a population with poor dental health, which may also affect epidemiological data at group level. A similar dilemma, with discrepancies in the number of teeth in dental records and registry output has also been noted with respect to the Swedish Dental Health Register (87). Only dft/DFT, and not deft/DMFT, are used in epidemiological data by the National Board of Health and Welfare (112). This is an important consideration in interpreting epidemiological data. Apart from being missing due to caries, teeth may also be missing due to MIH, orthodontic treatment, agenesis, etc. There might be problems related to how extracted or missing teeth (for other reasons) are recorded in the dental records. There are probably human errors involved here.

Quality registry-based research is possible only if registrations in patient dental records are complete. There is always a risk of false variables in data records, registering the wrong tooth or entering the wrong diagnosis for a tooth. Crucial to the quality of SKaPa’s data is good record-keeping, whereby all diagnoses and measures are correctly documented in the patient’s records. Information sent to SKaPa of an extracted tooth always remains in the registry as an extracted tooth, even if the status in the dental record were to be changed.

There is a need to develop strategies for more accurate reporting of extracted and missing teeth in the dental records. In order to disclose the full consequences of dental caries, it is important that this stage is correctly managed. The causes of the problems can be several – e.g. registration with the help of scroll bars results in choosing the wrong data in haste. Dentists, dental hygienists, and dental nurses may not be aware of the consequences of erroneous registration. If SKaPa’s output data regarding missing/extracted teeth is to be included in research, it is recommended that for greater accuracy, treatment codes for extractions should be used instead.

A weakness in patient dental records is that there are patients for whom the recording of their actual dental status is incomplete, especially in cases of emergency treatment. When a patient presents for emergency treatment, the dental team often registers only procedures carried out in that specific session. This false or incomplete status is then transferred into SKaPa. When a new patient presents for dental care, the patient data record system suggests a primary or permanent dentition for that particular patient. If the status of the patients’ teeth in the dental record is not updated, all teeth are registered as intact – and this status is transferred to the SKaPa registry despite not being correct. A solution to this could be to remove the default values of teeth and instead require the examiner to manually fill in the correct number of teeth in the patient dental record (87).
Before computerised dental journals, patient dental records were on paper, with different markings for the teeth during eruption, extraction etc. It was a safe method: it is not unreasonable to expect that the digital era should be able to provide a simpler but accurate means of valid record-keeping.

The component d/D of the dft/DFT represents only caries which penetrates the dentin. This means that individuals are registered as caries-free even if they in fact have signs of the disease, manifested only as initial or incipient lesions. However, these individuals are not really caries-free and according to current practice, such lesions should not be treated invasively, by restoration, but by preventive measures e.g. with fluoride treatment, behavioural change, etc. When reporting epidemiological data to the National Board of Health and Welfare in Sweden, the definition of caries is a lesion which penetrates the dentin. If the first clinical signs of caries - enamel caries, were to be included in the diagnosis, the number of individuals with caries would be much higher. In a study from 1992, of 632 children examined at 3 years of age, 16% were diagnosed with manifest caries: when initial caries lesions were included, the score increased to 28% (113). Presumably the situation is similar today, 30 years later.

The SKaPa registry does not provide information for all dental care measures, as the registry is based on the national coding system for dental diagnoses/condition and treatment codes only. Diagnoses such as Molar Incisor Hypomineralization (MIH), trauma or dental erosion, endodontic diagnoses or information about missed appointments are not included. It is unfortunate that ICD-10 codes were not included in the dental record systems. If these were available for SKaPa, this would provide a broader coverage and facilitate and enable epidemiological studies and registry studies in a different way.

The validation studies were conducted in the county region of Värmland, where the data system Carita (Swedish Care System AB) is used to register patient data in the dental records. Carita is used in 4 of the 21 regions, representing almost 22% of the total child population in Sweden. Other dental data systems were not evaluated. However, all dental record providers use the same file specifications, with the same structure and transfer method to SKaPa.

Dental health and dental care in children placed in OHC (Paper V)

In accordance with previous studies (3, 5, 6) this thesis confirms that children in OHC have poorer dental health and receive different dental care and dental treatments than other children.

This study clearly shows that children in OHC have more neuropsychiatric diagnoses and depression than their peers, which is in accordance with other studies. In a Danish study, Egelund et al. (2008) showed that compared to their peers, foster children were significantly more likely to have complicated medical diagnoses, long-term illness or disability (114). Might that have motivated their
placement in OHC in the first place? Children in OHC are more often exposed to adverse circumstances early in life, both before and during their placement in OHC. They have more health-related problems, seek mental health care more than others, receive less general preventive health care and have poorer school results than their peers in parental care (71). Is it the upbringing or the environment? How can these disturbing findings be explained?

Children and young people placed in care have often experienced an unstable home environment and broken relationships. Children in OHC often move many times. One of the children in this study underwent 12 moves within a total placement period of less than a year. Similar findings have been reported previously (110). There is a probable risk that children in OHC feel adrift, following earlier unstable home conditions and unstable placements. There may be a risk that they lack meaningful social networks and social integration, factors which can lead to stress and depression (10). According to Wilkinson & Picket, stress at an early age can affect growth, emotional, social and intellectual development, as well as health and health behaviour later in life (115).

There is clearly inequality in regularity of dental examinations between children in OHC and other children. According to the Dental Care Act (16), the goal of dental care is good dental health and dental care on equal terms for the entire population. However, because of dysfunctional Social Services routines, county councils/regions/public dental clinics are not always informed that a child has been placed in OHC within the region. After the new law in 2017, the rate of examinations was higher in 2018. As dental examination rates increased in both groups, it is uncertain whether this is due to the law or if it is a general trend. Nevertheless, an increase was detected, and this is positive. However, compared to other children, a smaller proportion of the children in OHC was examined. There is a need to study this phenomenon further in a few years’ time when the pandemic effect of delayed examinations has declined.

A greater number of traumatic injuries to the teeth and jaws of children in OHC was reported from medical clinics. The reason is unknown. Are children in OHC at greater risk for trauma in their environment? Do they take more risks in everyday life? Do they get into fights more easily? There are studies showing that children in OHC are more exposed to violence than other children. A Swedish survey conducted in grade 9 in elementary school, of which 71 students were placed in OHC showed that almost half the students placed in OHC (48%) stated that they had been subjected to severe physical violence such as being beaten with a fist, kicked or similarly, compared to 8% among the pupils who were not placed in OHC (40). Another study showed that high school students (mean age 18 years) in OHC had been exposed to more physical abuse than their peers (116). Had it been possible to retrieve trauma diagnoses from SKaPa, a broader overview of this topic would have been of interest.
This study signals that the dental health needs of children in OHC are generally neglected and that these children are repeatedly let down by society. In many cases the children have grown up with parents who have not, for some reason, shown parental responsibility, i.e., parental neglect. Further neglect occurs when the child is placed in OHC. This time, it seems that the municipalities do not fulfil their obligation to ensure that the children’s health and dental care needs are met. Furthermore, the dental care system has also neglected these children: the Swedish regional authorities have a responsibility to ensure that all children receive regular dental examinations. In this context it is also important to remind of health professionals’ obligation to report child abuse, neglect, maltreatment to Social Services. In 2021, only 1% of all reports of concern to Social Services about children were from dental personnel, although as many as 95% of all Swedish children and adolescents are regular dental attenders (18, 39).

Based on the current state of knowledge, it is obvious that children in OHC do not receive the dental care to which they are entitled by law. Lack of effective routines is likely to contribute to conditions under which this highly vulnerable group of children is being denied the possibility of health and oral health on the same terms as others. Thus, in terms of healthcare, they are significantly disadvantaged from the start, and this may negatively affect their overall health for years to come. Children placed in OHC should be considered to be at high-risk of future dental health problems and also other health problems.

Suggestions for improvements

Apparently, the quality of dental records could be improved. There is a need for continuous discussions about quality assurance of dental records. Dental health professionals need support and continuous training in how to keep the patient dental records complete and correct for all teeth in the dentition, so that status is correct for every tooth. Further, the system for recording diagnoses in the dental records is far from optimal. Diagnoses of e.g. trauma, mineralization disturbances, erosions, soft tissue problems do not have any codes in the present system, therefore it is not possible to compile statistics or use registries to evaluate treatment of these diagnoses and conditions. To remedy this, it would be desired that the Dental and Pharmaceutical Benefits Agency (TLV) developed new codes for several diagnoses/conditions or supplemented the current system with ICD-10 diagnoses. By doing so, much more valuable information could be obtained from SKaPa.

This thesis shows that the dental health of children in OHC is poor. Poor dental health can lead to both aesthetic and functional problems. Being able to smile, chew, talk and socialize with others is essential and poor dental health has a negative impact on quality of life. The reasons underlying the poor dental health and sporadic dental care in children in OHC was not investigated in this thesis.
There are, however, some plausible explanations. The child’s parents could for some reason be unable to fulfil their parental responsibility for the child's oral health, in the form of diet and oral hygiene. Reinforcing the role of parents, by providing early interventions of help and support to families in need and educating parents in parental responsibility would probably be an effective preventive measure, promoting better dental health and perhaps even reducing the risk of children having to be placed in OHC.

Another reason for the poor dental health may be a combination of unclear guidelines for the social workers in the different municipalities when placing the child in OHC and inadequate time available for assessments when decisions about placements must be made (117, 118). This might also be attributable to the high workload and large staff turnover of municipal social workers in Sweden: the system thus becomes vulnerable (117). Improved guidelines are probably not enough. There seem to be a need for new working tools to facilitate the social workers’ ability to manage and ensure that the health examinations required by law are carried out. It has been proposed that digital tools should be developed to assist both child welfare professionals and health care providers. If so, such tools should be integrated with nationally developed checklists for planning health and dental care assessments, for example with a digital health card, which can accompany children if they are relocated to other municipalities (67). The main cost of this digital tool would comprise the construction of a national digital process, but once established, the costs would be moderate and the benefits obvious (67). Further, for the organisational systems to work there has to be someone who represents the child.

Foster parents and staff in special supervisory homes also need to know that they play an important role in assisting the children to establish good dental hygiene habits and promoting compliance with regular dental visits. This should be an obvious obligation and should be made mandatory in contracts.

In addition to improvement at the organisational level of Social Services, there is a need to scrutinise the dental care organisations: under the present system, children are seldom seen a dentist: instead, they see dental nurses and dental hygienists, who mostly look for health indicators and often have limited knowledge of the neglected child and the role of Social Services. All children should have a responsible dentist, and there is a need for routines to follow up children who do not keep their dental appointments. Further, there should be more complete therapy plans, including preventive measures to be undertaken before the next dental examination and better risk assessment systems where it would be obligatory to include assessment of the child’s social situation. All dental staff should also receive continuous awareness training about children who are being maltreated.

For children in OHC, there are obstacles to dental care, for example, the cost of treatment for a child living in a region other than where he/she is registered. A
national child allowance for the regions could be a solution for this, so that dental care is not missed or delayed for financial reasons. Another obstacle is the requirement of parental consent for the child to receive dental care in another region. This administrative work is time-consuming and delays dental care. Dental care should be regarded as in the best interests of the child, and it should be possible to circumvent the requirement for parental consent.

Looking further afield for solutions may sometimes be rewarding. One example is a preventive working mode called “Skolfam”, intended to improve school results for children in OHC. “Skolfam” is available in several municipalities in Sweden: Social Services, schools and family homes collaborate, for the purpose of improving school results for children in OHC. The working model has been evaluated, with a tendency in favour of the intervention (119). A similar concept, for health, has been created in Region Uppsala in Sweden, with multi-disciplinary health examinations for children in OHC (120,121). Collaboration and cooperation, beyond traditional professional boundaries, could be the key to making a change for children in OHC.

Broader knowledge is needed, based on interdisciplinary perspectives and the experiences of different professions. There is a need for cooperation among health, dental and Social Services personnel, to form a fine-mesh safety net, to ensure that the routines function. One obstacle is the isolation of the different professions: there are few opportunities to break patient confidentiality and secrecy. Perhaps a review of the legislation is needed if the best interests of the child are to be safeguarded?

Many regions are extending the intervals between dental examinations for the child population, which means that some children do not have their first dental examination before the age of three years old and the next examination several years later. Particularly in the primary dentition, dental health status can deteriorate in a fairly short period of time. It is important from a public health point of view to see the children regularly and of course to see the whole child, within his or her context. Regular dental examinations also increase the possibility that the dental team will identify children who are maltreated.

From 2025, the Swedish government proposes lowering the age limit for free dental care to 19 years of age. This can result in even poorer dental health for those exiting OHC, as many such young adults have low educational achievements (109) and difficulty finding employment and a regular income. They are more often dependent on social welfare than their majority-peers (122). There is a need for greater political awareness. It is the politicians who have the mandate and the financial resources to make a change.
Things to consider when giving dental care to children in OHC

When a child placed in OHC presents for dental care, the clinic staff need to be aware that the child may have a history of negative experiences. It is important to be empathetic and respect the fact that dental personnel do not need to know all the details. The dental staff should be able to perceive the child's needs, understand that the child may react negatively and be able to manage the situation. Treatment needs to be introduced carefully and proceed in small steps. It is most important to establish a positive interaction between the patient and the dental staff and that trust is built. If the child is to move to another placement, perhaps out of the region, it is important that a referral is sent to the dental clinic nearest the new address, to ensure continued dental care. All children should receive the treatment and care that they need.
CONCLUSIONS

- Young adults who have been placed in OHC at some time during their childhood have poorer dental health, with more emergency dental treatment visits and more tooth extractions. The dental health of those who had been placed in OHC for most of their childhood was no better than that of those who had been in OHC only for a shorter period. Young adults who have been placed in OHC in childhood do not have the same opportunities to achieve good dental health and dental healthcare habits as other young adults.

- There are no studies of satisfactory quality assessing the effects of organisational models on accessibility of health and dental care for children placed in OHC. Thus, when such models are planned and introduced, high quality follow-up studies are needed.

- Data on dft and DFT in the SKaPa registry may be regarded as safe and reliable for the purposes of population-based evaluations, epidemiological research, for evaluating different preventive measures and for registry-based research on children. However, as agreement was substantially lower for e/M, especially in 12-year-olds, at present the use of SKaPa output data on deft or DMFT for research purposes is not advised.

- Children in OHC have poorer dental health and receive less dental care than other children. They have more caries, more emergency dental treatment visits, and more tooth extractions. Higher frequencies of dental health examinations were found after the legislative amendment in 2017. There is a need for reappraisal of guidelines, legislation, and organisational models which determine the provision of dental care for children placed in OHC that enable placed children to receive their dental care.
This thesis shows that children in OHC have more caries and receive less dental care than other children, but multivariate analyses of background factors are incomplete. Further analysis of the Swedish Out-of-Home Care Children cohort (SweOHC) will continue. Some issues are particularly urgent, such as closer scrutiny of socioeconomic factors and the causes underlying the complexity of dental health in these children. To plan and improve dental care over time, there is a need to know more about the children placed in OHC. Studying the underlying factors and continuously evaluating dental health and dental care in children placed in OHC will allow the development of strategies to ensure that these children have the same right to dental health and access to dental care as other children. There is a need to determine whether there are differences between children placed in care under the auspices of LVU or SoL. What is the standard of dental health of the siblings of children in care?

During my years as a PhD student, many potential research questions about this particular group of children have arisen. For example, a qualitative study as to how children in OHC perceive their life situation and context, their health and dental health status, and how they deal with ups and downs in life. It would also be interesting to investigate how children in OHC experience and handle stress and to evaluate their quality of life. It would also be of interest to monitor the progress of the dental examination rate of children in OHC some years hence, to determine whether the rate has continued to rise after the law changed year 2017.

There is much to be explored in this area, and further research is most important, in order to raise awareness of the plight of these children among politicians, regions, Social Services and others, so that routines are developed and implemented, to ensure that these children receive the healthcare and dental care to which they are entitled. It is also important to undertake well-conducted studies to evaluate the effect of routines.
With reference to the problem encountered with SKaPa output data of e/M for 12-year-olds, a study is planned to evaluate the accuracy of the data for 19-year-olds, to determine whether the above-mentioned problems related to e/M differ between the mixed dentition and the young permanent dentition. A corresponding validation study on the adult population would be of value. There is also a need to study the accuracy of SKaPa data on periodontal diseases.
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Dental healthcare utilisation among young adults who were in societal out-of-home care as children: A Swedish National Cohort Study

Berlin M., Mensah T., Lundgren F., Klingberg G., Hjern A., Vinnerljung B., Cederlund A. Dental healthcare utilisation among young adults who were in societal out-of-home care as children: A Swedish National Cohort Study

We used Swedish national registers to analyse dental health care among young adults with childhood experience of out-of-home care (OHC), in Cox regression analyses. All 1.7 million Swedish residents born in 1980–1994 were included, of whom 4% had been in OHC. The population was followed up in the Dental Health Register from age 20 to 29, during the period 2009–2014. We found that persons with short or long OHC experience made emergency dental care visits more often than their majority-population peers: 17–23% versus 9–10%, (adjusted Hazard ratios [HR:s] 1.60–2.02); they more often had tooth extractions, 9–12% versus 3% (HR:s 2.33–3.03); but less regularly visited a dentist for planned check-ups, 61–77% versus 80–87% (HR:s 0.76–0.78). Since dental health in young adulthood reflects dental health and dental care in childhood, the findings of this study call for improved preventive dental health care for children in OHC.

Introduction

In Sweden, approximately 4% of all children are at some time during their childhood placed in societal out-of-home care (OHC, foster family or residential care), around the same proportion as in Denmark and the UK (Fallesen, Emanuel, & Wildeman, 2014; McGrath-Lone, Dearden, Nasim, Harron, & Gilbert, 2016; Vinnerljung, 1996a; Vinnerljung, Hjern, Weitoft, Franzén, & Estrada, 2007). For several decades, studies from various Western countries have reported strikingly high levels of somatic health problems in this group of children (Arora, Kalnter, & Williams, 2014; Chernoff, Combos-Orme, Risley-Curtiss, & Heisler, 1994; Haflon, Mendonca, & Berkowitz, 1995; Hansen, Mawjee, Barton, Metcalf, & Joyce, 2004; Kling, Vinnerljung, & Hjern, 2016a; Nathanson & Tzioumi, 2007; Schor, 1982; Steele & Buchi, 2008; Turney & Wildeman, 2016; Zewdu, 2010). In addition, adults with childhood experience of OHC have far higher rates of health problems than peers without this background (Vinnerljung, Brännström, & Hjern, 2015; Schneider et al., 2009; Viner & Taylor, 2005; Zlotnick, Tam, & Soman, 2012).

In contrast to this abundance of research, less is known about dental health and dental care needs of OHC children (Wadell, 2007). Sarri, Evans, Stansfeld, and Marceenes (2012) performed an epidemiological study of dental neglect among 1,030 15–16 year olds in a deprived UK geographic area (Sarri et al., 2012). Nested within the sample was a small subgroup (n = 32) living in OHC. These children had considerably worse rates on all indicators used in the study (treated and untreated dental caries, dental pain, traumatic dental injuries). High rates of dental problems among children and youth entering or residing in OHC have also been reported in a sprinkling of small sample studies, from the USA, Australia, Spain and Sweden (Kling, Vinnerljung, & Hjern, 2016a; Melbye, Chi, Milgrom, Huebner, & Grembowski, 2014; Nathanson & Tzioumi, 2007; Olivan, 2003; Randalsu & Laurell, 2017; Swire & Kavaler, 1977). These results are not surprising, in that research has shown that there are strong links...
between child maltreatment and poor oral health (Cornelius et al., 2004; Greene, Chisick, & Aaron, 1994; Kvist, 2016; Valencia-Rojas, Lawrence, & Goodman, 2008).

Looking at OHC children in a life-course perspective, we were unable to locate a single study that reported on any aspect of dental health in adults with OHC experience. Addressing this gap in knowledge, we used the Swedish Dental Health Register (which covers the entire adult national population), in combination with several other national registers, to examine dental healthcare among adults who had entered OHC at least once during their childhood/adolescence (0–19 years). This explorative study was guided by the following research questions:

- To what extent do young adults (age 20–29) who have been in OHC during childhood visit a dentist for check-ups and preventive care, compared with their majority-population peers?
- To what extent do they see dentists for emergency visits or tooth extractions, compared with majority-population peers?
- Are there any differences in dental healthcare utilisation among different groups of young adults with OHC experience, with respect to age at entry into care and length of stay?

Setting: child dental health care in Sweden

In an international perspective, Swedish children and youth have good dental health (Helsedirektoratet, 2013). This is due in part to a universal programme of recurring voluntary dental check-ups and free dental care, including preventive care, for all Swedish children and adolescents. Until 2016, all Swedish residents up to age 19 were included in the programme. From 2017, free dental care was expanded to include young adults up to their 21st birthday, and further extended in 2018 to the year of their 23rd birthday. Approximately, 95% of all children and adolescents receive dental care on a regular basis. The dental care is provided either by the Public Dental Service (approximately 85% of the dental care volume) or by contracted private practitioners (Privatandläkarna, 2017). When Swedish residents reach an age when they are no longer covered by this comprehensive system, the major part of costs for dental care is paid for by the individual her/himself.

Several factors probably contribute to OHC children benefiting less than their peers from this universal programme, both before entry into OHC and while in OHC. Before entry into care, some parents may fear that dental check-ups might reveal indications of child maltreatment, which could result in a report to the child welfare authorities. For some parents, neglect of their children’s health is part of a behavioural pattern, often coupled with addiction or mental health problems (Kvist, 2016). Changes of placement environment are common in OHC, also in Sweden (Vinnerljung & Sallnäs, 2008; Vinnerljung, Sallnäs, & Berlin, 2017). Frequent changes of domicile/address create difficulties for the dental health care system to locate the child for regular dental check-ups, or invitations to scheduled visits may get lost in the paper trail. Administrative procedures have improved somewhat in recent years. If the child does not show up for a scheduled dental check-up after receiving an invitation from the local dental health clinic, a number of reminders will be sent out. Repeated failure to show up can result in a report to the child welfare authorities, but in practice local routines for this process vary considerably.

Methods

This study was based on record-linkages between national registers, held by the Swedish Board of Health and Welfare and by Statistics Sweden. The overall quality of the registers is regarded as high (Cnattingius, Ericson, Gunnarskog, & Källen, 1990; Ludvigsson et al., 2011). The registers were linked by use of the individually unique 10-digit personal identification number (PIN) that follows all Swedish residents from birth (or date of immigration) until death. The PIN enables researchers to trace individuals over the life course in national data bases, with low attrition (Ludvigsson, Otterblad-Olausson, Pettersson, & Ekbom, 2009). Also, outcomes can be analysed with adjustments for socio-economic background and other factors.

The following registers were used. The registers held by the Swedish Board of Health and Welfare include: the Swedish Dental Health Register (DHR), which, since 2009, has compiled information on individual use of dental care services for the entire adult population of Sweden; the Child welfare Intervention Register, which is based on data from the local child welfare authorities, covering full birth cohorts since 1971 and has information on placements in OHC; and the Swedish Cause of Death Register, which covers all registered deaths in Sweden since 1961, whether the death occurred within or outside the country. Among the registers held by Statistics Sweden, we used The Swedish Register of Education, which contains information on level of educational attainment and is updated yearly. This register is supplemented with demographic data from the Total Population Register.

Study population

The study population consisted of all Swedish residents born in 1980–1994 and who, according to data in the Total Population Register, were alive and
Dental care utilisation among young adults from out-of-home care

residing in Sweden at age 20. The study includes roughly 1.7 million individuals in total, of whom around 4% \((n = 65,261)\) had entered OHC at some point during their childhood or adolescence (age 0–19). The population was divided into four mutually exclusive study groups, of which one group (the majority population) had never experienced OHC. This categorisation of children with OHC experience has been used in a host of previous national cohort studies (e.g. Brännström, Vinnerljung, & Hjern, 2015, 2016; Vinnerljung & Hjern, 2014), and has shown good discriminatory qualities:

- **Short OHC \((N = 16,094)\):** Persons who were placed in OHC for the first time before age 13 and who stayed in care less than five years totally before age 20. The average age of first placement was 6 years and the average time spent in care was 1.3 years.
- **Long OHC \((N = 11,153)\):** Persons who were placed in OHC for the first time before age 13 and who remained in care for five years or more. The average age of first placement was 5 years and the average time spent in care was 11.2 years.
- **Teen placements \((N = 38,014)\):** Persons who entered OHC for the first time after their 13th birthday, regardless of total time spent in OHC. This group differs from the other two groups in that 40–50% of adolescents in OHC are placed due to antisocial behavioural problems, for example juvenile delinquency or illicit drug use (Vinnerljung, Sallnäs, & Kyhle-Westemark, 2001). The average age of first placement was 16 years and the average time spent in care was 1.7 years.
- **Majority population \((N = 1,667,660)\):** Persons who had never been in OHC during their childhood, according to the Child Welfare Intervention Register.

The register does not contain data on reasons for care entries, but we know from other studies (e.g., Khoo, Skoog, & Dalin, 2012; Vinnerljung, 1996b) that the vast majority of children placed in OHC for the first time before age 13 (here: Short OHC and Long OHC), were placed in OHC for reasons related to parental behaviour/child maltreatment.

Outcome variables

The cohort members were followed in the Swedish Dental Health Register (DHR) from age 20 to 29, during the period 2009–2014. The DHR was initiated in 2008 and contains individual data on dental healthcare for the entire Swedish population from age 20 and upwards. Data include clinical information on diagnoses, number of remaining teeth, number of intact teeth and type of dental care intervention provided. Classifications of diagnoses and dental care interventions are decided by The Dental and Pharmaceutical Benefits Agency of Sweden.

We used the following outcome variables, constructed from data in the DHR:


The DHR contains rather complete data for visits to dental health clinics. However, at present there are no estimates of how complete the data are for other dental care measures (e.g., diagnoses). There are few missing data on individual variables, which occurs when information has been omitted. That dentists receive a compensation or reimbursement when they report to DHR gives them an economic incentive for reporting. Cosmetic dental care interventions are not reimbursed by the dental care system and hence not covered by the DHR (Socialstyrelsen, 2017).

Although the incidence in the DHR of missing data on certain variables (not utilised in this study) is very low, it is more common in the OHC groups. This is mainly a consequence of a higher proportion of emergency visits, compared with majority-population peers. In the OHC groups, 10–12% of those who had visited dental care services had made emergency visits only, compared with 4% in the majority population of peers. Further, for 44% of those who had made emergency visits only, there was no information on number of remaining teeth and number of intact teeth. The corresponding proportion of missing values among those who had made check-up visits or preventive care visits was 4%. However, these variations did not affect this study, since only data on type of dental visits (e.g., emergency visits) and number of extracted teeth (other than wisdom teeth) were used as outcome variables. The latter variable had no missing values.

Number of extracted teeth is considered a measurement of poor dental health status, because dentists in Sweden are reluctant to do this intervention, especially for younger patients. We assumed that the vast majority of the extractions in our sample were due to poor dental health. Tooth extractions can be performed based on various diagnoses, but it was not possible to evaluate the reasons for the extractions in this study since DHR does not contain this information. Orthodontic treatment and abnormalities in enamel or tooth formation are more common reasons for extractions for younger individuals than for adults. However, as the individuals in this study were 20–29 years old, it is reasonable to believe that the majority of extractions were carried out because of pathology-like extensive dental caries, periodontal...
disease or pulp pathology. As the OHC groups were compared with their majority-population peers, there is no reason to assume that the underlying diagnoses leading to tooth extraction would differ between the groups.

**Background/confounder variables**

Sex and year of birth were retrieved from the Total Population Register. Women have been found to be more likely to use preventive care and they generally have better dental health (Cederlund, Lundgren, Tranæus, & Norlund, 2016). Because we followed the cohort members for a different number of years and at different ages, the results were adjusted for year of birth.

Maternal education was used as an indicator of parents’ socioeconomic status. There are strong links between families’ socioeconomic status and their children’s dental health (Socialstyrelsen, 2013c). Good dental care habits are learned early in life and passed on from parent to child (Kinirons & McCabe, 1995; Mohebbi, Virtanen, Murtomaa, Vahid-Golpayegani, & Vehkalahti, 2008; Poutanen, Lahti, Tolvanen, & Hausen, 2006). In this study, data on maternal education refer to the birth mother’s level of educational attainment when cohort members were 20 years of age. The data retrieved from the Swedish Register of Education were categorised as ‘Short’ (< 9 years), ‘Medium’ (10–12 years) and ‘Long’ (≥ 13 years). Paternal education was not used in the analyses due to a high rate of missing information, especially for the OHC groups.

**Summarised sample description**

Sex distribution was fairly even in the study groups, with a slight overrepresentation of boys in the two study groups who were placed before their teens, Short OHC and Long OHC (Table 1). In the Teen care group, a higher proportion were born in the latter years of the cohort range (1980–1994). This was due in part to an increasing number of unaccompanied asylum-seeking teenagers from year 2005 onwards. In the Teen care group, 36% of the male adolescents and 23% of the female adolescents were born abroad, compared with 6–12% in the other two OHC groups (Table 1). Since our data set contains information on country of birth only for the OHC group, we were unable to report how many of the majority-population peers were born outside of Sweden and, thus, were unable to adjust the analyses for Swedish-born or foreign-born. However, we did examine whether there were substantial differences within the OHC groups between Swedish-born and foreign-born individuals (Appendix Table A1). The level of maternal education was considerably lower in the OHC groups than in the majority-population peer group (Table 1).

**Statistical analysis**

All analyses were made with the aid of the SAS software package (procedure given in brackets). The yearly percentage who had made dental healthcare visits for various reasons (Figures 1 and 2) refers to the frequencies for each separate year (PROC FREQ).

The prevalence of having made at least one tooth extraction at different ages (Figure 3) was estimated using survival functions with the life-table method (PROC LIFETEST), and refers to accumulated

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**Table 1. Distribution of sex, year of birth, and maternal education, in study groups, and foreign-born in OHC groups.**

<table>
<thead>
<tr>
<th></th>
<th>Majority population</th>
<th>Short OHC</th>
<th>Long OHC</th>
<th>Teen care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>854,818</td>
<td>51</td>
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</tr>
<tr>
<td>Women</td>
<td>812,842</td>
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<td>7,521</td>
<td>47</td>
</tr>
<tr>
<td>Total</td>
<td>1,667,660</td>
<td>100</td>
<td>16,094</td>
<td>100</td>
</tr>
<tr>
<td>Year of birth</td>
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<td>1980–89</td>
<td>1,041,122</td>
<td>62</td>
<td>10,066</td>
<td>63</td>
</tr>
<tr>
<td>1990–94</td>
<td>626,538</td>
<td>38</td>
<td>6,028</td>
<td>37</td>
</tr>
<tr>
<td>Total</td>
<td>1,667,660</td>
<td>100</td>
<td>16,094</td>
<td>100</td>
</tr>
<tr>
<td>Maternal education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(birth mother’s)</td>
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<td>94,658</td>
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<td>1,933</td>
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<tr>
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<td>4,588</td>
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<td>Medium&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>7,347</td>
<td>46</td>
</tr>
<tr>
<td>Long&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>2,166</td>
<td>13</td>
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<tr>
<td>Total</td>
<td>1,667,660</td>
<td>100</td>
<td>16,094</td>
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<td>Foreign born</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>987</td>
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<td>410</td>
<td>7</td>
</tr>
<tr>
<td>Women</td>
<td>898</td>
<td>12</td>
<td>334</td>
<td>6</td>
</tr>
</tbody>
</table>

Note: Numbers (N) and per cent (%). All Swedish residents born in 1980–1994 who were residing in Sweden at age 20

<sup>a</sup>Educational level: Short ≤ 9 years, Medium 10–12 years, Long ≥ 13 years.
experiences of tooth extraction over time (2009–2014). The same method (PROC LIFETEST) was used for calculating the percentage in the population who had had at least one check-up/preventive dentist visit or emergency visit (Table 2) at the end of the follow-up period (2014). (Allison, 2010).

In addition, Cox proportional hazards models were used to calculate adjusted hazard ratios of dental healthcare visits and tooth extractions (PROC PHREG) (Tables 3 and 4) (Allison, 2010). This was done in two steps. In the first step, the model included sex, year of birth (continuous variable) and study group. In the second step, maternal education was added.

In both the survival and hazard functions, time (person-years) was calculated with the entry date defined as the year of the 20th birthday (only persons living in Sweden at age 20 were included in the study population), and the exit date, defined as the first year of outcome (event), or date of death or emigration (censored), or end of follow-up (December, 2014). Information on year of death was collected from the Swedish Cause of Death Register and year of emigration from the Total Population Register.

**Results**

The results show that persons who had been in OHC during childhood did not visit the dentist for check-ups and preventive care to the same extent as their peers in the majority population (Figure 1). This is unlikely to be an expression of better dental health, since the individuals in the OHC groups made far more emergency dental visits than the majority-population peers (Figure 2). Another important indication was the higher prevalence of tooth extraction.

![Figure 1](image1.png)

*Figure 1. Percentage of the population subgroups who have visited the dentist for check-ups or preventive care, by age, sex and study group. Dental visits 2009–2014, Swedish residents born in 1980–1994 who were residing in Sweden at age 20.*

![Figure 2](image2.png)

*Figure 2. Percentage of the population subgroups who have only done emergency dental visits during (no check-ups or preventive care visits), by age, sex and study group. Dental visits 2009–2014, Swedish residents born in 1980–1994 who were residing in Sweden at age 20.*
in the OHC groups (extraction of wisdom teeth not included) (Figure 3). Emergency visits and tooth extractions increased with age, as did the differences between the majority-population group and the OHC groups.

The Teen care group had the highest proportion of persons with extracted teeth (Figure 3). At age 29, it was approximately four times as high in the Teen care group (12% and 11% among the males and females, respectively) as in the majority-population group (3%, regardless of gender). The proportion was slightly lower in the Short OHC group and the Long OHC group (9–10% among males and 9% among females), but approximately three times as high as in the majority-population peer group. Differences between those who had more experience of temporary care (Short OHC, average 1.3 years in care) and those who had been in long-term care (Long OHC, average 11.2 years in care) were negligible.

At the end of follow-up (2014), the prevalence of check-up visits in the OHC groups were 77% among the females and 61–64% among the males (Table 2). The corresponding rate in the majority-population group was 87% among the females and 80% among the males. This means that the proportion who had not had any check-ups in six years was almost double in the OHC groups, compared with the majority-population group. Tables 3 and 4 show the adjusted hazard ratios of dental health care visits – check-ups and emergency visits – and tooth extractions at any time during the follow-up period, which stretched over six years (2009–2014).

The results show that the gender and birth-year adjusted ratios (Table 3, Model 1) of having had at least one check-up or preventive dental care visit were approximately 30% lower in the OHC groups, compared with the majority-population group. The risk of having to make an emergency visit was nearly double for the OHC groups (point estimates of HR 1.8–2.2), and the risk of having a tooth extracted was three to four times higher (point estimates HR 2.9–3.8), compared with majority-population peers. Adjusting for maternal education (Table 3, Model 2) gave the greatest effect for the Long OHC group and for the two outcomes that are associated with poor dental health, that is, emergency visits (point estimate HR 1.6) and tooth extraction (point estimate HR 2.1). The relative risk of tooth extraction decreased by

Table 2. Percentage (life-table method) and numbers of the population subgroups who have made any check-ups and emergency visits during follow-up (2009–2014), by sex and study group.

<table>
<thead>
<tr>
<th></th>
<th>Majority population</th>
<th>Short OHC</th>
<th>Long OHC</th>
<th>Teen care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Check-up</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Men</td>
<td>577,686</td>
<td>80</td>
<td>4,475</td>
<td>64</td>
</tr>
<tr>
<td>Women</td>
<td>607,374</td>
<td>87</td>
<td>4,850</td>
<td>77</td>
</tr>
<tr>
<td>Emergency</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>52,725</td>
<td>9</td>
<td>912</td>
<td>17</td>
</tr>
<tr>
<td>Women</td>
<td>55,194</td>
<td>10</td>
<td>836</td>
<td>18</td>
</tr>
</tbody>
</table>

Note: Swedish residents born in 1980–1994 who were residing in Sweden at age 20.
29% in the Long OHC group, and 18–19% in the other two OHC groups. The corresponding decrease for emergency visits was 14% in the Long OHC group and 9% in the other two OHC groups (Table 3, Model 2). Table 4 shows the association for the background factors used in this study. The male young adults had lower risks than the female, for all outcomes, and younger individuals had lower risks than older, except for emergency visits. There was a clear social gradient: Individuals whose mother had a longer education had a lower risk for emergency visits and tooth extraction than those whose mothers had shorter education.

Lastly, we conducted sensitivity analyses (shown in Appendix Table A1) to examine whether the foreign-born individuals in the OHC groups had any impact on the results. This was most important for the Teen care group since it included a subgroup of unaccompanied asylum-seeking adolescents. For two of the outcomes, there were no differences between being foreign-born or Swedish-born. However, for tooth extractions, Swedish-born young adults had higher HR’s than their foreign-born peers, most pronounced in the Teen placement group which included an unknown number of adolescent unaccompanied asylum seekers (HR point estimates 3.5 vs. 2.2).

**Discussion**

Dental health-related behaviours are established early in childhood and are of great importance for dental health in adulthood (Blinkhorn, 1981; Grytten, Rossow, Holst, & Steele, 1988). These behaviours are transmitted from parents, particularly the mother, and vary between groups depending on socioeconomic

Table 4. Risk of dental visits (check-up and emergency) and extracted teeth other than wisdom tooth during follow-up (2009–2014), by study group and background variables.
status and cultural background (Mohebbi et al., 2008; Pine et al., 2004; Poutanen et al., 2006). Several studies have demonstrated that social differences, such as education, occupation, income, sex and ethnicity, affect both the incidence and severity of dental caries, in virtually every country studied (Hjern, Grindefjord, Sundberg, & Rosén, 2001; Petersen, 2005; Petersen, Bourgeois, Ogawa, Estupinan-Day, & Ndiaye, 2005; Pine et al., 2004). Social inequality in dental health is a universal phenomenon. Dental caries influences daily life by causing pain and affecting the ability to eat, speak, interact socially and perform adequately in school. Children with poor oral health are nearly three times as likely to miss days from school (Jackson, Vann, Kotch, Pahel, & Lee, 2011).

In recent decades, in many countries the prevalence of dental caries has decreased significantly among children and adolescents (Malmö University, 2017). However, despite the fact that tooth decay is a disease which – with the right knowledge and effective interventions – can be prevented and treated, dental caries is still the most prevalent non-communicable disease in the world (Kassebaum et al., 2015). A host of studies has shown that socioeconomic factors, such as low parental income and education, are strongly associated with higher risks for children and adolescents to develop dental caries (Grindefjord, Dahllöf, Ekström, Höjer, & Modéer, 1993; Hamasha, Warren, Levy, Broffitt, & Kanellis, 2006; Harris, Nicoll, Adair, & Pine, 2004; Hobdell et al., 2003; Jiménez, Tapias-Ledesma, Gallardo-Pino, Carrasco, & de Miguel, 2004; Schou & Uitenbroek 1995; Socialstyrelsen, 2013c). Children who develop tooth decay in early childhood are also at high risk to experience continued tooth decay later in life (Alm, Wendt, & Koch, 2004; Grindefjord, Dahllöf, & Modéer, 1995).

In this study, we analysed dental health care utilisation among young adults who had been in public OHC during their childhood or in adolescence. Children and adolescents who had been in OHC were less likely to have visited dentistry for check-ups after age 19, and were far more likely to have made emergency dental health clinic visits or experienced a tooth extraction, compared with their peers in the majority-population group. This pattern of results was not substantially altered by adjustments for parental education.

Since poor oral health status (measured as the need for emergency visits and tooth extraction) accumulates over time, the higher risks seen in the OHC groups are likely to have antecedents in childhood. This is also indicated by the fact that the differences between young adults who had been in OHC, and those who had not, were visible already in the first studied year, while cohort members were in their early twenties. This hypothesis is also tentatively confirmed by results from four Swedish regional studies. In one study, 120 children were given a systematic health assessment upon entering OHC, including a rudimentary oral health check-up (Kling et al., 2016a). One out of two school-aged children (7–16 years) had severe dental decay that required immediate treatment. Similar results have recently been reported in another Swedish study (Randsalu & Laurell, 2017), and in a study of youth entering secure residential care (Kling et al., 2016b). In addition, Kling and Nilsson (2010) examined case files for 150 children who had been in OHC for at least a year. They found that the OHC children did not attend scheduled dental check-ups to the same extent as other children. Only 60% of OHC children responded to invitations to scheduled dental check-ups compared with 90% of a comparison group of peers who were not in OHC, but who were living in the residential neighbourhoods that the OHC children had originally come from. Similar results have been found in a recent population-level study in Scotland (McMahon et al., 2018). OHC children had high levels of severe dental decay and were less likely to visit a dentist regularly, which could not be explained by socioeconomic factors.

That there are minor or no differences between the two OHC groups who had entered care before their teens is noteworthy. One might expect that children who have been in OHC for a long time – here, on average almost two-thirds of their childhood (11.2 years) – would be better off than those who have been in care for only a shorter period (in our sample, on average slightly more than one year). This is assuming that long-term care is associated with a more favourable upbringing situation, but also with closer monitoring of children’s/adolescents’ health from child welfare authorities. This lack of compensatory effect of long OHC has been demonstrated in previous Swedish studies with high excess risks within the group for different adverse outcomes such as criminality, alcohol and drug abuse (e.g. Berlin, Vinnerljung, & Hjern, 2011), risk factors which are known to be associated with poor health. The high prevalence of such risk factors is one plausible explanation for the small differences between the OHC groups in this study. Another possible explanation is the instability that is prevalent in both long-term foster care and early childhood placement (Vinnerljung & Salnäs, 2008; Vinnerljung et al., 2017). Repeated moves make it hard for the dental services to locate the child for regular dental check-ups, and without a continuing care provider the child’s compliance with the comprehensive general dental healthcare system might be disrupted. That children in OHC fail to attend dental check-ups (Kling & Nilsson, 2010;
McMahon et al., 2018; Randsalu & Laurell, 2017) points to an urgent issue, namely, how to organise communication and cooperation between the social services and healthcare providers (cross-sector collaboration) in order to ensure that children in OHC receive the same medical and dental healthcare as other children.

There are indications that the health and dental healthcare situation of children in OHC in Sweden may improve in coming years. Recent changes in legislation (from April 2017 but not yet implemented) stipulate that all children entering OHC should be given a health assessment that includes dental health. (prop. 2012/13:10; Socialstyrelsen, 2013a; 2013b, 2015; SOSFS 1997:15; SOSFS 2013). Detecting different health problems is an important measure, in that carers without medical and dental health training might underestimate OHC children’s health needs (Kaltner & Rissel, 2011). It is hoped that this measure will not only increase their access to dental health care upon entering OHC, but also contribute to providing a systematic strategy for dental healthcare throughout their time in care and thereby reduce the need for excessive dental treatment in adulthood. The comprehensive dental care system for children and youth has also been improved recently. As mentioned earlier, free dental care (including preventive care) for all Swedish residents was extended in 2017 to age 21, and from 2018 youth are eligible for free dental care up to age 23.

The changes in legislation regarding free dental health up to age 23 is good news for youth exiting societal care in late adolescence. They have been described by the English scholar Mike Stein (Stein, 2006) as the most excluded group of youths in European societies. They tend to enter adulthood without adequate adult or financial support (Höjer & Sjöblom, 2010, 2011, 2014). Many have weakened family networks, partly because many parents are no longer living (Franzen & Vinnerljung, 2006) and partly because a childhood spent in OHC has failed to provide them with a family that is willing and able to support them after they leave their substitute homes. The growing demand in recent decades for having a higher education being a condition for successful entry into the labour market has also led to an extended period of becoming established, and thus an increasing dependency on parents during young adulthood (Lager, Berlin, Heimerson, & Danielsson, 2012). Many of the youth exiting OHC have low educational attainment (Berlin et al., 2011), and they have difficulty in obtaining employment and a sufficient income. Far more than their majority-population peers, they are dependent on social assistance/welfare in young adulthood to make basic ends meet (Vinnerljung, Franzen, Hjern, & Lindblad, 2010). In contrast to many other countries, Sweden has no ‘after care’ services for youth who ‘age out’ of OHC. Therefore, extended free dental care has at least a theoretical potential to improve dental health for young persons who transit from OHC to independent living in late adolescence (usually at age 18).

Limitations
All register-based studies have inherent limitations and ours is no exception. Register data provide mainly an ‘aerial view’ of a complex reality. An obvious limitation is that Sweden does not compile national, individual data on dental care before the age of 19. Therefore, we were unable to extend the analyses with data on important antecedents of poor adult oral health, for example dental health visits and treatments during childhood and adolescence. This shortcoming in available data also excluded us from analysing the importance of pre-placement factors versus placement-related factors. Thus, issues of causality remained outside the scope of this study. The Child welfare Intervention Register does not contain data on the reasons for entry into OHC. Thus, analyses that relate outcomes to more specific childhood indicators, for example experience of abuse, were also outside the scope of this study.

Regarding generalisability, we do not know if our results are valid for other countries, or for different time spans than our follow-up period.

The strengths of the study are access to data for the entire national population, including robust socioeconomic confounder data (maternal education), with only minor attrition. In addition, to the best of our knowledge, this is the first study of its kind – also in an international perspective.

Conclusions and implications for practice
The results of this study indicate that individuals who have been in OHC during their formative years do not have the same opportunities to achieve good dental health and sound dental healthcare habits as their peers in the majority population. Furthermore, this study shows that this also applies to young adults who have spent most of their childhood in societal care.

Realistic paths towards improvement are the application and auditing of minimal healthcare standards for OHC. These standards should be non-negotiable for local child welfare authorities. In a European perspective, England is an outstanding model for this approach (Care Quality Commission, 2016; Department of Education & Department of Health, 2015; NHS, 2015; Vinnerljung & Hjern, in print). Minimum requirements should include a full dental health assessment at time of entry into OHC, and
mandatory monitoring of placed children’s dental health through annual check-ups at a dental health clinic. Furthermore, foster parents and residential staff have an important role to play in helping the children in their care to establish good dental hygiene habits, but also in promoting compliance with scheduled clinical visits. In our opinion, these tasks for carers should be regulated in contracts between child welfare authorities and care providers.

References


Dental care utilisation among young adults from out-of-home care


Appendix


<table>
<thead>
<tr>
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<td>HR (95% CI)</td>
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<td>1 (Ref.)</td>
<td>1 (Ref.)</td>
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<td>2.40</td>
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<td>0.75</td>
<td>(0.71–0.80)</td>
<td>1.57</td>
<td>(1.38–1.80)</td>
<td>1.81</td>
<td>(1.50–2.18)</td>
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<td>(0.67–0.81)</td>
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<td>(1.11–1.67)</td>
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<td>(1.80–2.00)</td>
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</table>

Note: CI = Confidence interval, OHC = Out-of-home care. Ref. = Reference group (HR = 1).

aAdjusted for gender, year of birth, and maternal education.
Organisational models of health services for children and adolescents in out-of-home care: Health technology assessment

Tita Mensah1,2 | Anders Hjern3,4 | Kickan Håkanson5 | Pia Johansson5,6 | Ann Kristine Jonsson5 | Titti Mattsson7 | Sofia Tranæus5,8,9 | Bo Vinnerljung10 | Pernilla Östlund5,8 | Gunilla Klingberg1

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6Public Health & Economics, Huddinge, Sweden
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Abstract

Aim: Decades of research confirm that children and adolescents in out-of-home care (foster family, residential care) have much greater health care needs than their peers. A systematic literature review was conducted to evaluate organisational health care models for this vulnerable group.

Methods: A systematic literature search was undertaken of the following databases: Academic Search Elite, CENTRAL, Cochrane Database of Systematic Reviews, Cinhil, DARE, ERIC, HTA, PsycInfo, Psychology and Behavioural Sciences Collection, PubMed, SocIndex. Randomised and non-randomised controlled trials were to be included. Two pairs of reviewers independently assessed abstracts of the identified published papers. Abstracts meeting the inclusion criteria were ordered in full text. Each article was reviewed independently, by pairs of reviewers. A joint assessment was made based on the inclusion criteria and relevance. Cases of disagreement were resolved by consensus discussion.

Results: No study with low or medium risk of bias was identified.

Conclusion: In the absence of studies of acceptable quality, it is not possible to assess the impact of organisational models intended to ensure adequate health and dental care for children and adolescents in out-of-home care. Therefore, well-designed follow-up studies should be conducted following the implementation of such models.

KEY WORDS
health care interventions, utilisation of health care, systematic review, foster care, dental...
INTRODUCTION

Studies from Scandinavia, the UK and the United States show that 3–6 per cent of all children will be placed in societal out-of-home care (OHC; foster family and residential care) before the age of 18.1–4 Eurochild (2010) estimated that in the EU-countries, around one million children were in OHC on a given day.5 For decades, studies from Europe, North America and Australia have consistently reported that these children have significantly greater health problems and greater health care needs than their peers in the general population. This applies not only to somatic health,6,8,17,19,24,27,37 but also to dental health18,26,27,29,38–42 and mental health.7,25,43–72

Children and adolescents in OHC comprise a vulnerable subpopulation, for whom society de facto has assumed parental responsibility (in loco parentis). However, despite extensive reporting of high rates of unmet health care needs, surprisingly, little seems to be known about effective strategies for provision of health care to children and adolescents in OHC.

In Nordic countries (Sweden, Denmark, Norway, Finland and Iceland) child welfare legislation and in the present review, OHC includes placement of severely anti-social children and adolescents in secure units and other forms of residential care.

1.1 Promising initiatives

In a report to the EU-commission, the authors identified four promising models of ‘good practice’.73 Supplement S4 presents a summary of these models.

In this context, a systematic literature review was conducted, of studies evaluating models for delivery of health services to children in OHC.

1.2 Purpose of the systematic review

The protocol for this systematic review was registered in PROSPERO CRD42016049484, available at https://www.crd.york.ac.uk/prosp ero/ and was conducted as a project by the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU).74

The purpose was to evaluate organisational models for systematic delivery of health and dental care to children and adolescents in OHC, with special reference to the following questions:

- What are the effects of organisational models intended to ensure that OHC children receive health and dental care?
- Which are the core ethical, social and legal issues to be considered when selecting organisational models?

MATERIALS AND METHODS

Eligibility (inclusion/exclusion) criteria were specified using the population, intervention, comparison and outcome approach (PICO).

2.1 Inclusion criteria

Population: Children/adolescents to age 17 who are about to enter OHC or are already in OHC.

Intervention: Organisational models for delivery of health and dental care to children and adolescents in OHC.

Control intervention: No restriction.

Efficacy Endpoints: Access to health and dental care.

Types of Studies: Systematic reviews, randomised controlled trials (RCT) and non-randomised studies with pre-and post-measurement of outcome.

Follow-up time: Not specified.

Study size: Not specified.

Languages: Swedish, Norwegian, Danish, English, Spanish, French and German.


2.2 Exclusion criteria

Studies without a control group and without pre-and post-measurement of outcome.

2.3 Literature search and procedure

Systematic search strategies were designed and implemented by an information specialist, in consultation with the review team. The focus of the searches was broad and comprehensive, particularly with respect to interventions. The following databases were searched: Academic Search Elite (EBSCO), CENTRAL, Cochrane Database of Systematic Reviews, Cinahl (EBSCO), DARE, ERIC (EBSCO), HTA, PsycINFO (EBSCO), Psychology and Behavioural Sciences Collection (EBSCO), PubMed (NLM) and SocIndex (EBSCO) (Supplement S1). The final search was conducted in March 2018. Reference lists were controlled. No language restrictions were applied in the literature search.

2.4 Screening of abstracts search

Two pairs of authors screened the search results (title and abstract) independently, according to the defined inclusion and exclusion criteria. If at least one reviewer considered an abstract relevant, the paper was included and read in full text.
2.5 | Assessment of risk of bias and data extraction
The risk of bias was assessed with respect to selection, performance, detection, attrition, reporting and conflict of interest, according to the SBU standardised checklists for assessing how well studies meet basic quality criteria. This checklist is similar to the Cochrane checklist (http://www.cochrane.org/). For bias assessment regarding systematic reviews, the AMSTAR instrument was used. The quality of included studies (i.e. risk of bias) was rated as high, moderate or low. Only studies with moderate to low risk of bias were considered for grading of scientific evidence and conclusions. Any disagreements with respect to the quality rating of individual studies were resolved by consensus within the reviewer group. Thereafter, data were extracted from the included publications. All recorded extracted data were checked by the authors in pairs and were included only after consensus discussions. All decisions were documented.

2.6 | Grading of certainty
The quality of the evidence for outcome measures was assessed according to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.

3 | RESULTS OF THE SYSTEMATIC REVIEW
The database searches identified 14,576 abstracts. A further nine studies were identified through manual searching, giving a grand total of 14,585 papers. Figure 1 shows the total number of abstracts and studies identified in the searches.

3.1 | Systematic reviews
With respect to systematic reviews of studies investigating the effects of organisational models for provision of health and dental care to children and adolescents in OHC, no reviews with low or medium risk of bias were identified.

3.2 | Primary studies
With respect to primary studies of the effects of organisational models for provision of health and dental care to children and adolescents in OHC, no studies with low or medium risk of bias were identified. Excluded full-text papers are described with full reference and reason for exclusion in Supplement S2.

3.3 | Excluded studies of interest
Supplement S3 includes a description of studies that did not meet the inclusion and quality criteria overall, but which may still be of interest. There were a few studies of quasi-experimental design which did not meet the inclusion criteria. Other studies of potential interest were cohort studies with pre- and post-measurement, time-series studies without a comparison group and studies for validation and testing of standardised instruments. However, the results of these
4 | DISCUSSION

Of the total of 14 585 studies, 271 were read in full text. Despite the high volume of published papers, critical scrutiny failed to identify any study with low or moderate risk of bias. This result is disconcerting, given that children and adolescents placed in OHC are extremely vulnerable, with high rates of somatic, dental and mental health problems. This has been acknowledged by the scientific community since the 1970s, in literally hundreds of studies from many different countries. Furthermore, these children should be regarded as highly dependent on state initiatives to ensure that they receive adequate health care, on par with other children in the community.

Although Swedish children in OHC are included in the universal health care system, including free preventive child health care and dental health care, several studies have indicated that they are not well served by this system.26,27,29,30 International research, summarised in a recent report to the EU-commission, has reported similar findings.73. The consequence is that the health care needs of children in OHC are often neglected, and the children are thereby denied their right to the best attainable health.

4.1 | Reasons for high rates of health problems

There are several possible reasons why children in OHC—and subsequently also as adults—have more health problems than their peers.73 These include a history of abuse and neglect, parental neglect of health care needs, older children commonly failing to attend medical and dental appointments, parental mental health problems leading to genetic vulnerability, and poverty and stress leading to early adverse effects on health. Moreover, adverse childhood experiences have a cumulative effect, strongly linked to somatic and mental health problems.73,78,79 However, there is also accumulated evidence of negative consequences attributable to a general lack of systematic routines for provision of health services in OHC, over-reliance on carer observations and even of neglect of health issues by child welfare authorities.9,26,29,30,80-84 The instability of OHC (multiple placements/changes of residence over time are common) probably contributes significantly to this issue.20,81 Not everything can be blamed on the birth parents or on the children themselves.

Since the 1970s, researchers, paediatricians and others have recommended that child welfare and health authorities should develop regulations and models for systematically ensuring comprehensive health care (including preventive and dental health care) to children and adolescents in OHC.73 There are promising initiatives, at national and local levels, but to date, these models have not been subjected to rigorous scientific evaluation.

4.2 | Ethical, social and legal aspects

Ethical, social and legal issues arise in selection of organisational models for provision of health services to children in OHC. The encompassing principle in the Nordic child welfare systems is that children in OHC are entitled to the same standards of health and dental care as other children in the community. The regulations include legal responsibility for society to provide good care for children and adolescents in OHC, whose parents (for various reasons) are unable to meet their legal parental obligations. The legal and ethical values are best summarised by the credo ‘in loco parentis’, ‘in the place of parents’.86-88 When the state assumes responsibility for non-temporary, 24-hour care of children, the state should meet our expectations of reasonably able parents, including adequate care of the children’s health. This issue is, however, complicated by the fact that responsibility for the children’s wellbeing is fragmented: several agencies are involved, for example child welfare authorities and health care providers. Thus, the distribution of responsibility may be unclear.

One way to support child welfare authorities in the work of addressing the children’s health needs is to implement high quality and well-functioning organisational models, with routines and supporting documents for the daily work of child welfare authorities. To clarify the agencies’ respective responsibilities, Swedish legislation was amended in 2017, with more stringent requirements for health care providers to investigate the health and dental care needs of children in out-of-home placements (Lag (2017:209) om hälsoundersökning av barn och unga som vårdas utanför det egna hemmet). The new regulation has not yet been evaluated, and to date has been implemented only sporadically.74,89

A paramount principle of relevance to any organisational model is to avoid inequalities in the provision of health care for children in OHC, compared with other children in the general population, and to compensate for inadequate health care before placement in OHC. These goals require legal clarity and a strong need for systematic procedures and documentation to ensure that these children’s health care needs are not addressed randomly or unfairly by the authorities. However, equivalent treatment should not mean that the authorities treat all children according to the same template, without regard to individual needs. The conclusion of this review is that special organisational solutions are necessary to ensure that OHC children receive the health and dental care they need.

Another principle concerns children’s rights under the United Nations Convention on the Rights of the Child (CRC). In recent decades, the rights of children with respect to their contact with authorities have been gradually incorporated into legislation in the Nordic countries. The right of children to health care on equal terms is a fundamental component of the Convention. According to Articles 24 and 25, all children have the right to health care. Other key elements of the Convention are the right not to be discriminated against (Article 2), the best interests of the child (Article 3) and the right to be heard (Article 12). The Convention also affirms the aforementioned significant in loco parentis principle. In January 2020, the Convention
will be incorporated into Swedish law (Lag [2018:1197] om Förenta
nationernas konvention om barnets rättigheter). This will enable
Swedish agencies to cite the CRC directly as a basis for their decisions.

4.3 | A hypothetical organisational model

In the HTA-project conducted by the Swedish Agency for Health Technology Assessment and the Assessment of Social Services, a hypothetical organisational model was described and estimated cost calculated.\(^7\) The model was inspired by the English model and the Mariagerfjord process (see Supplement S4) but adapted to current conditions at local government level in Sweden. The model includes a standardised comprehensive health and dental status check-up by specialist health and dental personnel when the child or young person is placed in OHC; nationally developed, age-specific checklists with supplementary local information to plan the health and dental care measures; and an update twice a year by the child’s designated social worker on measures taken to remedy health and dental problems. The resource requirements and costs for this hypothetical organisational model are modest; per child and year estimated costs of SEK 3 500 (approximately € 350). The initial health and dental status check-up when the child is placed would require around 4 hours of a specialist medical officer’s time and 1 hour of a specialist dental officer’s time, at an estimated total cost of SEK 4 900 (approximately € 490). When ending placement in OHC, there is also need for a specialist dental officer to do a full dental examination including referral to general practitioner at an estimated cost of SEK 2 400 (approximately € 240). The estimate for specialist medical officer is based on a need for the medical officer to go through all available medical records from different health care providers and a comprehensive medical assessment including acquired medical and psychological tests. The cost for the dental specialist is based on the social insurance system’s level of reimbursement for a comprehensive dental examination by a specialist. The most expensive item would be setting up the model, which includes training of social workers and collating the information for the national and local checklists, estimated to cost around SEK 5.5 million (approximately € 550 000) during the first year of model implementation.

4.4 | Need for further research

There are several reasons why this systematic review failed to identify studies on effective strategies to health care before, during or after placement in societal out-of-home care. Firstly, there are obvious legal issues. In most countries, medical, dental and social care are regulated by different legislation. This results in health and welfare officers working in isolation, with infrequent communication across the jurisdictions. Sometimes, the confidential nature of health care, which precludes disclosure of information, may hinder or complicate necessary inter-disciplinary collaboration.

The acceptance and adoption of evidence-based medical care have resulted in greater stringency with respect to research methodology and study design. Today, this is a prerequisite for attaining funding, ethical approval and acceptance of manuscripts for publication. This might be more readily achieved in medicine than in many other scientific fields, because the research conditions are less complex. In order to facilitate important evaluation and identification of significant and effective concepts in social sciences, greater consistency in study designs is advocated, to facilitate comparison of interventions or methods.

There is a fundamental need for rigorous evaluations of current models (see Supplement S4) for systematic assessment of health care needs and provision of health care to children in OHC. Moreover, experience from England has clearly shown that systematic follow-ups of initiatives from legislators, at the national level, are needed if new guidelines and legislation are to be more than ‘fancy words’.\(^7\)

5 | CONCLUSION

This systematic review of the literature failed to disclose any studies of adequate quality. It is therefore not possible to determine the effects of organisational models for providing health and dental care to children and adolescents in out-of-home care. Henceforth, when organisational models are implemented, well-conducted follow-up studies should be undertaken to evaluate their effects. There is also a need for studies that assess the prevalence of physical, dental and mental health problems and oral disease among children entering or already placed in out-of-home care.

ACKNOWLEDGEMENTS

We gratefully acknowledge Joan Bevenius Carrick for language revision.

CONFLICT OF INTEREST

In accordance with SBU’s regulations, the experts involved in the project have submitted declarations of conflict of interest. These documents are available at SBU’s office. SBU has deemed that the declarations confirm that the participants fulfil the requirements of objectivity and impartiality.

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Anders Hjern \(\text{https://orcid.org/0000-0002-1645-2058}\)

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35. Zewdu AM. Health-related benefits among children in the child welfare system: prevalence and determinants of basic and/or attendance benefits. Norsk Epidemiologi. 2010;20:77-84.


SUPPORTING INFORMATION

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

### Supplement 1. Literature search strategies

**Cochrane library via Wiley Mar 15 2018**

Title: Organisational models for securing access to health and dental care services for children and adolescents in out-of-home care

The literature search is performed by Ann Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnerljung.

#### Search terms

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<tr>
<td>[Child, Institutionalized] explode all trees</td>
<td>57</td>
</tr>
</tbody>
</table>

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- DE "Foster Care" 3355
- TI foster N2 child* OR TI foster N2 parent* OR TI foster N2 care* OR TI foster N2 home* 5759
- MeSH descriptor: [Foster Home Care] explode all trees 127
- MeSH descriptor: [Child, Institutionalized] explode all trees 57

- Foster care** or "correctional facility** or forensic mental health setting** or forensic psychiatric** or forensic patient** or "group care** or "group home** or incarcerated** or "institutional care** or jail or "juvenile detention** or "family-based setting** or "Foster care** or "Foster child** or "Foster famil** or "Foster home** or "Foster parent** or "Foster youth** or "Fostering orphan** or "looked after children** or "out-of-home care** or "out-of-home placement** or "substitute care** or "looked after youth** or "Family-based setting** or LACYP or "children's homes** or "young offender institution** or "early institutionalization** or "juvenile justice institution** or "orphange care** or "care placement** or "Juvenile Justice Aftercare** or "juvenile hall** or "juvenile detention** (TIAB) (Word variations have been searched) 49
- (foster and children) and (foster and care) (TIAB) (Word variations have been searched) 425
- (foster care or "correctional facility" or "correctional facility") and (residential or institutional or foster care) and (adolescent or adolescents or teen or teenagers or youth or youths or youthful or adolescence or juvenile) 191
- (residential or institutional or foster care) and (adolescent or adolescents or teen or teenagers or youth or youths or youthful or adolescence or juvenile) (TIAB) (Word variations have been searched) 191

#### Combined sets

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2. TI ("Foster care" OR "foster child" OR "foster family**" OR "Foster Home" OR "Foster parent**" OR "Foster youth**" OR "Foster orphan**" OR "looked after children**" OR "out-of-home care**" OR "out-of-home placement**" OR "substitute care**" OR "looked after youth") OR LACYP OR "children's homes" OR "young offender institution**" OR "early institutionalization**" OR "juvenile detention**" OR "juvenile justice institution**" OR "orphange care**" OR "care placement**" OR "Juvenile Justice Aftercare**" OR "juvenile hall**" OR "juvenile detention**" (TIAB) (Word variations have been searched) 5759
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### Multisearch

**Academic Search Elite, CINAHL with Full Text, ERIC, Psychology and Behavioral Sciences Collection via EBSCO Mar 15 2018**

Title: Organisational models for securing access to health and dental care services for children and adolescents in out-of-home care

The literature search is performed by Ann Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnerljung.

#### Intervention/Organisation

- DE "Access to Health Care" OR DE "Barriers" OR DE "Health Insurance" OR DE "Health Needs" OR DE "Integrated Services" OR DE "Health Programs" OR DE "Immunization Programs" OR DE "Mental Health Programs" OR DE "Neonatal Health Services" OR DE "Nutrition Services" OR DE "Public Health Services"
- TI (access OR accessing OR access OR accessing OR "ask OR asks") OR "Ages and stages questionnaire" OR barriers OR care OR CBC OR checklist OR checkup OR checkup OR continuity OR coverage OR dental OR dentist OR detection OR evaluation OR health OR improving OR instrument OR intervention OR "insurance OR insurance OR medical OR mental OR monitoring OR needs OR oral OR physical OR policies OR policy OR practice OR... 478955
Title: Organisational models for securing access to health and dental care services for children and adolescents in out-of-home care

The literature search is performed by Anne Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnerljung.

Search terms

- DE "Foster Care" OR DE "Foster Parents" OR DE "Foster Children"
- TI foster OR foster parents OR foster children

Population:
- DE "Foster Care" OR DE "Foster Parents" OR DE "Foster Children"
- TI foster OR foster parents OR foster children
- AU = Author
- ZC = Methodology Index
- * = Truncation
- " " = Citation Marks; searches for an exact phrase

The search result, usually found at the end of the documentation, forms the list of abstracts.

The search, usually found at the end of the documentation, forms the list of abstracts.
mental OR mentoring OR needs OR oral OR physical OR policies OR policy OR practice OR program OR psychiatric OR psychological OR screening OR services OR somatic OR (access OR barriers OR care OR continuity OR coverage OR evaluation OR health OR interventions OR needs OR outcome* OR policy OR policies OR services OR status OR utilization))

AB ("access to care" OR "access to dental" OR "access to health" OR "access to mental" OR "ASQ" OR "ASQ-SE" OR "Ages and stages questionnaire" OR "assessment tool" OR "barriers to dental" OR "barriers to health" OR "care needs" OR "CASB" OR checklist OR checkup OR check-up OR "child psychiatry" OR "continuity OR dental care" OR "dental examination"

The literature search is performed by Ann Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnerljung.


16 AND 15 26242

Combined sets

16 AND ("Meta Analysis" OR "systematic review" OR "meta analysis") OR (TX ("dental pathway" OR "oral health" OR "oral health care" OR "oral health care needs" OR "oral health care outcomes" OR "oral health care services" OR "oral health screening" OR "oral health status" OR "oral health utilization" OR "oral public health" OR "oral public health care" OR "oral public health care services" OR "oral public health screening" OR "oral public health status" OR "oral public health utilization" OR "oral child psychiatry" OR "oral public health care needs" OR "oral public health care outcomes" OR "oral public health care services" OR "oral public health screening" OR "oral public health status" OR "oral public health utilization")) TX ((randomized) N2 random*) OR (case w1 control*) OR (observation w1 study*) OR (random* N3 (assign* OR allocation)) OR (cohort* OR longitudinal* OR followup* OR "follow up" OR (pre w1 post*) OR (pre w1 test*) OR (post w1 test*) OR (prepost* OR (pre w1 post*) OR (pre w1 test*) OR posttest* OR (program w1 evalut*))

16 AND 18 Limits - Publication Year: 2000 - Peer Reviewed

5368

16 AND Limits - Publication Year: 2013-2023 - 2013-2017 Peer Reviewed

6493

PubMed via NLM Mar 15 2018

Title: Organisational models for securing access to health and dental care services for children and adolescents in out-of-home care

The literature search is performed by Ann Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnerljung.
SocIndex via EBSCO Mar 15, 2018

Title: Organisational models for securing access to health and dental care services for children and adolescents in out-of-home care

The literature search is performed by Ann Kristine Jonsson in collaboration with Anders Hjern, Gunilla Klingberg, Tita Mensah, and Bo Vinnetjung.

Population:

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Combined sets

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5 AND Filters activated: Publication date from 2012/02/01-8968

The search result, usually found at the end of the documentation, forms the list of abstracts.

[MeSH] = Term from the MeSH controlled vocabulary, including terms found below this term in the MeSH hierarchy
[MeSH NoExp] = Does not include terms found below this term in the MeSH hierarchy
[MBJ] = MeSH Major Topic
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[TW] = Text Word
Systematic[SB] = Filter for retrieving systematic reviews
* = Truncation

Intervention/Organisation

TI[access OR accessing OR assessment OR ASQ OR ASQ-SE OR "Ages and stages questionnaires" OR barriers OR care OR CBCL OR checklist OR checkup OR check-up OR continuity OR coverage OR dental OR dentist OR detection OR evaluation OR health OR improving OR instrument OR intervention* OR insurance OR medicare OR medical OR mental OR mentoring OR needs OR oral OR physical OR policies OR policy OR practice OR
The search result, usually found at the end of the documentation, forms the list of abstracts.

AB = Abstract
AU = Author
DE = Term from the thesaurus
MM = Major Concept
TI = Title
TX = All Text. Performs a keyword search of all the database's searchable fields
ZC = Methodology Index
* = Truncation
" " = Citation Marks; searches for an exact phrase

Limiters - Scholarly (Peer Reviewed) Journals; Date of Publication: 20000101-

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Limiters - Scholarly (Peer Reviewed) Journals; Date of Publication: 20000101-
## Supplement 2. Excluded studies

<table>
<thead>
<tr>
<th>Paper</th>
<th>Main reason for exclusion</th>
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<tr>
<td>A new service for Initial Health Assessments for 16+ young people across Kent Community Health NHS Trust, UK. Adoption &amp; Fostering 2013;39:86-90.</td>
<td>Does not answer the research question of the present systematic review</td>
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<td>American Academy of Pediatrics. Committee on Early Childhood, Adoption and Dependent Care. Health Care of Young Children in Foster Care. Pediatrics 2002;109 No. 3 March.</td>
<td>Does not answer the research question of the present systematic review</td>
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<td>Aton-Kay M, Jorge E. Does providing social services with information and advice on immunisation status of “looked after children” improve uptake? Arch Dis Child 2003;88:299-301.</td>
<td>High risk of bias</td>
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<tr>
<td>Belkaert S. Meeting the health needs of young offenders. Paediatric Nursing 2008;2(09):14-7.</td>
<td>Does not answer the research question of the present systematic review</td>
</tr>
</tbody>
</table>

### Does not answer the research question of the present systematic review


### Does not answer the research question of the present systematic review


Kling S, Vinnenberg B, Hjenn A. Somatic assessments of 120 Swedish children Does not answer the research question of the present systematic review.

Jones AM, Morris T. Psychological Adjustment of Children in Foster Care: Permanent placement outcomes from a randomized trial. Child Maltreatment 2006;11(1):90-120.
Does not answer the research question of the present systematic review.


Promoting the quality of life of looked-after children and young people [Structured abstract], Health Technology Assessment Database (2010).


Woolley D, Fink G, Bambra C. Do we have the right to health? The case of vulnerable groups. Public Health 2009;133:747-54.
Supplement 3. Excluded studies of interest

Below is a description of the studies which did not meet the inclusion and quality criteria overall, but which may still be of interest. There were a few studies of quasi-experimental design. Other studies of potential interest were cohort studies with pre- and post-measurement, time series studies without comparison group, and studies for validation and testing of standardized instruments. However, the results of these studies should be interpreted with caution, as these study designs may increase the risk of bias.

Use of standardized instruments for assessing mental health

In England’s legal framework, mandatory for child welfare authorities and health care providers, all children entering OHC should be screened for indications of mental health problems, with the Strengths and Difficulties Questionnaire (SDQ) [1]. In addition, progression of mental health and well-being over time should be monitored through annually repeated tests with the same instrument. Six studies from different countries and a recent systematic review have affirmed that SDQ is a "sufficiently good" instrument to detect indications of mental health problems that should lead to diagnostic clinical assessment [1-6].

A group of studies from the US has examined whether screening with standardized instruments makes any difference, compared to "usual practice" for health assessment of placed children. Lee and co-workers conducted three studies where results from screening with standardized instruments were compared with non-systematic clinical assessments at time of placement in OHC [5,7,8]. In the first study of screening with the Ages and Stage Questionnaire (ASQ), an instrument used to identify children with delayed development, 251 pre-school children assessed with ASQ were compared with 181 children who had been examined at the clinic before systematic use of ASQ was initiated [7]. In the group screened with ASQ, there were twice as many children with indications of delayed development (58% vs. 29%). In the second study using similar methodology, a related instrument was used to identify pre-school children with early socio-emotional problems [8]. In the study, 159 children who had been screened with the Ages and Stages' Questionnaire - Social Emotional (ASQ-SE) were compared with children who received conventional health assessments from the same clinic before the introduction of standardized instruments. Screening with ASQ-SE disclosed problems in 24 percent of children in the group, compared with 4 percent in the group which underwent a conventional, non-systematic health assessment. In the third study, 195 OHC children aged 11–17, were screened with SDQ for indications of mental health problems [3]. The comparison group comprised children in the same age group who had undergone health assessments at the same clinic before the inclusion of SDQ (and other standardized instruments) as part of mandatory routines. Screenings with SDQ disclosed twice as many children with indications of mental health problems (54% vs. 27%).

In the US, Gallagher and co-workers investigated whether screening for symptoms of suicidal behaviour in juvenile delinquents on admission to residential care influenced subsequent rates of suicide attempts during residential care [9]. Data from 3 690 institutions were analysed using multilevel analyses. The results showed that residential care units which did not screen within 24 hours of admission had significantly higher rates of serious suicide attempts among the incarcerated (OR 1.3–4.7).

Studies on systematic reassessment of prescribed psychotropic drugs

Three studies investigated the effects of systematic reassessment of prescribed psychotropic drugs for children and adolescents in OHC. Belloni and co-workers studied 531 subjects, aged between 7 and 18 years, placed in residential care units because of serious behavioural problems [10]. Systematic reassessment, based on medical data and tests with standardized instruments, led to a reduction in administration of psychotropic drugs in 55 percent of the subjects, an increase in dosage in 14 percent, and unchanged treatment in 20 percent. Finally, one group (11%) received no prescribed psychotropic drugs before or after the reassessment. The primary outcome measure was the number of violent incidents during the subject’s period in care. After systematic reassessment of medications, incidents of violence at the two units - from date of admission to care to date of exit were reduced by 62 percent, compared to rates prior to intervention. Moreover, the rate of coercive interventions by staff (e.g. physical restraints) fell by 72 percent.

Huefner and co-workers studied 228 youths of similar background [11]. After a systematic reassessment of medication with psychotropic drugs, the subjects were followed individually up to the time of exit from care (average 4.5 months). The results showed significant decreases in aggressive episodes over time, decreasing internalisation symptoms, and reduced coercive interventions by the staff, as well as fewer incidents of suicidal behaviour.

In another study, Lee and co-workers used administrative data to investigate the effects of new guidelines for use of prescribed psychiatric drugs for youths placed in residential care because of serious behavioural problems [12]. The study group comprised three units which had enrolled more than 10 800 youths over a period of 10 years. Implementation of the new guidelines led to reduced costs over time, without increases in incidents of violence or other aggressive acts.

By comparison, another American study used administrative data to investigate possible effects on placement stability of prescribing antipsychotics for children in foster family or residential care, over a six-month period [13]. Using propensity score matching, 65 children receiving antipsychotics were compared with 325 matched foster children (including psychiatric diagnosis) who had not been prescribed antipsychotic drugs. The rates of placement disruption were basically the same for both groups.

References

Supplement 4. Promising initiatives

In the previously mentioned report to the EU-commission, the authors identified four models of ‘good practice’ that held substantial promise. The common component is that responsibility for OHC-children’s health care has in effect been transferred from the local child welfare authorities to the health care system.

England has developed a national, comprehensive system based on mandatory guidelines for both child welfare and health care organisations at national, regional and local levels [see Simkiss, S, 2018 and Vinnerljung & Hjern, 2018 for detailed descriptions [1,2]]. The model includes mandatory specialist functions at different levels in health care provider organisations, with specific responsibility for OHC-children. The guidelines specify that all children entering OHC should receive a comprehensive health assessment with a compulsory annual follow-up (including dental and mental health). Local and regional compliance with the guidelines is monitored annually by means of performance indicators and auditing reports. The English national model has yet to be rigorously evaluated, but time series studies indicate improved outcomes, particularly for vaccination rates and dental health assessments [3,4-7].

New legislation and guidelines from Norwegian national authorities stipulate mandatory cooperation between local child welfare offices and regional health care providers. However to date this has been restricted to those in residential care [1,8]. Parts of the Norwegian model with ‘enhanced cooperation’ share common ground with the English system, for example that every residential care unit is required to have an attending physician under contract. A core component is that regional health care authorities are given specific responsibility for mental health services to those in residential care. To date there are no studies available on the effects of the new guidelines. However, serious concerns have been raised about the limitations of the reforms: they mainly address adolescents in residential care, who comprise only 10 percent of the OHC-population [8].

In Mariagerfjord, Denmark, local community nurses are responsible for OHC-children’s health care [see Vinnerljung & Hjern for detailed description [9]]. Standardized and age-specifed check-lists and guidelines constructed in consultation with community paediatricians are used, annual health assessments are provided by a visiting nurse and the community nurses provide foster parents with guidance in health care matters. The model is currently under evaluation, but the anecdotal evidence is promising.

The ‘Medical home’/’foster care clinic’ model has been fairly common in the US since the late 1980’s. A ‘Medical home’ is a centralized clinic, responsible specifically for providing health assessments and coordinating health services for children and adolescents in OHC in a geographic area, even when children are moved from one OHC-facility to another. In most cases, it is staffed by a multi-disciplinary team of health professionals [9,10-13]. The guiding principles are detailed recommendations from the American Academy of Pediatrics (AAP), including rapid identification of health care needs when children enter OHC [14].

Of the four models described above, the ‘Medical home’ has been studied most, but has not been evaluated in a study of rigorous design. Generally, data indicate more cost-effective use of primary health care and substantial improvements in timely identification of mental health care needs [11,12]. However, a large study of compliance with AAP guidelines among different facilities targeting OHC-children found no evidence of that the ‘Medical home’ model was superior [13,15]. The model is currently replicated in Uppsala county (covering 8 municipalities with 360 000 inhabitants). Multi-disciplinary services are delivered at Uppsala University Hospital, based on standardized guidelines [16]. To date there are no studies reporting outcomes. To our knowledge, this is the first time that the US ‘Medical home’ model has been tried in Europe.

References

Swedish quality registry for caries and periodontal diseases (SKaPa): validation of data on dental caries in 6- and 12-year-old children

Tita Mensah1,2*, Sofia Tranæus3,4,5, Andreas Cederlund6, Aron Naimi-Akbar4 and Gunilla Klingberg1

Abstract

Background: The Swedish Quality Registry for caries and periodontal disease (SKaPa) automatically collects data on caries and periodontitis from patients’ electronic dental records. Provided the data entries are reliable and accurate, the registry has potential value as a data source for registry-based research. The aim of this study was to evaluate the reliability and accuracy of the SKaPa registry information on dental caries in 6- and 12-year-old children.

Method: This diagnostic accuracy study compared dental caries data registered at an examination with dental health status registered in the patient’s electronic dental records, and with corresponding data retrieved from the SKaPa registry. Clinical examinations of 170 6- and 12-year-old children were undertaken by one of the researchers in conjunction with the children’s regular annual dental examinations where the number of teeth were registered, and dental caries was diagnosed using ICDAS II. Teeth with fillings were defined as filled and were added to the ICDAS II score and subsequently dft/DFT was calculated for each individual. Cohen's Kappa, the intraclass correlation coefficient (ICC), and sensitivity and specificity were calculated to test the agreement of the ‘decayed and filled teeth’ in deciduous and permanent teeth (dft/DFT) from the three sources.

Results: Cohen's Kappa of the dft/DFT-values was calculated to 0.79 between the researcher and the patient record, to 0.95 between patient dental record and SKaPa, and to 0.76 between the researcher and SKaPa. Intraclass correlation coefficient (ICC) was calculated to 0.96 between the researcher and the patient journal, to 0.99 between the patient dental record vs. SKaPa, and to 0.95 between the researcher and SKaPa.

Conclusion: The SKaPa registry information demonstrated satisfactory reliability and accuracy on dental caries in 6- and 12-year-old children and is a reliable source for registry-based research.

Keywords: Data accuracy, Registries, Child, Dental caries, Validation study, Diagnosis, Sensitivity and specificity

Background

Oral and dental health are important components of general health, well-being, and quality of life [1]. In children and adolescents, dental caries is the most common chronic disease, often causing pain and requiring invasive interventions. In general, the dental health of Swedish children and adolescents is good. The Swedish National
Board of Health and Welfare has compiled data on manifest caries at certain ages (3, 6, 12 and 19 years) annually since 1985. According to the last report for the year 2019, 72% of 6-year-olds and 67% of 12-year-olds in Sweden were caries-free [2]. A contributing factor is the free dental care for children and adolescents 0–19 years of age and the organization of dental services whereby the county councils have overall responsibility for delivery of dental care to children and young people. Approximately 95% of Swedish children and adolescents undergo regular dental examinations. The dental care is delivered by the Public Dental Service or by contracted private practitioners [3].

While most children are relatively healthy, some groups of children remain at higher risk for caries, with strong links to overall health and socio-economic factors [4]. One approach to the complex task of exploring such relationships is through registry-based studies. Official national registries are important tools for monitoring dental health in populations and also for registry-based research, in which data from different registries can be merged, to analyze relationships and to understand the interaction between dental health and different social factors, medical diagnoses and general health.

Sweden has a long history of national registries and registry-based research [5], made possible through the system of unique personal identity numbers, consisting of a twelve-digit-PIN, maintained by the National Tax Board for all individuals resident in Sweden since 1947. This identity number makes it possible to link data from different registries to a specific individual [6]. The more than one hundred national quality registries in Sweden are incorporated into clinical workflows and include individualized data about different medical interventions, procedures, and outcomes. They are thereby important tools not only for improving quality in the health sector but are also open for research [7].

As all dental records in Sweden are electronic and use the personal identity number as well as a national coding system to record diagnoses and treatment items [8], data on oral care are readily accessible for research. The Swedish Quality Registry for caries and periodontal disease (SKaPa) is a national registry started in 2008, initially involving Public Dental Services (PDS) at county level, but gradually extending nationwide to now include all PDS in Sweden and more and more private practitioners [9]. It currently includes data on about 90% of the child population (0–19 years of age) [10] and is the only dental registry in Sweden which includes children.

SKaPa is solely based on automatic retrieval of information from electronic dental records about all dental appointments (examinations, health status and treatments) that is subsequently delivered into the registry. This is different from most other registries where data are entered manually. All software systems for electronic dental records in Sweden can communicate with SKaPa. The registry stores information about dental clinics, dental health professionals and patients. Information at a patient level includes the personal identity number, sex, age, dental status on tooth level regarding diagnoses and treatments, risk assessments for caries and periodontitis, and dental care provided.

Although the SKaPa registry started the year 2008, information about validation of the registry has not been published. A prerequisite for using a register such as SKaPa for research is that one can trust the data extracted from the registry, therefore a validation of the quality of the data is of great importance. This validation study is the first systematic evaluation of the quality and validity of this type of dental registry with automatic retrieval of information from electronic dental records. As SKaPa covers such a large proportion of the population, and extensive datasets are available, the registry is potentially a valuable source of data for researchers, provided the validity is high. Knowledge from the study will be valuable for future studies where the SKaPa registry is used for research.

The main research question in this study was therefore: How reliable and accurate is SKaPa registry information on dental caries in children and adolescents?

The following hypothesis was tested: Comparison of clinical registrations with those in the electronic dental records, and with data retrieved from the SKaPa registry differ minimally regarding number of decayed and filled teeth (dft in the primary dentition and DFT in the permanent dentition) in 6 and 12-year-old children.

Methods
After verbal and written information, the legal guardian signed an informed consent form. All children received age-appropriate information and consented to participation. The research was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. The Regional Ethics Review Board in Uppsala, Sweden (#2016/051) approved the study. The study was also registered in Clinical Trials (www.ClinicalTrials.gov; NCT03039010).

Study design
In this diagnostic accuracy study the children were first examined by their customary examiners, who entered the dental status into the electronic dental record (which in this case uses the software Carita, Swedish Care®) followed by clinical examinations conducted by one of the authors (TM), a specialist in pediatric dentistry. Comparisons regarding dental caries were made between the
researcher’s registrations, the data entered in the electronic dental records by the customary examiner and the data retrieved from the SKaPa registry. Thus, the study follows the entire chain of data: data from clinical dental examinations, dental health registrations in the electronic dental record and information on dental health retrieved from the SKaPa registry (Fig. 1).

Setting and study population
This study was carried out in the County of Värmland, Sweden. The background child and adolescent population was about 55,000 with approximately 2,700 children in each age group (0–19 years old) at the time of data collection. The sampling procedure was undertaken in consultation with a biostatistician specialized in epidemiology, in order to make sure even distribution with respect to both socio-economic status and dental caries status, to ensure inclusion of children with expected higher prevalence of caries as well as relatively healthy children. The sample size was determined by using bootstrap resampling simulation based on a fictive sample size of 100,000 individuals. The simulation aimed to estimate a sample size that was enough in size given the initial proportion of 20 percent with caries and 80 healthy individuals. The resampled sample size increased for each iteration with 1 individual, where the true proportion of caries/healthy individual increased for each iteration. The cut-off was arbitrary based on the limitation of the number of possible participants in the study. The simulation showed that if the assumption of the proportion 20/80 for individuals with caries/healthy respectively is true, the sample of 75 is reasonable. The number of samples individual reflect a margin of error on the assumed proportion less than 10%. On this basis a final minimal study population was determined, of at least 75 children in each age category. Of the county’s 25 dental clinics 12 were chosen with enough children (>10 per year group). These clinics included both rural and urban areas, child patients with different caries incidence, and reflected socioeconomic differences. Finally, 177 children were invited to participate: 83 6-year-olds, and 94 12-year-olds from twelve PDS clinics, with 11–17 children per clinic.

We also performed a post hoc sample size calculation to ensure a sufficient sample size. This showed that with a power of 0.90 and a significance level of 0.05 and to test the hypothesis that an assumed real ICC in the sample of 0.95 would differ significantly from a reference ICC of 0.90 we would need 83 subjects. To have at least that precision in each age group, our final sample size of 170 subjects is satisfactory.

Training and calibration
Prior to the clinical examinations, the examiner (TM) underwent training and calibration in ICDAS II (International Caries Detection and Assessment system) scoring by e-learning (https://www.icdms-web.com) and radiographic registration of caries [11, 12]. ICDAS II is a standardized visual system for coding tooth decay. It provides options for coding six different stages of lesions (0 = sound, 1 = first visual change in enamel, 2 = distinct

Fig. 1 Schematic description of data collection. Every child was examined twice, independently by the researcher and the child’s customary examiner. The customary examiners entered the dental status in the electronic dental record. Comparisons were made between the researcher’s registrations, the data entered in the electronic dental records and the data retrieved from the SKaPa registry.
visual change in enamel, 3 = localized enamel breakdown, 4 = underlying dentin shadow, 5 = distinct cavity with visible dentin, and 6 = extensive cavity with visible dentin). The radiographic registrations were calibrated with another dentist from the research group, on 76 patients, a total of 152 radiographs. The calculated Kappa value was 0.79, with 95% confidence interval from 0.64 to 0.93. The strength of agreement was considered to be ‘substantial’. Besides the e-learning, the examiner was also clinically trained and calibrated on ICDAS II. In a calibration exercise TM and another dentist from the research group independently examined ten children, all having teeth with as well as without carious lesions. For calibration as well as for TM’s clinical registration in the study each tooth was scored according to ICDAS II. A tooth with an ICDAS II score of 3–6 was defined as cavitated, i.e., a carious tooth. Teeth with fillings were defined as filled and were added to the ICDAS II score and subsequently dft/DFT was calculated for each individual. In the calibration a total agreement was reach on every tooth.

Clinical examination
From December 2016 to March 2017, in conjunction with their annual dental check-ups, the participating children had an additional clinical examination by TM at their regular dental clinics. TM underwent an update and a new session in ICDAS scoring by e-learning prior to every visit to the different dental clinics. At the clinic, every child was first examined by the customary examiner at the clinic who decided, based on individual indications, whether radiographs were taken. This is the standard procedure and in accordance with legal requirements in Sweden. The children were examined in a normal dental clinic setting, seated in the dental chair using artificial light, a dental mirror and a probe. The teeth were dried with compressed air.

The customary examiner registered oral health status including caries in the electronic dental record. According to clinical guidelines manifest dental caries are defined as visible tooth substance loss without the characteristics of a developmental defect, or in pits and fissures when the point of the probe “caught” upon gentle pressure. Manifest radiographic caries is defined as lesion extending beyond the enamel-dentine junction. The child was then immediately re-examined by TM, registering the number of teeth and dental caries using the ICDAS II score and dft/DFT was calculated for each individual.

All registrations were blinded: the research examiner (TM) had no access to the registrations made earlier the same day by the customary examiner. TM used existing radiographs for diagnosis and no extra radiographs were taken for this study. Comparisons were made between the researcher’s (TM’s) registrations of dental health, the dental health status in the electronic dental records (customary examiner’s registrations), and the data retrieved from the SKaPa registry.

Statistical analyses
To test the agreement in dft/DFT between the researcher’s dental examination, the data registered in the electronic dental record and the SKaPa registry, intraclass correlation coefficient (ICC) was calculated. Separate calculations were made of researcher examination/ SKaPa, dental records/SKaPa and researcher examination/dental records. The calculations were stratified according to age, i.e. 6 and 12 years.

To test the accuracy of caries diagnostics at tooth level, calculations were made for sensitivity, specificity, predictive value of positive test (PV+), predictive value of negative test (PV−) with 95% confidence intervals. Also, Cohen’s Kappa was calculated for the agreement on tooth position level. Kappa was also used for calculation level of agreement of radiographic diagnosis in the calibrations prior to clinical examinations. All statistical analyses were performed using Stata 15 SE. P-values less than 0.05 were considered statistically significant.

Results
Altogether 177 children (83 6-year-olds, 94 12-year-olds) from twelve PDS dental clinics were invited to undergo clinical examination in conjunction with their annual check-up. 171 children presented for examination. One declined to participate. All seven children not included in this study were reported to have been assessed as low caries risk at examination the year before. Finally, 170 children underwent examination: 84 boys (40 6-year-olds, 44 12-year-olds) and 86 girls (43 6-year-olds, 43 12-year-olds). Bitewing radiographs were taken by the customary examiner on 77 of the children (30 6-year-olds, 47 12-year-olds). Table 1 presents the mean value of the caries-index ‘decayed filled teeth’ (dft/DFT) reported by the researcher (TM), the electronic patient dental record and SKaPa, respectively.

Agreement for dft/DFT-values on tooth position level for the three data categories (the researcher’s clinical examination, the electronic patient dental records and the SKaPa registry) was calculated using Cohens Kappa and revealed generally very good correlations (Table 2). Also, the intraclass correlation coefficient (ICC), which reflects the degree of agreement was calculated and revealed very good correlations (Table 3). Calculations of sensitivity and specificity also showed very good agreement (Table 4).
The aim of this study was to disclose the level of agreement (regarding dft/DFT) between the researcher’s clinical dental examination, dental health status registered in the electronic dental record, and data retrieved from the SKaPa registry. The intraclass correlation coefficient (ICC) has previously been categorized as values less than 0.5 are indicating poor, between 0.5 and 0.75 as moderate, between 0.75 and 0.9 as good, and greater than 0.90 as excellent reliability [13].

Kappa has been categorized that values between 0.00–0.20 are indicating slight, 0.21–0.4 fair, 0.41–0.60 as moderate, 0.61–0.8 as substantial and 0.81–1.00 as almost perfect strength of agreement [14]. Our calculations of Cohen’s Kappa of the dft/DFT-value was calculated to 0.79 between the researcher and the patient record, to 0.95 between patient dental record and SKaPa, and to 0.76 between the researcher and SKaPa, indicating “substantial” to “almost perfect” agreement. The intraclass correlation coefficient (ICC) was calculated to 0.96 between the researcher and the patient journal, to 0.99 between the patient dental record vs. SKaPa, and to 0.95 between the researcher and SKaPa indicating “excellent” reliability. The results confirm the reliability and accuracy of the data in the SKaPa registry. The clinical status for dft/DFT in 6 and 12-year-old children differs minimally from data entered into the SKaPa registry, and from that retrieved from the registry.

Table 1 Decayed filled teeth (dft/ DFT-value) in 6- and 12-year-old children, reported by the researcher’s clinical examination, electronic patient dental record and SKaPa

<table>
<thead>
<tr>
<th></th>
<th>Total (n = 170)</th>
<th>6-year-olds (n = 83)</th>
<th>12-year-olds (n = 87)</th>
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<tbody>
<tr>
<td>Researcher</td>
<td>Mean 0.68</td>
<td>Min–max 0–8</td>
<td>SD 1.48</td>
</tr>
<tr>
<td>Patient dental record</td>
<td>0.72</td>
<td>Min–max 0–7</td>
<td>SD 1.44</td>
</tr>
<tr>
<td>SKaPa</td>
<td>0.72</td>
<td>Min–max 0–7</td>
<td>SD 1.48</td>
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</table>

Table 2 Agreement for reported dft/DFT-value on tooth level between the researcher, the patient dental records and the SKaPa-registry (Cohen's Kappa)

<table>
<thead>
<tr>
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<th>Kappa (SE)</th>
<th>Agreement (%)</th>
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<tr>
<td>Researcher/patient dental record</td>
<td>0.91 (0.02)</td>
<td>99.4</td>
</tr>
<tr>
<td>Patient dental record/SKaPa</td>
<td>0.93 (0.02)</td>
<td>99.5</td>
</tr>
<tr>
<td>Researcher/SKaPa</td>
<td>0.87 (0.02)</td>
<td>99.2</td>
</tr>
</tbody>
</table>

Table 3 Intraclass Correlation (ICC) of reported dft/DFT in 6- and 12-year-old children between the researcher, electronic patient dental record and SKaPa

<table>
<thead>
<tr>
<th></th>
<th>Total (n = 170)</th>
<th>6-year-olds (n = 83)</th>
<th>12-year-olds (n = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher/patient dental record</td>
<td>0.96</td>
<td>95% CI 0.94–0.97</td>
<td>0.96</td>
</tr>
<tr>
<td>Patient dental record/SKaPa</td>
<td>0.99</td>
<td>95% CI 0.98–0.99</td>
<td>0.99</td>
</tr>
<tr>
<td>Researcher/SKaPa</td>
<td>0.95</td>
<td>95% CI 0.93–0.96</td>
<td>0.96</td>
</tr>
</tbody>
</table>

Table 4 Accuracy of caries diagnostics. Comparisons between researcher, patient dental record and SKaPa registry

<table>
<thead>
<tr>
<th></th>
<th>Sensitivity</th>
<th>95% CI</th>
<th>Specificity</th>
<th>95% CI</th>
<th>PV + 95% CI</th>
<th>PV – 95% CI</th>
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<tbody>
<tr>
<td>Researcher/patient dental record</td>
<td>0.93</td>
<td>95% CI 0.87–0.97</td>
<td>1.00</td>
<td>95% CI 0.99–1.00</td>
<td>0.90</td>
<td>95% CI 0.83–0.94</td>
</tr>
<tr>
<td>Patient dental record/SKaPa</td>
<td>0.97</td>
<td>95% CI 0.93–0.99</td>
<td>1.00</td>
<td>95% CI 0.99–1.00</td>
<td>0.90</td>
<td>95% CI 0.84–0.94</td>
</tr>
<tr>
<td>Researcher/SKaPa</td>
<td>0.93</td>
<td>95% CI 0.87–0.97</td>
<td>0.99</td>
<td>95% CI 0.99–1.00</td>
<td>0.83</td>
<td>95% CI 0.76–0.89</td>
</tr>
</tbody>
</table>

Values for sensitivity, specificity, predictive value of positive test (PV+), predictive value of negative test (PV–) and 95% confidence intervals.
Caries can be diagnosed clinically by visual inspection or by probing, supported by radiographic evidence, and more recently by adjunctive methods such as fiberoptic transillumination and laser fluorescence [16]. A combination of visual-tactile and radiographic examination is more reliable than either method used separately, but to date there is inadequate scientific support for other adjunctive diagnostic tools [17]. Intra-examiner reliability is usually higher than inter-examiner reliability when diagnosing dental caries [18].

In general, accuracy in excluding the presence of caries is greater than in confirming its presence [19]. Bitewing radiographs were taken on 77 of the children in this study. Radiographs should only be taken on individual indications, according to the standard procedure and the legal regulations in Sweden. As radiographs were unavailable for 93 of the children, there could be a risk that some caries lesions were undetected. Further, in all analyses, the lowest agreement was between the researcher and the SKaPa registry. This is what would be expected as it is the comparison with the most potential sources of error, with the differences between two examiners as well as the potential error in the data transfer.

The outcome measures in this study were the number of teeth with caries, expressed as dft and DFT in the two age groups, respectively. Originally it was intended to use the outcome measure deft/DMFT (including e = extracted, M = missing due to caries) but as there was a problem to retrieve e/M from the registry we assessed this variable to be unreliable and it was not included in this study.

It is important to consider possible shortcomings of using SKaPa registry data for this kind of study. The registry shows calendar year status, i.e. from 1st January to 31st December, so that when a restoration or an extraction is undertaken during the year the status registered in SKaPa changes. Therefore, the diagnostics made during the examinations did not always conform with the data extracted from SKaPa, which represents the accumulative status in 31st of December. In this study there were a few individuals with differences in deft/DFT in the electronic patient dental record and the data extracted from SKaPa, which in turn affects Cohen's Kappa, ICC and calculations of specificity and sensitivity. Review of the dental records of these patients disclosed that they had developed new caries lesions during the calendar year, after the examination date, and as SKaPa displays the dft/DFT values for the full calendar year, the data differed. Another limitation could be that only ten children were examined for calibration before the clinical examinations. The WHO recommends at least 25 children for epidemiological studies. Yet, these ten children were not caries-free and there was a perfect agreement on caries scoring.

Generally, the dental health of Swedish children is good. This can be a shortcoming in this kind of study, as it includes many children with good dental health. We have tried to accommodate this by distributing both socio-economic status and occurrence of dental caries through both urban and rural parts of Värmland.

Population-based dental registries make it possible to monitor dental health changes in a population. They are also important tools in health care research, for studying risk factors and evaluating interventions. As SKaPa holds information about diagnoses and treatment it is possible to use the registry for different types of research and in large groups of patient populations, e.g. longitudinal follow-ups of treatment, comparisons of oral health in different subgroups, exploring dental health in relation to general health issues by linking with other registries etc. Further, the registry is also available for international research collaborations, why its properties are of interest also outside of Sweden. However, quality registry-based research is possible only if registrations in patient dental records are complete and are transferred to the registries without error. There is always a risk of false variables in data records. Validation of registries is highly important, to ensure that the data are valid and reliable [20]. This was also the scope of the present study, and from that perspective it is both important and promising that this study shows very good correlation between the registered data and that retrieved from the SKaPa registry.

Conclusions
The SKaPa registry information demonstrated satisfactory reliability and accuracy on dental caries in 6- and 12-year-old Swedish children and is a reliable source for registry-based research.

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Authors’ contributions
TM, GK, ST and AC conceived ideas and designed the study. TM organized the data collection and drafting of the manuscript. ANA and TM analyzed the materials. ANA also contributed to the statistical analysis and together with TM and GK participated in interpretation of the study results. All authors contributed to the manuscript and read and approved the final draft. All authors read and approved the final manuscript.

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Accuracy of the Swedish quality registry for caries and periodontal diseases (SKaPa) – evaluation in 6- and 12-year-olds in the region of Värmland, Sweden

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\textbf{ABSTRACT}

\textbf{Objectives:} This study evaluates the agreement of data on dental caries between electronic dental records and data retrieved from the national SKaPa-registry (Swedish Quality Registry for caries and periodontal disease), with special reference to e/M in deft/DMFT.

\textbf{Methods:} In a random sample of 500 6- and 12-year-old children having received dental care in 2014 in the county region of Värmland, Sweden, the diagnostic accuracy of data in electronic dental records with corresponding data obtained from the SKaPa-registry was compared by using Cohen’s Kappa and Intraclass correlation coefficient (ICC).

\textbf{Results:} For dft/DFt the Kappa was 0.95, and ICC 0.98 (total population). For deft/DMFT in the total population the Kappa was 0.80 and ICC 0.96. For 6-year-olds (deft) the Kappa was 0.89 and ICC 0.99 and for 12-year-olds (DMFT) the Kappa was 0.70, and ICC 0.83. The corresponding figures for Kappa and ICC when excluding individuals without caries (deft/DMFT = 0) were: Total population 0.63 and 0.94; 6-year-olds 0.79 and 0.99; 12-year-olds 0.42 and 0.68.

\textbf{Conclusion:} Agreement between data in the dental records and SKaPa was very high for dft/DFt confirming that transfer from the dental records to the SKaPa-registry is safe and correct. As the accuracy of deft/DMFT was considerably lower than for dft/DFt we advise against using deft/DMFT data from SKaPa for research purposes at this point.

\textbf{Introduction}

Registries compiling data on diseases, medical and dental diagnoses, treatments, and treatment outcomes are important in public health work. Depending on how the registries are constructed and their degree of coverage of the population, they can provide useful information for monitoring health and enable evaluation of treatments and interventions. The Nordic countries, including Sweden, have a long tradition of official national registries and registry-based research \cite{1,2}. A key element in registry-based research is the possibility to combine information about individuals from different registries. In Sweden, this is possible thanks to a personal identity number (PIN). Everyone who is registered in the country has a unique PIN consisting of twelve digits \cite{3}. The first eight digits show date of birth (year, month and day of birth) and are followed by four check-digits where sex is shown by the second last digit, even for female and odd for males \cite{4}. The PIN is used as a person’s identifier in all communication with government authorities, with banks, tax agency and in all medical and dental records. The PIN is also shown on all identification cards, passports etc.

All dental records in Sweden are electronic, and in addition to using the PIN, they also use a national code system for documentation of diagnoses and treatments linked to the social insurance system regulating dental care and reimbursement for Swedish citizens \cite{5}. This allows development of dental health registries that can be used for studies of dental treatment measures and oral health. Further, by combining dental health registries with e.g. registries for medical conditions, taxation, level of education etc. it is possible to monitor and follow oral and general health in large populations and also to study the impact of possible risk factors and to evaluate interventions \cite{6}.

Swedish healthcare is governed by 21 county regions. Their councils have the over-riding responsibility to ensure
that dental care is available for people living in the region with a special obligation to ensure comprehensive dental care, including specialist dental care, for children and young adults (up to the age of 23 years). They are also responsible for the Public Dental Service (PDS) [7]. Dental care is free of charge up to the age of 23 and can be carried out by either PDS (responsible for approximately 88% of the dental care for children and young adults in Sweden) or private practitioners (PP). About 95% of Swedish children and adolescents undergo regular dental examinations and comprehensive dental care over a period of one to three years.

The Swedish Quality Registry for caries and periodontal disease (SKaPa) is a national registry started in 2008, comprising data which is transferred completely automatically from dental records held by dental clinics within the PDS and many PP across all of Sweden [8]. More than 8.5 million individuals are recorded in SKaPa and the registry receives data from six different digital dental record systems (Lifecare Dental, Carita, T4, FREENDa, ALMASOFt and OPUs Dental). The registry holds information about dental care organizations and dental professionals individually for each patient. At a patient level, the information covers the PIN, age, sex, dental health status, dental diagnoses, dental treatment, and risk assessments for caries and periodontal disease [9]. SKaPa is the only quality registry in dentistry in Sweden incorporating children, and presently it includes data on about 90% of the Swedish child population (0-19 years of age). The registry produces continuous national, regional and local epidemiological information and provides a resource for dental research and health economic evaluations of dental healthcare [9].

It is important that the quality of data in SKaPa is high. To ensure this it is essential that the clinical registrations of diagnoses and treatment are made correctly, that the transfer of data to SKaPa works without interference, and finally that the data extracted from SKaPa provide accurate information. With respect to dental caries (defined as decayed and filled teeth), this has been evaluated in a previous study which followed the whole chain of data [10]. That study compared dental health registrations from the researcher’s clinical dental examination, dental health status recorded by the child’s customary examiner (i.e. registrations in the electronic dental records for 6- and 12-year-old children) and dental health data retrieved from the SKaPa registry in 170 children. Reliability and accuracy were satisfactory along the whole chain: between the researcher and the customary examiner; between the researcher and SKaPa; and between the customary examiner and SKaPa. At that time, it was not possible to retrieve data for extracted/missing teeth (et/MT) in the deft/DMFT (number of decayed, extracted (due to caries), or filled primary teeth/number of Decayed, Missing (due to caries), or Filled permanent Teeth) from SKaPa, but for dft/DFT (number of decayed, or filled primary teeth/number of Decayed, or Filled permanent Teeth) both reliability and accuracy were very good throughout the entire data chain. Since patients having teeth extracted because of dental caries may have a more severe degree of the disease the dft/DFT indices overestimate the oral health in these individuals. As the SKaPa registry is used for planning of resources for the dental care and for research, also the deft/DMFT indices, particularly the variable et/MT, as well as data on dental treatments need to be further validated. As the previous study [10] showed very good agreement between the researcher and the customary examiner it was possible to establish that the electronic dental records are valid as reference standard. This is important as it makes it easier to include larger groups of patients when continuing to validate the SKaPa registry. Against this background, the research questions in the present study were: How well do the data on dental caries (including extracted and missing teeth in deft/DMFT) and dental treatments (treatment codes for nine preventive treatments) in the electronic dental records in 6- and 12-year-old children agree with the data retrieved from the SKaPa registry? The following hypothesis was tested: The data in the electronic dental records for 6- and 12-year-old children, with respect to dft/DFT, deft/DMFT and preventive dental treatments differ minimally from data extracted from the SKaPa registry (defined as an Intraclass Correlation Coefficient (ICC) with the lower bound of a 95% confidence interval above 0.90).

Material and methods

Study design

This retrospective study compared data for the year 2014 in electronic dental records in the data system Carita (Swedish Care System AB), with data extracted from the SKaPa-registry for the same time period. Carita is used in four county regions representing almost 22% of Swedish children and adolescents. The study was carried out in one of these regions.

Participants and setting

A random sample of 500 6- and 12-year-old children (250 per age group) having received dental care in 2014 was identified by the PDS (Public Dental Service) administration in Värmland. The children had not been included in the preceding study [10].

The study was carried out in the county region of Värmland, Sweden. Värmland is situated almost in the middle of Sweden and on the border to Norway and has about 283,000 inhabitants. There are both rural and urban areas and the main city Karlstad hosts a university. Approximately 92% of the children in Värmland receive their dental care within the PDS. The year 2014 was chosen as it at this time was mandatory to carry out annual dental examinations of children in Värmland. In 2015 Sweden received more than 70,000 asylum seekers under the age of 18, mainly from Syria. Many of these children needed emergency dental care and registrations from emergency appointments are likely to be less accurate that could have affected the present study. Excluding asylum seekers would require collation with other registries and this was not possible in this study. Data compilation from dental records started in 2017 and were finalized in 2018. After that SKaPa provided output data and statistical analyses were completed in 2021.
In 2014 there were approximately 2,700 children aged 6 and 12-years, each, in Värmland. Of these, 2,623 6-year-olds and 2,460 12-year-olds had a dental examination carried out within the PDS. According to PDS statistics, the dental health in this background population was good; 78% of 6-year-olds and 74% of 12-year-olds in the region were reported to be caries free (6-year-olds: dft mean 0.72; sd 1.79; 12-year-olds: DFT mean 0.48; sd 1.06). Based on this information and in consultation with a biostatistician, it was decided that a random sample of 250 from each age group (approximately 10%) would be sufficient to ensure inclusion representative of the background population.

### Test methods

Output data from the SKaPa registry was used as index test (the test that is being evaluated against a reference standard) while data from the electronic dental records served as reference standard. Dental caries diagnoses (represented by the indices dft/DFT, et/MT, deft/DMFT) and dental treatments, namely nine different codes for preventive treatments, were compiled independently from dental records and SKaPa. The preventive measures were chosen as they were likely to be common treatments and thereby frequent findings in the dental records. All variables are described in Table 1.

Starting with the dental records, information for all variables were gathered and registered in Excel® by two of the authors (TK and CC), Figure 1. Prior to the registrations they underwent training and calibration in data extraction from dental records in the dental record system Carita (Swedish Care System AB). Thereafter output data from SKaPa on the same variables were added for each individual matched by the PIN. Data were pseudonymized throughout the compiling and analyzing process.

### Statistical analysis

The proportions of registrations with exact agreement (exactly the same measure in both data sources) between index (SKaPa) and reference (electronic dental records) were calculated and are presented as exact agreement in percentage. To provide more information and give a better understanding of the data we also included two other measures of agreement between index and reference. Cohen’s Kappa, which is presented with the test statistic and standard error and, Intraclass Correlation Coefficient (ICC), which is presented with the test statistic and 95% confidence interval. All analyses were performed using Stata 15 SE.

### Ethics

The study was registered in Clinical Trials [www.clinicaltrials.org; NCT03039010](http://www.clinicaltrials.org) and approved by the Regional Ethics Review Board in Uppsala, Sweden in 2016 (#2016/051).

### Results

#### Participants

The study population included 250 6-year-olds (46% boys, 54% girls) and 250 12-year-olds (48% boys, 52% girls). Information on dental caries and frequency of preventive measures recorded from the dental records (reference standard) is shown in Table 2.

#### Test results

For the total group of 500 individuals the Kappa value was calculated for agreement in dft/DFT between the
electronic dental records and the SKaPa-registry to 0.95 (Table 3), ICC was calculated to 0.98 (Table 4). There was an exact agreement in 490 cases (98%) for dft/DFt between dental records and SKaPa (whereof 373 cases with dft/DFt = 0).

The calculated Cohen’s Kappa for deft/DMFt for the total population was 0.80, deft (6-year-olds) 0.89 and DMFt (12-year-olds) 0.70 (Table 3). The Intraclass correlation coefficient (ICC) for deft/DMFT was calculated for the total population: 0.96, deft (6-year-olds) 0.99 and DMFT (12-year-olds) 0.83 (Table 4). There was an exact agreement in 454 cases (91%) for deft/DMFT between dental records and SKaPa (whereof 353 cases with deft/DMFT = 0).

To fully understand how an extracted or missing tooth (et/Mt) affects the accuracy of data in SKaPa we calculated Cohen’s Kappa, exact agreement and ICC for et/Mt and also for individuals with caries, i.e. for cases where the values of dft/DFT, deft/DMFT and et/Mt, exceeded 0 in the dental records. As shown in Tables 3 and 4 this resulted in a clear decrease of outcomes in all comparisons (Kappa, exact agreement and ICC) most pronounced in the 12-year-olds.

Three treatment codes for preventive measures (codes 204, 313 and 314) were not used at all. The remaining six codes were identified in dental records of 284 children (at least one measure). Comparisons with output data from SKaPa for these six codes revealed very high Kappa values and ICC. Cohen’s Kappa varied between 0.99 and 1.00 for the six preventive measures and the ICC varied between 0.99 and 1.00.

### Discussion

This study shows that calculated Kappa and ICC values for agreement in dft/DFT between the electronic dental records and the SKaPa-registry were very high, whereas the agreement for deft/DMFT values were considerably lower. The discrepancies are related to extracted or missing teeth (et/Mt) and the problem is greater among 12-year-olds compared to 6-year-olds.

As SKaPa is a national quality registry, intended to monitor dental health in the population and for registry-based research, with the potential for linking into other registries, it is important to ascertain that the quality of data in SKaPa is high. Our results confirm that transfer of data for dft, DFt and treatment codes from electronic dental records to the SKaPa-registry is safe and correct. Thus, these variables can be used in registry-based studies incorporating output data from SKaPa. However, the results also clearly show that the accuracy concerning deft and DMFt is too low why it is advised not to use these variables.

By merging official registries, it is possible to analyze and identify differences in general and dental health in specific societal groups. Registry-based research is likely to increase as more registries become available [1, 11]. This kind of research enables inclusion of large populations and data volumes which makes it an attractive way to gain new knowledge. At the same time, there is a risk that researchers fail to see the challenges of registry research, e.g. ethical issues and the importance of the quality of the registries [12–16].
Table 3. Agreement between data on dental caries from patients’ electronic dental records and the SKaPa registry shown as Kappa-values with standard error (SE), and exact agreement in percent. Data on dft, deft and et provided for primary teeth in 6-year-olds, and DFT, DMFT, and MT for permanent teeth in 12-year-olds. For the total group dft/DFT, deft/DMFT and et/MT are combined. For dft/DFT > 1 only, deft/DMFT > 1 only and et/MT > 1 only the analyses include cases where the value for dft/DFT/deft/DMFT/et/MT exceeds 0 in the dental record.

<table>
<thead>
<tr>
<th></th>
<th>Total (6- and 12-year-olds)</th>
<th>6-year-olds</th>
<th>12-year-olds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Kappa (SE)</td>
<td>Exact agreement (%)</td>
</tr>
<tr>
<td>dft/DFT</td>
<td>500</td>
<td>0.95 (0.03)</td>
<td>98.0</td>
</tr>
<tr>
<td>dft/DFT &gt; 1 only</td>
<td>126</td>
<td>0.91 (0.04)</td>
<td>92.9</td>
</tr>
<tr>
<td>deft/DMFT</td>
<td>500</td>
<td>0.80 (0.03)</td>
<td>90.8</td>
</tr>
<tr>
<td>deft/DMFT &gt; 1 only</td>
<td>144</td>
<td>0.63 (0.03)</td>
<td>70.1</td>
</tr>
<tr>
<td>et/MT</td>
<td>500</td>
<td>0.38 (0.03)</td>
<td>91.8</td>
</tr>
<tr>
<td>et/MT &gt; 1 only</td>
<td>45</td>
<td>0.13 (0.04)</td>
<td>26.7</td>
</tr>
</tbody>
</table>

Table 4. Intraclass Correlation Coefficient (ICC) and 95% confidence interval (CI) of dental caries in 6- and 12-year-old children recorded in electronic patient dental records and SKaPa. Data on dft, deft and et provided for primary teeth in 6-year-olds, and DFT, DMFT, and MT for permanent teeth in 12-year-olds. For the total group dft/DMFT, deft/DMFT and et/MT are combined. For dft/DFT > 1 only, deft/DMFT > 1 only and et/MT > 1 only the analyses include cases where the value for dft/DFT/deft/DMFT/et/MT exceeds 0 in the dental record.

<table>
<thead>
<tr>
<th></th>
<th>Total (6- and 12-year-olds)</th>
<th>6-year-olds</th>
<th>12-year-olds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>ICC 95% CI</td>
<td></td>
</tr>
<tr>
<td>dft/DFT</td>
<td>500</td>
<td>0.98 0.98 0.99</td>
<td>250</td>
</tr>
<tr>
<td>dft/DFT &gt; 1 only</td>
<td>126</td>
<td>0.97 0.96 0.98</td>
<td>65</td>
</tr>
<tr>
<td>deft/DMFT</td>
<td>500</td>
<td>0.96 0.96 0.97</td>
<td>250</td>
</tr>
<tr>
<td>deft/DMFT &gt; 1 only</td>
<td>144</td>
<td>0.94 0.90 0.96</td>
<td>68</td>
</tr>
<tr>
<td>et/MT</td>
<td>500</td>
<td>0.36 0.29 0.44</td>
<td>250</td>
</tr>
<tr>
<td>et/MT &gt; 1 only</td>
<td>45</td>
<td>0.05 −0.17 0.30</td>
<td>18</td>
</tr>
</tbody>
</table>
The benefit of the SKaPa-registry is that the data are exported automatically from the dental records to SKaPa [9] and it is expected that this should result in safer data transfer to the registry than manual registration, but this has not been fully evaluated. A previous study which followed the complete chain of data, for dft and DFT in 170 child patients from the researcher’s dental examination and the data registered in the electronic dental record, to the data retrieved from the SKaPa registry, showed very good correlations [10]. That study did not investigate if data on deft/DMFT, et/MT, or treatments are transferred correctly to the SKaPa registry. This was evaluated in the present study based on 500 new dental records, where no records from the previous study were included.

The present evaluation was conducted in the county region of Värmland, where the data system Carita (Swedish Care System AB) is used to register patient data in the dental records. Other dental data systems used in Sweden were not evaluated in this study. However, the same file specifications are used from all providers of dental records, and the structure and transfer method to the registry is the same. As Carita is used in 4 of the 21 regions representing almost 22% of the total child population in Sweden the present study is an important indicator that the data transfer works.

We included several measures of agreement, ICC, Cohen’s Kappa, and exact agreement. We would have preferred ICC only, as it is a more effective method fitting our data, and this is also our main analysis. However, we also included Kappa and exact agreement as we believe that some readers might have interest in that information and as all measures combined could give a better understanding of the data. A large proportion of the included patients were caries free which is good from an oral health perspective, and this also mirrors the relatively good oral health status in children in Värmland.

At the same time, this floor effect is likely to impact on both ICC and Kappa values as it might be easier to identify a caries free tooth compared to diagnose caries and define if a lesion is incipient or manifest (cavity). This was also found in the present study where it was addressed and emphasized by adding the stratified analyses that only included those with registered values above 0 in the dental records.

The accuracy of deft/DMFT was considerably lower than for dft/DFT, whereby it is assumed that dft/DFT is more stable than deft/DMFT. As severe dental caries may result in extractions, the level of agreement for e/M in the deft/DMFT was of special interest. When we saw lower correlations for deft and DMFT compared with dft and DFT we decided to analyze the agreement for the part of the population having dental caries (i.e. individuals with dft/DFT/deft/DMFT values of 1 or more) separately. Doing so it became evident that the e/M component is less accurate and inclusion of the variable e/M in deft/DMFT would give a misleading information for SKaPa on dental health status.

The difference was larger in 12-year-olds, possibly a consequence of the mixed dentition stage, where registration of dental health status in the dental records must accommodate both primary and permanent teeth, a complication which increases the risk of errors. There is a risk that a not yet erupted permanent tooth that is missing in the oral cavity can be unintentionally, but wrongly, recorded as extracted. In the same way primary teeth that are missing because of exfoliation can be wrongly registered as extracted. This misclassification is due to the human factor, a tick in the wrong box happens in digital systems. The risk is larger in the mixed dentition and especially if it is a new patient where the dentist starts a new dental record with no history of previous treatment. If a tooth is wrongly marked as extracted in the dental record and this has been undersigned by the dentist, the information about an extracted tooth will be sent to SKaPa. This underlines the importance of the dental team ensuring that accurate registrations are entered into the dental record, so that the status of each tooth is correct. This is particularly important in children with unerupted or extracted teeth, or hypodontia. False registrations affect the variable missing/extracted in deft/DMFT and there is a potential risk of systematic errors. Another problem is that the digital dental record systems don’t provide options that specify the reason for a tooth being missing, it cannot identify if a tooth was extracted due to caries or due something else like trauma, periapical lesion etc.

Based on our results we advise researchers and public health workers to refrain from using output data from SKaPa on the et/MT and deft/DMFT indices. At the same time this is far from optimal as excluding the variable e/M in deft/DMFT can distort the statistics: there is a risk that children with the poor dental health are not identified in the data, that dental health is overestimated. If correlation analyses are made with only dft/DFT and not deft/DMFT, the effect size of dental disease will be overestimated. However, it is worth noting that a similar dilemma with discrepancy in number of teeth between dental records and registry output has been described for another registry of dental health in adults (the Swedish Dental Health Register) [17]. That study reported of a high accuracy when comparing number of intact teeth between dental records and the registry for patients having less than 32 intact teeth (but not edentulous) while the correctness for patients being edentulous or having 32 remaining intact teeth was low [17]. Further, the Swedish National Board of Health and Welfare has chosen to exclude e/M when compiling and reporting of dental health in children and adolescents [18].

The reported low accuracies for extracted and missing teeth in the registries are problematic as they impose bias to both dental health monitoring and research. It is therefore an urgent need to develop conditions and strategies for a more accurate reporting of extracted and missing teeth in the dental records, including reason for extraction or why a tooth is missing.

As the present study showed high agreements between data in the electronic dental records and the SKaPa-registry regarding treatments it is in the meantime recommended to use treatment codes for extractions if researchers wish to gather output data from SKaPa on missing teeth. It may also be of value to look at older age groups in adolescents in future studies to see if the problems related to e/M is different in the young permanent dentition compared with in the mixed dentition.

Systematic collection of health data is important for modern health evaluation and research [13] and consequently...
accurate dental health data in registries are central. More and more dental registries are developed in other countries, and it will be possible to link registers from different countries for collaboration. Since SKaPa has a high national coverage and is available for international research collaborations its properties are of interest also outside of Sweden. This study shows that with the SKaPa-registry it is possible to evaluate the prevalence of dental caries in children and to analyse the effects of interventions based on dft and DFT. But, at this moment there is too much uncertainty around extracted and missing teeth why we recommend great caution when using the variables dft/DMFT.

**Conclusion**

The present study reveals high agreement between data in the electronic dental records and the SKaPa-registry regarding dft/DFT and six preventive treatments. Data from the SKaPa-registry dft and DFT may be regarded as reliable for the purposes of monitoring dental health in the population, for studying different preventive measures and for registry-based research. As the agreements were substantially lower for dft/DMFT, especially in 12-year-olds, we advise against using output data on dft or DMFT from SKaPa for research purposes at this point.

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**Author contributions**

TK, GK, ST and AC conceived ideas and designed the study. TK and CC managed the data collection. TK, ANA and GK performed the statistical analysis. All authors participated in interpretation of the study results, contributed to the manuscript, and read and approved the final draft. All authors read and approved the final manuscript.

**Disclosure statement**

No potential conflict of interest was reported by the authors.

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**References**


The Swedish Out-of-Home Care Children Cohort (SweOHC) – evaluation of dental health and dental care

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Abstract

Objectives: Children in out-of-home care (OHC) are at greater risk of ill health than other children in the community. The aim of this registry-based cohort study was to compare the oral health and dental care needs of children in OHC with those of other children in Sweden, by merging data from different Swedish registries. A further aim was to analyse whether children in OHC received more dental examinations after 2017, following implementation of a law requiring mandatory health evaluations prior to placement. Methods: We identified an exposed cohort of Swedish children and young people, 0–19 years old, who had been placed in OHC 2010-2018 (N=59,348), and an unexposed cohort, five times larger, matched for age, sex and county of residence (N=296,730). Data on dental health, dental care, socioeconomic background and medical diagnoses were retrieved from several registries. Results: During the study period, children in OHC received relatively fewer regular, scheduled dental examinations (4.35 vs. 4.94; p=0.000). More children entering OHC in 2018 received dental examinations (72,86%) compared with 2016 (66,78%) (p=0.000), but this was still lower than the proportion of controls. Moreover, during the study period, dental caries affected more teeth in children in OHC than in the controls (dft 6-year-olds 1.54 vs. 0.72; p=0.000, and DFT 12-year-olds 1.14 vs. 0.70; p=0.000), more extractions and more emergency dental appointments than children who had never been in OHC. Conclusion: Not only do children in OHC have poorer oral health than other children, they also receive less support from the dental health services. It seems that society has failed in its mission to ensure that children in OHC are not disadvantaged with respect to health and access to comprehensive healthcare. Thus, there is an urgent need for reappraisal of guidelines, legislation, and organizational models for providing dental care to children and adolescents in OHC.

Key words: child; adolescent; foster care; dental health; registries

Introduction

In Sweden, the state has overriding responsibility for the well-being of children in out-of-home care (OHC). However, the living conditions of this vulnerable group of children fall far short of that of other children. At some time during childhood, about 5% of all children in Sweden will be placed in OHC [1]. This is an intervention used by child welfare services, when children are deemed to be at risk of compromised health, or disturbed development, due to their home environment, or their own behavior [1]. Placement may take the form of foster care (including municipal foster homes, emergency placement foster homes, kinship/family network foster homes and also private, consultant-supported foster homes) or institutional settings (municipal group homes, private group homes, or state-run residential care facilities) [2]. Many studies show that children in OHC have more health problems and a greater need for healthcare than their peers [3-11]. The same seems to apply to oral health. Reports from the National Board of Health and Welfare show that children in OHC have poorer oral health and need more extensive treatment for caries but have less frequent dental examinations [12].

The Swedish healthcare system is intended to be socially responsible and equally accessible and is mainly tax funded. According to Swedish law, all
citizens have the right to appropriate treatment and healthcare, with priority to those in greatest need [13]. All children and adolescents are entitled to comprehensive health and medical care, free of charge, up to 18 years of age and free dental care up to and including 19 years of age. In 2019, free dental care was extended to include young adults up to the age of 23 years. Dental care is available from either the Public Dental Service or private practitioners. Although children in OHC in Sweden are included in the general healthcare system and health and dental care are free, several studies have shown that these children are not well served by the system [3, 11, 14]. Similar findings are reported in other countries [6, 15] and a systematic review concluded that special organizational solutions are necessary to ensure that children in OHC receive the health and dental care they need and are entitled to [4].

On 1 January 2013, the Social Services Act declared that the local Swedish councils should act to ensure that children placed in out-of-home care receive the healthcare they need and are entitled to, and that their health should be monitored during placement. Since 2017, it has been mandatory for local Swedish councils to provide comprehensive health assessments (somatic, dental and mental), for children and young adults up to the age of 20, when they are entering out-of-home care [16]. On 1 January 2020, The United Nations Convention on the Rights of the Child (CRC) was adopted as Swedish law. According to CRC, equal access to health care is a fundamental right of children.

Many previous studies of dental health in children in OHC are based on local, small samples. As there are many high-quality population-based registries in Sweden, registry-based research can be undertaken by combining information from different registries [1]. This is possible thanks to a 12-digit personal identity number (PIN) that is unique for every person registered in the Swedish Population Register. The PIN is provided by the Swedish Tax Agency and consists of numbers which specify the date of birth and sex [17]. The PIN system allows researchers to link data from different registries to a specific individual. There is also a dental health registry including children (The Swedish Quality Registry for caries and periodontal disease (SKaPa)) which enables studies on dental health and dental care [18]. The validity of SKaPa has been shown to be high with respect to dft/DFT (number of decayed, or filled primary teeth/number of Decayed, or Filled permanent Teeth) and dental treatment [19]. However, data for teeth extracted or missing due to caries, which is included in deft/DMFT (number of decayed, extracted (due to caries), or filled primary teeth/number of Decayed, Missing (due to caries), or Filled permanent Teeth), has been reported to be less accurate [20]. Thus, data on caries and filled teeth, but not on extracted or missing teeth, can be used for registry-based research in children [20]. The overall quality of the registries maintained by The National Board of Health and Welfare and Statistics Sweden is regarded as high [1, 21].

There are obvious risks that children in OHC do not receive dental care on the same premises as others and this can impact negatively on their oral health. Thus, in this registry-based cohort study, the aim was to investigate oral health and dental care needs among children in OHC by linking data from different registries.

The specific research questions were:

1. Are there differences between children in OHC and other children regarding the dental care they receive (dental examinations, emergency appointments, extractions) and their oral health (dft, DFT, fractures of teeth or jaws)?

2. Has implementation of the new law in 2017 resulted in any differences in frequency of dental examinations in close relation to placement?

**Hypothesis:** For many of the children placed in OHC, dental services are not readily accessible. They have poorer dental health and receive less regular dental care than other children.

**Methods**

**Study design**

This study is based on the Swedish Out-of-Home Care Children cohort (SweOHC). This registry-based cohort study merged data from different registries provided by The Swedish Quality Registry for caries and periodontal disease (SKaPa) and the registries...
maintained by The National Board of Health and Welfare and Statistics Sweden.

Data sources
Data were sourced from the following registries:

1. The National Board of Health and Welfare’s registries:
   a. National Register of Measures for Children and Young persons – to identify the exposed cohort (OHC placement), and information about placements.
   b. National Patient Register – information about diseases (ICD-10) which can be linked to an increased risk of deteriorating dental health.

2. Statistics Sweden:
   a. The Total Population Register – to identify the unexposed cohort, and data on deaths and emigration for all research subjects.
   b. The Longitudinal integrated database for health insurance and labour market studies (LISA) – data on socioeconomic variables among the research subjects and their parents.
   c. The Multi-Generation Register – to identify the parents of the research subjects.

3. Swedish Quality Registry for caries and periodontal disease (SKaPa) – for information about dental health and dental attendance

Workflow
The exposed cohort (OHC) was identified by the National Board of Health and Welfare via the National Register of Measures for Children and Young persons. All individuals, aged 0–19 years, who entered OHC at any time during the years 2010-2018 were identified. The National Board of Health and Welfare then sent information about their PINs to Statistics Sweden, whereby the unexposed cohort was constructed from the Total Population Register by randomly drawing unexposed comparators, in a ratio of 1:5 for each exposed research subject, matched by sex, age and county of residence. To be eligible, the comparators had to be alive and registered in Sweden at the time of inclusion in the study. Statistics Sweden also delivered data on deaths and emigration for the research subjects and identified the parents of both the exposed and the unexposed cohort from the Multi-Generation Registry and further, produced data on the parents’ socio-economic status from The Longitudinal integrated database for health insurance and labour market studies (LISA).

Statistics Sweden then sent PINs for both the unexposed and the exposed cohort to the National Board of Health and Welfare who retrieved data from SKaPa. The information from SKaPa comprised dental health and dental attendance records for all research subjects, from 2010 to 2020. All data delivered to the researchers were de-identified, without PINS, but with serial numbers, which enabled merging of the datafiles (Figure 1).

Participants
The subjects comprise an exposed cohort of children placed in OHC and an age- and gender-matched unexposed cohort, representing the total population. The exposed cohort comprises all children and adolescents, 0–19 years old, who were placed in OHC in Sweden sometime during the period 2010-2018. The unexposed cohort comprises children and adolescents who are not part of the exposed cohort, matched, at a ratio of 1:5, to the exposed research subjects, according to gender, age and county of residence. Children in the exposed group were stratified into three different groups, depending on how long they had been in OHC (total time in OHC):

- 1 = total time in OHC less than one year
- 2 = total time in OHC 1-3 years
- 3 = total time in OHC more than 3 years
- 0 = never placed in OHC (controls)

In order to allow comparisons with official Swedish dental health statistics, four specific age groups, 3-, 6-, 12-, and 19-year-olds, were used for analyses of dental health.

This is the first study to describe our cohort, the Swedish Out-of-Home Care Children cohort (SweOHC). Analyses of data from the cohort will continue and be presented subsequently.
Statistics
Categorical outcome variables are presented as numbers and proportions as percentages for the different exposure groups. Continuous and discrete variables are presented as mean values, with 95% confidence intervals and standard deviations. The two-sample t-test was applied to analyse differences between exposed (children in OHC) and unexposed controls with reference to the number of examinations and emergency appointments, dft/DFT and extractions. In addition, linear regression analyses were used to compare subgroups of OHC with controls, with reference to dental examinations, emergency appointments and dft/DFT. The Chi square test was applied to compare the number of ICD-10 diagnoses, emergency appointments, examinations at time of placement in OHC for individuals in OHC and the controls, and proportion of caries-free children in OHC and controls. To adjust for potential confounding factors when analysing the association between OHC and dft/DFT, a multiple linear regression analysis was applied, the model included the different exposure levels of OHC as dichotomous indicator variables and the controls were left out as reference category, parental educational level dichotomous indicator variables with the lowest level as reference, country of birth was included as dichotomous indicator variables with Sweden as reference. The model also included diabetes, mood disorders, mental and behavioral disorders, conduct disorders and hyperkinetic disorders, all as dichotomous variables (yes/no). STATA SE 15 software (Stata Corporation LLC, College Station, U.S.A) was used for all statistical analyses. P-values less than 0.05 was considered statistically significant.

Ethics
The research was conducted in accordance with the World Medical Association Declaration of Helsinki. The Swedish Ethical Review Authority approved the study (# 2020-01699 and 2020-06957).

Results
The total population comprised 409,638 individuals, of whom 68,273 had been placed in OHC at some point during the period 2010-2018. These figures included 8,925 immigrants with the status of unaccompanied minors: 88 % were boys, most born in 1999 and 2000. As unaccompanied minors, this group was considered not to have had access to dental health care on the same premises as others, and so they and their controls were excluded: 8,925 exposed children and 44,625 controls (a total of 53,550 individuals). Moreover, 10 controls were excluded because they had the status of unaccompanied minors. Thus, the final study population comprised 356,078 children (59,348 OHC and 296,730 controls) born between 1996 and 2016 (Table 1). In the SKaPa registry, registrations of dental procedures were found for 316,309 individuals. The characteristics of the study population are shown in Table 2. The mean number of placements in the OHC group was 3.21 with considerable variation in numbers among children in the OHC groups (Table 3).

Medical and psychiatric diagnoses
ICD-10 diagnoses from the medical system, retrieved from the National Patient Register, showed similar frequencies of diabetes in both OHC group and controls. However, children in OHC were diagnosed more frequently with mental and behavioural disorders (44.55% vs. 18.97%; p=0.000). Similarly, both boys and girls in the OHC group had higher frequencies of kinetic and conduct disorders, as well as mood disorders (Table 4).

Dental examinations and emergency appointments
Throughout the study period, children who had been placed in OHC underwent fewer dental examinations than the controls (Table 5). The opposite applied to emergency attendance: 18.92% of the OHC subjects have had at least one emergency appointment, compared with 14.93% of the controls (p=0.000). (Table 6).

The proportion of children in the OHC group undergoing dental examinations in close proximity to their placement in OHC (during the year of placement or the year after), was lower than the proportion of controls examined during the same period. When the new law on mandatory health examinations was implemented in 2017, more children in OHC underwent dental examinations (an increase from 66.78% in 2016 to 72.86% in 2018; p=0.000). During this period, there was a
corresponding increase in dental examinations in the controls (Table 7).

**Oral health**

Dental caries was studied separately for all children, at the ages of 3-, 6-, 12-, and 19-years. In all age groups, children in OHC had statistically significantly higher mean dft/DFT values than those who have never been in OHC (Table 8). The findings were similar for the proportion of caries-free children (dft or DFT = 0). For 3-year-olds, 90% of the children in OHC were caries-free, compared with 96% of the controls (p=0.000). For the 6- year-olds, the corresponding figures were 62% caries free in OHC and 79% in controls (p=0.000), for 12-year-olds, 54% and 66% respectively, were caries-free (p=0.000) and for 19-year-olds, 20% of the OHC group were caries free, compared with 37% of controls (p=0.000).

A model wherein parental education, country of birth, psychiatric diagnoses, diabetes and OHC group were applied as explanatory variables on dental caries revealed that in all age groups, an important variable for dental caries was OHC. The adjusted and unadjusted results for 6- and 19-year-olds are presented in Table 9.

Children in OHC had undergone more extractions than the controls. This applied to both the primary and permanent dentitions (Table 10). As shown in Figure 2a, the OHC-group had more extractions of primary teeth during the entire period of time in which the primary dentition predominates. In contrast, there was an increase in extractions of permanent teeth in the OHC-group in their late teens (Figure 2b).

Moreover, traumatic injuries to teeth and jaws, diagnosed within medical care, were more common in the OHC group. Overall, 0.53% of the children in the OHC group had experienced tooth or jaw fractures compared with 0.3% in the controls (p = 0.000). The differences applied to all diagnoses for boys and for the total group. With respect to girls, no differences emerged between those in OHC and those in the control group in terms of the number of tooth fractures or fractures of malar and maxillary bones (Table 4).

**Discussion**

This study shows that children in OHC have more dental caries, more extractions and more dental emergency appointments than children who have never been in OHC. At the same time children in OHC undergo fewer regular, scheduled dental examinations than other children. After the 2017 implementation of a new law on compulsory health assessments at the time of placement, the number of such examinations increased for OHC. However, the number of dental examinations remained lower than for controls.

It is apparent from this study that from many perspectives, children in OHC constitute a vulnerable group. This includes background social factors, for example compared to other children, there are fewer parents with higher levels of education and more children of immigrant background, as well as higher frequencies of psychiatric disorders. There was also a high number of changes of placement in the OHC group. Even among those whose total time in OHC was less than 1 year, there could be up to 12 different placements, which is remarkably high. Altogether, it is highly likely that these factors could affect oral health, as described in several previous studies [22-24]. The present study clearly supports these findings. Not only do children in OHC have more oral health problems, such as caries or trauma, but they also receive less support from dental services. Most obvious is the fact that they receive fewer regular dental examinations.

According to law, children about to be placed in OHC should undergo a dental examination and it is the responsibility of the municipalities and their social services to ensure this [16]. It is acknowledged that children in OHC run a higher risk of health problems. As society assumes responsibilities which usually rest with parents, society must also ensure that children in OHC are not disadvantaged. It is not an easy task, but the results of the present study indicate that society has failed to meet this obligation, a finding which is supported by previous research [4, 6].

The reasons for placing a child in OHC can vary from lack of parental care, unfavourable domestic conditions due to violence or drug abuse, to issues related to the child itself, e.g., behavioural...
problems, use of drugs or criminal activity [2, 5, 25]. It is understandable that many of the children in OHC do not prioritise their oral health care and that their self-care and dietary habits may be less conducive to oral health. Support from the foster family, or from staff at OHC is of course a key element in health prevention, but these children also need regular dental examinations, treatment planning and possibly treatment. If these needs are not met, oral health will be even more adversely affected.

Fewer dental examinations have been reported previously in OHC children [12], but here we were able to show that even the new law did not ensure that all children in OHC underwent a dental examination, even at the time of placement. One reason for the low number of examinations could be that many children in OHC move between different types of OHC, from OHC to their original family and back to OHC. They also move beyond their municipality or county region. Such numerous moves result in their inability to establish continuity of their relationship with the dental team or dental clinic. Further, the dental recall system does not cater for relocation by patients: it is difficult or even impossible for the system to keep track of the children. For these children there is a need for individualised transfer of dental health information, case history and treatment plans between dental clinics at the locations where the children are placed or live. No such system is currently in place, and it is unclear who should be responsible, social services or the dental care system? At present, no one is responsible and so children in OHC fall through the cracks.

Nonetheless, as social services are involved in the decisions about placement and have access to the address and geographic location of the placement, it is fair to state that they should always send priority letters to both those responsible at the OHC-accommodation and to the dental services when these children move, so that dental care is always ensured. Although dental care is free of charge for all children and young people there is a problem if the child moves to another region for placement in OHC but remains registered in the municipality of the family home. Not only is there a risk for delay related to a decision as to which region should assume responsibility for providing dental care, but questions also arise about reimbursement. The new region wants to be paid by the home region, which in turn must have a cost estimate that is approved. Often dental care is delayed until this is solved. This is of course unacceptable from the health perspective: these children should simply receive their dental care where they currently live, without bureaucratic obstacles.

This combination of less frequent dental visits, suboptimal self-care and delayed treatment needs will inevitably raise the risk of deterioration in dental health and a need for more advanced dental treatment in both the shorter and longer perspectives. The higher number of emergency appointments for children in OHC disclosed in the present study indicates that lack of regular dental examinations leads to health issues associated with unmet treatment needs. In the present study, this was confirmed by higher numbers of dft/DFT and also in more extractions than in the control children, who received more regular dental examinations. Although the study shows differences between OHC and controls in background factors such as parents’ educational levels, immigrant background and psychiatric health problems, the multiple linear regression analyses showed that OHC and the duration of placement were strong explanatory factors for dental caries.

Taking into account the complex case history, including placement in OHC itself, plus social factors, mental health issues and dental caries status, dentists should assess the risk of oral health problems in children in OHC as generally very high. In accordance with the risk assessment, the treatment plan should include preventive strategies as well as shorter recall intervals. When it is time to contact the patient to schedule check-ups or regular dental examinations, the administrative system should preferably generate an alert to the effect that this a high-risk patient who needs extra attention. Unfortunately, the present study indicates that this routine does not seem to work.

The timing of tooth extractions varied between children in the OHC and control groups. The differences were not analysed in detail but looking at dft/DFT values offers some possible explanations. In the primary dentition dft values were
considerably higher in the OHC groups and it is likely that some of the primary teeth were so badly broken down due to caries that they had to be extracted, especially if dental attendance was less frequent. There was greater variation in extractions of permanent teeth, although OHC had more dental caries. In the mixed dentition, up to around the age of 15 years, there were more extractions of permanent teeth among the controls, whereas after 15 years of age there were substantially more extractions in the OHC group. There could be several possible explanations. Compared with the OHC group, controls maybe underwent other types of dental treatment, e.g., more orthodontic treatment as they had lower caries risk, more regular dental care and more stable living conditions. Orthodontic treatment often involves extraction of permanent teeth. Children in OHC are more likely to have had permanent teeth extracted due to caries: this often occurs after the age of 15, by which time orthodontic extractions are less common. Increased numbers of tooth extractions have also been reported in young adults who had been in OHC during childhood [26]. Thus, tooth extractions may serve as an indicator that children in OHC not only have more dental health problems but are also offered different treatment from that of children who have not been placed in OHC. This also raises an issue with respect to the rights of all children to have equal access to health services.

In this study the number of diagnoses related to traumatic injuries was higher in the OHC group. However, as these data were retrieved from the medical health system and not from dental records, it is likely that the information on tooth fractures in particular is underestimated. In most cases, patients incurring traumatic dental injuries will seek dental treatment. Unfortunately, the Swedish dental care system does not provide codes for trauma diagnoses and the information is not retrievable from the SKaPa registry. It was therefore not possible to study this further. Jaw fractures will however, most likely be treated by the medical sector, and this study clearly shows that children in OHC, boys in particular, present with fractures to both the maxilla and mandible more often than other children. The reason for this was not investigated in this study, but it may be hypothesised that the circumstances underlying admission to OHC, e.g., hyperkinetic and conduct disorders could contribute.

Strengths and weaknesses
This study was based on a well-defined cohort, the Swedish Out-of-Home Care Children cohort (SweOHC), and included all children placed in OHC during a specified study period. Further, to enable valid comparisons with the background population five controls, matched for age, sex and county region, were identified for each child in the OHC group. This design and the high number of individuals included are important strengths of the present study. Another strength was the similarity in dental health between controls in this study and the official statistics on dental health published annually by the Swedish National Board of Health and Welfare [27], indicating that the controls reflect the background population well.

There are inherent limitations in a study such as this. As a registry-based study, information about risk factors for dental caries, such as diet or oral hygiene, are not available, nor do we have any information about the children’s perspectives. Furthermore, detailed information as to why the children were placed in OHC was unavailable, as the registries do not include that data. Moreover, as the main focus in this study was dental health, it is a further shortcoming that around 11% of the study population could not be found in the SKaPa-registry. There are two different explanations: the child has been treated by a dental healthcare provider who is not affiliated with SKaPa (the number of private dental practitioners who are not in SKaPa is still quite high), or the child has not had a dental appointment at all during the period, 2010–2020. However, the proportions of missing individuals were similar in the control and the OHC group and as the number of individuals included in the analysis was generally high it is fair to assume that the results are reliable. The study period also covered the year 2020 when the COVID-19 pandemic impacted on children’s access to dental care [28].

Conclusion
This study reveals that children placed in out-of-home care in Sweden have poorer dental health than others and that there are major shortcomings
in ensuring that these children receive the dental care to which they are entitled. The dental health needs of children entering or already placed in OHC should be met more effectively than they are today. There is a difference in dental health assessments before and after the year 2017, with higher frequencies of dental health assessments after the legislative amendment in 2017. There is a need for reappraisal of guidelines, legislation, and organizational models for providing dental care to children and adolescents in out-of-home care.

Disclosure statement
No potential conflict of interest was reported by the authors.

Author contributions
All authors conceived ideas and designed the study. TK, ANA and GK managed the data collection. TK, ANA and GK performed the statistical analysis. All authors participated in interpretation of the study results, contributed to the manuscript, and read and approved the final draft. All authors read and approved the final manuscript.

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Table 1. Study population by year of birth. Control group and children in out-of-home care (OHC), stratified according to duration of placement: less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC.

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<th>OHC 1-3 yrs</th>
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<td>2015</td>
<td>4,860</td>
<td>972</td>
<td>412</td>
<td>112</td>
<td>448</td>
</tr>
<tr>
<td>2016</td>
<td>3,695</td>
<td>739</td>
<td>300</td>
<td>86</td>
<td>353</td>
</tr>
<tr>
<td>Total</td>
<td>296,730</td>
<td>59,348</td>
<td>18,423</td>
<td>12,142</td>
<td>28,783</td>
</tr>
</tbody>
</table>
Table 2. Baseline characteristics of the study population. Control group and children placed in out-of-home care (OHC) less than 1 year; 1-to-3 years, more than 3 years, and all children placed in OHC.

<table>
<thead>
<tr>
<th></th>
<th>Controls</th>
<th>Children in out of home care</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=296,730 (%)</td>
<td>N=59,348 (%)</td>
<td>N=18,423 (%)</td>
<td>N=12,142 (%)</td>
<td>N=28,783 (%)</td>
</tr>
<tr>
<td><strong>In SKaPa</strong></td>
<td>263,063 (88.65)</td>
<td>53,246 (89.70)</td>
<td>16,480 (89.45)</td>
<td>10,607 (87.36)</td>
<td>26,159 (90.88)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>129,384 (43.60)</td>
<td>25,877 (43.60)</td>
<td>9,006 (48.88)</td>
<td>4,765 (39.24)</td>
<td>12,106 (42.06)</td>
</tr>
<tr>
<td>Male</td>
<td>167,346 (56.40)</td>
<td>33,471 (56.40)</td>
<td>9,417 (51.12)</td>
<td>7,377 (60.76)</td>
<td>16,677 (57.94)</td>
</tr>
<tr>
<td><strong>Parents’ educational level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mothers</td>
<td>Fathers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary/lower secondary school</td>
<td>83,727 (28.22)</td>
<td>28,170 (47.47)</td>
<td>9,007 (48.89)</td>
<td>4,498 (37.04)</td>
<td>14,665 (50.95)</td>
</tr>
<tr>
<td></td>
<td>116,361 (39.21)</td>
<td>26,595 (44.81)</td>
<td>8,638 (46.89)</td>
<td>4,310 (35.50)</td>
<td>13,647 (47.41)</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>68,074 (22.94)</td>
<td>7,140 (12.03)</td>
<td>2,776 (15.07)</td>
<td>1,270 (10.46)</td>
<td>3,094 (10.75)</td>
</tr>
<tr>
<td></td>
<td>58,238 (19.63)</td>
<td>5,781 (9.74)</td>
<td>2,053 (11.14)</td>
<td>1,018 (8.38)</td>
<td>2,710 (9.42)</td>
</tr>
<tr>
<td>Post-secondary school</td>
<td>134,665 (45.38)</td>
<td>6,828 (11.51)</td>
<td>3,211 (17.43)</td>
<td>1,292 (10.64)</td>
<td>2,325 (8.08)</td>
</tr>
<tr>
<td></td>
<td>102,474 (34.53)</td>
<td>5,858 (9.87)</td>
<td>2,733 (14.83)</td>
<td>1,112 (9.16)</td>
<td>2,013 (7.00)</td>
</tr>
<tr>
<td>Data unavailable</td>
<td>10,264 (3.46)</td>
<td>17,210 (29.00)</td>
<td>3,429 (18.61)</td>
<td>5,082 (41.85)</td>
<td>8,699 (30.22)</td>
</tr>
<tr>
<td></td>
<td>19,657 (6.62)</td>
<td>21,114 (35.58)</td>
<td>4,999 (27.13)</td>
<td>5,702 (46.96)</td>
<td>10,413 (36.18)</td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td>268,166 (90.37)</td>
<td>38,101 (64.20)</td>
<td>12,528 (68.00)</td>
<td>6,158 (50.72)</td>
<td>19,415 (67.45)</td>
</tr>
<tr>
<td>Other Nordic countries</td>
<td>1,652 (0.56)</td>
<td>329 (0.55)</td>
<td>125 (0.68)</td>
<td>59 (0.49)</td>
<td>145 (0.50)</td>
</tr>
<tr>
<td>Other European countries</td>
<td>7,061 (2.38)</td>
<td>1,533 (2.58)</td>
<td>625 (3.39)</td>
<td>308 (2.54)</td>
<td>600 (2.08)</td>
</tr>
<tr>
<td>Non-European countries</td>
<td>19,826 (06.68)</td>
<td>19,349 (32.60)</td>
<td>5,132 (27.86)</td>
<td>5,611 (46.21)</td>
<td>8,606 (29.90)</td>
</tr>
<tr>
<td>Data unavailable</td>
<td>25 (&lt;0.00)</td>
<td>36 (&lt;0.00)</td>
<td>13 (0.07)</td>
<td>6 (0.05)</td>
<td>17 (0.06)</td>
</tr>
</tbody>
</table>
Table 3. Study population stratified by frequency of placements. Children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Min -Max</th>
<th>1 placement N (%)</th>
<th>2-4 placements N (%)</th>
<th>&gt;5 placements N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHC &lt; 1yr N=18,423</td>
<td>1.67</td>
<td>1.10</td>
<td>1 - 12</td>
<td>11,328 (61.49)</td>
<td>6,544 (35.52)</td>
<td>551 (2.99)</td>
</tr>
<tr>
<td>OHC 1-3 yrs N=12,142</td>
<td>3.31</td>
<td>2.38</td>
<td>1 - 29</td>
<td>2,729 (22.48)</td>
<td>6,658 (54.83)</td>
<td>2,755 (22.69)</td>
</tr>
<tr>
<td>OHC &gt;3 yrs N=28,783</td>
<td>4.16</td>
<td>3.40</td>
<td>1 - 36</td>
<td>5,283 (18.35)</td>
<td>13,975 (48.55)</td>
<td>9,525 (33.09)</td>
</tr>
<tr>
<td>Total OHC N=59,348</td>
<td>3.21</td>
<td>2.88</td>
<td>1 - 36</td>
<td>19,340 (32.59)</td>
<td>27,177 (45.79)</td>
<td>12,831 (21.62)</td>
</tr>
</tbody>
</table>
**Table 4.** Study population stratified according to ICD-10 diagnoses retrieved from the National Patient Register. Control group and children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Chi-square tests for comparisons between controls and total OHC group.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Controls</th>
<th>Children in out-of-home care</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=296,730 (%)</td>
<td>Total OHC N=59,348 (%) OHC &lt;1yr N=18,423 (%) OHC 1-3yrs N=12,142(%) OHC &gt;3yrs N=28,783 (%)</td>
<td></td>
</tr>
<tr>
<td>Fracture of tooth (S02.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>131 (0.10)</td>
<td>31 (0.12)</td>
<td>0.399</td>
</tr>
<tr>
<td>Male</td>
<td>303 (0.18)</td>
<td>104 (0.31)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>434 (0.15)</td>
<td>135 (0.23)</td>
<td>0.000</td>
</tr>
<tr>
<td>Fracture of malar and maxillary bones (S02.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>37 (0.03)</td>
<td>13 (0.05)</td>
<td>0.077</td>
</tr>
<tr>
<td>Male</td>
<td>152 (0.09)</td>
<td>70 (0.21)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>189 (0.06)</td>
<td>83 (0.14)</td>
<td>0.000</td>
</tr>
<tr>
<td>Fracture of mandible (S02.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>73 (0.06)</td>
<td>29 (0.11)</td>
<td>0.001</td>
</tr>
<tr>
<td>Male</td>
<td>261 (0.16)</td>
<td>93 (0.28)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>334 (0.11)</td>
<td>122 (0.21)</td>
<td>0.000</td>
</tr>
<tr>
<td>Any diagnosis S02.4-S02.6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>228 (0.18)</td>
<td>67 (0.26)</td>
<td>0.005</td>
</tr>
<tr>
<td>Male</td>
<td>673 (0.40)</td>
<td>248 (0.74)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>901 (0.30)</td>
<td>315 (0.53)</td>
<td>0.000</td>
</tr>
<tr>
<td>Diabetes mellitus (E10-E14)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>980 (0.76)</td>
<td>222 (0.86)</td>
<td>0.092</td>
</tr>
<tr>
<td>Male</td>
<td>1,417 (0.85)</td>
<td>248 (0.74)</td>
<td>0.051</td>
</tr>
<tr>
<td>Total</td>
<td>2,397 (0.81)</td>
<td>470 (0.79)</td>
<td>118 (0.64)</td>
</tr>
<tr>
<td>Hyperkinetic disorders (F90)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>6,441 (4.98)</td>
<td>5,351 (20.68)</td>
<td>0.000</td>
</tr>
<tr>
<td>Male</td>
<td>13,203 (7.89)</td>
<td>7,486 (22.37)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>19,644 (6.62)</td>
<td>12,837 (21.63)</td>
<td>3,148 (17.09)</td>
</tr>
<tr>
<td>Conduct disorders (F91)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>397 (0.31)</td>
<td>1,181 (4.56)</td>
<td>0.000</td>
</tr>
<tr>
<td>Male</td>
<td>1,116 (0.67)</td>
<td>1,994 (5.96)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>1,513 (0.51)</td>
<td>3,175 (5.35)</td>
<td>726 (3.94)</td>
</tr>
<tr>
<td>Mood [affective] disorders (F30-F39)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7,641 (5.91)</td>
<td>4,497 (17.38)</td>
<td>0.000</td>
</tr>
<tr>
<td>Male</td>
<td>5,384 (3.22)</td>
<td>2,807 (8.39)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>13,025 (4.39)</td>
<td>7,304 (12.31)</td>
<td>2,006 (10.89)</td>
</tr>
<tr>
<td>Mental and behavioural disorders (F00-F99)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>23,374 (18.07)</td>
<td>12,102 (46.77)</td>
<td>0.000</td>
</tr>
<tr>
<td>Male</td>
<td>32,901 (19.66)</td>
<td>14,337 (42.83)</td>
<td>0.000</td>
</tr>
<tr>
<td>Total</td>
<td>56,275 (18.97)</td>
<td>26,439 (44.55)</td>
<td>7,064 (38.34)</td>
</tr>
</tbody>
</table>
Table 5. Mean number of dental examinations during the study period. Control group and children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Linear regression analyses comparing different OHC groups with controls, Two-sample t-tests for comparisons between controls and total OHC group.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controls</td>
<td>263,063</td>
<td>4.94</td>
<td>2.04</td>
<td>4.93 - 4.95</td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>16,480</td>
<td>4.47</td>
<td>2.20</td>
<td>4.43 - 4.50</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>10,607</td>
<td>4.04</td>
<td>2.18</td>
<td>4.00 - 4.08</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>26,159</td>
<td>4.40</td>
<td>2.21</td>
<td>4.37 - 4.43</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>53,246</td>
<td>4.35</td>
<td>2.21</td>
<td>4.33 - 4.37</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Table 6. Mean number and standard deviation (SD) of emergency dental appointments for children placed in out-of-home care (OHC) and control group. Children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Linear regression analyses comparing different OHC groups with controls, Two-sample t-tests for comparisons between controls and total OHC group.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controls</td>
<td>263,063</td>
<td>0.201</td>
<td>0.557</td>
<td>0.199 - 0.203</td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>16,480</td>
<td>0.269</td>
<td>0.660</td>
<td>0.260 - 0.279</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>10,607</td>
<td>0.301</td>
<td>0.721</td>
<td>0.287 - 0.315</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>26,159</td>
<td>0.255</td>
<td>0.647</td>
<td>0.247 - 0.263</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>53,246</td>
<td>0.269</td>
<td>0.666</td>
<td>0.263 - 0.274</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Table 7. Numbers and frequencies of children in out-of-home care (OHC) and their controls undergoing dental examinations during the year of placement or the following year. Placements in 2016, 2017 and 2018 and for control group and children placed in OHC for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Chi-square tests comparing controls and total OHC group.

<table>
<thead>
<tr>
<th>Year of placement</th>
<th>Examination</th>
<th>Controls</th>
<th>Total OHC</th>
<th>OHC &lt;1yr</th>
<th>OHC 1-3yrs</th>
<th>OHC &gt;3yrs</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes/No</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>Yes</td>
<td>26,503 (71.43)</td>
<td>4,956 (66.78)</td>
<td>1,471 (66.68)</td>
<td>860 (64.76)</td>
<td>2,625 (67.53)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>10,601 (28.57)</td>
<td>2,465 (33.22)</td>
<td>735 (33.32)</td>
<td>468 (35.24)</td>
<td>1,262 (32.47)</td>
<td></td>
</tr>
<tr>
<td>2017</td>
<td>Yes</td>
<td>18,847 (75.18)</td>
<td>3,388 (67.56)</td>
<td>781 (69.30)</td>
<td>1,330 (65.39)</td>
<td>1,277 (68.88)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>6,222 (24.82)</td>
<td>1,627 (32.44)</td>
<td>346 (30.70)</td>
<td>704 (34.61)</td>
<td>577 (31.12)</td>
<td></td>
</tr>
<tr>
<td>2018</td>
<td>Yes</td>
<td>24,200 (77.47)</td>
<td>4,552 (72.86)</td>
<td>2,195 (74.28)</td>
<td>1,223 (68.59)</td>
<td>1,134 (75.10)</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7,038 (22.53)</td>
<td>1,696 (27.14)</td>
<td>760 (25.72)</td>
<td>560 (31.41)</td>
<td>376 (24.90)</td>
<td></td>
</tr>
</tbody>
</table>
Table 8. Dental caries expressed as dft or DFT (decayed and filled teeth in the primary and permanent dentitions, respectively) for children aged 3-, 6-, 12- and 19 years of age. Comparisons within age groups between control group and children placed in out-of-home care (OHC) for less than 1 year, 1-to-3 years, more than 3 years, and all children placed in OHC. Linear regression analyses comparing different OHC groups with controls, Two-sample t-tests for comparisons between controls and total OHC groups.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>dft</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>3 yrs old</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td>50.985</td>
<td>0.134</td>
<td>0.814</td>
<td>0.127 - 0.141</td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>3.606</td>
<td>0.410</td>
<td>1.502</td>
<td>0.361 - 0.459</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>1.058</td>
<td>0.348</td>
<td>1.288</td>
<td>0.270 - 0.426</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>4.133</td>
<td>0.344</td>
<td>1.359</td>
<td>0.302 - 0.385</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>8.797</td>
<td>0.371</td>
<td>1.412</td>
<td>0.342 - 0.401</td>
<td>0.000</td>
</tr>
<tr>
<td><strong>6 yrs old</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td>77.384</td>
<td>0.717</td>
<td>1.852</td>
<td>0.704 - 0.730</td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>5.568</td>
<td>1.746</td>
<td>2.774</td>
<td>1.673 - 1.819</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>1.925</td>
<td>1.627</td>
<td>2.666</td>
<td>1.508 - 1.746</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>7.012</td>
<td>1.352</td>
<td>2.474</td>
<td>1.294 - 1.410</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>14.505</td>
<td>1.540</td>
<td>2.625</td>
<td>1.497 - 1.583</td>
<td>0.000</td>
</tr>
<tr>
<td><strong>DFT</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>12 yrs old</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td>141.599</td>
<td>0.695</td>
<td>1.280</td>
<td>0.688 - 0.702</td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>7.140</td>
<td>1.213</td>
<td>1.762</td>
<td>1.172 - 1.254</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>4.131</td>
<td>1.257</td>
<td>1.819</td>
<td>1.201 - 1.312</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>11.699</td>
<td>1.052</td>
<td>1.652</td>
<td>1.022 - 1.082</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>22.970</td>
<td>1.139</td>
<td>1.720</td>
<td>1.116 - 1.161</td>
<td>0.000</td>
</tr>
<tr>
<td><strong>19 yrs old</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td>114.619</td>
<td>2.187</td>
<td>2.895</td>
<td>2.170 - 2.204</td>
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</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>5.569</td>
<td>4.084</td>
<td>4.052</td>
<td>3.977 - 4.190</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>5.091</td>
<td>4.221</td>
<td>4.053</td>
<td>4.110 - 4.333</td>
<td>0.000</td>
</tr>
<tr>
<td>OHC &gt;3yrs</td>
<td>10.767</td>
<td>3.805</td>
<td>3.849</td>
<td>3.732 - 3.878</td>
<td>0.000</td>
</tr>
<tr>
<td>Total OHC</td>
<td>21.427</td>
<td>3.976</td>
<td>3.955</td>
<td>3.923 - 4.029</td>
<td>0.000</td>
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</tbody>
</table>
**Table 9.** Associations between OHC and dft/DFT at 6 years and 19 years of age were analyzed by multiple linear regression. Both unadjusted and adjusted regression coefficients are presented with 95% CIs and p-values. The model was adjusted for country of birth, mother’s education, father’s education, diabetes, mood disorders, mental and behavioural disorders, conduct disorders and hyperkinetic disorders.

<table>
<thead>
<tr>
<th></th>
<th>dft 6-year-olds</th>
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<th></th>
<th>DFT 19-year-olds</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Unadjusted</td>
<td>Adjusted</td>
<td>Unadjusted</td>
<td>Adjusted</td>
<td>Unadjusted</td>
<td>Adjusted</td>
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<td></td>
<td>Regression coeff.</td>
<td>95% CI</td>
<td>p-value</td>
<td>Regression coeff.</td>
<td>95% CI</td>
<td>p-value</td>
</tr>
<tr>
<td>Controls</td>
<td>ref.</td>
<td></td>
<td></td>
<td>ref.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OHC &lt;1yr</td>
<td>1.029</td>
<td>0.975</td>
<td>1.084</td>
<td>0.000</td>
<td>0.388</td>
<td>0.333</td>
</tr>
<tr>
<td>OHC 1-3yrs</td>
<td>0.910</td>
<td>0.820</td>
<td>1.000</td>
<td>0.000</td>
<td>0.336</td>
<td>0.243</td>
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<tr>
<td>OHC &gt;3yrs</td>
<td>0.635</td>
<td>0.587</td>
<td>0.684</td>
<td>0.000</td>
<td>0.048</td>
<td>-0.006</td>
</tr>
</tbody>
</table>

**Table 10.** Mean number and standard deviation (SD) of tooth extractions for children placed in out-of-home care (OHC) and control group. Data for primary teeth refer to children born 2008 to 2012; and data for permanent teeth to children born 1996 to 2004. Two-sample t-test.

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary teeth</strong></td>
<td></td>
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<tr>
<td>Total OHC group</td>
<td>8,363</td>
<td>0.794</td>
<td>1.609</td>
<td>0.759 - 0.828</td>
<td>0.0000</td>
</tr>
<tr>
<td>Controls</td>
<td>40,864</td>
<td>0.547</td>
<td>1.234</td>
<td>0.535 - 0.559</td>
<td></td>
</tr>
<tr>
<td><strong>Permanent teeth</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total OHC group</td>
<td>35,313</td>
<td>0.259</td>
<td>0.779</td>
<td>0.251 - 0.267</td>
<td>0.0000</td>
</tr>
<tr>
<td>Controls</td>
<td>175,392</td>
<td>0.222</td>
<td>0.766</td>
<td>0.219 - 0.226</td>
<td></td>
</tr>
</tbody>
</table>
Figure Legends

Figure 1. Flowchart of registry inquiry and recruitment of study population.

Figures 2a and b. Mean number and 95% confidence intervals of extracted primary teeth (a) and permanent teeth (b) according to age, in children placed in out-of-home care (OHC) and unexposed controls.
Figure 1.

NBHW= National Board of Health and Welfare, SCB=Statistics Sweden, SKaPa=Swedish Quality Registry for caries and periodontal disease, PIN=Personal Identification Number, OHC=children in Out-of-Home Care, NRMCY=National Register of Measures for Children and Young persons, TPR= Total Population Register, MGR= Multi-Generation Register, LISA= Longitudinal integrated database for health insurance and labour market studies, NPR=National Patient Register, NPDR=National Prescribed Drug Register; NCDR=National Cause of Death Register, NRCSA=National Register for Care of Substance Abuse. *=data from registry not used in this paper.
About 4-5% of children in Sweden are placed in out-of-home care (OHC) at some point during their childhood. From many perspectives, these children comprise a vulnerable group in society. It is the responsibility of social services to ensure that they receive comprehensive health and dental care. This thesis studies dental care and dental health in these children.

The results show that children in OHC have poorer dental health than other children of the same age. Despite this, they have significantly fewer regular dental examinations. Instead, they come to emergency visits. Hence the type of dental care they receive is different from that of other children. These inequalities persist into adulthood and the same patterns can be seen in young adults with a history of childhood OHC. In Sweden, dental care is free of charge for all children and social services are tasked with ensuring that children in OHC receive appropriate dental care. Nonetheless, under the present system, children in OHC do not have the same opportunity to have a good oral health.