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**Mazecaite-Vaitilaviciene, L., and Owens, J**

**Title**

Children with disabilities at risk of poor oral health in the Republic of Lithuania: A retrospective descriptive service evaluation.

**Abstract**

This retrospective service evaluation considers the oral health of children with disabilities in post-Soviet Lithuania. It identifies that they have extensive dental decay and that the predominant course of dental treatment for children with disabilities is tooth extraction under general anaesthetic. There is little in the way of specialist service provision, preventative care or oral health promotion for this group. This study adds to the literature by identifying and emphasising the impact on oral health of the sweeping economic and political changes, the move towards deinstitutionalization and new economic trends such as a market economy. In particular, the lack of social welfare support, high levels of child poverty, poor educational outcomes and the privatization of the oral health care system has served to increase oral health inequity for marginalised groups. The outcome is an increase in oral health inequalities for children with disabilities and an urgent need for policy and reform.

**Introduction**

The aim of this paper is to explore the oral health of children with disabilities in post-Soviet Lithuania. Although there are differences in prevalence between countries, oral health research suggests that children with disabilities have poorer oral health and experience more dental decay, periodontal disease and extractions (De Camargo and Antunes 2008, Stein, et al. 2013, Cardoso et al. 2015, Norderyd et al. 2017, Norderyd et al. 2018). The oral health research suggests that there are inequalities in oral health for children with disabilities. More significantly, a social determinants approach argues that inequalities in oral health are cumulative and pervasive across the lifecourse (Thompson 2012) which is of particular importance for children with disabilities because they are a marginalised group.

The social determinants have an impact on all aspects of health, including oral health. Although the links are highly complex and involve many factors, non-communicable diseases such as dental decay and periodontitis are preventable and can be associated with poverty, low socio-economic status, inadequate medical care, lower levels of education (or exclusion from education), social discrimination (marginalization), reduced social networks, residing in rural or urban places and across the life course unequal access to resources (Emerson, 2004, Hughes and Gazmararian 2005, Emerson and Hatton 2007, Kuo et al. 2014). Children with disabilities are more likely to be at increased risk of exposure to major categories of the social determinants of health, experience recurrent poverty and lower socio-economic status (Emerson and Spencer 2015). Although there are links between poverty and poorer health, a call has been made for these links to be more nuanced, highlighting the complexity and presence of political factors (Groce et al. 2011).

The Republic of Lithuania is situated on the east coast of the Baltic Sea and 2017 estimates give a population of approximately 2.8 million (<http://worldpopulationreview.com/countries/lithuania-population/>). Lithuania was previously a part of the USSR and with the end of communism and the decline of the Soviet Russia, Lithuania declared independence in 1990, with governance moving to a multi-party parliament called the Seimas. It was one of the three Baltic States to join the European Union (EU) in 2004; a condition of their entry was to improve human rights, especially for children and adults with intellectual disabilities. Lithuania is a relatively young country and is still undergoing numerous political and structural changes. For example, disability, social integration and inclusion still remain issues to be addressed. Entering the EU provided the theoretical basis for the development of the social model of disability within policies, so structural barriers to issues like access to healthcare and the skills and attitudes of service providers became a focus. The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol were ratified by the Republic of Lithuania in 2010 (The Parliament of The Republic of Lithuania, 2010).

Like many other post-Soviet countries, Lithuania originally retained the Soviet Semashko system of healthcare which relied on universal coverage, was heavily

medicalised, clinician centred, lacking in patient choice and respect for patients' rights (World Health Organisation 1998). The system was viewed as being inefficient, lacking in quality and unsustainable (Grabauskas 2000). Many post- Soviet countries then moved more towards a more democratic system and market economy comprising of a mixed system of healthcare funded by national and private insurance systems (Rechel et al. 2009). In cases like Bulgaria, and other Eastern European countries the transition had unintended negative consequences for child health and there was a decline in the quality and availability of child health services, especially for children with disabilities and this has been highlighted as an ongoing problem (Rechel and McKee 2008, 2009, Rechel et al. 2009). Although some research suggests that the quality and availability of healthcare was inadequate for children with disabilities during the Soviet period because they were not perceived as possessing any value for society and institutionalised (Phillips 2009). This perception remains a legacy of the Soviet period.

Within Lithuania there are also widening socio-economic and health inequalities with high levels of disadvantage in more rural areas which has a negative impact on the care and health of children with disabilities (Kalediene et al. 2015, Kaseliene et al. 2017). A prerequisite for health is the economic situation of a population, for example, the economic situation of women, even though their rate of unemployment is lower, means they earn less compared to men in Lithuania (Kalediene and Nadisauskiene 2002). The average monthly salary in Lithuania is between 400€ and 800€; there are high levels of child poverty and minimal social welfare support and the Lithuanian government spends the smallest amount of its gross domestic product (GDP) on families compared to Estonia, Hungary, the Czech Republic, Slovenia and the rest of Europe (Salanauskaite and Verbist 2013, Navickė and Čižauskaitė 2017). In 2012, 30% of people in Lithuania were facing the risk of poverty or social exclusion, with educational outcomes lagging behind other countries in the European Union (EU) and health outcomes being amongst the worst (Coady and Geng 2015).

The prevalence of poorer oral health and levels of dental decay is 2.5 times higher for children living on or below the poverty level (de Paula et al. 2015, Malecki et al. 2015). As far back as 2000, it was recognised that oral health for both adults and children at the lower end of the socio-economic scale is worse than those at the higher end

(Locker 2000). Further research around the oral health of children with disabilities reveals that there were higher unmet levels of need when parents experienced lower levels of education, lower levels of employment and higher levels of poverty (Chi et al. 2014, Wiener et al. 2016). Other research indicates that where there is a mixed service provision more acute services are funded better than less acute ones, reflecting an impetus to assist those in crisis, but failing to prevent levels of disease and promote health (Adler et al. 2016).

Oral health for children in Lithuania is poor generally. Oral health checks in 2004 revealed that children had poor oral health and a fluoride application programme for children's teeth was implemented, but funding to maintain the programme decreased and oral health checks in 2007 revealed that 75-83% of children's teeth were decayed (National Audit Office of Lithuania, 2008). A more recent study exploring the oral health of pre-school children suggests that the dmft for this group was 6.5 and that there were poor levels of nutrition, a lack of oral hygiene practices and parental awareness of oral health (Slabšinskienė et al. 2010). Despite the risks, the majority of children undergo a dental general anaesthetic for removal of teeth and many children are under the age of six (Jankauskienė et al. 2013).

Of all the health care areas that have undergone reform in Lithuania, dental care has experienced the highest levels of privatisation and more than 60% of dental practitioners now work in the private sector (Health Information Centre, 2012). This means that oral health care is beyond the reach of many people in the population, especially those with lower levels of education, poorer access to employment and living on or below the poverty margin. This is particularly important for children with disabilities who are more likely to reside in families at the lower end of the socio-economic scale. Therefore, this research gives an overview of the oral health of children with disabilities in Lithuania and begins to address the gap in the evidence base.

## **Aims and Objectives**

The aim of this retrospective service evaluation was to highlight the oral health of children with disabilities in post-Soviet Lithuania.

The objectives of the study were:

- To analyze the most recent (those allowed by personal data law in Lithuania) dental records of children with any type of disability (from 1-17 years of age), who attended the University Hospital in Vilnius for dental treatment in 2 consecutive years: 2013 and 2014
- To record the number of decayed teeth
- To calculate the distance between home and hospital locations and compare it with oral health status
- To identify whether treatment took place under sedation or GA

## **Methods**

Data related to oral health status of children with disabilities in Lithuania is scarce; accessing parents is also difficult because of their widespread distribution, or no contact with their offspring because they are institutionalised and the lack of accurate records. However, it is possible to access data from medical records in the University Hospital in Lithuania. In order to gain a general idea a 'snapshot' was taken of the oral health status of a selected population -children with disabilities- at the time they were in the hospital for dental treatment in 2013 and 2014.

### *Design and sample*

This was retrospective descriptive study. The rationale for this design was that there was a paucity of information available about the oral health for children with disabilities in Lithuania; therefore the objectives of exploring a discrete sample were to:

- Provide informal information about the oral health of children with disabilities in Lithuania

- Gain an overview of the prevalence of oral health conditions for children with disabilities
- Identify areas for further research

#### Inclusion criteria

- Dental records of referred children with any type of disability
- Limit to 1<sup>st</sup> visit for diagnosis and full dental treatment plan
- Age range 1-17years because children would not be routinely seen below 1year of age and at 18 children are considered to be adults
- Number of decayed teeth recorded

Dental records for the years 2013 and 2014 were hand-searched and reviewed in the archives of the University Hospital in Lithuania in February 2016. The oral health of a selected population - children and young adults with cognitive and sensory impairments - was analysed. The main variable was the number of decayed teeth, this was selected to evaluate the oral health of children and derived from clinical diagnosis in the medical records. From the outset we knew that this study would only provide a snapshot of the frequency and characteristics of oral health for this particular group for a 2 year period. It was also acknowledged that because this was a convenience sample there would be the risk of bias, but because of the paucity of evidence it was considered to be enough of a starting point to gain insight into the level of need.

The full search strategy and how eligible documents were selected are displayed and explained in Figure 1.

#### **Ethics**

The research has been conducted in full accordance with the World Medical Association Declaration of Helsinki. The institutional review board at the University Hospital in Lithuania, which has its own ethical and privacy policies considered the

study and issued a permit to use anonymized data from medical records for a specific time period. The retrospective service evaluation was carried out according to Law on Protection of personal data of the Republic of Lithuania. There was no direct contact with patients. Patients were not identified and no personal details were released. The University of Sheffield Research Ethics Committee approved the study [application number 007059]. All data was anonymized and all identifiable details were removed to protect patients. Computers were password protected.

## Analysis

Descriptive data were presented to provide an overview of children referred into the University Hospital in Vilnius, Lithuania in terms of the total number, age and sex of patients, disability diagnosis at time of referral, number of decayed teeth, whether they were deciduous or permanent. Data was also collected as to distance travelled to the hospital in Vilnius. Data were analysed in SPSS v.24.

## Results

The results are presented in relation to sex, age, type of disability, number of decayed teeth and whether treatment was carried out under general anaesthesia or benzodiazepine sedation (Table 1).

	N	Age Range	Mean Age	N decayed teeth		GA	S	C P	D S	ASD	ID	Gen	Sight Hear Imp.	B
				d	P									
<b>M</b>	89	2-17	9	378	251	78	11	20	7	26	30	4	1	2
<b>F</b>	61	3-17	11	282	169	54	6	18	14	1	22	2	3	0
<b>Total</b>	150			660	420	133	17	38	21	27	52	6	4	2
<b>%</b>	100					89	11	25	14	18	35	4	3	1

Table 1: Descriptive data

Key; **d**: Deciduous teeth; **P**: Permanent Teeth; **GA**: General Anaesthetic; **S**: Sedation; **CP**: Cerebral Palsy; **DS**: Down syndrome; **ASD**: Autism Spectrum Disorders; **ID**: Intellectual Disability; **Gen**: Other types of genetic condition; e.g. Klinefelters, Prader Willi, Klippel-Feil; **Sight.Hear imp**: Sight and hearing impairments; **B**: Behavioural e.g. hyperactivity and Attention Deficit Hyperactive Disorder (ADHD)

When we convert the totals to percentages, 10% of females had sedation, compared to 12% of males. From the data, 89% of children with disabilities were given repeated



general anaesthetics for general dental treatment, some as young as 2. Children with sight and hearing impairments, but with no cognitive impairments were also given a GA for treatment and indications in the notes were that dental practitioners were not comfortable communicating with the children with comments written such as 'difficulty communicating' and 'poor communication'. Children with ADHD were also referred for GA; this appears to suggest that disability may be the reason for referral for some children rather than anxiety or lack of co-operation. There was evidence of gross decay for the majority of children; three children had as many as 18 decayed teeth which were treated by extraction. There was a high level of unmet dental need in this sample of children as illustrated in Figure 2.

Distance travelled varied according to area of residence but some children travelled over 450km to be seen at the hospital, whilst others lived in Vilnius itself, overall the average distance travelled was 50km.

We hypothesised that because of rural inequalities and poor access to services, the number of decayed teeth would significantly increase with distance from the hospital.

The results were subjected to a Spearman's Rho test to identify if there was a significant relationship between distance from hospital and number of decayed teeth.

*Table 2* Distance from hospital and level of decay

			Rank of Decayed teeth by Diagnosis	Distance from Hospital
Spearman's rho	Rank of Decayed teeth by Diagnosis	Correlation Coefficient	1.000	.031
		Sig. (2-tailed)	.	.708
		N	150	150
	Distance from Hospital	Correlation Coefficient	.031	1.000
		Sig. (2-tailed)	.708	.
		N	150	150

The observed value;  $r(150) = 0.031$   $p > .05$ . We can therefore suggest that there is a very weak positive correlation between number of decayed teeth and distance from hospital which is not statistically significant.

## **Discussion**

The results from this retrospective descriptive service evaluation reveal that the oral health of children with disabilities at the time they attended the hospital in Vilnius, Lithuania was very poor; 72% of children had 5 or more decayed teeth and 27% of children had 10 or more decayed teeth requiring extraction on the day they arrived to the hospital. Only 1 child was a self-referral with the parents insisting they have a general anaesthetic for the extraction of 1 decayed tooth. The remaining children were referred from general dental practitioners and paediatric dentists in the wider community. Even though there was a weak positive correlation between number of decayed teeth and distance from the hospital in Vilnius this was not statistically significant.

We could argue that the cases seen in the hospital are referred and therefore the worst cases to be found. For this reason the findings cannot be generalized to whole population of children with disabilities in Lithuania. Alternatively, we could infer that DMFT/dmft (decayed missing and filled teeth in primary teeth, DMFT in permanent teeth) indices may give even worse results, because we would also be recording decayed, missing and filled teeth. Research in Lithuania suggests that the prevalence of poor oral health for children without disabilities appears high compared to other countries worldwide, with a dmft/DMFT score of between 5 and 8 for eight to fifteen year olds (Milčiuvienė et al. 2009). This is high compared to other post-communist countries such as neighbouring Poland which has a dmft/DMFT of between 3 and 6 (Emerich and Adamowicz-Klepalska 2010). Research in Russia infers that oral health provision, although free for children, is not a priority with low workforce numbers and poor regional provision, meaning that access to oral health care is not always satisfactory, even more so for children with disabilities because they are often an excluded group (Widström et al. 2010).

Tackling social inequities in health is of particular importance in countries like Lithuania that are undergoing social, economic, and political transition. For Lithuania, rapid political and economic changes have exerted an influence on health (Kalėdienė et al. 2008). If we consider its historical and political milieu, we can suggest that although the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol were ratified by the Republic of Lithuania in 2010, the oral health of children and young people with disabilities was not an immediate priority for the government. This is possibly the result of a legacy of medicalised thinking inherited from the Soviet Semashko system of healthcare. The establishment of economic and political structures was considered to be the main priority during the first years of transition and this could further explain the lack of development in welfare and health policies (Atas 2018).

Prior to independence, all health care workers used to be salaried employees, today they are mostly part of a free market (Widström et al. 2001). Mixed private and public practice now prevails with a predominantly private sector in dentistry (Liseckiene et al. 2007). Although public dentistry provides free dental treatment for all children, there is still a two tier system in operation and there are barriers to accessing health care for children with disabilities (Janulyte et al. 2014).

Families with children with disabilities usually have limited financial resources, are more disadvantaged and are excluded from the possibility of accessing private dental care (Hjern et al. 2001; Shahtahmasebi et al. 2011). More cynically, we could suggest that the private sector is being driven solely on a market economy; based on the concept of profit, therefore it has no incentive or desire to reduce oral health inequalities. It can be debated, that at this point health and oral policy provided by the government, as suggested by other researchers, should be more responsible for addressing health inequalities for children with disabilities and indeed anyone viewed as vulnerable and at risk (Bartley, 2004, p.164-178).

Within Lithuania, the question remains as to whether the system is working to the mutual benefit of children with disabilities or is based more on referring cases to other providers because there is a lack of countrywide oral health provision and specialist

care? The data in this retrospective service evaluation suggests the latter. There appears to be little attempt at trying to increase health equity and engage with other sectors of government and society in order to address the determinants of health and well-being with the aim of promoting oral health and preventing decay, thereby reducing in-patient admissions for dental decay which is mostly a preventable non-communicable disease.

The service evaluation results indicate that the majority of general dental practitioners send their patients to hospital for treatment. The limitations of the research do not allow us to make any conclusions, because it is unknown whether primary dental care tried to or performed any type of oral health care for children with disabilities prior to referring them to secondary care. We could suggest here that primary dental care practitioners operate a gatekeeping role in relation to oral health care for children with disabilities. Future interventions may focus on developing their existing skills in working with children with disabilities which may help with a reduction in referrals for all but the most challenging cases.

We could argue that the social reforms in Lithuania need more time and people have to be prepared for the changes. One suggestion may be that better results will be achieved if the oral health of children with disabilities could be addressed through a few different channels; schools, health visitors and ancillary staff, thereby taking a whole systems approach into consideration. Current social reform and deinstitutionalization in Lithuania means that adults and children with disabilities are being moved from hospital to community care. Deinstitutionalization is a new trend in Lithuanian social politics and if it is not organized effectively, there is the potential to create more obstacles for delivering a better quality of life across the lifecourse for people with disabilities.

For example, children living in institutions will need lessons in developing social skills, they will also need instruction in self-care and oral health care is one of these areas of instruction that could be developed. The social welfare system needs to increase its support to parents and service provision needs to be improved. To facilitate much of the oral health delivery within Lithuania there needs to be adequate evidence to

support some of the arguments within this paper. Therefore, the authors argue that a national epidemiological survey of the oral health of children with disabilities needs to be conducted by experts in dental public health, in order to prepare and implement a lifecourse oral health care plan for children with disabilities in Lithuania.

### **Conclusions and Policy Implications**

The sweeping political changes in post-Soviet Lithuania, the move towards deinstitutionalization and new economic trends, such as the privatization of the oral health care system has meant increasing oral health inequalities for children with disabilities. The social cost of the transformation from planned to market economy has affected the lives of children with disabilities and their families. The predominant course of treatment for dental decay in children with disabilities is an in-patient general anaesthetic and there is little in the way of preventative care or oral health promotion for this particular sample. The high level of unmet dental need indicates the necessity of a comprehensive and effective dental programme which includes training in working with children with disabilities, oral health promotion, prevention and early detection of oral disease and treatment. There needs to be an emphasis on implementing policy and programmes which aim to increase health equity and reduce in-patient admissions for dental decay, which is mostly a preventable non-communicable disease.

### **Limitations and Bias**

The main limitation of the study was its relatively small sample size. It was also acknowledged that due to the convenience sample there was a risk of bias, but the study still illustrated the children with disabilities appear to have high levels of dental decay.

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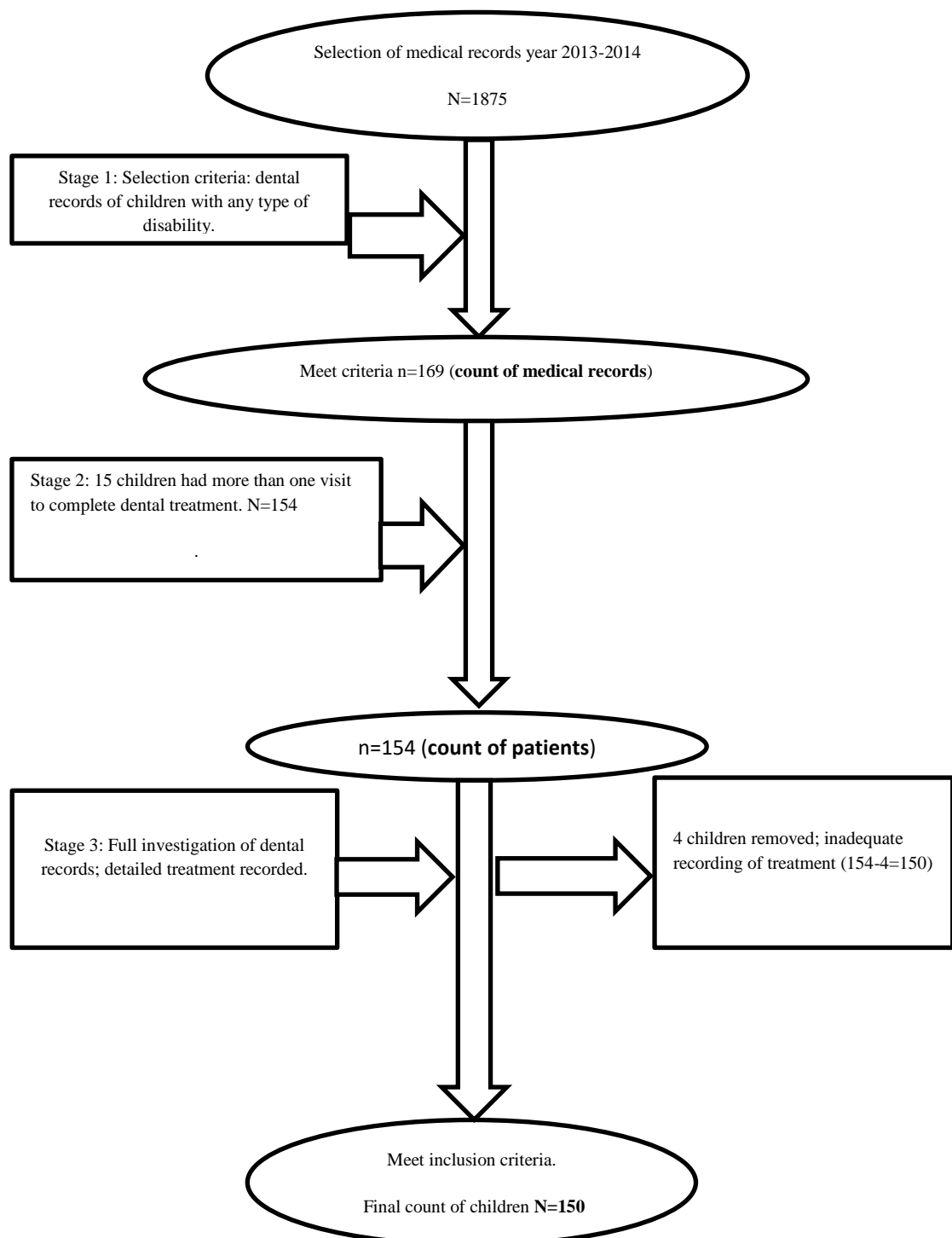


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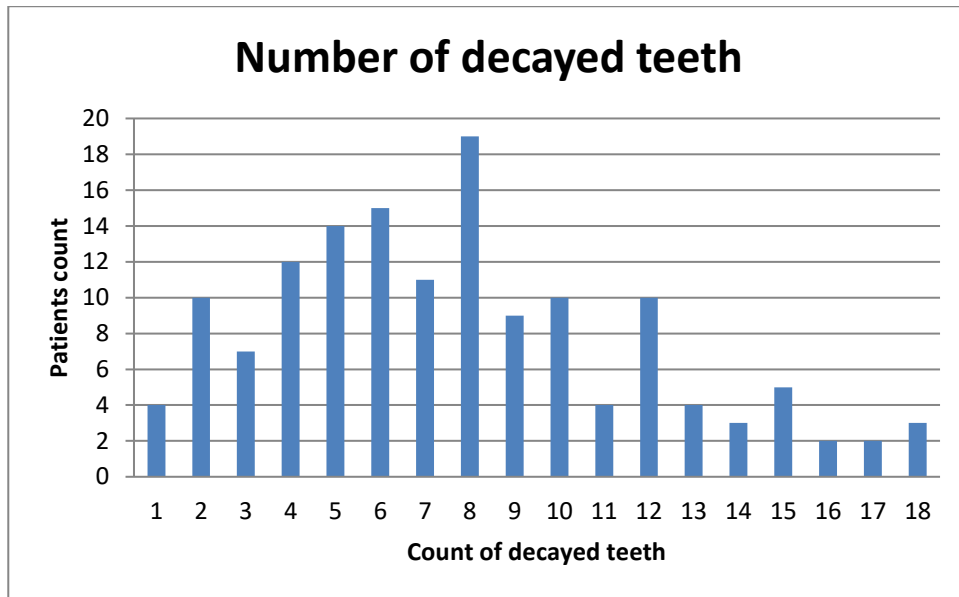
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**Figure1.** Search strategy



**Figure.2.** Number of decayed teeth per child