



**Oral Health of athletes with intellectual disability
from Europe and Eurasia**

by

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Glossary

AAIDD: American Association on Intellectual and Developmental Disabilities

APA: American Psychiatric Association

CDC: Centre for Disease Control and Prevention

CI: Confidence Interval

CPI: Community Periodontal Index

CRPD: Convention on the Rights of People with Disabilities

DPSI: Dutch Periodontal Screening Index

EEA: European Economic Area

EU: European Union

FDI: International Dental Federation

GA: General Anaesthesia

GDP: Gross Domestic Product

GLMM: Generalized Linear Mixed Models

ICF: International Classification of Functioning, Disability and Health

ID: Intellectual Disability

IQ: Intelligence Quotient

NHANES: National Health and Nutrition Examination Survey

NHIT: National Health Insurance Trust

OH: Oral Health

OHDRES:	Oral Health Data Registration & Evaluation System
OR:	Odds Ratio
PBN:	Pilot Study: Oral Care for Persons with Special Needs
RRCC:	Regional Research Collaborating Centre
SD:	Standard Deviation
SO:	Special Olympics
SOEE:	Special Olympics Europe/Eurasia
SOEG:	Special Olympics European Games
SPSS:	Statistical Package for Social Sciences
SS:	Special Smiles
UK:	United Kingdom
UN:	United Nations
UniVISS:	Universal Visual Scoring System
US:	United States
WHO:	World Health Organization

List of Publications

This dissertation is based on the following articles:

- **Fernandez C.**, Kaschke I., Perlman S., Koehler B., Marks L.
Dental trauma among Special Olympics athletes from Europe and Eurasia
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Chapter 3
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Oral health needs of athletes with intellectual disability in Eastern Europe: Poland, Romania and Slovenia.
International Dental Journal doi: 10.1111/idj.12205.
Chapter 6

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Chapter 7

International Presentations

International Oral Presentations

- International Association for Disability and Oral Health, IADH Congress 2014, Berlin, Germany [1].
- International Association of Paediatric Dentistry, IAPD Congress 2015, Glasgow, UK [2].

International Poster Presentations

- European Association of Paediatric Dentistry, EAPD Congress 2014, Sopot, Poland [3].
- International Association for Disability and Oral Health, IADH Congress 2014, Berlin, Germany [4].

1.1. Motivations

Oral health has been widely studied and its relations with general health, oral hygiene, diet and oral microorganisms have been well established. The emphasis is currently placed on disease prevention and health promotion, considering the importance of population's awareness of the relevance of oral health. The global burden of oral disease has increased in the last 20 years, mainly as a consequence of population growth and aging. Although some conditions, like tooth loss, have declined worldwide, disease has shifted towards severe periodontitis and untreated decay. Increases have also been observed in untreated caries and periodontitis, especially in the younger age groups and in regions less advanced in the demographic and epidemiologic transition. As a consequence it will not be surprising to observe high levels of tooth loss in these areas in the future.

Clearly, oral health problems are far from been resolved and vulnerable populations are expected to be at major risk. Yet little has been done to elucidate the trends of oral disease in the population with intellectual disability [5], who may have poor oral health due to factors related to their condition and or related to their access to oral care.

This particular group has special needs and requires special dental care due to the complexity of management in a dental practice. Moreover their oral treatment demands additional skills from care providers and teamwork [6]. Oral health professionals and authorities should seek to ensure the oral healthcare, not only

regarding the treatment of oral disease, but also the integral management of individuals, considering their physical and functional impairments as well as their intellectual limitations and needs. In this context, knowing the real burden of oral disease in this population group may be important to develop more efficient health promoting programs, increased accessibility, and a more appropriate health system design.

1.2. Disability

1.2.1. Definition of disability

Different conceptual models have been used to describe disability. In the past, disability was defined as the consequence of a disease on an individual who requires a treatment, according to a medical model. Later this concept evolved to a social model, and environmental factors were acknowledged to describe disability. Those factors were considered as barriers for the normal function and social integration [7,8].

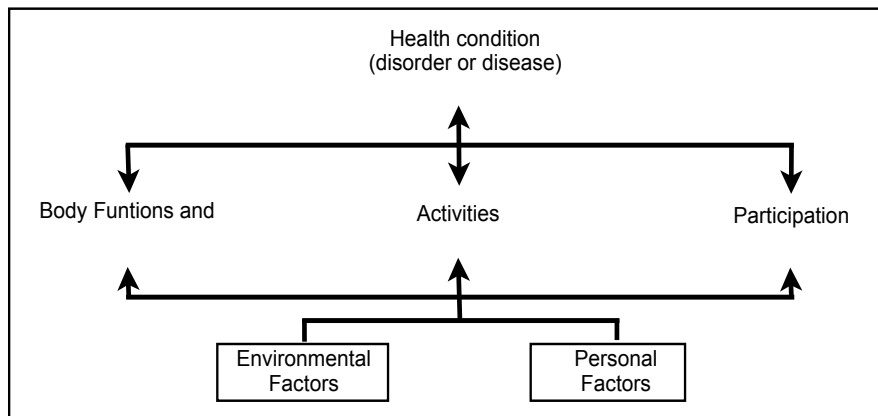


Fig. 1 Interactions between components of the International Classification of Functioning, Disability and Health (ICF, WHO 2001). Extracted from: The international classification of functioning, disability and health: an overview. World Health Organization. Geneva (2001). [9]

In 2001, the World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF) (Fig. 1). This new model includes both medical and social concepts to define a 'biopsychosocial' approach in which a disease is developed. This term includes functional and structural limitations and their effects on participation and daily activities [10]. Moreover, it indicates the influence of contextual factors (environmental and individual factors) on body functions, participation and daily activities [7,9].

1.2.2. Prevalence of disability

The WHO estimates that 10% of the world's population has a disability (approximately 600 million). The percentage of population that are also involved as caregivers, family or community, has been estimated at 25% [7,9].

Table 1. Prevalence of disability

Unit: Thousand, Time: 2012, Age: 15 years and over. Extracted from: Eurostat, Statistical Office of the European Communities. Eurostat: Regional Statistics, (2014).[11]

HLTH_PB GEO	% of Disabled	Disabled	Not Disabled	Total
European Union (27 countries)	17.6	73,030.6 ^(e)	342,560.8 ^(e)	415,591.4 ^(e)
Belgium	16.6	1,553.4	7,710.1	9,263.6
Bulgaria	21.4	1,369.5	5,019.8	6,389.4
Czech Republic	14.2	1,272.1	7,692.1	8,964.2
Denmark	20.1	919.3	3,665.3	4,584.5
Germany (until 1990)	20.1	14,783.8	55,744.0	70,527.8
Estonia	19.9	225.1	906.8	1,131.9
Greece	17.9	1,686.6	7,686.9	9,373.5
Spain	16.7	6,551.1	32,618.7	39,169.8
France	13.3	6,805.4	43,054.5	49,859.9
Italy	14.5	7,399.5	43,708.2	51,107.7
Cyprus	15.0	104.1	590.6	694.7
Latvia	23.5	405.4	1,315.7	1,721.0
Lithuania	22.9	585.5	1,964.7	2,550.2
Luxembourg	16.1	68.3	355.3	423.6
Hungary	24.8	2,072.8	6,298.6	8,371.4
Malta	12.0	42.1	308.0	350.1
Netherlands	17.2	2,395.1	11,506.5	13,901.7
Austria	16.4	1,162.7	5,947.6	7,110.3
Poland	17.7	5,805.1	26,914.3	32,719.5
Portugal	14.6	1,224.5	7,189.7	8,414.2
Romania	18.0	3,263.6	14,860.7	18,124.4
Slovenia	18.2	320.3	1,440.5	1,760.7
Slovakia	17.8	814.1	3,748.7	4,562.8
Finland	17.1	767.5	3,721.0	4,488.4

Sweden	14.5	1,165.0	6,779.0	7,994.0
United Kingdom	19.7	10,268.5	41,813.5	52,082.0
European Economic Area (EEA 18-2004, EEA28- 2006, EEA30-2013, EEA31)	17.6	73,894.9 ^(e)	346,014.2 ^(e)	419,909.0 ^(e)
Iceland	16.0	40.8	214.6	255.4
Norway	20.3	823.5	3,238.8	4,062.3

^(e) estimated

The Environment Health and Safety Information System (EHSIS) designed a survey to measure the biopsychosocial model of disability introduced by the International Classification of Functioning, Disability and Health (ICF, World Health Organization, 2001). According to the survey people with disabilities are those who face barriers to participation in any of the 10 life areas associated with a health problem or basic activity limitation. Therefore, a person identifying a health problem or basic activity limitation as barrier in any life domain is categorized as disabled. This survey was applied to populations aged 15 and over living in private households in 26 member states. Data collection lasted 1.5 months (Hungary) to 8 months (Portugal) between September 2012 and July 2013. In the European Union (EU) one out of six people has a disability (approx. 80 million) [11] (Table 1), although this rate differs from one country to another depending on the prevalence of disability and the national population (Fig. 2). Despite the high general prevalence, people with disabilities are often unable to participate in society because of individual and environmental barriers [11,12].

Age has also been identified as a risk factor for disability. This trend is present in all countries, although the rate of progression differs from one country to another. For example, from the age of 40 onwards Finland presents the highest prevalence of disability with more than 52% for 60–64 year-olds. While a lower percentage was found in Belgium;, Greece, Ireland and Italy had values near 20% for 60–64 year-olds [13]. These percentages are expected to rise as the population ages in Europe.

These data are based on people who receive disability-related benefits and percentages are expected to rise with the aging of the European population. Unfortunately, in some countries disability pensions are changed when adults reach certain age for benefits for elders and therefore the data were included only up to 64 years of age. Furthermore, the comparability of these data across countries required

aggregations as the Member States use different classifications depending on the specific benefit offered.[14]

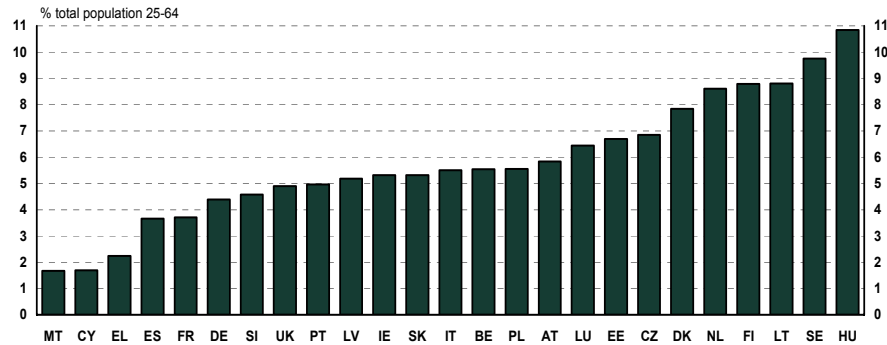


Fig. 2 Recipients of disability-related benefits, 25-64 in 2005. Benefits Included are: Contributive invalidity pensions, non-contributive disability allowances, pensions for occupational accidents & diseases, and war pensions. Data may include double counts. . Countries: Malta, Cyprus, Greece, Spain, France, Germany, Slovenia, UK, Portugal, Latvia, Ireland, Slovakia, Italy, Belgium, Poland, Austria, Luxembourg, Estonia, Czech Republic, Denmark, Nederland, Finland, Lithuania, Sweden and Hungary. Extracted from: T. Ward, S. Grammenos, M. Huber, N. Rabemiafara. Study of compilation of disability statistical data from the administrative registers of the member states. Vienna 2007.[14]

The nature of disability, or in other words the type of disability and the degree of severity are determinant factors for the performance of individuals. The prevalence of recipients of disability-related benefits in European countries, by nature of disability, is presented in Fig. 3. It is evident that in the region, physical and motor impairments are more prevalent than mental and/or psychological impairments as literature reports 30% of the disabled people presenting mental and/or psychological impairments [14]. On the other hand, differences in severity influence the degree of functional limitations. In those over 75-years of age with disabilities (approximately one third of people in this age group), some can function independently with a few additional supports, while over 20% are considerably restricted and require extra support [12]. However, these data on type and degree of disability have comparability issues because of the different categories and thresholds used in the different countries. It has to be noted that the data takes into account contributory and non-contributory benefits. In some countries like France these two types of benefits exist

while in others, like Sweden only one type of benefit is exists. Therefore both types (contributory and non-contributory) are included. For receiving contributory benefits a person not only has to meet the eligibility criteria, in this case having a disability, but also must have paid a minimum of insurance contributions to qualify. To qualify for non-contributory benefits, a person has to meet the eligibility criteria regardless of whether contributions have been made [12].

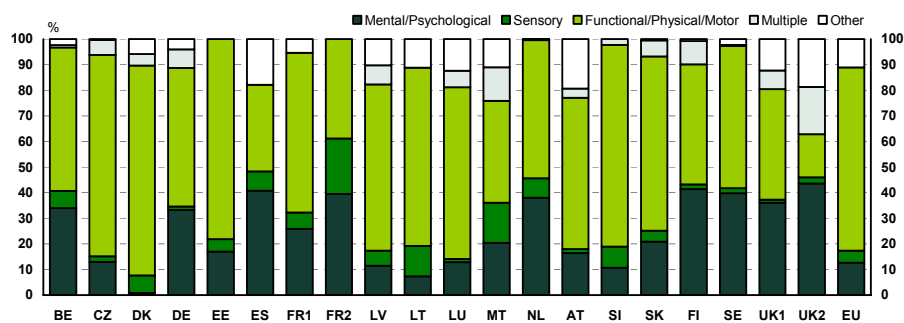


Fig. 3 Recipients of disability-related benefits, by nature of disability, 2005. Data include both contributory and non-contributory benefits. Countries: Belgium, Czech Republic, Denmark, Germany, Estonia, Spain, France 1 (Invalidity pensions), France 2 (Allocation aux adultes handicapés (AAH)), Latvia, Lithuania, Luxembourg, Malta, Nederland, Austria, Slovakia, Finland, Sweden, UK1 (Longterm incapacity benefits), UK2 (Severe Disablement allowance), European Union. Extracted from: T. Ward, S. Grammenos, M. Huber, N. Rabemiafara. Study of compilation of disability statistical data from the administrative registers of the member states. Vienna 2007. [14]

1.3. Intellectual disability

1.3.1. Definition of intellectual disability

The term 'intellectual disability' (ID) refers to the limitation of mental abilities and compromise of learning processes affecting general intellectual and adaptive functioning [7,15].

In 1992, the American Association of Intellectual and Developmental Disabilities, formerly the American Academy of Mental Retardation, defined intellectual disability

(previously known as Mental Retardation) as the onset of significant limitations in both general intellectual and adaptive functioning during the developmental period (18 years and under) [15]. The most accepted procedure to measure general Intellectual functioning is the Intelligence Quotient (IQ) test. An IQ score that falls two standard deviations below the population mean of 100 (<70) indicates a limitation. On the other hand, to measure adaptive functioning, professionals look at what a person can do in comparison to others in the same age group in relation to conceptual, social and practical skills. Thereby, scores of approximately two standard deviations below the average score for the specific age group indicate adaptive functioning limitations [7,15].

The American Psychiatric Association (APA) published the Diagnostic and Statistical Manual of Mental Disorders in 2013, which takes into account the same criteria for intellectual disability diagnosis. Significant limitations in the intellectual (mental abilities) and adaptive functioning must be present, as well as onset during childhood, which means that the limitations were developed before the age of 18 [16].

1.3.2. Etiology of Intellectual Disability

Many factors have been identified as related to the etiology of Intellectual Disabilities [17].

- Chromosomal or hereditary disorders: Most of these cases are patients with Down syndrome, but other disorders such as fragile X chromosome syndrome are also related conditions.
- Hereditary factors (such as phenylketonuria).
- Congenital Acquired factors: Metabolic (i.e. neonatal hypothyroidism); Toxic (i.e. lead poisoning, fetal alcohol syndrome, prenatal exposure to substances); Infectious (i.e. rubella, Cytomegalic Inclusion Body Disease, syphilis, etc.).
- Developmental Acquired factors: Complications during pregnancy, perinatal or postnatal periods.

- Environmental and sociocultural factors: Poverty, infant mistreatment, low level of stimulation and education, among others.

1.3.3. Severity of Intellectual Disability

Within Intellectual Disabilities there are three levels of severity [16].

- Light intellectual Disability

People classified in this group constitute 75% of the ID population and have an I.Q. score in the range 52–68. They can develop social and communication skills and have the capacity to adapt and integrate into employment. Additionally, they present a minimal delay in perceptual and motor areas.

- Moderate Intellectual Disability

This group is 15-20% of the ID population with an I.Q. score of 36-51. They are able to learn personal and social autonomy. They may learn to communicate through oral language, but frequently present with difficulties in speaking and understanding social conventions. They generally have acceptable motor development and may learn basic technological skills.

- Severe Intellectual Disability

Individuals with an I.Q. score of 20–35 are included in this group. Only 3-5% of the ID population fall into this category. Generally, they need protection or assistance because of a poor level of autonomy. They often present with significant psychomotor impairments. They can learn some communication systems, but their spoken language is very poor and they require continued support and care.

1.4. Disability in the European community: Historical perspective

Member States of the European Union agree on the need to improve the conditions of people with disability. For this purpose, during the last 40 years, several initiatives have been taken and public policies have been developed in order to improve inclusion for the population with intellectual disabilities.

In 2000, the Charter of Fundamental Rights of the European Community pleaded for the respect and protection of human dignity. The charter stipulated that the EU recognizes and respects the rights of individuals with ID, in autonomy, social and professional integration, and participation in community, while it forbids disability-related discrimination [18].

Despite the charter, the rights of people with disabilities were not fully respected and were mostly illusory in the EU member states. Therefore in 2007, the Treaty on the Functioning of the EU established the fundamentals of the European Union and stipulated that the EU would take measures against discrimination of people with any kind of disability [19].

1.4.1. United Nations Convention on the Rights of People with Disabilities

The United Nations Convention on the Rights of People with Disabilities (CRPD), signed by 160 countries worldwide in 2006, was the first legally binding human rights instrument to demand countries to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by individuals with disabilities, and to promote respect for their inherent dignity. A person with long-term physical, mental, intellectual, and/or sensory impairments is to be considered as a person with disability. Furthermore, the convention provided a concept of equity that demands adequate responses to the particular needs of all individuals in society [20,21].

The main principles of the Convention include respect for inherent dignity, individual autonomy, identity, full and effective participation and inclusion in society, equality of opportunity, accessibility, gender equality, respect for difference, acceptance and non-discrimination [21].

According to article 25 of the CRPD, which addresses the rights of health, people with disability are entitled to receive care of the same quality and standard without discrimination, as other people [21].

The CRPD initiated changes in the EU policy, providing a vision and promoting law reform. But its success on equality for persons with ID depends on the response of national authorities to the convention demands.

1.4.2. European Disability Strategy 2010–2020

In 2003, after the European Year of People with Disabilities, the European Commission launched the EU Disability Strategy 2003–2010 with the goal of achieving 'Independent Living of People with Disabilities'. At the end of this period, the European Commission developed a new strategy, the European Disability Strategy 2010–2020, that calls the EU member states to work together in building a Europe where people with disabilities encounter no barriers to full participation in society on an equal basis with others. This strategy established the mechanisms needed to implement the UN Convention at an EU level and to help individual national initiatives in three main areas: awareness-raising, financial support and data collection [12].

1.5. Health of people with ID in Europe

The International Conference on Primary Health Care conducted in Alma Ata in 1978 emitted a declaration that emphasized the need of social justice and the right of good equal health [22,23]. Achieving health equality goals requires the inclusion of people with disabilities within health surveys [24]. Additionally, each country should be able to identify health problems, health status, and needs of its population, in order to assess the prevalence and distribution of health indicators and population trends.

Acknowledging the gap of information on health of the population with intellectual disabilities, the Health Monitoring Unit of the European Union launched the Pomona project. In this project several health indicators specific for people with intellectual disabilities were developed and tested in 14 European countries to gather information on lifestyle, health status, behaviour and access to healthcare. This followed the approach of the European Community Health Indicators (ECHI) project concerning the health indicators for general population [25]. The objective was to get a better understanding of health determinants among people with intellectual disabilities.

1.6. Oral health of people with ID

Oral health is essential for general health and influences quality of life. The two most prevalent oral diseases are dental caries and periodontal disease. Both of them have potential effects on eating, speech processes, and self-esteem [7,26]. Evidence

shows that poor oral health is associated with malnutrition, weight loss, systemic diseases, and focal infections which may increase morbidity and mortality [27,28]. Untreated tooth decay was the most prevalent disease condition among 291 diseases studied in the Global Burden of Disease Study (1990-2010) with a global prevalence of 35.3%. Gingival bleeding with calculus is the most prevalent score for periodontal disease in all WHO regions and severe periodontal disease affects 10 to 15% of the world adult population [5,29].

It has been reported in several studies that people with disabilities are vulnerable to oral disease as a consequence of their impairments and/or oral manifestations of their condition which compromises oral hygiene and their oral health needs [30–34]. Most of the studies have concluded that people with a disability have poorer oral hygiene in comparison to the general population. In consequence, the oral health of children with disability was reported to be poor and to worsen with age [35]. Furthermore, they may present abnormalities in the tooth morphology or eruptive pattern like enamel hypoplasia or delayed eruption, high palate, maxillary hypoplasia, malocclusions and open bite, among others.

Anders and Davis conducted a systematic review to analyse the differences in oral health status between patients with ID and the general population, which included 27 studies. This review confirmed that people with ID have higher plaque levels and poorer oral health due to a lack of manual dexterity, limited natural cleansing of oral musculature, and inadequate support from caregivers. Although oral hygiene is directly related with decay and periodontal disease, patients with ID were found to have a higher prevalence of periodontal disease, but lower or similar prevalence of decay than the general population [33,35,36]. It was proposed that this could be related to the early extraction of decayed teeth, based on the high rates of extracted teeth and low prevalence of filled teeth [37]. This may be explained by the fact that people with disabilities seek dental treatment when it is considered an emergency, instead of getting regular preventive care. As a consequence, the cost of the treatment increases and the outcome is often dental extraction, instead of fillings, crowns or bridges [38].

Additionally, people with ID often present with self-inflicted traumatic injuries due to Angle Class II malocclusions and open bite coupled with coordination difficulties,

seizure episodes, and slow reflexes [39]. While, tooth grinding can be an expression of a muscular tension releasing habit. [6]

Individuals with Intellectual Disability have more prevalent and severe periodontal problems [36,40] The impact of the severity of disability on oral and periodontal status was evaluated in 105 adults with ID considering periodontal parameters as plaque index, gingival index, bleeding on probing, probing depth, and clinical attachment level. Plaque index was correlated with periodontal disease. The indicators of periodontal disease development (probing depth and clinical attachment loss) scored higher in those with severe ID. Therefore it was concluded that periodontal status of the population with ID is related to poor oral hygiene and the need for periodontal treatment is greater for those with severe ID [33,36,41]. The prevalence estimates of gingivitis in people with ID is 1.2 to 1.9 times the estimates for general population [7,30,42,43].

Patients with Down syndrome also have a higher prevalence of periodontal disease and the onset is usually at a very early age. It is therefore common to find chronic marginal gingivitis and pocket formation in the region of the lower incisors, caused by a functional failure of the neutrophil granulocytes. Furthermore, they do not only present determinant factors for changes such as tooth malposition, poor oral hygiene and increased susceptibility to infections, but also for high incidence of acute ulcerative gingivitis [44,45].

The living conditions are related with the oral health needs of people with ID. People with ID living in institutions are mostly those with more severe disabilities and less likely to receive oral care. Institutionalized individuals with ID were found to have a comparable incidence of caries but poorer oral hygiene and more untreated disease than the general population. Individuals with ID that do not live in institutions presented with higher caries incidence rates compared to the general population and more caries and extracted teeth than those who live in institutions [42,46].

In 2010 the Belgian National Institute for Health and Disability Insurance (NIHDI) launched a pilot study to lay the foundation towards better oral care for individual with special needs (PBN Project). This project, developed in collaboration with dental professional organizations and universities, consisted of a National epidemiological

survey and oral examinations. The study population obtained by two-stage sampling consisted of 707 adults with disability, 22–65 years old, who were approached in residential settings, day care centers, and sheltered workplaces. The interview was related to oral health habits, dental attendance, access to oral care and subjective oral care needs. Most of the individuals presented visible dental plaque (78%) and calculus (68%). Half of the participants showed signs of gingivitis (Dutch Periodontal Screening Index DPSI with a highest individual score of 1 or 2) and 23% presented shallow pockets (4–5 mm). Regarding caries experience, 56% had untreated caries and 64% had at least one missing tooth [27,34]. The results revealed that for most clinical parameters, these individuals scored worse than the available data of the Belgian general population.

The World Dental Federation (FDI) developed policy statements to promote optimal oral and general health for all people. The policy statement for oral and dental care for people with disabilities establishes that all people should have access to oral healthcare, with the same standards and without discrimination. It also indicates that the oral health of people with disabilities should be managed through education and prevention of oral diseases [47]. Still, a permanent challenge for the governments of EU members is to address the oral health needs of a diverse group of people, including people with disabilities, who may have compromised oral health due to their condition, hygiene, medications or lack of access to care.

1.7. Access to health care

Access to oral care is defined as the ability to obtain, or make use of, dental care [48]. In this context, people with disabilities or their caregivers, as the general population, has to seek dental care, but their actual access to dental care is affected by many factors.

First, the living conditions may be considered as a barrier depending on the degree of independence and level of support that the individual possesses. Similarly, the geographic location of their house or institution relative to the dental service providers could be a barrier to access oral care, if they live far from dental clinics where attention to special care patients is offered the travel and means for transportation could limit their possibilities to attend the dentist.

Financial factors may also become a barrier for attending dental appointments and accessing dental care [34,49,50]. Individuals may have a lack or inadequate dental health insurance, low income or unaffordable dental treatment costs [51,52].

Furthermore, other barriers may be related to the importance given to oral health by people with ID, which is influenced by their level of understanding and education received on the matter. Therefore the relevance given to oral care by the caregivers is another involved factor. Individuals with ID may be aware of they need of oral care but other factors such as fear or anxiety may become barriers and play against patient's cooperation [53].

It is known that communication is an essential factor for a positive relationship between patient and dentist but it may be influenced by fear, anxiety and sensory limitations, obstructing diagnosis, instructions, record of patient's history and access to oral care [34,35,53]. On one hand, a visit to the dentist often triggers anxiety, even with non-disabled patients. The anxiety may interfere with the patient being unable to cooperate with any assessment [35,53]. On the other hand, some people with ID may have difficulties describing pain or other symptoms, or may present with visual and hearing limitations [54].

Meeting the oral health needs of people with ID not only requires access to dental care, but also access to appropriate dental care, which depends on the skills and training of service providers. In fact, all individuals who provide healthcare should receive specialized training. Finally, oral care must be affordable and it must include the adequate infrastructure and facilities, which relies on the responsibility of the authorities [55].

1.8. Role of healthcare systems

Increasing resources for oral health care and improving the systems are the actions that governments must take to ensure an efficient healthcare system: equal, affordable, of good quality, and meeting the needs of the population. Therefore, it is essential to identify health determinants; ie: population size, age and sex distribution, health status indexes and epidemiologic trends, in order to develop research-based

solutions [22]. In brief, governments should be able to identify the health needs of their populations, satisfy the demand of care, and promote this demand [56,57].

It is important to note that the health-related needs of a population are not always fully reflected on the demand of healthcare, since part of the population is not aware of their needs of care until they are in pain. The challenge is major as healthcare demand increases continuously and every country should face it along with the aging population.

Governments may identify the areas in which changes could help to reduce oral health disparities, in order to develop strategies. For example, authorities can create strategies against geographic misdistribution or to improve the overall number of providers. Furthermore, to improve the access to healthcare it is essential to remove economic barriers by increasing the number of practitioners participating in government-sponsored coverage plans which are a primary source of care for low-income people [57].

1.8.1. Funding of healthcare systems

In general, there are in three ways to finance healthcare systems [58]:

- Public Finance by general taxation, known as the Beveridge model.
- Public Finance by compulsory social insurance, named the Bismarck model.
- Private Finance, which is based on voluntary private insurances.

The population is considered the first party and must pay to care providers, who are the second party. Most of the time, there is an additional third party that ensures the expenses when the beneficiary becomes a patient [56].

One of the most important challenges faced by the European countries of concerns the financing structure of the health sector. Out-of-pocket expenses or co- payments are an important financing source of the systems in some countries of the region. Although there are differences between European regions, the percentage of the Gross domestic product (GDP) corresponding to health care expenditure is higher in Europe (8.32% of GDP, in average) than in other world regions (Table 2).

Table 2. Health care expenditure as percentage of GDP.

GEO \	TIME					
	2007	2008	2009	2010	2011	2012
Austria	9.74	9.95	10.54	10.48	10.24	10.41
Belgium	9.62	9.94	10.65	10.56	10.61	10.89
Bulgaria	6.50	6.60	7.06 ^(b)	7.54	7.66	:
Croatia	:	:	:	:	7.08	7.04 ^(b)
Cyprus	5.89	6.67 ^(b)	7.17	7.09 ^(bp)	7.27 ^(p)	7.26 ^(p)
Czech Republic	6.31	6.65	7.63	7.24	7.36	7.42
Denmark	9.56	9.77	11.04	10.68	10.47 ^(p)	10.59 ^(p)
Estonia	5.08	5.81	6.65	6.27	5.75	5.81
Finland	7.63	7.89	8.68	8.56	8.53	8.86
France	10.35	10.46	11.17	11.13	11.07	11.16
Germany (until 1990)	10.12	10.33	11.33	11.15	10.87	10.89
Greece	:	:	10.03	9.34	9.67	9.16
Hungary	7.42	7.28	7.57	7.83	7.80	7.73
Iceland	9.09	9.13	9.64	9.29	9.05	9.04 ^(p)
Latvia	6.22	5.99	6.23	5.47	:	:
Lithuania	5.82	6.34	7.43	6.89	6.56	6.37
Luxembourg	6.18	6.67	7.63	7.19	6.94	6.77
Netherlands	9.96	10.20	11.01	11.20	11.22	11.77
Norway	8.20	8.11	9.25	9.07	8.94	9.03 ^(b)
Poland	5.93	6.43	6.72	6.55 ^(b)	6.39	6.33
Portugal	9.35	9.65	10.24	10.15	9.66 ^(p)	:
Romania	5.14	5.27	5.59	5.82	5.51	5.46
Slovakia	7.38	7.63	8.61	8.48	7.60 ^(b)	:
Slovenia	7.49	7.88	8.59	8.58	8.55	:
Spain	8.17	8.63	9.33	9.41	9.27	9.16
Sweden	8.54	8.80	9.48	8.97	8.96	9.07
Switzerland	10.21	10.29	11.00	10.91	11.05	11.43 ^(p)

Unit: Percentage of gross domestic product (GDP). Time: 2015.

: not available, (b) break in time series and (p) provisional.

Extracted from: Eurostat, Statistical Office of the European Communities. Eurostat: Regional Statistics, (2014). [11]

Public finance is the major source of funding in most of EU member states. In 2012, public funding covered from 54.3% (Bulgaria) to 80% (Sweden, Czech Republic, Denmark, Luxembourg and Netherlands) of the total health care expenditure, with the exception of Cyprus (46.5%) [14]. Within public funding, social security funds are the most common financing method for healthcare, covering more than 75% of the total healthcare expenditure in Netherlands, Czech Republic and Croatia in 2012. The private funding is mostly generated by direct out-of-pocket payments, while

private health insurance accounts for fewer than 5% of the total expenditure among the European Members. This private insurance market has decreased in Ireland and Spain but in Western Europe the trend is growing [14,56].

Given the financing overview and since health care expenditure differs from one country to another, setting priorities is important for the organization of healthcare systems and preventive care and research-based programs become a cost-effective alternative.

1.8.2. Overview of European Healthcare Systems

In Europe there are many different oral health systems that provide oral healthcare by means of public or private services, with compulsory or voluntary insurance systems [22]. The main reason behind such a variety of systems relies on the economic and human resources available in each country.

The health systems in Finland, Greece, Ireland, Italy, UK, Sweden and Spain are mainly financed by general taxation, supplemented by private finance and direct payment. Denmark and Portugal have the same funding based on general taxation but only supplemented by direct payment. Belgium, Netherlands, France and Germany are countries with social insurance for health care financing supplemented with public taxation and direct payment. In these western European countries oral treatments are fully funded for children with mental disabilities with the exception of orthodontics, in comparison with general population. In these countries, adults with mental disabilities receive less financial contribution than children. Northern European countries have special reimbursement in dental care for people with special needs. Finally, in Southern Europe, Eastern Europe and Eurasia, a limited amount of dental treatments are fully or partially funded for children with mental disabilities. [56,59]

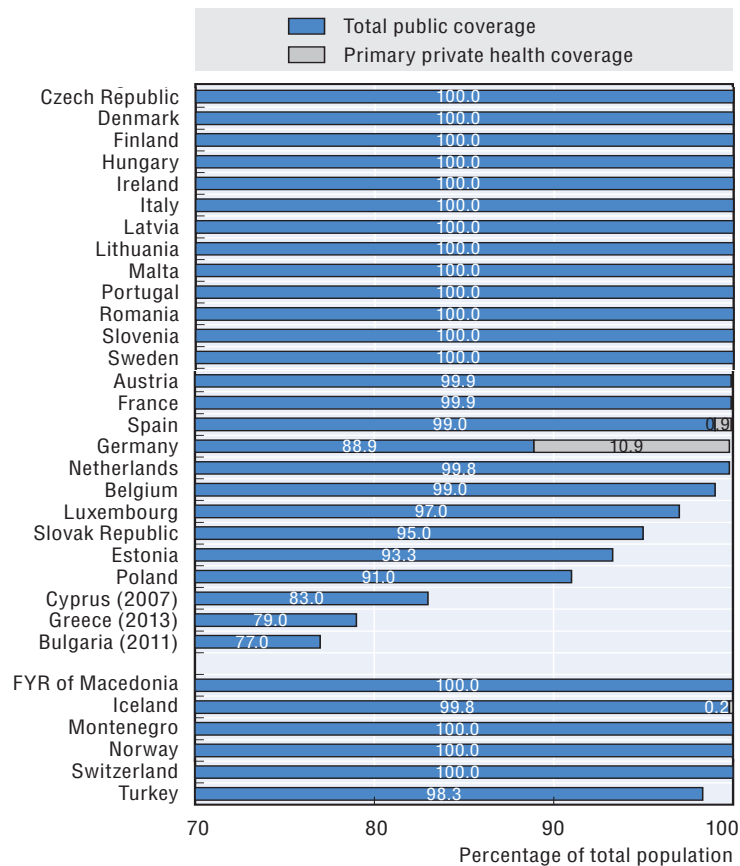


Fig. 4 Health insurance coverage, for a core set of services, 2010. European Union members in higher place on the graph. The coverage rate for Luxembourg is underestimated since the number of European civil servants and their family member's is unknown. Extracted from: OECD Health Data 2014, Organisation for Economic Co-operation and Development (2014).
 Extracted from: http://stats.oecd.org/index.aspx?DataSetCode=HEALTH_STAT. [60]

The existence of health insurances, either public or private, provides a certain degree of financial protection against disease. However, the services provided vary widely between the countries. Even if a country provides almost full insurance coverage to its population, the access to care can be seriously limited by co-payments and/or a

poor set of covered services [60]. Differences between public and private health insurance coverage in 2010 are presented in Fig. 4.

1.9. Special Olympics

Special Olympics® (SO) was launched in United States, in 1968, with the mission of improving the quality of life of athletes with ID through training, competition, and sport. Encouragement and team participation were acknowledged to be beneficial for this population. Nowadays Special Olympics has become the largest non-profit sport organization for people with ID, with games organized on a regular basis at local, regional and national levels in more than 150 countries World Games take place every two years. [61]

Special Olympics Europe Eurasia (SOEE) has an active role in supporting the development of 58 Special Olympics National Programs in Western Europe, Eastern Europe and Central Asia. The region embraces the mission of Special Olympics and acknowledges the need of research in the field of sports and social inclusion of people with intellectual disabilities across Europe, for which the SOEE Regional Research Collaborating Center (RRCC) was established in 2010.

Special Olympics Healthy Athletes® is a program created in 1996 for health promotion and prevention among the athletes who participate in Special Olympics®, to help them to improve their health and fitness. Healthy athletes® consists of seven screening programs addressing the varied health concerns of people with special needs. They are Opening Eyes®, Healthy Hearing®, Fit Feet®, FUNfitness®, Health Promotion® and Special Smiles® (SS). The latter addresses the oral health of athletes and seeks to continually expand standardized data collection sites, in order to report region-specific information that may be used to improve access to dental care for people with special needs [62,63].

In 1996, a feasibility study was conducted in the University of Medicine and Dentistry of New Jersey. The aim was to assess whether the data obtained from the Special Smiles program can be used to determine the oral health status of people with ID

and whether the setting for the data collection would not compromise the objectives of the oral health program [62].

It was concluded that the non-intimidating setting (out of a dental practice) of the screenings was beneficial for the interaction between dentists and athletes, and a unique opportunity to observe and learn from the athlete's interaction with family or team members, for better communication and treatment. Finally, the program was successful in determining the feasibility of collecting epidemiologic data among people with ID.

Originally produced by the U.S. Centers for Disease Control and Prevention, the screening protocol and the data-collection form were developed in a format to facilitate comparisons with Healthy People program targets. The format consists in variables with a dichotomous nature (untreated decay, missed teeth, gingival disease), which exposes the need for oral care but is an underestimation of disease. Following the protocol, the presence of each condition is reported, but not its severity, because the report based only on a visual examination and the goal is to expose the need of treatment for the athletes. The protocol was tested in three events in 1997 and it has been used since then in all Special Smiles programs around the world [63].

1.10. Highlights from previous findings

From the literature review presented above, we can highlight the following:

1. People with ID are more vulnerable to oral disease as a consequence of their conditions. Furthermore, evidence shows that they have poorer oral hygiene and overall oral health than the general population.
2. In order to explain the oral health disparities that negatively affect people with ID, several risk factors have been proposed that may become barriers for the access to oral healthcare. For example, financial status, severity of disability and healthcare systems.
3. Health systems differ from region to region and from country to country. The main common problems are the inability of the systems to maintain control over

costs, to utilize healthcare resources efficiently and to provide equal access to services for all of the population, thus failing in the achievement of EU goals on equality.

4. Up to now, the oral health data collection and analysis for the population with ID has not been a priority in many countries. In some cases, representative country data were not available, while the available data were not collected on a continuous or regular basis. It is fundamental to collect epidemiologic data to assess the outcomes of existing policies and to organize oral care and insurance systems, in order to elucidate the real extent of treatment needs on the population.
5. Large-scale international data on the oral health status of people with intellectual disabilities are scarce. This could be an important source to compare outcomes between countries and to stimulate international interventions and joint actions for health promotion and disease prevention.

1.11. Objectives

Studying the change of oral health status over time is essential for the assessment of the need for oral care and professional treatment. It is also important to generate understanding around the areas that need improvement.

The overall aim of the present thesis was to gain further knowledge regarding oral health status and treatment needs of athletes with ID in Europe and Eurasia.

The specific aims were:

- To assess the prevalence of dental trauma among Special Olympics athletes in countries of Europe and Eurasia.
- To explore the prevalence of signs of gingival inflammation and its relationship with oral cleanliness and age among people with ID from Europe and Eurasia.
- To evaluate the oral condition and treatment needs of young athletes who participated in Special Olympics European Games (SOEG) Antwerp 2014

- To determine the predictive capacity of explanatory variables of untreated dental caries and signs of gingival disease.
- To evaluate the oral health status and treatment needs of Special Olympics athletes of Eastern European countries.
- To explore variations in oral health needs in Eastern European countries.
- To evaluate trends in oral health condition and treatment needs of participants of SO in Belgium, by comparing oral health parameters recorded in 2008 and 2013.
- To assess the impact of screening and referral within SS on the oral health outcome of individual athletes who participated in the Special Olympics Belgium in two consecutive years (2012 and 2013).

Chapter 2

Methodology

2.1. Study design and settings

This thesis addresses the analysis of datasets obtained by oral screening examinations of athletes with ID who participated in Special Olympics events in Europe and Eurasia (Fig. 5). This region includes Northern Europe, Western Europe, Eastern Europe, Southern Europe, Russia, Turkey, Kazakhstan Georgia and Azerbaijan. The study population was based on convenience sampling. That is, the sample population was selected because access was available to the database of 51 countries of Europe and Eurasia (Table 3). Therefore the results are only representative for this population and cannot be directly extrapolated to the whole population with ID.

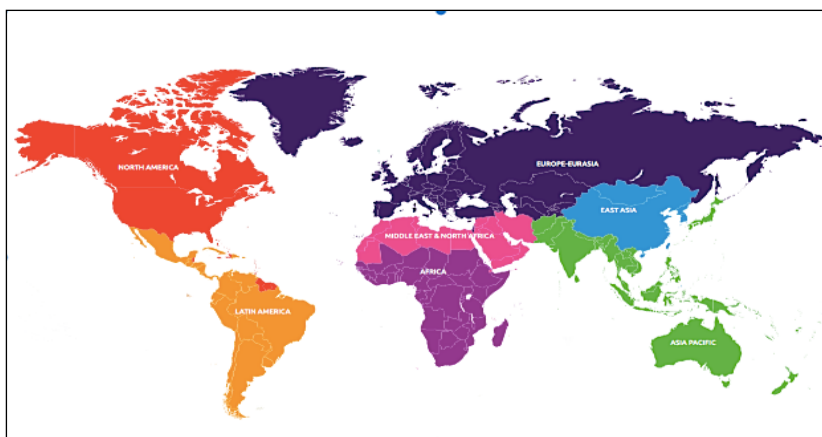


Fig. 5 Europe and Eurasia Region (dark purple). Extracted from Ref. [64]

Table 3. Screenings per country

Country	N° of Screenings	% Male	% Female	% Unknown
Germany	3584	36,86%	62,86%	0,28%
Romania	1683	39,57%	60,13%	0,30%
Poland	1569	30,66%	68,90%	0,45%
Italy	1043	39,21%	60,40%	0,38%
Belgium	898	36,97%	62,81%	0,22%
Spain	838	40,45%	59,19%	0,36%
Netherlands	798	39,97%	59,77%	0,25%
Ireland	745	37,05%	62,82%	0,13%
Kazakhstan	741	40,62%	59,11%	0,27%
Turkey	711	39,10%	60,62%	0,28%
Greece	535	36,82%	62,99%	0,19%
Slovenia	293	36,18%	63,82%	0,00%
Russia	258	44,96%	55,04%	0,00%
Belarus	236	33,90%	66,10%	0,00%
Israel	231	38,53%	61,47%	0,00%
Hungary	152	37,50%	61,18%	1,32%
Albania	147	35,37%	64,63%	0,00%
France	110	50,00%	50,00%	0,00%
Armenia	73	36,99%	54,79%	8,22%
Finland	73	36,99%	61,64%	1,37%
Sweden	71	25,35%	71,83%	2,82%
Azerbaijan	66	51,52%	48,48%	0,00%
Great Britain	66	46,97%	53,03%	0,00%
Portugal	56	35,71%	64,29%	0,00%
Austria	54	48,15%	51,85%	0,00%
Isle of Man	54	31,48%	68,52%	0,00%
Luxembourg	50	32,00%	68,00%	0,00%
Bulgaria	49	38,78%	61,22%	0,00%
Malta	48	39,58%	60,42%	0,00%
Lithuania	47	46,81%	53,19%	0,00%
Switzerland	47	44,68%	55,32%	0,00%
Uzbekistan	46	41,30%	58,70%	0,00%

Denmark	45	35,56%	64,44%	0,00%
Latvia	45	28,89%	71,11%	0,00%
Gibraltar	43	30,23%	69,77%	0,00%
Slovakia	42	28,57%	71,43%	0,00%
Ukraine	40	37,50%	62,50%	0,00%
Czech Republic	38	52,63%	47,37%	0,00%
Turkmenistan	38	31,58%	68,42%	0,00%
San Marino	37	32,43%	64,86%	2,70%
Macedonia	34	41,18%	58,82%	0,00%
Moldova	33	54,55%	45,45%	0,00%
Iceland	31	38,71%	61,29%	0,00%
Cyprus	29	51,72%	48,28%	0,00%
Tajikistan	26	42,31%	57,69%	0,00%
Norway	25	36,00%	64,00%	0,00%
Bosnia & Herzegovina	23	28,95%	71,05%	0,00%
Georgia	20	70,00%	30,00%	0,00%
Montenegro	20	45,00%	55,00%	0,00%

2.2. European Regions

Data collected from a Special Olympics European Games event (Chapter 5) was grouped in European regions in order to be analyzed. Namely: Northern Europe, Western Europe, Eastern Europe, Southern Europe and Eurasia.

In general, European regions differ widely economically and politically, but countries belonging to same European regions may be similar due to economic situation, historical similarities and structure of their systems. Therefore, the sample of athletes was clustered and the athletes from the same cluster were expected to have a certain unknown and unmeasured correlation.

2.3. Data collection

Oral health data were collected through interviews and oral examinations of athletes participating in annual Special Olympics events, between 2007 and 2014. They were invited to the 'Special Olympics Special Smiles' site, where they had their teeth examined on a voluntary basis. Consent was obtained from the athlete and one

parent or guardian. The Joint Ethical Committee of the Ghent University Hospital approved the study as 2013/816.

The collected data consisted of demographic data (age, gender and date of birth), oral health screening, and education in oral hygiene techniques. Standardized data collection forms were used to record the following information: edentulism, untreated decay, filled or missing teeth, sealants, tooth injury and signs of gingival disease.

In each Special Olympics event, the SS program included a registration/check-in station, a non-invasive dental screening station and a dental hygiene education station. At the dental screening station, oral screeners were prepared with disposable gloves, a disposable mouth mirror and a flashlight to check the athletes' teeth. The screeners were dentists recruited from university dental schools and dental professional organizations, who were previously trained and strictly calibrated according to the Training Manual for Standardized Oral Health Screening [63].

The standardized examination protocol, developed for SOSS by the U.S. Centers for Disease Control and Prevention, Division of Oral Health [63], was strictly followed. This protocol prescribes a specific sequence and includes the assessment of each condition in a separate cycle, independent of others. If two conditions are present in one tooth, both of them are marked (i.e. if a tooth has a filling but there are also caries, untreated decay and/or filled teeth, all will be reported). Lastly, third molars or partially erupted teeth are not taken into account.

Dentists are invited on a voluntary basis to Special Olympics events to perform oral screenings and to give oral-hygiene instruction to the athletes. One of the goals of Special Smiles® is to encourage dentists to treat patients with special needs, which has resulted in many professionals being involved in the data collection procedure. The drawback of this situation is that interexaminer and intraexaminer reliability are not being measured. As a rule, the calibration process for examiners of oral health surveys include a learning process of the diagnostic criteria, followed by a training process with calibration exercises. Later, the diagnostic criteria is tested and the results are finally analysed in order to obtain Kappa indicators and percentage of agreement between examiners. Following the Training Manual for standardized Oral Health Screenings [63], screeners are educated, trained and tested. However, no

statistical analyses are performed and, therefore, they are trained examiners but not calibrated examiners.

Each screener should receive a copy of the training manual and participate in the training sessions. The first training session should take place at least a couple of days before the event and be repeated every day of the event. The training session consists of a presentation in which the Site Data Coordinator goes through the case definitions and photos in the manual, standardized exercises and a question-and-answer period in which the standardization exercises are discussed [63].

The data cleaning procedure was performed as follows: (1) when age is missing the complete screening of this person is excluded (row- wise deletion). (2) Screenings of unified partners (athletes without ID that participate as half of the sports teams for training and competition) were excluded from the database.

2.3.1. Venue configuration

The configuration of the site depends on the available rooms, and it varies from one event to another and from one country to another. Still, the basic configuration recommended in the Local Clinical Director's Handbook [65], created for the Special Smiles Program, is presented in Fig. 6. The main idea of the venue configuration is to define a clear direction for athlete flow, and volunteer staff areas separated from athlete areas. [62]

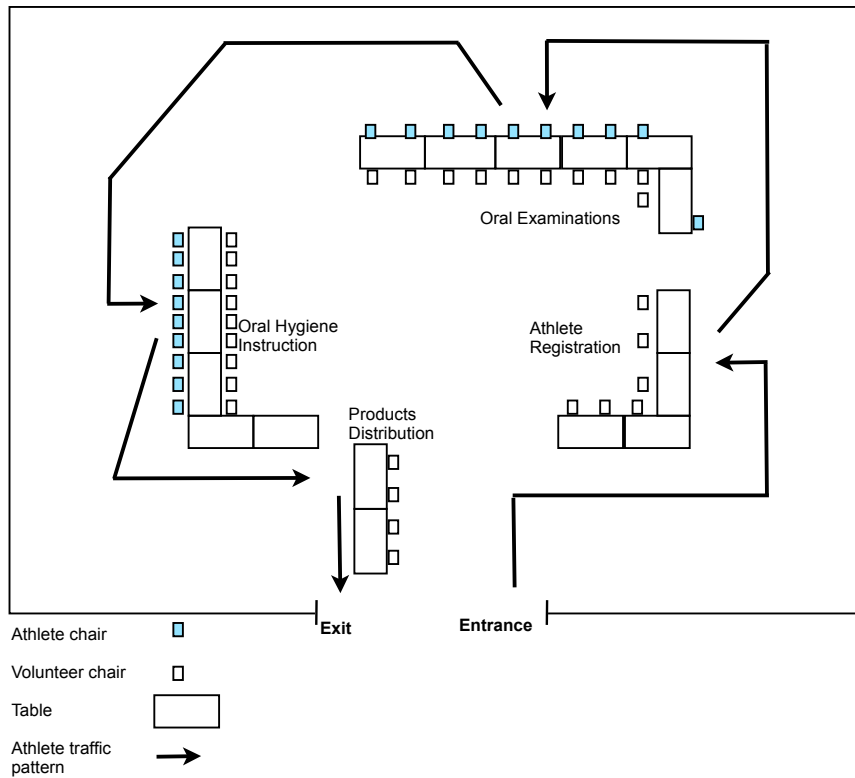


Fig. 6 Special Smiles on-site layout. Adapted from Ref. [62,65]

Usually, the registration desk is placed at the entrance, on one side of the venue, followed by the place where oral screenings are performed. Then, there is a site for hygiene education and, just before the exit, a section where 'goody bags' are given to the athletes, which in most cases contain toothbrush, toothpaste and mouthwash. Some events may include nutrition advice and/or a place where mouth guards can be provided [62].

2.3.2. Screening forms

Screening forms used for this work were also created for Special Smiles screenings. The form consists of a yes/no assessment of every measured oral health parameter, so that it provides a simple method for recording data. (Annex Section)

2.3.3. Variables collected by interview

2.3.3.1. Demographic variables

The first step of the data collection was the registration of age, gender, date of birth and country.

2.3.3.2. Frequency of oral cleaning

Frequency of oral cleaning was an ordinal variable, asked to the athletes. For evaluation of brushing habits the dentist performing the screen asked the athlete how often he/she cleaned his/her mouth. In particular, the question 'How often do you clean your mouth?' was asked rather than 'How often do you brush your teeth?' because the goal was to assess the frequency of the oral hygiene effort, regardless of the specific devices used or the effectiveness of technique.

2.3.3.3. Oral pain assessment

The presence of oral pain was dichotomous, reported by the athletes. If pain was present in the mouth of the athlete, if pain was present in the mouth of the athlete, then the athlete was asked to point to the place where the pain was, 'Tooth pain' or 'other oral pain' were the possible answers for the nominal variable of Pain location. After these questions, the athlete decided if they wanted to continue to the oral examination.

2.3.4. Variables collected by clinical examination

2.3.4.1. Edentulism assessment

The presence of edentulism was a dichotomous variable examined by the screeners. Edentulism was recorded when an athlete presented neither teeth nor root remnants.

2.3.4.2. Untreated decay assessment

The examiners assessed the dichotomous variable of untreated decay in both primary and permanent dentition (except for 3rd molars) when at least one area of cavitation fitting a 0.5mm-diameter (or larger) bur, was detected (as reference Table

4 & Table 5 from scores M). The location of the caries “anterior, premolar or molar” was registered in some countries.

In fact, any decay that has the previously defined features, present on any surface of the tooth including root surfaces, should be reported as well as root remnants after severe caries. Untreated decay was also used to describe teeth with restorations, recurrent decay, fractured, and unrestored teeth with decay fitting the definition.

Table 4. Universal Visual Scoring System for smooth surfaces. Cavities >0.5mm from score M. Extracted from: J. Kühnisch, I. Goddon, S. Berger, H. Senkel, K. Bücher, T. Oehme, et al. Development, methodology and potential of the new Universal Visual Scoring System (UniViSS) for caries detection and diagnosis. *Int. J. Environ. Res. Public Health.* (2009) 6:2500–2509.. [66]



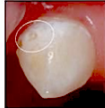
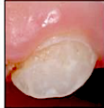












Universal Visual Scoring System for smooth surfaces (UniViSS smooth)						
Second step: Discoloration Assessment	First step: Lesion Detection & Severity Assessment					
	First visible signs of a caries lesion	Established caries lesion	Microcavity and/or localised enamel breakdown	Dentin exposure	Large cavity	Pulp exposure
	Score F	Score E	Score M	Score D	Score L	Score P
Sound surface (Score 0)	No cavitations and/or discolorations are detectable.					
White (Score 1)						
White-brown (Score 2)						
(Dark) Brown (Score 3)						
Greyish translucency (Score 4)						

Table 5. Universal Visual Scoring System for pits and fissures. Cavities >0.5mm from score M. Extracted from: J. Kühnisch, I. Goddon, S. Berger, H. Senkel, K. Bücher, T. Oehme, et al. Development, methodology and potential of the new Universal Visual Scoring System (UniViSS) for caries detection and diagnosis. *Int. J. Environ. Res. Public Health.* (2009) 6:2500–2509. [66]

Universal Visual Scoring System for pits and fissures (UniViSS occlusal)						
Second step: Discoloration Assessment	First step: Lesion Detection & Severity Assessment					
	First visible signs of a caries lesion	Established caries lesion	Microcavity and/or localised enamel breakdown	Dentin exposure	Large cavity	Pulp exposure
	Score F	Score E	Score M	Score D	Score L	Score P
Sound surface (Score 0)	No cavitations or discolorations are detectable.					
White (Score 1)						
White-brown (Score 2)						
(Dark) Brown (Score 3)						
Greyish translucency (Score 4)						

2.3.4.3. Filled teeth assessment

The dichotomous variable of “filled teeth” was assessed by the examiners. Any dental restorative work exclusively done as a response to decay and partially or entirely lost restorations were coded as ‘filled tooth’ (e.g., fillings, inlays or crowns, including stainless steel crowns).

Some exceptional cases like incisal (diagonal or horizontal) restorations and/or crowns on anterior teeth, which may or may not be caused by decay, were not marked as filled teeth. Interproximal restorations were always considered as placed due to decay and then, always recorded as ‘filled tooth’.

2.3.4.4. Missing teeth assessment

The screeners were also responsible for the evaluation of the dichotomous variable of “missing teeth”. If a tooth was absent at the time of the exam, with exception of premolars, wisdom and unerupted teeth, missing teeth was marked. In some of the countries the location of the missing teeth was also reported as anterior or molar.

2.3.4.5. *Dental trauma assessment*

For the dichotomous variable presence of “dental signs of trauma”, only maxillary and mandibular central and lateral incisors in the permanent dentition were considered. This score was recorded when a tooth was either absent, fractured with or without decay or restoration, and/or discoloured indicating a loss of vitality.

2.3.4.6. *Sealants assessment*

The dichotomous variable of “presence of sealants” was recorded when material placed as a preventive measure covered the pits and fissures of the occlusal surface(s) on first and/or second permanent molars. (Fig. 7)



Fig. 7 Fissure sealant on molars. Extracted from: J.A. White, E.D. Beltran. Training Manual for Standardized Oral Health Screening, 2004. [63]

2.3.4.7. *Signs of gingival disease assessment*

“Signs of gingival disease” was a dichotomous variable that was recorded when free or attached gingival margins or papillae were moderately red or showed significant deviations from normal contour or texture and/or when they were present in three or more teeth within the same area. (Fig. 8)



Fig. 8 Signs of gingival disease. Extracted from: J.A. White, E.D. Beltran. Training Manual for Standardized Oral Health Screening, 2004.[63]

2.3.4.8. *Treatment needs assessment*

At the end of the oral inspection, the ordinal variable treatment urgency was assessed based on clinical findings as follows:

- Maintenance follow-up

When there was no pain complaint, no untreated decay or dental injuries and no signs of gingival disease, the athlete was recorded for maintenance follow-up.

- Non-urgent treatment

In cases of absence of pain, presence of decay not involving the pulp or defective fillings and gingival problems without abscess formation, the athlete was referred for non-urgent treatment.

- Urgent treatment

When there was pain inside the mouth, teeth with possible pulpal involvement, broken or missing fillings with decay or periodontal abscess formation, the athlete was referred for urgent treatment.

2.4. Instruction on Oral Hygiene

The screening was concluded with an individual oral hygiene instruction that was performed considering the athlete's capacity of understanding and response. The role of the volunteers at this station was to help the athletes understand how to

perform their oral hygiene properly. The report card with the treatment need (urgent, non-urgent or maintenance) that came from the screening station was used as a guide for the oral hygiene needs. Each volunteer should have used a puppet or tooth model, a manual toothbrush, and floss for this procedure and spent up to five minutes with each athlete (the time was adjusted, depending on the needs of the individual athlete) [65].

This part of the intervention included the use of tooth models and puppets to demonstrate proper use of toothbrushes. At the end athletes received a gift box including a toothbrush, toothpaste, and mouthwash.

Chapter 3

A multicenter study of dental trauma in permanent incisors among Special Olympics athletes in Europe and Eurasia

3.1. Introduction

Special Smiles (SS) is the oral-health screening program of Special Olympics Healthy Athletes that provides comprehensive oral healthcare information, including free dental screenings and instruction on correct brushing and flossing techniques. One of the main goals of the Healthy Athlete Special Smiles program is to continually expand standardized data collection sites in order to report region-specific information that may be used to improve access to dental care for people with special needs and to educate healthcare professionals as to the health problems these individuals face [63].

People with disabilities, estimated to be approximately 10% of the world's population [9], are more vulnerable to health problems, have a high incidence of co-morbidities and their oral diseases have been reported in several studies [33,34,36,67]. The focus of this research will be with individuals with an Intellectual Disability (ID), previously termed 'Mental Retardation.' In 1992, the American Academy of Mental Retardation defined mental retardation as the set of significant limitations in general intellectual and adaptive functioning during the developmental period (under the age of 18 years).

Individuals with intellectual disabilities may present with several problems, such as traumatic injuries or self-injurious behaviour [39]. Specifically, patients with ID, cerebral palsy, and seizure disorders are reported to be more vulnerable to dental injuries due to poor lip closure, slow response to environmental obstacles, pathologic oral reflexes, or dental features like an over jet of more than 3mm in the maxillary incisors [68]. The consequences of dental trauma can affect not only the individual's appearance but also their function and social performance [69,70].

The oral health policies, in the context of healthcare systems, must be researched based [22]. Governments should be able to identify the needs of health in their populations and promote and advocate for their care [56]. Population data seems to be missing in this context. The periodical assessment of the need for oral health assistance and treatment is essential to understand which areas need improvement. Thereby, the aim of this study is to assess the prevalence of dental trauma among Special Olympics athletes in countries of Europe and Eurasia [71].

3.2. Materials and Methods

A retrospective longitudinal study was performed with data collected through interviews and oral examinations from athletes participating in Special Olympics Special Smiles events held in different European countries between 2007 and 2012.

The study population consisted of 15,958 athletes from Europe and Eurasia, who were competing during the Special Olympics event. They were invited to the Special Olympics Special Smiles venue where they could have their oral screening. Prior consent was obtained from a parent, guardian, or the athletes themselves.

The data of this multicenter study were collected by dental professionals previously trained and calibrated according to the Training Manual for Standardized Oral Health Screening developed by the US Center for Disease Control and Prevention [63]. Therefore, the use of this globally standardized protocol allows comparison with other existing and future data from Special Olympics Screenings [32].

Data collection was performed as described in Chapter 2. The presence of dental injury, following the strict CDC protocol, considered only maxillary and mandibular central and lateral incisors in the permanent dentition that were either absent,

fractured or discoloured indicating a loss of vitality. Missing homologous teeth, crowns on central and/or lateral incisors, teeth with only interproximal restorations, or injury in teeth other than central and lateral incisors, were not considered for the study.

The data collected was compiled in an Excel worksheet, then transferred to an SPSS data file in order to be analysed and descriptive parameters were obtained.

The general data from Europe-Eurasia (SOEE) and the data from the countries with larger samples: Belgium, Germany, Italy, Poland, and Romania were classified in three age groups as follows: 'under 18 years,' 'between 18 and 25' and '26 or older'. The new data were analysed with One-Way ANOVA and Multiple Comparisons LSD tests to assess differences in the mean dental trauma between the three age groups. The level of significance was predetermined at a p value < 0.05.

3.3. Results

Initially a total of 15,968 athletes with ID from 51 countries in Europe and Eurasia participated in the study. Only countries with a minimum of 20 screened athletes were included. Therefore, a total of 15,941 subjects from 49 countries were considered for the present study. There were differences between countries in the amount of athletes screened, the minimum of 20 (Montenegro and Georgia), a median of 54 (Isle of Man and Austria) and maximum of 3,584 (Germany).

The mean age of subjects was 28.5 years with a standard deviation of 5.9 years and there were 6,012 females (37.7%) and 9,878 males (61.97%). (Fig. 9)

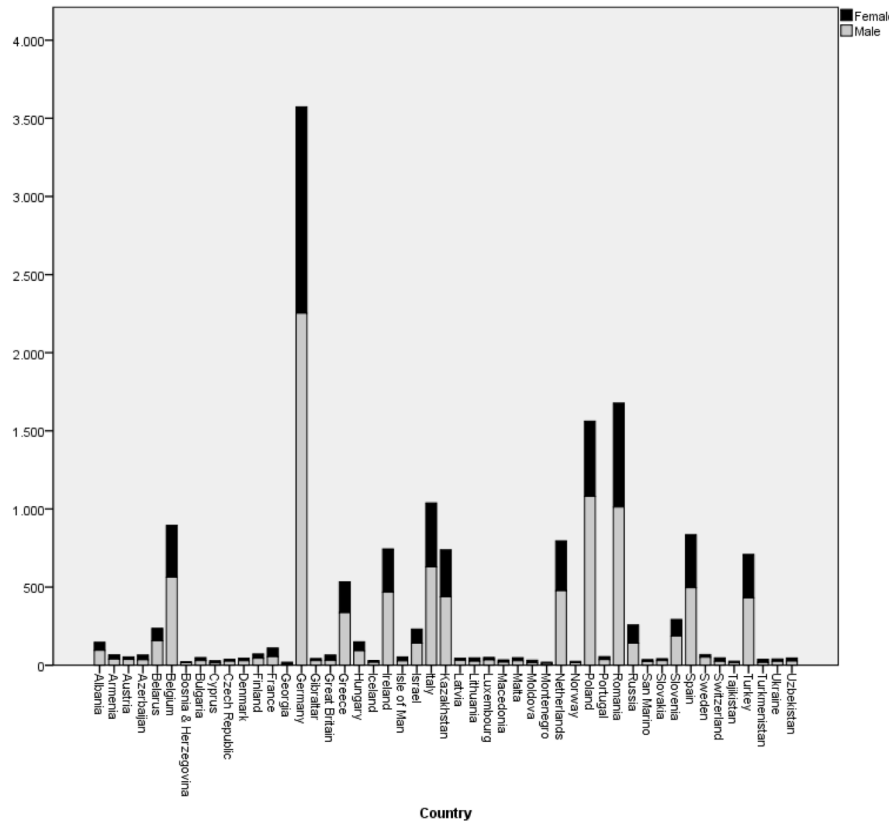


Fig. 9 Gender distribution among screened subjects
Detailed data in Table 3 (Chapter 2)

A total of 2,190 athletes had dental injury (13.02%) with a std. deviation of 5.02%. Fig. 10 illustrates the ranking of the countries according to the prevalence of dental injury. The highest prevalence of dental injury was found in athletes from Poland (25.73%), Cyprus (25%) and Switzerland (23.91%). The countries with the lowest prevalence of dental injury were Montenegro (0%) and Armenia (4.11%).

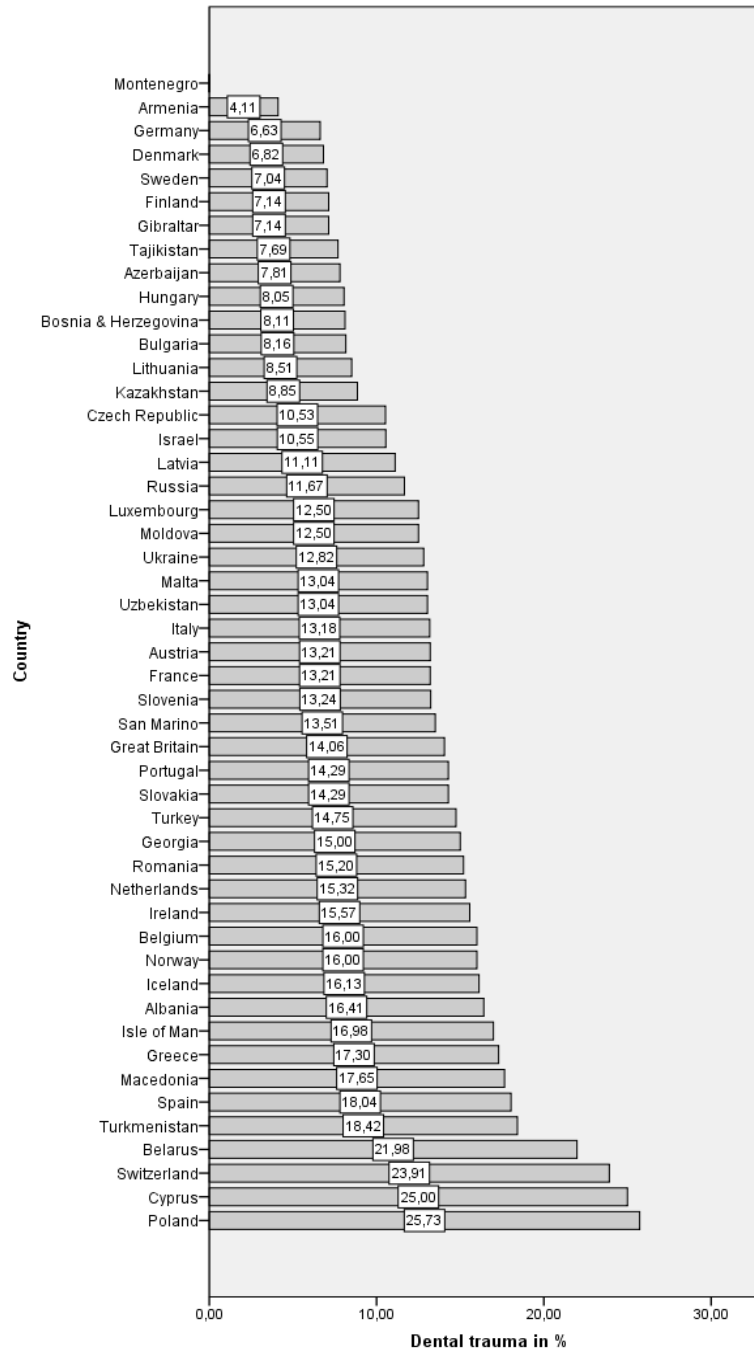


Fig. 10 Prevalence of dental trauma

The distribution of dental trauma was assessed comparing three different age groups (Fig. 11 & Fig. 12) and no significant differences were found (One-Way ANOVA, $p=0.136$) in mean dental injury between age groups. This result was confirmed with Multiple Comparisons LSD test.

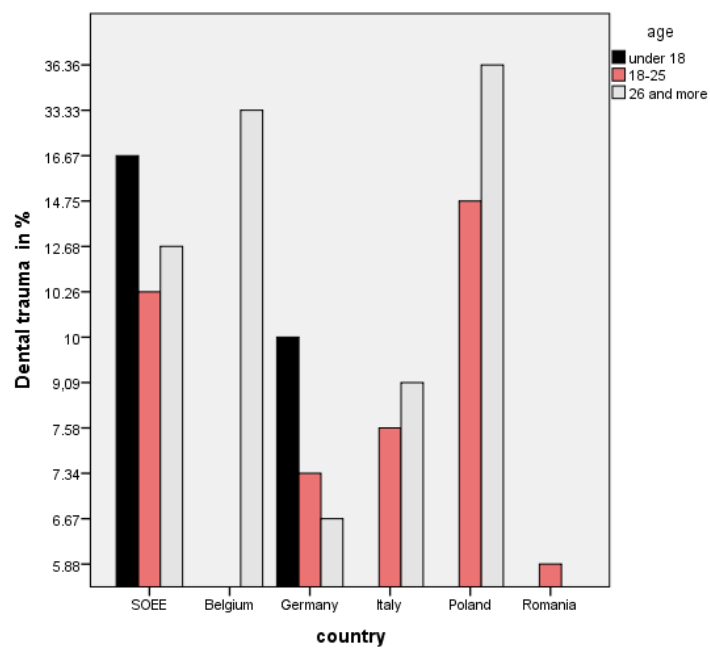


Fig. 11 Prevalence of Dental trauma per age group

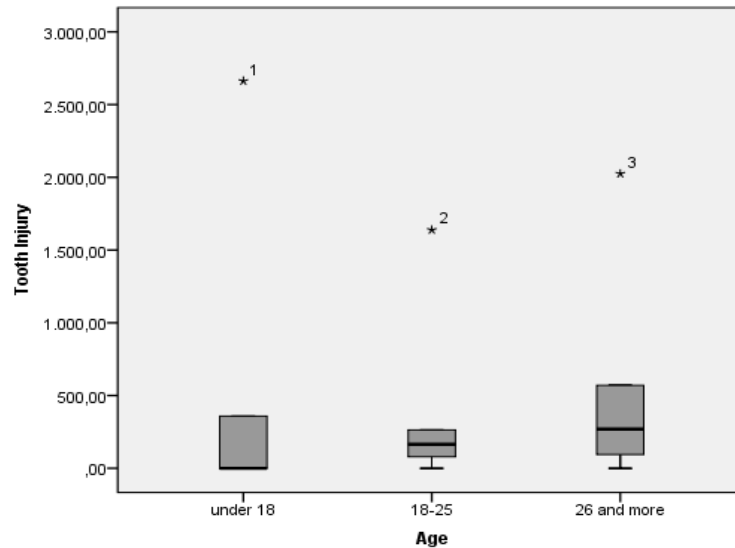


Fig. 12 Distribution of dental trauma per age group

3.4. Discussion

Dental trauma in the general population has been extensively studied over the last two decades, mostly among children and young adults, and prevalence rates from 6% to 27% have been reported. The main cause has been falls during athletic competition [72–76]. The prevalence of dental trauma in the population with special needs, however, has been far less studied [77–79] even though individuals with special needs have more risk factors for injury. Furthermore, it is extremely difficult to compare the results of the different studies because they are based on specific groups and differ in trauma classification and dentition studied, studies are mostly performed in children and with different methodology [72]. In this study, for instance, only permanent maxillary and mandibular incisors were included and the sample of the population was composed of athletes who participate actively in sports and therefore have more chance of dental injury.

This study reported a general prevalence of 13.02% of dental trauma among 15,941 Special Olympic athletes from 49 countries from Europe and Eurasia. In general,

there were large variations in prevalence of dental injury between countries (0%-25.73%). There are many factors that could explain those differences. Among them the type of sports, or the use of mouthguards, and even the differences in sample sizes. Indeed, the objective of this study was not to compare prevalence between countries but to expose the extent of dental trauma among people with ID. It was remarkable, however, that the prevalence was quite high in many countries, particularly in Poland, where the sample size was also high.

Trauma is reported to be more prevalent in younger athletes and in contact sports, but the literature shows great discrepancies as to dental trauma rates among sports practitioners, depending on age and type of sport, that will determine the risk of high impact collisions. The prevalence of dental trauma, however, ranges from 2% to 33% [80,81]. Prevalence of dental trauma in sports was 28.8% among professional and semi-professional athletes of contact sports [82] and 9% among Israeli young adults between 18-19 years old [83], 5.8 % among soccer players and 14.7% of rugby players in Japan [84]. When comparing with published results obtained among Special Olympics athletes, the results of this study are comparable with those obtained in the U.S. 12.5% [85], Indonesia 12.33 % [32] and Belgium 12% [67], but higher than those from New York 6% [86] and Nigeria 6.6% [87].

Even though gender differences were found in the amount of screened population (33.7% females and 61.97% males), this fact does not affect the objectives of the study and is not related to a higher prevalence of males in population with ID. This difference is merely attributed to the larger amount of male athletes participating in Special Olympics events.

Additionally, the study of the prevalence of dental trauma among the different age groups in the countries with higher sample sizes revealed that no strong relationship was found between age and dental trauma. The literature reports that dental trauma prevalence in individuals with special needs is highest between 11 and 15 years of age. The higher prevalence among this population can be attributed to delayed neuro-psychomotor maturation [68,78]. On the contrary, in this study, there were no statistically significant differences between the three age groups. This can be due to the fact that all the subjects were athletes participating in sports, some involving contact that would put them at risk for traumatic injuries, and because of the

previously mentioned additional risk factors such as: coordination difficulties, seizure episodes, slow reflexes, poor lip closure and increased over jet of maxillary incisors. In some European countries like Cyprus, Poland and Switzerland, 25% of the athletes with special needs had dental trauma. Besides, dental trauma may have several consequences, in worst cases causing irreparable dental loss if not at the accident time, also due to lack of treatment or follow up. When considering that the study population's mean age was 28.5 years, the question that arises is whether older and lesser functioning individuals with disabilities that suffer dental trauma receive any oral care as they may be more uncooperative for oral treatment.

It has to be noted that no information was recorded as to whether the athletes received any treatment or took any medication or whether or not they were using a mouth guard for contact sports. The use of mouth guards could prevent dental trauma during sports [88]. Furthermore, the relationship between gender and trauma, the principal risk factors that are involved, the type of injury, teeth with higher prevalence of trauma, or whether the tooth was fractured, discoloured or avulsed, were other aspects not included in this study due to the limitations of the screening protocol. There is an evident need of treatment but further research is crucial to clarify those questions and to achieve a complete understanding of the magnitude of this problem among people with special needs.

Finally, the standardized SOSS protocol has been widely used [67,86,87,89–92] but interpretation of the data must be made with the understanding of its potential weaknesses. First this study was conducted in athletes with ID who participate in Special Olympics events. The study participants belong to a younger, supported, and higher functioning stratum of the population with intellectual disabilities in Europe [32,68]. This means that the results of the study can only be related to this group and not necessarily representative of the population of individuals with ID. However, it is valuable due to the lack of data and the exhibition of evidence or the burden of dental trauma over this population. It is also possible that some athletes could have participated in more than one screening event during the years of collecting the data. Therefore, bias in data collection may be involved but there are no means in the study to determine or measure it.

The CDC protocol was established to ensure the reporting of standardized data. The training of the screeners consists of a presentation, exercises and a question and answer period. It reduces bias due to screener variability and results should therefore be valid and reliable. The use of a standardized procedure allows data from multiple sites to be combined with existing and future data from Special Olympics Global Screenings. In this case, data of almost 16,000 athletes from many countries can be used as a baseline in the comprehension of the needs of individuals with ID in relation to dental trauma.

3.5. Conclusion

This study suggests that dental trauma is a problem among individuals with special needs. From the data reported, there is a mean prevalence of 13.2% of dental trauma in this population. The distribution of prevalence among the different countries had a remarkable variability, including some European countries with prevalence as high as 25%, so further studies are needed to elucidate the reasons of this variability. Given that the screening protocol only assesses the presence of dental trauma but not its severity, it appears that a relatively high proportion of this population is in need of preventive programs for the athletes, parents and caregivers. It is important to be aware of the need to use mouthguards for athletes participating in contact sports. Moreover, dentists should be prepared to meet the special needs of this population and minimize the burden of dental trauma.

3.6. Acknowledgements

The authors are grateful to all the volunteers and athletes who participated in the screenings of this multicenter study during the period of study and the Special Smiles clinical directors of Albania, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia & Herzegovina, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, France, Georgia, Germany, Gibraltar, Great Britain, Greece, Hungary, Iceland, Ireland, Isle of Man, Israel, Italy, Kazakhstan, Kyrgyz Republic, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Macedonia, Malta, Moldova, Montenegro, Netherlands, Norway, Poland, Portugal, Romania, Russia, San Marino, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Turkmenistan, Ukraine, and Uzbekistan for their cooperation in providing the data for this study.

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Chapter 4

Oral Cleanliness and Gingival Health Among Special Olympics Athletes in Europe and Eurasia

4.1. Introduction

As reviewed in Chapter 1, the concept of disability has evolved from a medical model to a social model in which environmental factors can also be considered as barriers for normal function and social integration.[8] Normal function involves the ability to perform daily activities like any other individual. In this context, the topic of concern is the ability of a person to correctly perform personal oral hygiene [10,30].

People with disabilities are more vulnerable to oral health problems as a consequence of their oral health habits. Their oral health needs have been reported in several studies during the last decade [32,33,36,62,67,87], and the data overwhelmingly supports the fact that people with ID have much worse oral hygiene in comparison to the neurotypical population [33,36], due to inability to perform adequate personal oral hygiene. This causes higher levels of gingival inflammation, plaque, and periodontal disease [30,44,45,85,87].

A systematic review published in 2010 [36] studied the differences of oral health between the general population and people with ID. All studies reported that people

with ID have much worse oral hygiene, higher plaque levels, and a higher incidence of gingivitis and periodontitis than the neurotypical population. [33,36]

Oral hygiene is compromised in people with ID due to impaired motor and cognitive skills and poor lip closure, the latter affecting the natural cleansing of the oral cavity. There are, however, other factors involved. The severity and type of disability is directly related with physical coordination and cognitive skills of each individual, as well as the ability to comprehend and learn the importance of oral health. According to the evidence, individuals with moderate or severe intellectual disabilities have reported brushing their teeth more regularly than those with a mild disability [93], presumably because they are dependent upon a caregiver for their oral hygiene and its frequency. The living arrangements are also considered to be a relevant factor in oral hygiene because people living in institutions have demonstrated to have a higher prevalence of gingivitis and poorer oral hygiene [33].

Periodontal disease is an infectious disease that involves gingival inflammation and the loss of connective and bone tissue supporting the teeth. The risk factors of periodontal disease include personal oral hygiene, gender, age, smoking, alcohol, diabetes, osteoporosis, inadequate dietary calcium, stress, and genetic factors [94].

The prevalence of gingivitis is reported to be 60% to 97% among individuals with ID compared to 28% to 75% in the general population [7,29]. The most affected are children and adults with Down syndrome, the elderly, and those who still reside in institutions. A study performed in Greece in 2005 showed the oral health of 70 adolescents with Down syndrome, 70 with cerebral palsy and 121 controls. Probing depth, probing attachment level, bleeding on probing, hygiene and microbiology were assessed and it was concluded that people with Down Syndrome had worse oral hygiene, more bleeding on probing and more severe periodontal destruction [44]. The direct relation between plaque accumulation and infection has been broadly studied however, it is clear that the influence of other factors must also be considered. Patients with Down syndrome are known for presenting with an increased prevalence of gingivitis that is related to a higher level of a specific subgingival bacterial species associated with periodontal disease [95] and impaired immunologic responses [33,44,96]. As periodontal disease is marked by the permanent processes of tissue destruction and regeneration, patients with Down

syndrome present with impaired gingival fibroblast motility, decreased phagocytic and chemotactic responses, altered enzymes and increased amount of Prostaglandin E2 (PGE2); all having the potential to affect the regeneration of periodontal tissue [33,44,45,97].

Besides the findings that individuals with Down syndrome have additional risk factors, individuals with ID have more prevalent and severe periodontal disease [36,40]. A recent publication from Turkey evaluated the impact of the severity of disability on the oral and periodontal status of 105 adults with ID by evaluating periodontal parameters of plaque index, gingival index, bleeding on probing, probing depth, and clinical attachment level. Positive correlations were found between plaque index and periodontal disease while the scores of indicators of periodontal disease development (probing depth and clinical attachment loss) increased with the severity of ID. It was concluded that the periodontal status of this population could be most likely explained by poor oral hygiene with the need for periodontal treatment greater in individuals with severe ID. [41]

Special Olympics Healthy Athletes Special Smiles, described in Chapter 2, aims to collect standardized data to improve access and dental care for people with special needs [62,67,85–87,98]. In the absence of reliable and comprehensive international surveys of people with ID, the SS program provides a unique opportunity to conduct a large number of examinations. The indices reported include basic, epidemiologic, and clinical data allowing countries to identify the oral health needs of this population [22].

The purpose of this study was to explore the prevalence of signs of gingival inflammation and its relationship to oral cleanliness and age among people with ID from Europe and Eurasia. The data, obtained from 49 different countries, will contribute to evidence for the development of oral health policies and interventions in relation with oral hygiene and gingival health [99].

4.2. Material and Methods

A retrospective longitudinal study was performed with data collected through interviews and oral examinations from athletes participating in the annual Special

Olympics Special Smiles events held in different European countries between 2007 and 2012. The athletes were examined at a venue in an Olympic town setting during breaks in the sports competition with consent obtained from the athlete and a parent or guardian. The Joint Ethical Committee of the Ghent University Hospital approved the study as 2013/816.

Data collection on frequency of oral cleaning and presence of signs of gingival disease was performed as described in Chapter 2. [67]. Subsequently, the data was compiled and transferred to an SPSS data file and descriptive parameters were obtained. Afterwards the data from countries with larger sample sizes (Belgium, Germany, Italy, Poland, and Romania) was divided into three age groups as follows: 'under 18 years,' 'between 18 and 25,' and '26 and over'. The data were analysed with the One-Way ANOVA test and the Chi-Square test was performed to assess the relationship between age group and frequency of oral cleaning. The level of significance was set at $p < 0.05$.

4.3. Results

A total of 15,968 athletes with ID from 51 countries throughout Europe and Eurasia were screened. From this data set, only countries where at least 20 athletes were screened were selected. Therefore, a total of 15,941 subjects from 49 countries were considered for the present study. The amount of athletes screened per country had a minimum of 20 (Montenegro and Georgia), median of 54 (Isle of Man and Austria), and maximum of 3,584 (Germany). The mean age of the subjects was 28.5 years with a std. deviation of 5.9 years and there were 6,012 females (37.7%) and 9,878 males (61.97%).

A total of 7,754 athletes presented signs of gingival disease (48.64%) with a std. deviation of 12.48%. The highest prevalence was found in athletes from Luxembourg (72.92%), Romania (70.41%) and Portugal (67.86%). The three countries with the lowest prevalence of athletes with gingival signs were Armenia (22.22%), Sweden (27.14%) and Kazakhstan (27.69%). (Fig. 13)

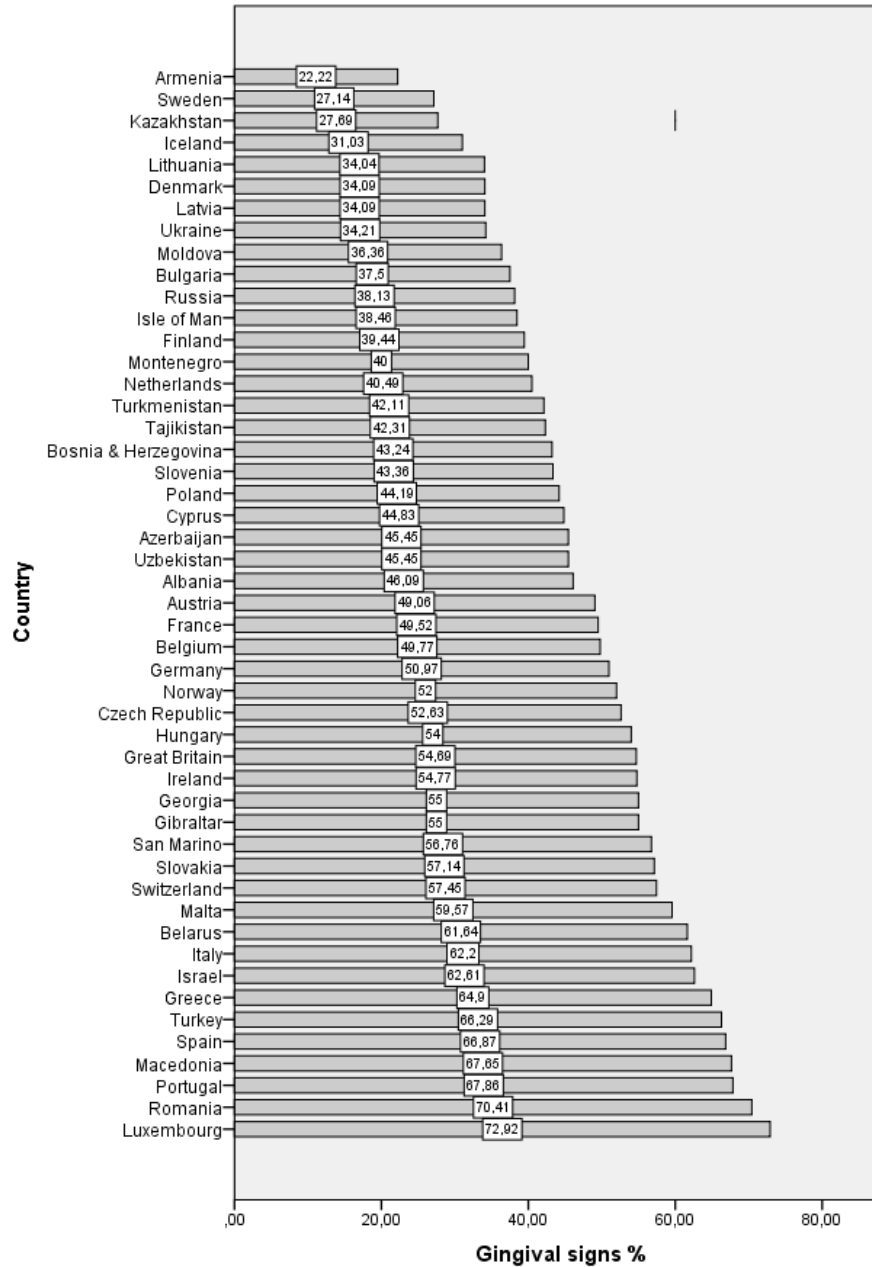


Fig. 13 Prevalence of signs of gingival disease per country

No significant differences were found in the mean signs of gingival disease between the different age groups (under 18, between 18-25 and over 26) with One-Way ANOVA ($F=2.768$, $P=0.095$) and Multiple Comparisons LSD tests. (Fig. 14)

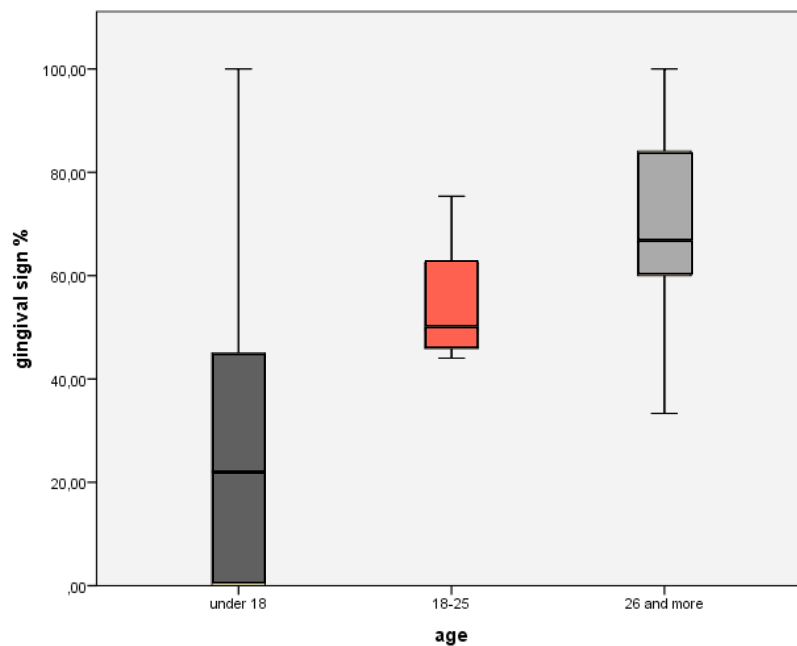


Fig. 14 Distribution of the prevalence of signs of gingival disease per age group

Fig. 15 illustrates oral hygiene behaviour with 60.38% of athletes cleaned their mouth at least once per day and 20.13% two to six times per week. A 56.7% of the group of age 'under 18' and 98.31% of the group 'between 18-25' reported cleaning their mouth more than once a day. In the group of '26 and over', however, 46.27% cleaned their mouth more than once a day and 44.71% two to six times a week. With values of Pearson Chi-square 1555, $p < 0.001$ and $\Phi = 0.986$, the association between oral cleaning and age was statistically significant; the older athletes brushing their teeth less frequently.

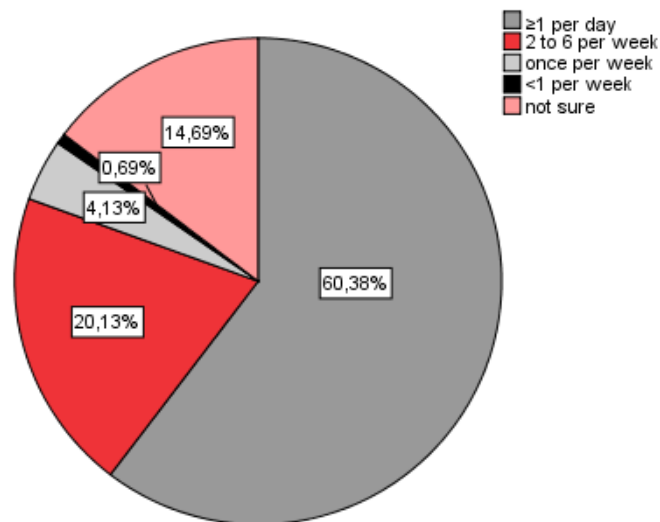


Fig. 15 Frequency of oral cleaning. Grey: Once or more per day; Red: Two to six times per week; Light grey: Once per week; Black: Less than once per week; Pink: Uncertain.

4.4. Discussion

Gingival signs were reported in 48.64% of the 15,941 Special Olympic athletes from 49 countries throughout Europe and Eurasia. The prevalence varied widely between countries (22.22%–92.72%), which could be explained by differences in sample sizes. In fact, the five countries with larger sample sizes, Poland, Germany, Romania, Italy and Belgium, showed a prevalence of more than 50%, which is remarkable considering this study was based only on the examination of the gingiva within the buccal area of the mandibular arch, cuspid to cuspid, and the permanent dentition. Moreover, the result was considered as positive when at least three or more teeth presented gingival signs. This prevalence of gingival signs contrasts strongly with the reported frequency of oral cleaning where 60% of the athletes declared brushing their teeth once or more a day. This apparent contradiction between reported and data obtained from oral examination can be related to the

athlete's ability to perform adequate personal oral hygiene and their comprehension of the questions.

The results obtained on the prevalence of signs of gingival disease are comparable with other studies based on data from Special Olympics Special Smiles screens held in the United States 2001 (40.1%)[85], Puerto Rico (42%)[90], Venezuela (45%) 2013[90], UK 2005 (63%)[98], Italy 2009 (60 %)[89] and Mexico 2013[90] (52%).

Several aspects were considered. In this study, age was not significantly related to the prevalence of gingival signs even though existing evidence indicates that the prevalence of periodontal disease is lower in young individuals than in adults. On the other hand, age did show a strong relation with oral cleaning behaviour, although this data was obtained by interview of the athlete and could have been influenced by the previous knowledge of the ideal frequency of oral cleaning. Most of the younger athletes reported cleaning their mouths one or more times a day, which is very positive even though the effectiveness of technique was not measured. It is also relevant that even when the data relates to higher-functioning athletes, almost half of the older athletes did clean their mouths every day. Nevertheless, far worse values would be expected from lower-functioning athletes and this evidence demonstrates the need for educational programs for prevention.

Albeit not part of the study, the severity of disability has an obvious influence over cognitive and motor skills and may limit the ability to comprehend or perform personal oral hygiene making it necessary to rely on a caregiver for supervision or assistance. Caregivers who perform daily oral hygiene should be trained in order to perform this task [30] because frequency of cleaning is not directly related to effective plaque removal and oral health preservation [100].

The devices used to perform oral hygiene at home were not considered in this study. Other studies have demonstrated the advantages of power assisted toothbrushes for removing dental plaque in people with ID and have proven to be significantly helpful [101,102].

Another relevant aspect is the frequency of professional dental care. Those individuals who periodically receive dental care should be expected to have better

oral hygiene and less gingival signs. When people with disabilities and/or their caregivers seek dental care, access is affected by many factors. It is beyond the scope of this article to review all these aspects, however they should be considered in order to understand the different barriers that confront this vulnerable population that together with all other factors considered are responsible for the need for improved oral health.

As discussed in the previous chapter, the standardized SOSS screening protocol has been widely reported [67,86,87,89–91], but analysis of the data must be made with caution. The participants in the study were relatively young with a mean age of 28.5 years, therefore this sample cannot be considered representative for all people with ID because they are considered to be part of a younger, healthier, higher-functioning and better supported stratum of that population [32,68,92]. The relevance of this is that the oral cleanliness and presence of gingival signs in the rest of this population would be expected to be worse.

The screening methods of this work consisted of the detection of signs of gingival disease. Periodontal disease was not assessed. The drawback is that there is an important underestimation of disease in our results as we only see the presence of deviations from normal gingiva that could hide serious periodontal conditions that were not reported.

Finally, people with intellectual disabilities are reported to have a higher prevalence of gingival signs, principally being affected by age, behaviour, type, and severity of disability. In this study, the mean prevalence of signs of gingival disease was 48.64%, but over 50% in more than 20 countries. Given these important values, further research is needed with the inclusion of plaque index and periodontal status to explore the severity of the conditions. Also, it appears that a high percentage of this population and their caregivers are in need of education and oral health preventive programs. Improvements in these indicators will have a strong impact in the oral health and quality for life for people with ID.

4.5. Acknowledgements

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Chapter 5

Treatment Needs and Predictive Capacity of Explanatory Variables of Oral Disease in Young Athletes with an Intellectual Disability in Europe and Eurasia.

5.1. Introduction

The oral treatment needs among people with ID were introduced in Section 1.6. In general, decay and gingival diseases are considered among the top ten secondary conditions among individuals with ID [103]. Strong evidence also supports that poor oral hygiene is the main cause of the higher prevalence of severe periodontal disease [33,36]. In comparison to a neurotypical population, people with ID have poorer oral hygiene, higher rates of self-inflicted traumatic injuries [39], more untreated decay, and a greater number of extracted teeth than people without a disability [8,104]. On the other hand, some studies have found that prevalence of decay appears to be similar in both groups [33,35,36].

The prevalence of caries and gingival disease among young people is worrying given the long-term negative impact of tooth decay on speech and nutrition, and in general health. For instance, bacteria from the oral cavity may cause infection in other parts

of the body when the immune system has been compromised by disease or medical treatments (e.g., infective endocarditis). Furthermore, periodontal disease has been associated with a number of systemic conditions and major chronic diseases share common risk factors with oral disease. [105] Nevertheless, for clinicians the diagnosis of disease in this population is not always accurate due to possible difficulties describing pain or other symptoms. Some individuals may not be able to cooperate with the assessment of their oral condition [35].

The access to oral care for people with disabilities is influenced by many factors, as explained in Section 1.7 [48]. Among them, living conditions, fear, anxiety, lack or inadequate dental health insurance or low family income may be barriers for the oral care [106].

Preventive measures and health promotion are effective in the prevention of oral diseases, as oral health research has demonstrated [26]. However, large-scale oral health data regarding people with ID is scarce, even though these data could be crucial for evaluation of existing policies.

The lack of reliable international surveys on oral health in this population strata makes the Special Olympics Special Smiles program, introduced in Chapter 2, a unique opportunity to conduct a large number of examinations and interviews and provide education [63].

The goals of this study were to 1) evaluate the oral condition and treatment needs of young athletes who participated in Special Olympics European Games (SOEG) in Antwerp, 2014 and 2) determine the capacity of explanatory variables to predict untreated dental caries and signs of gingival disease.

5.2. Methods

Oral health data were collected through interviews and oral examinations of athletes participating in the SOEG 2014 event held in Antwerp, Belgium. The athletes were invited to the Special Olympics Special Smiles venue where they could have their teeth examined on a voluntary basis. Written consent was obtained from the athlete and a parent or guardian. In full accordance of the World Medical Association Declaration of Helsinki, the Joint Ethical Committee of the Ghent University Hospital

approved the study as 2013/816. Data collection was performed as described in Chapter 2, [63] and later, the data were entered into an Excel spread sheet. For data cleaning, the row-wise deletion method was used. When country, gender or age was missing, the complete screening of the athlete was excluded.

5.2.1. Statistical analysis

Descriptive statistics were performed on SPSS 22 software. The first section of analysis included logistic regression analysis for simple and multiple explanatory variables for signs of gingival disease and untreated decay, using the JMP software version 11. The null hypothesis of the whole model test was that none of the variables were significant. If that hypothesis was rejected then a simplified Effect Likelihood-ratio Chi-square test was performed with the variable found to be related.

The second section consisted in Multilevel Generalized Linear Mixed Models (GLMM) performed in SPSS 22 software. A correlation was expected within subjects from the same countries but as the number of athletes per country was too small (503 athletes from 53 countries), it was decided to use 'European regions' as clusters. The unobserved heterogeneity at the cluster level represents confounders that are omitted either because they cannot be measured or because their existence is unknown. However, ignoring the clustered nature of the data leads to biased parameter estimates of fixed effects. Therefore differences between clusters are considered in terms of the random or unobserved cluster-specific effects [107,108].

The GLMM models include random effects of clustered variables in addition to fixed effects of regression analysis and response variables with non-normal distributions. Moreover, the models are able to test the hypotheses concerning fixed and random effects (or their variances) in separated form [107]. Explanatory variables for untreated decay and signs of gingival disease were tested taking into account the random effects of the European Region where the athlete belongs as level 1 and individual variability as level 2. The level of significance for all tests was set at a p-value < 0.05.

Table 6 shows the 53 countries of origin of the athletes' sample and the European Region in which they were grouped.

Table 6. Countries and screenings per European region

Regions	Countries	n	%
Northern Europe	Denmark, Estonia, Finland, Iceland, Latvia, Lithuania, Faroe Islands, Sweden, Norway, United Kingdom, Ireland and Isle of Man.	109	21.6
Western Europe	Austria, Belgium, France, Germany, Liechtenstein, Luxembourg, Netherlands and Switzerland.	92	18.4
Eastern Europe	Armenia, Azerbaijan, Russia, Ukraine, Belarus, Moldova, Czech Republic, Hungary, Poland, Romania, Slovakia, Slovenia.	120	23.8
Southern Europe	Andorra, Gibraltar, Portugal, Spain, Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Greece, Kosovo, Macedonia, Romania, Serbia, Cyprus and Malta.	96	19.1
Eurasia	Turkey, Israel, Kazakhstan, Kyrgyzstan, Georgia, Tajikistan and Turkmenistan	86	17.1

5.2.2. GLMM models development

Basically, the GLMM model consists in the selection of the best model that describes the data, in order to interpret the results on the basis of intercepts and odds ratios. The models were built in three steps to incrementally explore the effects of gender, age, untreated decay, oral pain and oral hygiene frequency as independent variables for signs of gingival disease. Whereas the effects of age, gender, signs of gingival disease, oral hygiene frequency, oral pain and fissure sealants were explored for untreated decay.

First, a Model 1 was created. This was the most basic multi-level model with binomial distribution and log link function and included only the intercept (European Region). The idea was to assess if the European Region can predict the outcome. Model 2 was created using binomial distribution and logit link function. In this model gender and age were included as fixed (non-random) effects. Model 3 was created with

binomial distribution and logit link function. This was obtained via incremental addition of the independent variables with a different intercept for each European Region.

The best fitting model was selected considering the Akaike Information Criterion (AIC) and Bayesian scores, based on the -2 log pseudo likelihood algorithms. Bayesian scores involve measuring the goodness-of-fit to evaluate whether the chosen final model provides an adequate fit to the data and to firmly establish the model's credibility. Therefore, models with smaller information criterion (AIC) values and smaller Bayesian scores fit better.

5.3. Results

Descriptive

A total of 1405 participated in the SOEG Special Smiles program in 2014. 503 of them were younger than 21 years of age and were included on this study. The athletes were from 53 countries of Europe and Eurasia. The mean age was 17.8 with a SD of 2.16, minimum age of 10 and maximum of 21 years. Gender distribution showed 222 females (44.1%) and 281 males (55.9%). Table 7 presents demographical characteristics, reported oral hygiene habits and clinical findings of participants.

Table 7. Demographic characteristics, reported OH habits and clinical findings.

Variables		n (n=503)	%
Oral cleaning frequency	Once or more a day	441	87.7
	2 - 6 times a week	39	7.8
	Once a week	0	0
	Less than once a week	11	2.2
	Not sure	11	2.2
	No data	1	2.5
Oral pain	No	460	90.2
	Tooth pain	29	5.7
	Other pain	8	1.6

	No data	13	2.5
Signs of Gingivitis	No	306	60.8
	Yes	193	38.7
	No data	4	0.8
Untreated decay	No	334	61.3
	Yes	168	33.4
	**anterior decay	39	7.8
	**premolar decay	56	11.1
	**molar decay	149	29.4
	No data	1	0.2
Filled teeth	No	261	51.9
	Yes	240	47.7
	No data	2	0.4
Missing teeth	No	373	74.3
	Yes	127	25.2
	**Missing anterior	17	3.4
	**Missing molar	87	17.3
	No data	3	0.6
Injury	No	445	88.7
	Yes	54	10.7
	**not treated	29	5.7
	No data	3	0.6
Sealants	No	450	89.5
	Yes	50	9.9
	No data	3	0.6
Fluorosis	No	475	94.4
	Yes	27	5.4
	No data	1	0.2
Treatment Urgency	Maintenance	217	43.1
	Non-urgent	214	42.5
	Urgent	71	14.1
	No data	1	0.2

5.3.1. Results of Logistic Regression tests

The variables of age and gender were not related to the variables of oral hygiene frequency, fluorosis, injury, sealants, or treatment urgency.

For gingival signs of disease, the variables of gender, age, oral pain, untreated decay and oral hygiene habits were tested. The whole model test had a p value of 0.001; therefore we rejected the null hypothesis that none of the variables were significant. The model showed that untreated decay was the only significant variable, so the simplified Effect Likelihood-ratio Chi-square test (Table 8) confirmed that untreated decay was significant to predict signs of gingival disease (p-value 0.0008).

Table 8. Odds Ratios and Confidence Intervals for signs of gingival disease

Level1	/Level2	Odds Ratio	P	Lower 95%	Upper 95%
Untreated decay	No untreated decay	0.523	0.0008*	0.357	0.764
No untreated decay	Untreated decay	1.912	0.0008*	1.309	2.798

Odds for absence of gingival disease vs. presence of gingival disease obtained with Logistic Regression.

The variables of gender, age, oral pain, gingival signs, fissure sealants and oral hygiene habits were tested as predictor variables for untreated decay. The whole model had a p value of 0.046 therefore we concluded that at least one of the variables was significant. The parameter estimates showed that only the variable of oral pain was significant. The simplified Effect Likelihood-ratio Chi-square test (Table 9) confirmed that oral pain was significant (p-value 0.007) to predict untreated decay.

Table 9. Odds Ratios and Confidence Intervals for Untreated decay

Level1	/Level2	Odds Ratio	P	Lower 95%	Upper 95%
Tooth pain	No pain	0.337	0.005*	0.153	0.718
Other pain	No pain	3.339	0.196	0.586	62.724
Other pain	Tooth pain	9.917	0.015*	1.490	198.238
No pain	Tooth pain	2.969	0.005*	1.392	6.526
No pain	Other pain	0.299	0.196	0.016	1.705

Tooth pain	Other pain	0.101	0.015*	0.005	0.671
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Odds for absence of untreated decay vs. presence of untreated decay obtained with Logistic Regression.

5.3.2. Results of GLMM for Signs of gingival disease

Model 1 stated that the variable European Region was able to predict the chances of an athlete having gingival signs. The intercept estimate of -0.948 is a significant indicator of gingival signs in a European region.

$$e^{-0.948} = 0.387$$

$$p_g = 0.387 = 38.7\%$$

where p_g is the probability of having gingival signs

With no predictors in the model, the probability of having gingival signs is 38.7% per European region. The variance of the intercept coefficient is 0.019.

In Model 2, no interaction effects were identified among age and sex and signs of gingival disease.

Model 3 was the best statistical model in regard to untreated decay, age groups, and oral hygiene frequency. Independent variables showed that the absence of untreated decay was associated with lower chances of gingival signs. The estimated parameter for absence of untreated decay was -0.67 (Table 10). This indicates that, holding all other variables constant within a European Region, the odds of having gingival signs are $\exp(-0.67) = 0.51$ times the odds of having signs of gingival disease when untreated decay is present. The variance of the intercept coefficient was 0.036.

Table 10. Fixed Coefficients for signs of gingival disease

Model Term	Coefficient ▼	Std.Error	t	Sig.	95% Confidence Interval	
					Lower	Upper
Intercept	0,001	0,667	0,001	,999	-1,309	1,311
UntreatedDecay=0	-0,668	0,203	-3,295	,001	-1,066	-0,270
UntreatedDecay=1	0 ^a					
AgeGroups=1	-0,016	0,392	-0,040	,968	-0,786	0,754
AgeGroups=2	-0,244	0,202	-1,210	,227	-0,640	0,152
AgeGroups=3	0 ^a					
MouthHygiene=0	0,125	0,650	0,193	,847	-1,152	1,402
MouthHygiene=1	0,055	0,725	0,076	,940	-1,370	1,480
MouthHygiene=2	0,383	0,910	0,421	,674	-1,405	2,171
MouthHygiene=5	0 ^a					

Probability distribution: Binomial
Link function: Logit

^aThis coefficient is set to zero because it is redundant.

5.3.3. Results of GLMM for Untreated decay

Model 1 stated that the variable European Regions was able to predict the chances of an athlete having untreated decay. The intercept estimate of -1.162 is a significant indicator of gingival signs in a region.

$$e^{-1.162} = 0.312$$

$$p_u = 0.312 = 31.2\%$$

where p_u is the probability of having untreated decay.

With no predictors in the model, the probability of having untreated decay is 31.2% per European Region. The variance of the intercept coefficient is 0.179.

In Model 2, no interaction effects were identified among age and sex and signs of gingival disease, and therefore, these terms were omitted from the analysis. Model 3 was the best statistical model and included fissure sealants, oral pain, and oral hygiene frequency as independent variables and showed that untreated decay was related with absence of fissure sealants. The estimated parameter for absence of fissure sealants was 0.922 (Table 11) and indicated that, holding all other variables constant within a European Region, the odds of having untreated decay are $\exp(0.922)=2.51$ times the odds of having untreated decay when at least a molar is sealed. The variance of the intercept coefficient was 0.346.

Table 11. Fixed Coefficients for untreated decay

Model Term	Coefficient ▼	Std.Error	t	Sig.	95% Confidence Interval	
					Lower	Upper
Intercept	-1,992	1,364	-1,461	,145	-4,672	0,688
MouthPain=0	1,129	1,089	1,037	,300	-1,011	3,270
MouthPain=1	2,211	1,156	1,913	,056	-0,061	4,482
MouthPain=2	0 ^a					
Sealants=0	0,922	0,449	2,054	,041	0,040	1,804
Sealants=1	0 ^a					
MouthHygiene=0	-0,844	0,690	-1,224	,222	-2,199	0,511
MouthHygiene=1	-0,565	0,770	-0,734	,463	-2,078	0,948
MouthHygiene=2	-0,064	0,963	-0,067	,947	-1,957	1,828
MouthHygiene=5	0 ^a					

Probability distribution: Multinomial

Link function: Generalized logit

^aThis coefficient is set to zero because it is redundant.

5.4. Discussion

A convenience sample of 503 screenings was used, recruited on-site during the Special Olympics European Games event. The primary dataset included 511 screenings and 8 data points were deleted with the data cleaning procedure.

The globally used standardized SOSS protocol enabled comparisons between the obtained results with all existent and future data of studies performed with the same methodology as the protocol is widely accepted and referred to in the literature [67,78,86,89–92]. However, as explained In Chapters 3 and 4, the study results cannot be extrapolated for all of the population with ID. [32,85].

The most worrying findings were the high prevalence of gingival signs, missing teeth, untreated decay and urgent treatment recommendations. 38.7% of the athletes had signs of gingival disease, even though most of them (87.7%) cleaned their mouth once or more a day. This incongruence has several possible explanations. Oral cleaning frequency was asked to the athletes and the answers could have been influenced by previous knowledge of the ideal brushing frequency. Furthermore, an inadequate technique, due to lack of dexterity in brushing the teeth, could explain the high prevalence of gingival signs as effectiveness in plaque removal, was not measured. [100] Besides technique, athletes with Down Syndrome were expected to have higher prevalence of gingivitis, related to a higher level of specific subgingival bacterial species and impaired immunologic responses [33,44,45]. The results obtained on signs of gingival disease agree with those from other studies based on data from Special Olympics events from Germany in 2010 (46.9% of athletes between 12- 17 years old), the United States in 2001 (40.1%), and Puerto Rico in 2013 (42%), but lower than those from Mexico in 2013 (52%), New Jersey in 1996 (60%), Italy in 2009 (60 %) and the UK in 2005 (63%) [62,85,89,90,92,98].

One third of the young athletes presented untreated decay when only lesions with a diameter of 0.5 mm were considered. This is disturbing because the actual prevalence may be higher with radiography support for its detection. In addition, it was found that 25% of the athletes under 21 years of age had already lost at least one tooth. The evidence regarding prevalence of untreated decay shows great

variability, with figures between 19% and 79% in several studies that used the same standardized protocol [32,62,90,92].

The low prevalence of fissure sealants (9.9%) supports a persistent need for preventive treatment. Similar results were found in an American review released by the Third National Health and Nutrition Examination Survey (NHANES III) in 1996, even though during the last two decades preventive measures like application of sealants, salt fluoridation or fluoride varnish/gel application have been introduced in most European countries. This American review stated that 18.5% of 12-17 years old children had at least one sealed tooth and this prevalence decreased dramatically to 5% in 18-24 year old young adults [109,110].

In Chapter 1, it was mentioned that people with ID may present some individual features like poor lip closure, slow response to environmental obstacles, oral pathologic reflexes, or large over-jet of maxillary incisors. These features are directly related with self-inflicted traumatic injuries [39,71,111] that, in addition to potential dental injuries associated with the sports activities the athletes engages in, may explain the prevalence of dental injury of 10.7%.

A recommendation of urgent treatment was given to 14.1% of the athletes. This finding was consistent with results obtained in Italy and the U.S. [85,86] but much lower than in the other countries [90,91]. Furthermore, half of the athletes were in need of non-urgent treatment. The total need of treatment was found to be 56,7% of the screened population.

From the first section of statistical analysis, no significant relation was found between gender or age and oral hygiene frequency, fluorosis, dental injury, sealants and treatment urgency. This could be explained by the uniformity of gender distribution and the sample's small age variability as only athletes between 10 and 21 years old were included in the study.

Signs of gingival disease were strongly related with the presence of untreated decay and most of the affected individuals presented not only decay or gingival disease, but combined oral diseases. On the other hand, mouth-cleaning frequency was not significantly related to the presence of signs of gingival disease, although there was a

chance of misclassification of the frequency of mouth-cleaning because it was a parameter asked to the athlete as explained in Chapter 2. [63]. Correspondingly, the first analysis for untreated decay confirmed its expected significant relation with oral pain, and more specifically tooth pain.

As far as the dataset is concerned a correlation between subjects from the same European Region was expected due to national healthcare systems and insurance coverage. Therefore the GLMM models were built adding 'European region' (Fig. 16 & Fig. 17) as a cluster variable with expected correlations with the other variables and the model estimates its random effect, as well as the random effect of the individual variability of the athletes. From the GLMM models, a considerable variation in the presence of signs of gingival disease and untreated decay could not be explained by variables. This was expected because both are multifactorial diseases and many involved factors (i.e. diet, smoking habits, socio-economic status) were not included in the screening and consequently not controlled in the model.

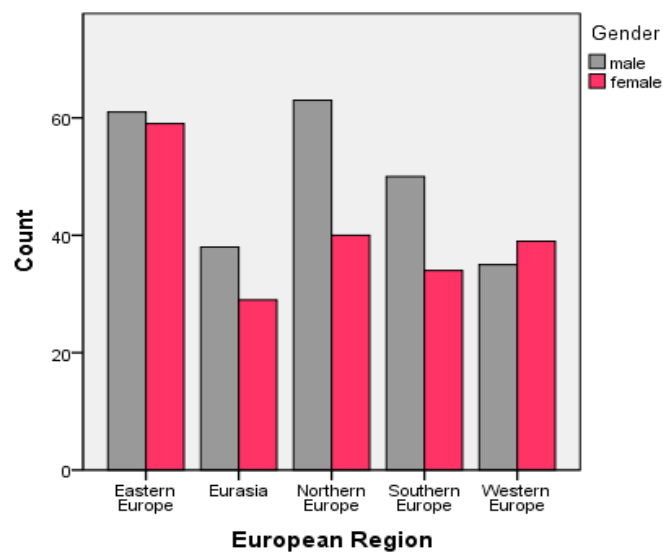


Fig. 16 Gender distribution per European Region.

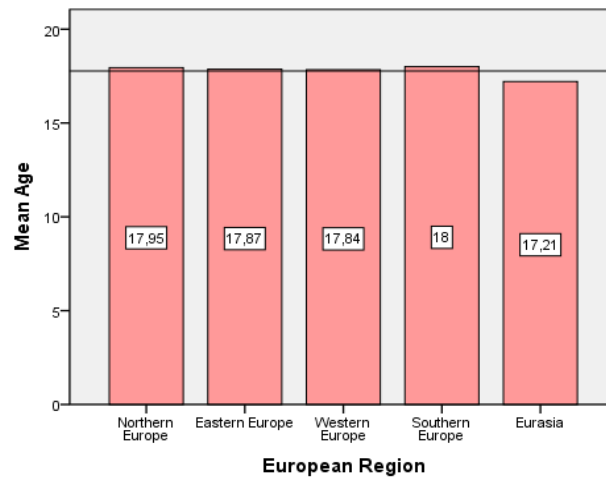


Fig. 17 Mean age per European Region.

Within European Regions, as discussed previously, there was an association between untreated decay and signs of gingival disease. Additionally, untreated decay was related to the absence of fissure sealants, which was also expected and revealed the need for preventive measures.

Moreover, it seemed that the European Region effect alone was able to predict the chances of an athlete having untreated decay or signs of gingival disease. In the best fitting models that included explanatory variables, most of the variance occurred at the individual level. The low variability may be explained by a similarity of the barriers faced by an individual with ID in accessing oral care. Nevertheless, European health managers must consider regional variables in health policy planning in order to reduce health inequalities.

Particularly, the findings from this study identified that there was a high-unmet treatment need among young athletes with ID in Europe and Eurasia. Besides, the predictive capacity of the explanatory variables was low and most of the variance was attributed to the individual level rather than to a regional level. Nonetheless, European Regions are an important focus for interventions to promote preventive

measures in oral health such as fissure sealants, in addition to the current focus of interventions directed primarily at country and individual level factors.

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Chapter 6

Oral Health Needs of Athletes with Intellectual Disability in Eastern Europe: Poland, Romania and Slovenia

6.1. Introduction

Most Eastern European countries (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Romania) have health-care systems in transition. Since 1989, insurance-based systems have been implemented in these countries, reducing public health provision. This process of change has been difficult, essentially because of the influence of the Soviet model on the previous systems. As a result, these countries have had to overcome a legacy of centralized and inequitable allocation of resources, in addition to the lack of responsiveness to local needs and poor-quality primary care services. Furthermore, only a limited proportion of the gross domestic product (GDP) was dedicated to healthcare [26,59,112,113].

The population with intellectual disabilities is known for being more vulnerable to oral health problems. This topic was reviewed in Section 1.6. On average, the population with ID has worse oral hygiene and higher plaque levels, more severe gingivitis and periodontitis, and overall worse oral health [33,36]. Nonetheless, large-scale oral health data on people with intellectual disabilities in Eastern European countries is

scarce, even though these data could be crucial in evaluating the oral health-care systems. As already known, most oral health diseases are preventable and consequently, healthcare promotion and preventive measures are critical. However, policies must be research-based, allowing each government to be able to identify the health needs in its population [26].

Special Olympics (SO) is an international sports organization for children and adults with intellectual disabilities. For the athletes participating in this event, the Healthy Athletes program was developed in the USA to help them improve their general health and fitness. The oral health branch of Healthy Athletes is Special Olympics Special Smiles (SS), and its main goal is to collect standardized and region-specific data to improve access to dental care for people with intellectual disability. Because of the absence of reliable surveys on the oral health of this population, the S OSS program has become a unique opportunity to conduct a large number of examinations and interviews and to provide education [63].

The aim of this study was to evaluate the oral condition and treatment needs of SO athletes from Poland, Romania and Slovenia. In general, this work explored the oral health needs in order to inform local policy-makers in an attempt to improve the oral status of persons with ID in these Eastern European countries.

6.2. Methods

This paper presents cross-sectional data collected through interviews and oral examinations from athletes participating in SO events held in Poland in 2012, in Romania in 2011, and in Slovenia in 2012. The participants were invited during the games to the Special Smiles site where they could have their oral cavity screened on a voluntary basis after informed consent was obtained from them and from a parent or guardian. The eligibility criteria considered only athletes with intellectual disability participating in National SO games. In full accordance with the World Medical Association Declaration of Helsinki, the Joint Ethical Committee of the Ghent University Hospital approved this cross-sectional study (2013/816), including the written consent procedure for adults and minors (less than 18 years of age).

The procedure consisted of recording demographic data (age, gender, and country) followed by oral screening, and individual education in oral hygiene techniques. For the oral screening, a standardized examination protocol developed by the U.S. Centers for Disease Control and Prevention was used as described in Chapter 2.

Dentists were recruited from university dental schools and dental professional organizations to perform screenings and data collection. All the volunteers were previously trained according to the Special Olympics Special Smiles Training Manual for Standardized Oral Health Screening [63]. This procedure consisted of training sessions held each day of the event before the beginning of the screenings, in which all volunteers participated in after studying the training manual. The training session included a presentation with case definitions and photographs, followed by a standardized exercise and a question-and-answer period, in which the standardization exercise was discussed.

All data were entered into an Excel worksheet and transferred to an SPSS data file where descriptive statistics were obtained using IBM SPSS Statistics 22 software. Row-wise deletion was performed for data cleaning.

6.3. Results

A total of 3545 Special Olympics athletes from Poland (n=1569), Romania (n=1683) and Slovenia (n=293) participated in this study. The population was mainly adult.

The average age of participants varied according to nationality: 23.2 years (Poland), 22.9 years (Romania) and 27.8 (Slovenia).

Gender distribution in the Polish group was 30.66% females and 68.90% males, while 0.45% of the athletes were recorded under uncertain gender, which resulted from gaps in the examination forms. The Romanian participants were 39.57% females, 60.13% males and 0.3% of uncertain gender. Lastly, the participants from Slovenia were 36.18% females and 63.82% males. The distribution of all the presented parameters among the three countries is presented in Table 12.

Table 12. Distribution of oral health parameters.

		Poland n =1569 male=1081 female=488		Romania n=1683 male= 1012 female=671		Slovenia n =293 male=187 female=106	
Variables		n	%	n	%	n	%
Frequency of oral cleaning	1 or more/ day	1220	77.8	1237	73.5	280	95.6
	2-6/ week	215	13.7	217	12.9	7	2.4
	Once/ week	52	3.3	56	3.3	3	1.0
	< once/ week	44	2.8	49	2.9	0	0.0
	Not sure	38	2.4	124	7.4	3	1.0
Oral Pain	Yes	122	7.8	241	14.3	10	3.4
Edentulism	Yes	62	0.4	10	0.6	21	0.7
Signs of gingivitis	Yes	693	44.2	1185	70.4	127	43.4
Untreated decay	Yes	642	40.9	321	19.1	181	61.8
Filled teeth	Yes	1112	70.9	571	33.9	243	83.0
Missing teeth	Yes	828	52.8	646	38.4	139	47.4
Sealants	Yes	67	4.3	64	3.8	110	37.7
Injury	Yes	403	25.7	256	15.2	39	13.2
Fluorosis	Yes	53	3.4	12	0.7	12	0.4
Treatment urgency	Maintenance	408	26.0	211	12.5	151	51.4
	Non-urgent	427	27.2	1097	65.2	85	29.0
	Urgent	734	46.8	375	22.3	57	19.6

6.4. Discussion

This study provides a unique set of data that describe the oral health status of athletes with intellectual disability from Poland, Romania and Slovenia. The globally used Special Smiles protocol allows these data to be compared with existing and future data obtained using the same methodology [67,78,86,89–92]. The results of a comprehensive and standardized procedure reported and revealed five remarkable aspects.

First, despite the high frequency of mouth cleaning reported, the prevalence of signs of gingival disease was high. In particular, 70.4% of Romanian athletes presented

signs of gingivitis, higher than data from the USA, Puerto Rico, Venezuela, the UK, Italy and Mexico [62,85,89,90,98]. Even though published data showed that gingivitis affects 28% to 75% of the general population worldwide [7,29], this study considered only anterior mandibular teeth. The prevalence may be explained by an inadequate brushing technique or motor and coordination impairments. Moreover, athletes with Down syndrome have a higher risk of gingivitis, related to specific subgingival bacterial species and impaired immunological responses [33,44,45].

Second, the prevalence of untreated decay was 40.9% in athletes from Poland and 61.8% in athletes from Slovenia, compared with 19.1% among Romanian athletes. Existing evidence in this regard shows great variability, with values ranging from 19% to 79% in several studies that used the protocol [62,85,89,90,98]. By contrast, the US National Institute of Dental and Craniofacial Research reported data from the National Health and Nutrition Examination Survey 2004 in which the prevalence in the general population of untreated decay was 23% in children and 26% in adults of 20–64 years of age.

The third finding, which was worrying, was the lack of fissure sealants as a preventive measure in Polish and Romanian athletes, with prevalence of only 4.3% and 3.8%, respectively. In contrast, among Slovenian athletes, this proportion was almost ten times higher, at 37.7%. These results highlight the need for preventive fissure sealants in Poland and Romania.

Fourth, dental trauma prevalence varied from 13.2% to 25.7%. A certain level of trauma was expected because the athletes are at major risk of trauma while competing and from individual characteristics, as described in Chapter 3 [39,68,71,111].

Finally, although reports on present oral pain ranged from 3.4% in Slovenian athletes to 14.3% in Romanian athletes, one in every five Slovenian and Romanian athletes and one in every two Polish athletes were estimated to need urgent treatment (an urgent treatment recommendation was given in the presence of oral pain, possible pulpal involvement or missing fillings with decay, or periodontal abscess formation

[63]). In the case of Poland, these findings reflected a serious need for treatment among SO athletes that should not be overlooked.

The results of this study must be interpreted with caution because some parameters, like domestic oral hygiene habits and oral pain, could be under-reported because questions were asked of the athletes [67,98]. Also a convenience sample was used, recruited on-site during the Special Olympics events. Therefore, study results cannot be extrapolated for the general population of individuals with ID in these regions [32,85].

6.4.1. Situation of oral care in Poland

For many years, during the communist regime in Poland, oral healthcare in the public sector was free of charge. Dental practices were owned by the state and only a few private practices existed. This period was also characterized by an uneven geographical distribution of care providers [59,114,115].

The reform of the healthcare system began in 1989. During the first 10 years there was an increase in the number of dentists in the private sector. Dentists were allowed to combine public practice with private practice. Additionally, a sickness fund was created and the compulsory insurance system was established.

The current oral care system has approximately 25,000 active dentists in a country of 39 million inhabitants. The healthcare expenditure is 6% of the GDP of which 0.18% is on oral care. Dentists are paid through fees per item of service [113–115] and the services covered in by the insurance system are: Preventive treatments, diagnostic procedures, curative services, endodontic treatment of all teeth for people younger than 18 years old and of incisors and canines in adults, treatment of lesions on the mucosa, extractions, basic periodontal treatment and orthodontic treatment with removable appliances. Procedures that are not covered can be obtained by co-payment, depending on availability at the practice. In addition, optional private oral health insurances are available that complement the national oral health insurance [59,113].

Even though sealants (for children <7 years of age), restorations, and basic periodontal treatment are offered by the public health system, our Polish sample

does not reflect this, showing a high need for those treatments. Although we acknowledge the influence of many other individual factors on lack of treatment, the system's age limitation for sealants allows dentists to seal only first molars, and only if they erupt early enough, which is not always the case. Another related factor could be the lack of dentists who treat special patients and/or a still-uneven geographical distribution of providers. Also, the fee that a dentist receives for the treatment of non-disabled children or adults is the same as the fee that he/she receives for a patient with intellectual disability, so there could be no motivation for treating the latter group. Additionally, there could be a financial barrier when children or adults with intellectual disability receive no financial aid from the government for co-payment.

6.4.2. Situation of oral care in Romania

The main features of the previous Romanian healthcare system were universal coverage and free service provided by government financing. There was no private sector and all professionals in the health system were salaried. Since 1989, healthcare has gradually become decentralized as private healthcare units have begun to coexist with state units.

The National Health Insurance Trust (NHIT) is the main source of funding for the healthcare system. According to Romanian law, social health insurance is compulsory for all citizens, but a few categories of individuals, such as children, people with disabilities and pregnant women, are exempt from insurance contributions and cost sharing [112].

Population estimates from 2014 (Jan 1st) revealed 19.781.410 inhabitants. The public expenditure on health as a percentage of GDP was 4.2% in 2014, of which 0.26% was for oral care, according to the National Ministry of Health.

More than 14,000 active dentists (according to the data of the National College of Dentists, 2014)[116] provide oral care through more than 3,500 dental-care units, about 90% of which are located in urban areas. Health insurance covers only a few procedures performed in dental-care units where the dentists have a contract with the NHIT. It is important to mention that the percentage of dentists working in

collaboration with the NHIT has decreased considerably as a consequence of a dramatic fund cutting in 2013, when public financing for dentistry was completely suspended. It took about one and a half years to restart (in August 2014) to the same level as it was in 2012. As dentistry is mostly (over 90%) private and only very few private dental offices work in collaboration with the NHIT, poor funding can be regarded as one of the main reasons for the poor oral health of people with special needs in Romania. However, other factors may play an important role as many people with disabilities have a very low financial status, which makes dental treatment in private offices usually unaffordable for them, regardless of their age.

There are few dental procedures listed in the framework contract of the NHIT. Of those, 100% of the costs of dental treatment for children under 18 years of age are supported, and 60% of the costs of acrylic full and partial dentures (only one denture every 10 years), dental extractions and resin-metal crowns. In addition, emergency endodontic treatment, periodontal management of abscesses, or consultations regarding oral and neck cancer are free of charge [112].

The Romanian oral health system offers people with special needs free dental care under the same conditions as it does for the general population, but with exemption from insurance contributions. However, some of the limitations for access to dental care are related to the dentists as they are paid per item of clinical procedure and the fees are the same for treating those with or without disabilities. Furthermore, there is a maximum amount of money that the NHIT can pay each dentist every month and no supplementary funds are allocated for working with patients with special needs. Dentists easily reach this limit when treating the neurotypical population and consequently there is no financial incentive to treat patients with special needs [112,117]. A study published in 2008 pointed out that insufficient knowledge of how to approach and treat patients with special needs, together with fear of uncontrollable consequences of the patient's general condition and behaviour, and a poor time/benefit ratio, are the main reasons why Romanian dentists tend to avoid treating patients with special needs [117].

When comparing Romania with Poland and Slovenia, Romanian athletes presented a surprisingly lower prevalence of untreated, clinically detected decay. As there is no water or salt fluoridation in Romania (except for a few very limited geographical

areas), this could be related to variations in diet among the different countries, especially in the consumption of refined carbohydrates. However, this relationship needs to be studied further.

On the other hand, the prevalence of signs of gingival disease in Romanian SO athletes was far greater (70% versus 43-44% in the other two countries), indicating poorer oral hygiene and therefore a greater need for adapted oral health education programs targeted towards both athletes and caregivers.

All of the above shows that, in Romania, the changes to the medical system in the last years have not solved the problems of the services provided. There is no question about the importance of both preventive and restorative treatments for oral health. Therefore, the currently limited access of people with special needs to certain dental care services represents an important concern for both the present and the future.

6.4.3. Situation of oral care in Slovenia

Slovenia has a population of 2.06 million inhabitants. Since 1991, when the country became an independent state, the public healthcare network has been supplemented with private practices and clinics. At present, payments for compulsory health insurance are mandatory. This insurance aims to provide financial cover for a wide range of health-care services for all citizens, on the principles of social justice and solidarity, and is paid by all employees according to how much they earn. In addition, it is possible to purchase optional private health insurance to supplement the compulsory insurance to cover the costs of co-payments and extra costs required for certain treatments. In Slovenia, health expenditure is 8.30% of the GDP [118].

Oral healthcare in Slovenia is almost 60% private. Among the private practices 80% have contracts with the national insurance [118]. When a patient is receiving dental care from a dentist who has a contract with the Health Insurance Institute, the patient is obliged to remain with that particular dentist for at least 1 year, even if the dentist cannot provide the patient with all the necessary treatment (e.g. because of a long waiting list). The National Health Insurance Institute covers oral preventive and

treatment procedures for people under 19 years of age. For adults, there are some co-payments in different proportions for many of the dental procedures needed. Dentists working independently are free to establish their own price lists [113,118].

The group of Slovenian SO athletes was small and their mean age was higher than in the group of SO athletes from Poland and Romania. A high prevalence of untreated tooth decay and signs of gingival disease were observed. This probably reflects partly a lack of implementation of relevant oral-preventive measures and partly some weaknesses within the health-care system (e.g. long waiting lists of dentists). Furthermore, the group of athletes with ID is one of the underserved dental patient groups, with a higher prevalence of dental diseases and more difficult accessibility to dental care compared to other populations [119]. Many practitioners have limited experience in providing care for patients with special needs or/and are reluctant to provide services to patients with ID for a variety of reasons, including financial. [120] Some of these facts could also be reflected in the high proportion of Slovenian athletes with decayed teeth, gingivitis and urgent treatment needs.

The data showed that the proportion of Slovenian athletes with sealed and filled teeth was high. In Slovenia the proportion of 12-year-old children with sealed teeth was as high as 89% [121]. Therefore, it is not surprising that almost 40% of the Slovenian SS athletes had at least one sealed permanent molar. This shows that despite some shortcomings in the organization of dental services, dentists in Slovenia are aware of the importance of providing preventative dental care for patients with intellectual disability. Nevertheless, the challenge remains to be how to ensure effective oral healthcare for this sector of the population.

6.4.4. Eastern Europe

Access to dental care is defined as the ability to obtain or make use of dental care [48]. Access to dental care for people with ID is affected by many factors that were introduced in Section 1.7 [49,50]. There are other barriers to treatment, including the relevance that people give to oral health, and dental apathy or ignorance, whilst fear or anxiety may also affect interest in receiving treatment. Also, not all dentists treat people with disabilities due to lack of preparation, time, facilities or protocols in case of complications. All in all, in order to improve the oral health status of the population

with intellectual disability, individual countries should identify the relevant barriers and, depending on their possibilities, address them.

In the context of growing recognition of their government's responsibility in respecting the full and equal enjoyment of all human rights for its entire population, Poland, Romania and Slovenia signed the United Nations Convention on the Rights of People with Disabilities (CRPD) in 2007, and later the convention ratification. Under the Convention, every state must ensure that people with disabilities have equal access to the same range, quality, and standard of free or affordable healthcare and programs as provided to other people [20].

Eastern European countries have made major progress in the organization of oral healthcare, depending on the selected strategy, by giving priority to some aspects and sacrificing other aspects of the system. The reported oral needs of athletes from Poland, Romania and Slovenia may be reflecting a lack of national policy for oral health for persons with ID and limited resources available. Therefore affordable oral care and integrated disease prevention could be strengthened.

Since almost all athletes were raised under changing political systems (Mean age of athletes <22 years), further research is needed. Only research based on representative data of the population with ID will be able to show if the changes in oral healthcare systems have accomplished their goals for the entire population of the three countries.

6.5. Conclusion

In general, SO athletes from Poland and Romania presented with a great need for urgent and non-urgent treatment. While half of Polish athletes are in need of urgent care, Romanian athletes scored higher on gingival inflammation and Slovenian athletes on untreated decay. Therefore, the challenge for Romania, Poland and Slovenia would be to develop and evaluate mechanisms for outreach care to their populations with ID and facilitate the delivery of preventive care and health promotion.

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Chapter 7

Treatment Needs and Impact of the Oral Health Screening of Athletes with Intellectual Disability in Belgium

7.1. Background

Oral health is an integral part of overall well being that influences the quality of life and has a strong impact on general health [122–124]. Evidence shows that global oral disease has increased. While tooth loss is declining, higher rates of untreated decay and periodontal disease have been found, as a result of variations in population structure [5]. Overall health is poorer in socio-economically disadvantaged groups, minority groups, individuals with chronic diseases, and people with disabilities [26].

The Pomona project in 2005 [125] was addressed in Chapter 1. In this project, several health indicators specific to people with intellectual disabilities were developed (Pomona I) and tested in 14 European countries (Pomona II) to gather information on lifestyle, health status, behaviour and access to healthcare. The objective was to increase understanding of the determinants of health among people with intellectual disabilities. It was concluded that people with ID experience poorer health and poorer access to optimal healthcare. Moreover, they are more likely to incur secondary health conditions and report increased morbidity [125].

From the Pomona II health survey, information was gathered from interviews from a sample of 1,269 adults with intellectual disabilities from 14 European countries. 21% of those surveyed reported having intraoral pain (Belgium 19%). In 75% of those cases it was tooth pain. In the remaining cases the pain was in other areas of the mouth [125] .

The health status of a population is related with the organization of healthcare The Belgian system is characterized by mandatory health insurance and free choice of care providers [34]. The oral healthcare, in particular, is partially included in the health insurance and delivered almost exclusively by private practitioners [126]. For certain treatments, the amount of reimbursed money is determined by age [56,127,128]. For instance, reimbursement is 100% for the whole population under 18 year of age except orthodontic treatment. For adults the system covers 75–79% of the national fees for preventive and restorative care, removable dentures and minor oral surgery. However, people with disabilities older than 18 are entitled to a 100% reimbursement for restorative oral care (except for fixed prostheses and implants), prophylactic cleanings, extractions and debridement procedures [129,130].

Until now the oral health of people with disabilities has been reported to be poor [32,33,36,62,67,127]. As an illustration, a systematic review published in 2010 studied the differences in oral health between the general population and people with intellectual disabilities. People with disabilities were reported to have worse oral hygiene and higher plaque levels, more severe gingivitis and periodontitis, more untreated dental disease and higher numbers of extracted teeth [36] .

In 2012, an article was published that assessed the oral health status of Special Olympics athletes in Belgium based on the results obtained in 2008. The most relevant findings were the prevalence of signs of gingival inflammation in 44% of the athletes, the presence of untreated decay in 22% and urgent treatment need in 12%. Hence, it was concluded that the need of oral healthcare was huge [67] .

Although a number of papers have been published including Special Smiles analysis from all over the world, no analysis has been reported regarding the impact of treatment referral provided during the program, which makes the current paper unique.

The aim of this study is two-fold. First, this study aims to evaluate the oral health condition, treatment needs and explanatory variables for oral disease in participants of SO Belgium in 2013. The oral health parameters are compared with those recorded in 2008 and 2013. Second, this work aims to assess the impact of screening and referral within SS on the oral health outcome of individual athletes who participated in the Special Olympics Belgium in two consecutive years (2012 and 2013).

7.2. Methods

Oral health data were collected through interviews and oral examinations of the athletes participating in the annual Special Olympics event held in Belgium, both in 2012 and in 2013. They were invited to the Special Olympics Special Smiles site where they could have their teeth examined on a voluntary basis. Consent was obtained before the event from the athlete and a parent or guardian depending on the level of comprehension of the athlete. The Joint Ethical Committee of the Ghent University Hospital approved the study as 2013/816. This article also includes data collected in the SOSS 2008 Belgian event where identical methods were used [67].

Data collection was performed as described in Chapter 2 and later entered into an Excel worksheet and transferred to an SPSS data file. The analysis of data from 2013 consisted in descriptive statistics. These data was compared with data from 2008 with Chi Square tests. The data of 2013 was analyzed with univariable and multivariable logistic regression with oral hygiene frequency, presence of untreated decay, signs of gingival inflammation, dental injury, sealants and treatment urgency as explanatory variables to estimate crude and adjusted odds ratios for their explanatory capacity of untreated decay and signs of gingival disease.

The data from athletes who participated in both Special Olympics events (2012 and 2013) were compared using Exact McNemar's test and Chi-square test for homogeneity of proportions. The level of significance for all tests was set at a p-value < 0.05. Bonferroni correction was used for multiple comparisons according to the number of comparisons conducted.

7.3. Results

7.3.1. Results from 2013

A total of 627 athletes with ID participated to the SS program in 2013. The participants were mainly adult with 11.1% of athletes under 18 years old, 15.9% between 18 and 25 years, and 73% 26 years and older. Reported age groups were selected to be comparable with international multicenter publications [71]. Mean age was 33.02 (with a SD of 13.01), minimum age of 5 and maximum of 68 years.

Gender distribution showed 229 females (36.5%) and 398 males (63.5%). Table 13 presents demographical characteristics, reported oral hygiene habits, and clinical findings of participants of the 2013 survey, completed with corresponding data collected in the 2008 survey. For more detailed information on the latter sample we refer to Ref. [67].

Table 13. Demographic characteristics, reported oral hygiene habits and clinical findings in participants of 2008 and 2013 surveys.

Variables		2008* (n=687)		2013 (n=627)	
		n	%	n	%
Age	<i>Mean</i>	33y	SD:13	33.02y	SD: 13.02
	<i>Range</i>	9-80		5-68	
Gender	<i>Males</i>	408	60.1	398	63.5
	<i>Females</i>	271	39.9	229	36.5
Oral cleaning frequency	<i>Once or more a day</i>	581	84.6	497	79.3
	<i>2 - 6 times a week</i>	41	6.0	58	9.3
	<i>Once a week</i>	10	1.4	17	2.7
	<i>Less than once a week</i>	6	0.9	9	1.4
	<i>Not sure</i>	17	2.4	24	3.8
	<i>No data</i>	32	4.7	22	3.5
Edentulism	<i>No</i>	660	96.1	609	97.1
	<i>Yes</i>	27	3.9	18	2.9
	<i>No data</i>	0	0	0	0
Signs of Gingivitis	<i>No</i>	363	52.8	317	50.6
	<i>Yes</i>	291	42.4	278	44.3
	<i>No data</i>	33	4.8	32	5.1
Untreated decay	<i>No</i>	502	73.1	416	66.3
	<i>Yes</i>	144	20.9	170	27.1
	<i>No data</i>	41	6.0	41	6.5
Filled teeth	<i>No</i>	145	21.1	174	27.8

	Yes	503	73.2	424	67.6
	No data	39	5.7	29	4.6
Missing teeth	No	N	N	291	46.5
	Yes	N	N	311	49.7
	No data			24	3.8
Dental Injury	No	572	83.3	521	83.1
	Yes	82	11.9	78	12.4
	No data	33	4.8	28	4.5
Sealants	No	607	88.4	530	84.5
	Yes	41	5.9	60	9.6
	No data	39	5.7	36	5.6
Fluorosis	No	N	N	589	94.0
	Yes	N	N	4	0.6
	No data			34	5.4
Treatment Urgency	Maintenance	384	55.9	354	56.5
	Non-urgent	183	26.6	130	20.7
	Urgent	84	12.2	74	11.1
	No data	36	5.3	69	11

*2008 data derived from Leroy et al., 2012. [67]

N= no information available

7.3.2. Results from Logistic Regression analyses

Gender was not related to the variables oral hygiene habits, presence of untreated decay, signs of gingival inflammation, dental injury, sealants or treatment urgency.

Gingival inflammation was significantly related to age, presence of untreated decay, treatment urgency and reported oral hygiene habits (Table 14). Athletes under 18 years of age had a statistically significant smaller chance for having gingivitis than those older than 26 years (OR: 0.41; 95% CI: 0.20 to 0.84). A higher chance of presenting signs of gingival disease was found among athletes who received non-urgent treatment recommendations (OR: 3.86; 95% CI: 2.17 to 6.85) than maintenance.

Table 14. Effects of gender, age, untreated, decay and oral hygiene habits categorical (explanatory variables) on presence of signs of gingival inflammation (2013)

	<i>Univariable</i>			<i>Multivariable</i>		
	<i>OR</i>	<i>p</i>	<i>95% CI for OR</i>	<i>OR</i>	<i>P</i>	<i>95% CI for OR</i>
Gingival signs^a						
Gender						
Female vs. male	1.09	0.60	0.78-1.53	1.10	0.62	0.76-1.58

Age						
<18 vs. 26 or more	0.30	<0.001	0.17-0.55	0.41	0.02	0.20-0.84
18-25 vs. 26 or more	0.77	0.24	0.49-1.20	1.09	0.71	0.68-1.75
Untreated decay						
	0.52	<0.001	0.36-0.75	0.97	0.95	0.34-2.72
Oral hygiene habits*						
2-6/ week vs. ≥ 1 /day	1.71	0.07	0.97-3.02	2.46	0.34	0.39-15.36
Treatment Recommendation*						
Urgent vs. Maintenance	2.37	0.001	1.40-4.00	2.54	0.12	1.23-5.26
Non-Urgent vs. Maintenance	3.30	<0.001	2.13-5.11	3.86	0.001	2.17-6.85

*Only significant values are shown

Untreated decay was related with the frequency of oral hygiene habits (Table 15). Athletes who reported to clean their mouths 2-6 times a week presented with higher odds of having untreated decay than those who clean their mouths once or more a day (OR: 1.82; 95% CI: 1.00 to 3.31). However, it was less likely to be found in athletes younger than 18 years (OR: 0.28; 95% CI: 0.13 to 0.61) and between 18- 25 years old (OR: 0.42; 95% CI: 0.24 to 0.75) when comparing them with older athletes.

Athletes under 18 (OR: 3.13; 95% CI: 1.50 to 6.53), and between 18 and 25 (OR: 3.15; 95% CI: 1.66 to 5.98), presented significantly higher odds of having sealed teeth. Untreated decay, however, was related with absence of sealed teeth (OR: 0.45; 95% CI: 0.20 to 0.94) (Table 16).

Table 15. Effects of gender, age and oral hygiene habits (categorical explanatory variables) on presence of untreated decay (2013).

Categorical predictor	Univariable			Multivariable		
	OR	p	95% CI for OR	OR	p	95% CI for OR
Gender						
Female vs. male	1.03	0.90	0.70-1.50	1.04	0.83	0.70-1.55
Age*						
<18 vs. 26 or more	0.28	0.001	0.13-0.61	0.28	0.001	0.13-0.61

18-25 vs. 26 or more	0.42	0.003	0.24-0.74	0.42	0.003	0.24-0.75
Oral hygiene habits*						
<1 / week vs. \geq 1 /day	2.12	0.27	0.56-8.03	1.81	0.39	0.47-7.01
1/ week vs. \geq 1 /day	1.59	0.38	0.57-4.47	1.46	0.50	0.49-4.38
2-6/ week vs. \geq 1 /day	1.77	0.05	0.99-3.15	1.82	0.05	1.00-3.31

*Only significant values are shown

Table 16. Effect of age, gender and untreated decay (categorical explanatory variables) on presence of sealants (2013)

Categorical predictor	OR for sealants	p	95% CI for OR
Gender			
Female vs. male	1.31	0.37	0.73-2.35
Age			
<18 vs. 26 or more	3.13	0.002	1.50-6.53
18-25 vs. 26 or more	3.15	<0.001	1.66-5.97
Untreated decay	0.45	0.03	0.20-0.94

Only variables with significant values are shown

7.3.3. Comparison of results from 2008 and 2013 surveys

Both samples (Table 13) were similar in size and age distribution, with a mean age of 33 years in both groups. Between both surveys, there was a decrease in the number of athletes who reported to clean their mouths at least once a day, from 84.6% in 2008 to 79.3% in 2013 ($p < 0.001$). The overall prevalence of gingival signs was not different in 2013 and 2008 (44.3% and 42.4%) ($p = 0.43$). The burden of untreated decay affected 27.1% of the study population in 2013, showing a net increase in comparison to 2008 (20.9%) ($p < 0.01$); the prevalence of sealants increased from 5.9% (2008) to 9.6% (2013) ($p < 0.01$).

7.3.4. Changes between 2012 and 2013

A total of 132 athletes, who met the inclusion criteria of being a participant on both SO Belgium 2012 and 2013, formed the population for this part of the study. The age and gender distribution was very similar to that in the general sample with 8.3%

athletes under 18 years of age, 19.7% between 18 and 25 years, and 72% 26 years and older. There were 52 females (39.4%) and 80 males (60.6%). Mean age was 33.16 (with a SD of 13.01), minimum age of 10 and maximum of 61 years.

No significant differences were found in the proportion of untreated decay, sealants, signs of gingival disease, dental injury, restored or missing teeth between athletes participating in both of the SO events in 2012 and 2013 (Fig. 18). Moreover, no variations were found in reported oral hygiene habits or the need of treatment urgency (Fig. 19 & Fig. 20).

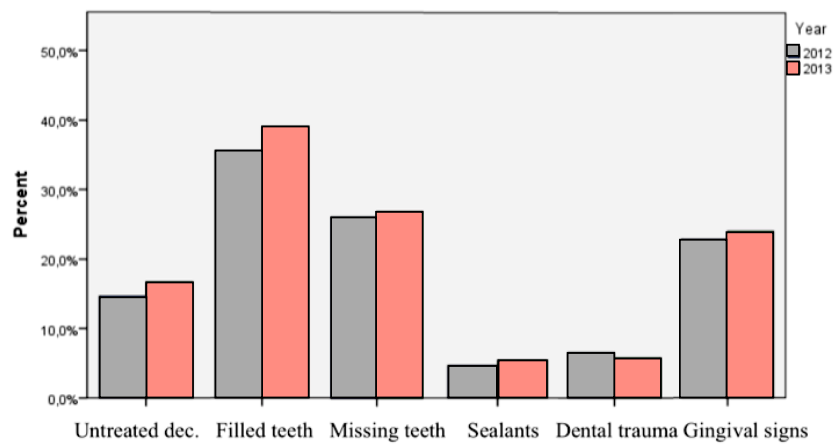


Fig. 18 Oral health parameters of athletes in 2012 and 2013 (n=132)

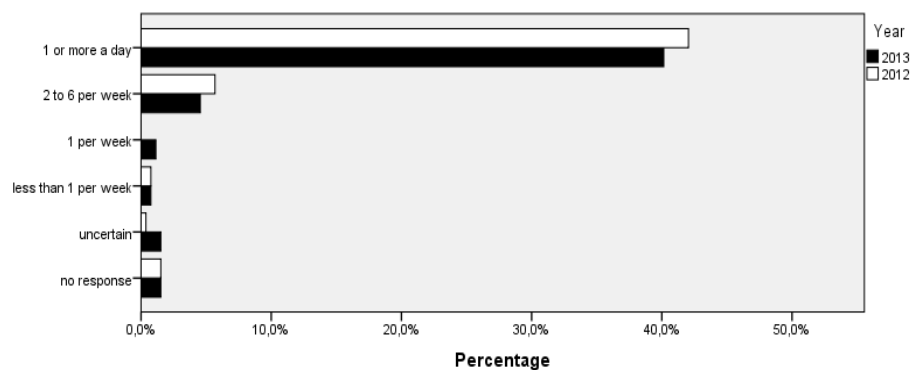


Fig. 19 Reported oral hygiene habits in 2012 and 2013.

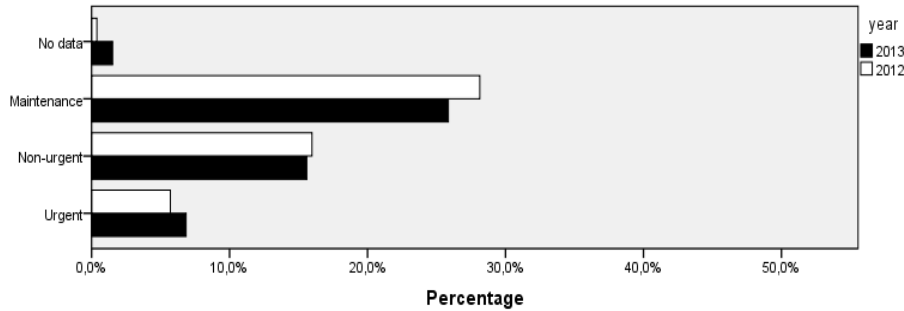


Fig. 20 Need of Treatment in 2012 and 2013.

7.4. Discussion

Oral cleaning habits are affected by an individual's cognitive and motor skills which, depending on the level of intellectual disability, may limit the ability to perform personal oral hygiene. In these cases, supervision and/or assistance of a caregiver becomes a necessity. Individuals with ID can also present poor lip closure affecting the natural cleansing of the oral cavity [7,93].

The most worrying findings were the high prevalence of gingivitis signs, untreated decay and urgent treatment recommendations. 44.3% of the athletes presented signs of gingival disease and the reported oral cleaning frequency was significantly related to the presence of signs of gingival disease. The majority of the athletes (79.3%) reported to brush their teeth at least once a day, but this reported data could have been influenced by previous knowledge of the ideal frequency of oral cleaning. Effectiveness in plaque removal, essential for oral health, was not measured, so an inadequate brushing technique could explain the high prevalence of gingival signs [100]. Athletes with Down syndrome, approximately 13% of SO athletes according to Special Olympics database, are expected to have a higher prevalence of gingivitis, due to their higher level of specific sub-gingival bacterial species and impaired immunologic responses [33,44,45]. The results obtained in the present study are comparable with those from other studies based on samples from Special Olympics participants in the United States (2001; 40.1%), Puerto Rico (42%) and Venezuela

(45%) in 2013, but lower than in New Jersey (1996; 60%), UK (2005; 63%), Italy (2009; 60%) and Mexico (2013; 52%) [62,85,89,90,98].

The burden of untreated decay that considered lesions with a diameter of 0.5 mm and without radiographical support for its detection, affected more than one fourth of the participants. For this reason, there is an underestimation of disease and the actual prevalence of decay may be even higher. This parameter was also strongly related to treatment urgency, as could be expected from the protocol guidelines for treatment recommendations, and less prevalent in athletes with gingival signs. The prevalence of untreated caries, reported in studies using the same standardized protocol, showed great variability with figures ranging between 19% and 79% [32,62,90,92].

Athletes over 26 years of age showed higher odds of presenting gingival signs of disease and less evidence of preventive care treatments like sealants. The low prevalence of fissure sealants is in agreement with an American review, released in 1996 by the Third National Health and Nutrition Examination Survey (NHANES III). This review indicated that 2% of 25 to 39 year old adults had evidence of dental sealants [109,110]. In Belgium, the Oral Health Data Registration & Evaluation System (OHDRES) ran between October 2009 and December 2010. This survey showed evidence of preventive treatment (fissure sealants/ preventive check-up) in more than 39.2% in adults between 25 and 34 years of age and 52.3% in participants younger than 25 years [131]. It is worth noting that the results of OHDRES overestimate the application of fissure sealants as it was based on oral care consumption and does not report independent values for fissure sealants and preventive check-ups.

Prevalence of edentulism was 2.9% but it has to be noted that the mean age of our athletes was 33 therefore this parameter is not representative. Prevalence of dental injury (12.4%) was expected, because the prevalence of dental trauma in the general population ranges from 2% to 33% [80,81] and also because it is known that self-inflicted traumatic injuries are common in people with ID [39,111] Individual characteristics may explain this tendency; i.e. poor lip closure, slow response to environmental obstacles, oral pathologic reflexes, and a large overjet of maxillary incisors.

Following the Special Smiles protocol for urgent treatment, recommendations were issued to 11.1% of the participants. Recommendations were made if athletes had oral pain or possible pulpal involvement. The percentage of urgent treatment need is comparable with results obtained in Italy and in the U.S. but much lower than in other countries [90,91].

According to the Belgian National Institute for Health and Disability Insurance (NIHDI) the healthcare expenditure was over 35 billion Euro in 2008 [132,133]. The expenditure in dentistry was 3.2% of the general healthcare expenditure in 2013 and its distribution between the different areas of dental care has been mostly constant over the last decade. From the budget, 52% goes to 'Conservative treatments' and this amount has slightly decreased over the years. The section 'Preventive care' (13.7%) has had a particularly strong growth since 2000 and is likely to become an important second section [126,129,134]. The comparison of the results of 2013 with the report from SO Belgium in 2008 (Figure 1), no evidence of important variations in oral health parameters in Belgian Special Olympics athletes over the last five years was found. The increase of sealants and the decrease in the need of treatment urgency is evidence of preventative and restorative oral care. Notwithstanding, the prevalence of signs of gingival disease, filled teeth and untreated decay suggest no improvements in oral disease and no broad variations in the need of education on oral healthcare.

The analysis of oral health parameters in athletes participating in SO Belgium 2012 and 2013 revealed only non-significant variations. It is remarkable that even though the individuals presented with more sealants, missing and restored teeth, proof of certain restorative and preventive care; the prevalence of gingival signs and untreated decay also increased after 1 year. There were no statistical differences in reported oral hygiene habits and treatment urgency despite the instruction on oral hygiene provided and the urgent treatment recommendation.

Overall, the effect of the annual SO oral health screening including individual oral hygiene instructions was very limited and did not yield significant changes when evaluating athletes one year later. The question remains if whether coaches and athletes did not understand that there were conditions that needed attention.

Although these results might be related to the limited sample size and short follow-up, oral health needs remained considerable and this could be related to a need for more intensive instruction, enhanced dentist training and/or improved facilities. This affects people with severe intellectual disabilities to a higher degree because they are more likely to require stabilization, sedation, or general anaesthesia, for which dentists need additional training.

The high need for preventive and restorative oral healthcare among this population persists. Clearly, from a one-time-a-year intervention in the scope of the Special Olympics events, improvements cannot be expected unless they are complemented with other interventions of oral health promotion and education of athletes, family and caregivers. Moreover, dental professionals should be more aware of the oral health needs of this population and more prepared to work with them.

Belgium belongs to the EURO A group in the WHO classification for Burden of Disease 2000 [135], the group with the best health situation among European countries, considering child and adult mortality. Its expenditure in health is one of the highest in Europe. The healthcare insurance system is mandatory and claims to cover a majority of the population. The oral health needs of the Belgian population with disabilities are huge. Although there is at least 90% reimbursement of treatment costs and several centers where Special Care Dentistry is offered, other factors seem to limit the access to oral healthcare. From all this, it is clear that there are specific barriers that affect the access of this population to oral healthcare which need to be further studied.

The strengths and limitations of the protocol have been discussed in previous chapters. In addition, the size of the sample used for the assessment of changes in treatment needs of athletes who participated in both 2012 and 2013 Special Olympics events was relatively small (n=132). This implies that future studies with a larger sample and longer follow-up period could reach stronger conclusions on the impact of the Special Smiles intervention. Additionally, further research including data on type and severity of disability and the use of specific index for caries and periodontal disease would benefit the comparison to other studies in literature.

7.5. Conclusion

The general results of the Special Olympics 2013 event indicate a considerable unmet treatment need among Belgian Special Olympics Athletes, persistent from 2008. Additionally, this study did not find any evidence of impact of the oral health screening among the athletes that participated.

Even though the sample is not representative of the whole population with ID the results support the need for increased promotion of health, prevention of disease and education, as well as preventive and restorative treatment.

7.6. Acknowledgements

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Chapter 8

General Discussion

The aim of this thesis was to study several aspects of the oral health status of athletes with ID. The selected approach was to focus on Special Olympics oral health screenings performed in 49 countries from Europe and Eurasia. The investigation led to a consistent pattern of results that will be discussed in this section.

Oral health has been neglected in athletes with intellectual disabilities from Europe and Eurasia. To improve this situation an essential requirement not only for but also for patients and their families or caregivers, is to understand the importance of oral health.

8.1. Topic of study

On the topic of concern, this work analysed the oral health status of athletes with ID, specifically regarding dental trauma, oral cleanliness and gingival health. Since there are important differences between the countries included in this study, particularly related to demographic characteristics, social-economic systems, and healthcare systems, this work was not based on the comparison of the oral health needs between all countries. The focus was placed on the assessment of the disease burden in this population and the trends of variation of the oral health needs of the athletes.

8.1.1. Main findings in relation to the oral health status of SO athletes

Improving oral health for individuals with disability is a matter of great interest as oral health has both local and systemic consequences. Poor oral health is a factor for co-morbidity when associated with systemic disease. It increases the risk of infectious complications for patients presenting with systemic diseases, such as congenital cardiac disease, immunodeficiency or diabetes, and for patients with internal prosthetics. Additionally, poor oral health plays a direct role in complications of chronic respiratory diseases [7,8]. People with disabilities who are under treatment with psychotropic drugs may show significant decrease in the salivary flow rate for long periods of time, which would favor the development of rampant caries, gum and soft tissues diseases [136,137].

Periodontal disease is perhaps the most common oral pathological condition that affects the general adult population. For individuals with ID it is the most prevalent dental problem in all ages. In this study, the signs of gingival disease presented a prevalence of 48.5% (over 50% in more than 20 countries) among the screened athletes in Europe and Eurasia, and 38.7% in young athletes participating in European Games. Gingival disease results from a large accumulation of plaque and the problem may be exacerbated in individuals with Down syndrome who, as explained in Chapter 4, have increased susceptibility to periodontal disease. Even though almost half of the athletes presented signs of gingival disease, the screening did not include the assessment of periodontal status. Therefore, the needs of periodontal treatment are underestimated. As gingival inflammation is the first stage and mildest form of periodontal disease, it was only possible to observe a small fraction of the problem.

A 33.4% of young athletes presented with untreated decay and 25.2%, missing teeth. This is concerning given the long-term negative effects on speech and nutrition. The results evidenced that most of the affected individuals suffer from both oral diseases.

The above-mentioned patterns of oral health were also found in the Belgian athletes (Chapter 7) and in athletes from Eastern European Countries (Chapter 6). Provided that the results of this work were obtained with higher-functioning individuals with ID, and most of the athletes were found to clean their mouths every day, the oral health

status in individuals with more severe disabilities among the studied countries remains unassessed.

At dental level, athletes may present morphological features related to their disability, such as abnormal tooth morphology, abnormal eruptive pattern, high palate and maxillary hypoplasia. As discussed in Chapter 3, Angle Class II malocclusions and open bite coupled with coordination difficulties, seizure episodes, and slow reflexes may influence the prevalence of dental trauma (13.02%) found in the athletes. However, it has to be mentioned that in our study the population was even more susceptible to dental trauma, as they were athletes and some of them participated in contact or collision sports.

8.1.2. Oral healthcare needs of SO athletes

Given the oral health condition of athletes, questions arise about the reasons behind the lack of treatment. Is it the dentists? The approach and effectiveness of oral care of individuals with ID depend on the attitude and training of dentists and support staff. Regrettably, few professionals are familiar with patients with ID and their needs.

The main reason why many dentists refuse to treat these individuals seems to be the lack of adequate training to face possible complications. Although some patients with ID require sedation or GA, others can be treated in private practice. Dentists and professionals should consider people with ID as individuals with oral health needs who are not always able to express their feelings and perceptions, such as fear or pain [47,138,139].

Another possible factor is the athlete's lack of awareness of their need of oral care. Within the population under study, 14.5% of the young European athletes and 29% of the Eastern European athletes received recommendations for urgent treatment. The total need of treatment (urgent and non-urgent) was up to 57% of the young athletes in Europe and 70% of the young athletes in Eastern Europe. Now, if we consider that the presence of pain was a determinant to refer athletes for urgent treatment, pain could have been underestimated given the difficulties of some patients with ID to identify and express the presence of pain. In the sample of Special Olympics Belgium

(Chapter 7), the outcome of these referrals was studied and no significant variations were found in the oral status of selected patients (n=132) after one year. The studied individuals did have more sealants, missing teeth and restored teeth, evidencing a certain degree of restorative and preventive care, but the prevalence of gingival signs and untreated decay also increased.

Finally, the judgement of family or caregivers on the need of oral health, coupled with the need to find willing care providers, transportation, etc., could be a barrier for access to care. Moreover, the care-giving responsibility of the families becomes more and more difficult with the ageing of parents. The Special Smiles program has addressed this problem by exposing the treatment needs, creating relationships with health professionals, and making referrals for more significant care when needed.

In summary, the results of this work showed that the intervention of the Special Olympics program did not succeed in motivating athletes to seek oral care. This may be explained by other barriers to the access to oral care, such as economic limitations or inadequate insurance for oral care. As these barriers are a public health problem, governments should address them.

8.1.3. Collaboration between member states

Acknowledging the common challenges that European countries face on the delivery of healthcare, the Maastricht Treaty on the European Union (1991) extended the European Economic Community to the areas of military, criminal justice, and judicial cooperation. Additionally, the treaty gave the Union new competencies in public health where the member states agree to collaborate in health promotion, health protection and health policy research.

The demand of oral healthcare for people with disabilities is expected to grow as a result of population ageing and increased awareness of people about their oral health needs [29]. The differences in healthcare systems between the EU countries play against a common fight against disparities and inequalities. While some governments have been increasing public provision and merging insurance systems, thus increasing governmental control, others have chosen to diversify the coverage with increased private oral care providers and open markets for private insurances [56].

To face the oral health needs of people with ID, countries should focus on improving the reimbursement of dental care services, training of dentists, and oral hygiene education [42]. Public finance programs could attract more dentists to provide care for people with ID and improve workforce distribution, so that the offer of dental care for people with disabilities may equal the demand of treatment. Besides, it has to be considered that special care dentistry requires extra education, training, infrastructure, and time investment from the dentist and health providers [57].

Finally, as discussed in Chapter 5, the European Region that the athlete was from was predictive of the chances of an athlete having untreated decay or signs of gingival disease, but most of the variance occurred due to individual variability of the athletes. Therefore, it stands to reason that all people with ID in Europe face similar barriers in terms of dental caries, and they could be indistinctly addressed at regional, national and individual level. Then, preventive programs against caries could for instance achieve a major impact in reducing oral disease and inequalities, if developed at these 3 levels.

8.2. Additional Points of Interest

- *Prevention of oral disease*

Prevention of oral disease is one of the most important and cost-effective interventions to improve oral health. An effective preventive program is extremely necessary for all populations with disabilities, and even more for children with disabilities, because of the social, economic, physical and medical factors that were already mentioned to compromise the dental care.

Regarding oral hygiene habits, as discussed in Chapter 4, it is fundamental that mouth-cleansing procedures are adequate and effective to preserve oral health. This implies that oral hygiene habits should be established as early as possible, and several adaptive instruments for people with disabilities are available. However, people with disability may have impaired neuromotor abilities and may be unable to independently and effectively perform oral hygiene, so they need help and/or supervision of another person. [30,100]

The governments should identify the treatment needs of vulnerable population groups to develop preventive programs. Ideally, these programs should be focused not only on the people with disabilities, but also extended to their families, caregivers and other health professionals. The follow-up and evaluation of program outcomes in the objective population is as important as the research-based intervention.

Education on oral hygiene should be continuous and special emphasis should be given to regular visits to the dentist. As discussed in Chapter 7, one-time intervention of the Special Smiles screening program in a year had no significant impact on the studied population. It failed to promote changes in their oral health needs, even when a specific recommendation for urgent treatment was issued to several athletes. Therefore, it is essential that not only people with disabilities acknowledge the importance of regular attendance to the dental practice, but also their caregivers.

Finally, the population with ID and their families and/or caregivers should be educated on dietary practices and nutrition. Although the relation between oral health and diet has many interrelating factors, it is known that inadequate nutrition, a sugary diet and the consumption of sugary drinks contribute to tooth decay, tooth erosion and gingival disease.

- *Multidisciplinary approach to oral healthcare*

In response to a growing global concern focused on oral health issues, especially those related to care access for the vulnerable population; a multidisciplinary approach to oral care has emerged. Physicians and nurses could have an important role in detecting oral health needs and making individuals with disabilities and their families and caregivers more aware of it. Unfortunately, medical professionals traditionally receive little training in oral healthcare [140].

8.3. Previous research

As already mentioned in Chapter 1 there are just few studies that compare the oral health of individuals with intellectual disabilities with large scale and international data. The present work is a first attempt in order to elucidate the burden of oral disease in population with ID. The findings are mostly agreeing with those from

several publications based on data from Special Olympics, that using the same methodology have shown that population with disabilities have poor oral health [32,85,86,87,89,90,92,98]. Even when the sample of athletes per country may not be representative of the total population with ID the general consistency of the oral health status of these athletes from the 49 countries supports the certainty of the findings.

With regard to the differences in oral health between general population and population with ID where addressed in a systematic review in 2010 were it was concluded that people with ID have worse oral hygiene and higher plaque levels, more severe gingivitis and periodontitis, more untreated caries and extracted teeth [36]. The present work did not compare oral status of population with ID and neurotypical population, yet it revealed similar oral health problems, especially gingival pathology.

A project carried out in Belgium in 2011 named “Pilot project for better oral care for population with special needs” (PBN project). This project consisted in a National epidemiological survey and oral examinations performed in a population obtained by two-stage sampling consisted of 707 adults with disability, 22–65 years old, who were approached in residential settings, day-care centers, and sheltered workplaces. As it may be noted this project differs from the present study in methodology and scope, but it can be used as a benchmark to compare our results.

Missing teeth were found on 64% of the individuals, whereas visible untreated decay was found in 56% of adults. In comparison, the findings of this study in relation to missing teeth and untreated decay are lower in the samples from Belgium, Poland Romania Slovenia and European Games. Nevertheless, the age distribution of the athletes was less spread with a mean age of approximately 22 years.

Oral hygiene was poor, dental plaque was registered in 65% of children and 78% of adults, while the periodontal status (measured with the DPSI score) revealed that children scored less periodontal health and more bleeding-on-probing than adults. Indeed, the presence of signs of gingival inflammation was one of the most prevalent oral health parameters found in SO athletes. However, periodontal status and dental

plaque were not assessed in the present work and given the results obtained it is strongly advisable to include it in national epidemiologic surveillance systems.

The PBN project also found significant relations between the reported last visit to the dentist of adults with disabilities, and the subjective need of treatment, the demand of care and the problems experienced in the organization of a dental appointment. Therefore the population with ID, families and caregivers need to be educated to become aware of the oral health problems so that they may seek oral care and take measures to prevent oral disease.

Our findings extend this line of research by looking upon the impact of the Special Smiles program and referrals one year after the intervention. The present study also sought to examine the predictive capacity of variables for oral disease in population with ID, providing a basis for international prevention programs.

8.4. Study Limitations

In general, this work took over the important task of collecting oral health data on people with ID, explored the impact on oral health needs of variations in oral healthcare systems, and evaluated the impact of the Special Smiles screening program on the improvement of Special Olympic athlete's oral health. However, given the population selected for this study, results cannot be extrapolated to the entire population of individuals with ID. Indeed, athletes participating in SO belong to a highly supported and less dependent subgroup of the population with ID and, therefore, they are expected to receive better medical and dental care than those who do not participate in SO [62].

Additionally, the sample sizes obtained were convenience samples with a great variability of sizes per country, therefore, there is chance of selection bias. Other limitations are associated with parameters obtained by athlete interviews such as oral cleaning frequency and oral pain. Depending on the level of understanding, the athletes may have given the answers that seemed appropriate to them, rather than real answers. Furthermore, there is also the possibility of recall bias, as it was not

possible to determine whether some athletes had already participated in events where data were collected.

The participation of many dentists as screeners makes calibration unpractical and difficult. In this case, the training manual developed by the CDC becomes important as the method for strict training of the examiners.

The degree of oral disease has been underestimated for several reasons. First, the dichotomous nature of the variables made it impossible to report the severity of disease per parameter (i.e. amount of teeth with untreated caries or amount of missing teeth). Second, the assessment was visual and did not include the use of explorers nor radiographies. However, the addition of radiography diagnoses and probes would have increased the cost and time of oral screenings and strict calibration. Third, limited parameters were assessed in the oral screening plaque index, periodontal status, use of mouthguard and devices used for oral hygiene, among others, were missing. The exclusion of periodontal status responds to time and costs reasons, as it requires strict calibration. Some studies have succeeded in the assessment of periodontal status on a large sample. The Belgian Pilot Project of Oral Care for Persons with Special Needs (PBN project) [27] cited above and in Section 1.6, is an example of this. The project used the Dutch Periodontal Screening Index (DPSI) which consists of the registration of only the highest individual score per sextant (between 0, healthy, and 5, pockets of >5 mm).

Another option would be Community Periodontal Index [29], which has been introduced by the WHO as a tool with which countries may produce profiles of their periodontal health status and plan intervention programs for effective control of periodontal disease. The CPI databank is continuously updated and may be helpful in oral health surveillance at country and inter-country levels, but only a few countries have carried out this survey on a systematic basis on the general population much less on the population with special needs. The advantages of the CPI and DPSI are simplicity, speed, and reproducibility but they give little information on loss of attachment. However, these indexes give a glimpse of the severity of the periodontal situation. The addition of such an index to the oral screening of Special Olympics would add significant information that is missing on periodontal condition of people

with ID. Its implementation in all countries must involve modification of the training procedure for screeners that should be practical and not only visual, which may increase the already mentioned limitations of time and resources.

Finally, given the large number of variables that contribute to existing oral health disparities and barriers for the access to oral health, the collected data did not address all contributing factors. However, the findings are intended to be an eye opener and to motivate the assessment of the oral care delivery systems for people with intellectual disabilities.

8.5. Future Directions

Our results point to a high need for oral treatment among athletes with ID, which suggests that the whole population with ID might have worse oral status. Unfortunately, minimal efforts have been put towards assessing the real burden of oral disease in the different countries. This prevents the development of adequate programs and policies. Future research should address a continuous assessment of oral disease in the whole population with ID and a more detailed analysis of the aspects not included in our study. For instance, based on our findings of the level of the athlete's gingival health, clinical indexes such as plaque index and periodontal status evaluation should be included in future studies.

This thesis provides a baseline to establish national and international surveillance programs, supporting the inclusion of training programs in the undergraduate curriculum of dental schools, in order to motivate dentists to treat individuals with ID. Incorporating special clinics for people with special needs in the universities would allow training students on the diagnosis and treatment of oral diseases for this specific population. As a result, the availability of oral care providers would be improved, increasing the access of people with ID to oral care.

The impact of the Special Smiles program could be better analyzed by studies including longer follow-ups for the athletes and the assessment of their condition over a number of years in order to determine whether the program really succeeds in the goal of improving access of athletes to oral care.

8.6. Recommendations

Based on the results of this work, an active intervention by the EU member states is proposed in order to guarantee the protection of health rights for people with disabilities. It is recommended that the authorities responsible for dental care services of European countries develop adequate national databases and promote the participation of families and caregivers in the development of oral health programs for people with ID. Training the caregivers at home, school, or institutions would help to preserve oral health through diet and oral hygiene. Overall, governments should explore ways to become more responsive to the challenges concerning people with ID and their needs.

Summary and Conclusions

9.1. Summary and Conclusions

Chapter 1 Patients with intellectual disabilities have a higher risk of oral disease due to the oral manifestations of their particular condition and compromised oral hygiene as a consequence of their impairment. Therefore they have an increased need for prevention and dental care. In order to document the aim of the current project, this chapter provides the background information relevant to the study and highlights the historical achievements of European Union on the struggle towards equal rights for individuals with disability. The literature review focuses on the main features of oral health of people with ID and the multiple barriers that could affect their access to oral care. The general aim of the study was to gain further knowledge regarding oral health status and treatment needs of athletes with ID in Europe and Eurasia.

Chapter 2 This work was based on data obtained from Special Olympics events held in 49 countries from Europe and Eurasia, through which the Special Smiles program offers a unique opportunity to collect large-scale data of the oral health of athletes with intellectual disability. The protocol of data collection was developed by the U.S. Centres for Disease Control and Prevention and described in the same Chapter.

In **Chapter 3** the prevalence of dental trauma among Special Olympics athletes was assessed. As the study subjects were athletes participating in sports, some in contact sports, they could have increased risk for traumatic injuries apart of the risk factors related to their condition like coordination difficulties, seizure episodes, slow reflexes, poor lip closure and other dental features. 13.02% of 15,941 athletes from 49

countries from Europe and Eurasia presented dental injury on maxillary or mandibular incisors. This study found no significant difference between the different age groups, but great variation was found between the countries and in some of them the burden of dental trauma accounted for more than 20% of the athletes.

Chapter 4 explores the prevalence of signs of gingival inflammation and its relationship to oral cleanliness and age among the athletes from 49 countries from Europe and Eurasia. From the results, 48.64% of the athletes presented with signs of gingivitis within the buccal area of at least three teeth of the mandibular arch, cuspid to cuspid, or permanent dentition. No significant differences in the mean prevalence of gingival signs were found between three age groups. The analysis of mouth-cleaning habits showed that 60.38% of the athletes cleaned their mouth at least once per day and athletes older than 26 years of age brushed their teeth with significantly less frequency. Gingival disease in people with disabilities is mainly increased by the type and severity of disability as well as by the oral hygiene habits. Consequently, athletes with limitations in their ability to comprehend or perform personal oral hygiene are in need of supervision or assistance in order to maintain gingival health.

The prevalence of caries and gingival disease among young people has several long-term negative consequences on the quality of life. In **Chapter 5** the treatment needs of 503 European athletes younger than 21 years of age were assessed. This study determined the predictive capacity of explanatory variables for untreated decay and signs of gingival disease with logistic regression analysis for simple and multiple variables and Multilevel Generalized Linear Mixed Models. Although 87.7% of the athletes cleaned their mouths one or more times a day, the prevalence of signs of gingivitis was 38.7%. One third of the young athletes presented with untreated decay and one fourth of them had at least one missing tooth. As far as the GLMM is concerned, an athlete is 1.9 times more likely to have no signs of gingival disease if he has no untreated decay rather than having untreated decay and 2.9 times more likely to not have untreated decay in absence of oral pain rather than in presence of pain. Nonetheless, the predictive capacity of the explanatory variables was low and most of the variance was attributed to individual level rather than to a regional level.

Chapter 6 explored the oral health needs of athletes from Poland, Romania and Slovenia. It was also found that the need of urgent treatment accounted for 20% of

Romanian and Slovenian athletes and 50% of Polish athletes. The reported oral needs of athletes may be a reflection of a lack of policies for oral health for persons with ID and/or limited resources available.

In **Chapter 7** the impact of Special Smiles screening and referral was evaluated in a group of 132 athletes who participated in Special Olympics Belgium in two consecutive years, 2012 and 2013. Additionally, the treatment needs of 627 participants of Special Olympics Belgium 2013 were compared with those published from 2008. This study provided disturbing results, revealing considerable unmet treatment needs. The prevalence of untreated decay of 27.1% showed a net increase in comparison to 2008 (20.9%), while the prevalence of signs of gingivitis in 2013 (44.3%) was only slightly higher than in 2008 (42.4%). It was also found that SO intervention had no statistically significant impact on the oral health of athletes between 2012 and 2013.

Chapter 8 contains the general discussion of the results obtained in the previous chapters. The oral health status and needs of the athletes are highlighted. Periodontal disease was the most common oral pathological condition and most of the affected individuals also presented with untreated decay. The possible reasons behind this lack of dental care are discussed and the collaboration between countries is regarded as a strategy for the common fight against health disparities. The need for prevention for the population with ID, the study limitations, and future directions are also reviewed at the end of this Chapter.

The general conclusions based on the results of this thesis are:

1. The results of this study show that among the population with ID oral health problems are common, therefore there is considerable need of oral care and improvement of oral cleaning behaviour.
2. The countries with higher prevalence of dental trauma are in need of preventive programs for the patients, parents and caregivers. Especially our population, which

consisted of athletes, must be aware of the need to use mouth guards for athletes participating in contact sports.

3. With respect to periodontal disease, half of the athletes in more than 20 of the 49 participant countries presented signs of gingival disease that may be influenced by inadequate oral hygiene. In this research, age was not a determinant for prevalence of gingival disease as in a neurotypical population even though younger athletes did brush their teeth more regularly; the effectiveness of brushing in plaque control was not evaluated.

4. The presence of oral pathology in young European athletes with ID comprised a high prevalence of gingival signs, missing teeth and untreated decay, and most of the athletes were in need of urgent treatment.

5. Most of the variability in the presence of signs of gingival disease and untreated decay could not be explained by age, gender, oral pain, untreated decay, fissure sealants and/or frequency of oral cleaning. This implies that other factors (i.e. diet, smoking habits), together with the barriers of access to oral care, could be playing an important role. Assessment of those factors was not included in the screening and therefore they were not controlled in the model.

6. This thesis found that people with ID from European Regions face similar oral health problems. Accordingly, the regions become an important focus for interventions to promote preventive measures in oral health in addition to the current focus of interventions directed primarily at country and individual level factors.

7. Important oral health needs were detected among athletes with ID in Eastern European countries, especially the need of overall treatment (urgent and non urgent). Therefore, the challenge for Romania, Poland and Slovenia would be to develop and evaluate mechanisms to meet the needs of the population with ID.

8. In Belgium, oral health needs of athletes persisted from 2008 to 2013 even though athletes have preferential reimbursement in the health insurance system. Additionally, this study did not find any evidence of impact of one-year-time

educational interventions and recommends the development of continuous educational programs.

9. People with ID have the right to achieve better oral health and thereby better quality of life.

9.2. Samenvatting en conclusies

Hoofdstuk 1 Patiënten met een mentale beperking hebben een verhoogd risico voor orale problemen. Deze het gevolg zijn van hun beperking en de hypotheek op de mondhygiëne als gevolg van hun afhankelijkheid van verzorging. Om deze reden hebben ze een verhoogde behoefte aan preventie en tandheelkundige zorg.

Dit hoofdstuk geeft de achtergrondinformatie en de historiek weer binnen de Europese Unie, waarbij nadruk wordt gelegd op de inspanningen voor gelijke rechten voor personen met een beperking. Het literatuuronderzoek richt zich op de belangrijkste kenmerken van de mondgezondheid van mensen met een mentale beperking waarbij meerdere barrières, die van invloed kunnen zijn op hun toegang tot mondverzorging, in kaart worden gebracht.

Het doel van de studie was om een bredere en diepere kennis te verwerven, met betrekking tot de status van de mondgezondheid en behandel nood van atleten met een mentale beperking, in Europa en Eurazië.

Hoofdstuk 2 Dit werk was gebaseerd op data die zijn verkregen tijdens de Special Olympics evenementen gehouden in 49 landen uit Europa en Eurazië. Het Special Smiles programma biedt een unieke gelegenheid om op grote schaal gegevens verzamelen rond de mondgezondheid van atleten met een mentale beperking. Het tandheelkundig protocol voor het verzamelen deze data werd ontwikkeld door de US Centers for Disease Control and Prevention (CDC) en werd beschreven in hetzelfde hoofdstuk.

In **hoofdstuk 3** werd de prevalentie van tandheelkundige traumata bij de atleten van Special Olympics in kaart gebracht en besproken. Daar dit onderzoek werd

uitgevoerd bij sporters, waaronder ook atleten die deelnemen aan contactsporten, kan dit leiden tot een verhoogd risico voor dentale traumatische letsels afgezien van de risicofactoren die gelinkt kunnen worden tot hun beperking. Bij deze laatste kunnen we coördinatie problemen, epileptische insulten, trage reflexen, beperkte lipsluiting en andere tandheelkundige anomalieën vermelden. Bij 13.02% van de 15.941 gescreende atleten uit 49 landen uit Europa en Eurazië werden tandheelkundige letsels, op maxillaire of mandibulaire snijtanden, vastgesteld. Dit onderzoek stelde geen significant verschillen vast tussen de verschillende leeftijdsgroepen. Wel werd een grote variatie gevonden tussen resultaten uit de verschillende deelnemende landen, waarbij soms bij meer dan 20% van de atleten een dentaal trauma werd vastgesteld.

Hoofdstuk 4 onderzoekt de prevalentie van tandvleesontsteking bij de beoogde doelgroep, haar relatie tot de mondgezondheid en de link met leeftijd bij atleten uit 49 landen uit Europa en Eurazië. Bij 48.64% van de atleten werden tekenen van gingivitis vastgesteld bij minstens 3 mandibulaire anterieure gebitselementen in het definitieve gebit. Bij de prevalentie van de gingivale problematiek werden geen significante verschillen aangetoond gevonden tussen drie onderzochte leeftijdsgroepen.

Analyse van de mondhygiëne toonde aan dat 60.38% van de atleten ten minste eenmaal per dag poetst en dat atleten, die ouder zijn dan 26 jaar oud, aanzienlijk minder frequent de tanden poetsen. De tekenen van gingivitis bij mensen met een beperking lijkt voornamelijk verhoogd door het type en de ernst van de beperking en van de mondhygiëne gewoonten. Als gevolg daarvan kunnen we stellen dat atleten met een beperkingen, in het uitvoeren van persoonlijke mondhygiëne, behoefte hebben aan toezicht of bijstand door een naaste, teneinde de mondgezondheid op een adequaat niveau te brengen. De prevalentie van cariës en gingivitis bij jonge mensen heeft op langere termijn gevolgen voor de algemene levenskwaliteit.

In **hoofdstuk 5** werd de mondgezondheid van 503 Europese atleten, jonger dan 21 jaar, beoordeeld. Deze studie bepaald het voorspellend vermogen van verklarende variabelen voor onbehandelde cariës en tekenen van gingivitis met logistische regressieanalyse voor eenvoudige en meerdere variabelen en Multilevel Generalized Linear Mixed (GLMM) modellen. Hoewel 87,7% van de atleten aangaf de tanden

minimaal één maal per dag te poetsen werd bij 38,7% tekenen van gingivitis vastgesteld. Een derde van de jonge atleten bood zich aan op de screening met onbehandelde tandbederf en een kwart van hen had ten minste één ontbrekend gebitselement. Wat betreft de GLMM resultaten blijkt dat een atleet 1,9 keer meer kans heeft op gezond tandvlees indien hij geen onbehandeld tandbederf heeft. Daarnaast blijkt een atleet die geen pijnklachten heeft in de mond 2,9 meer kans te hebben ook cariësvrij te zijn.

Het voorspellend vermogen van de verklarende variabelen is echter laag en de meeste variantie werd op individueel niveau en niet op regionaal/geografisch regionaal niveau toegeschreven.

Hoofdstuk 6 onderzocht de behoeften van de mondgezondheid van atleten uit Polen, Roemenië en Slovenië. Een dringende tandheelkundige behandeling bleek nodig in 20% van de Roemeense en de Sloveense atleten en tot zelfs 50% van de Poolse atleten. De gerapporteerde problematiek en behandel nood geeft een reflectie weer van het ontbreken van een gericht mondgezondheidsbeleid voor personen met een beperking en/of de beperkte middelen die het beleid ter beschikking stelt.

In **hoofdstuk 7** werd de impact van het Special Smiles programma op een groep van 132 atleten geëvalueerd die gedurende twee opeenvolgende jaren, 2012 en 2013 werden gescreend. Daarnaast werden de resultaten van 627 deelnemers aan het Special Smiles gebeuren in België 2013 vergeleken met de resultaten uit 2008. Deze studie bracht een aantal opmerkelijke resultaten aan het licht. De prevalentie van onbehandelde cariës van 27.1% in 2013 toonde een toename in vergelijking met 2008 (20,9%), terwijl de prevalentie van tekenen van gingivitis in 2013 (44.3%) ook net iets hoger dan was dan in 2008 (42,4 procent). Daarenboven bleek dat een vergelijking van een jaarlijks opeenvolgende screening bij dezelfde atleten in 2012 en 2013 geen statistisch significante invloed heeft op de mondgezondheid van atleten.

Hoofdstuk 8 bevat de algemene bespreking van de resultaten verkregen in de vorige hoofdstukken. De status van de mondgezondheid en de behandel nood van de atleten werd weergegeven waar bij de parodontale problematiek de meest voorkomende orale pathologie bleek te zijn. Ook onbehandeld tandbederf werd veelvuldig vastgesteld. De mogelijke oorzaken van dit gebrek aan tandheelkundige

zorg werd besproken. De mogelijke samenwerking tussen verschillende landen wordt beschouwd als een mogelijke strategie voor de gemeenschappelijke strijd tegen de verschillen in mondgezondheid. De noodzaak van preventie voor de bevolking met een beperking, de beperkingen van de studie en toekomstige mogelijke opties werden in kaart gebracht op het einde van dit hoofdstuk.

De algemene conclusies op basis van de resultaten van deze thesis zijn:

1. De resultaten van deze studie tonen aan dat onder de bevolkingsgroep met een mentale beperking de mondgezondheidsproblemen gemeengoed blijken zijn. Daarom is er duidelijke behoefte de mondverzorging en de mondhygiëne gewoonten aan te pakken en te verbeteren.
2. De landen met een hogere prevalentie van tandheelkundige traumata hebben behoefte aan duidelijke preventie programma's voor deze patiënten. Hierbij dienen zeker de ouders en verzorgers betrokken te worden. Vooral onze onderzochte groep, die bestond uit atleten, moet zich bewust zijn van de noodzaak voor het gebruik van mondbeschermers; zeker bij atleten die deelnemen aan een contactsport.
3. Met betrekking tot de tandvleesproblematiek scoorde in meer dan 20 van de 49 deelnemende landen meer dan de helft van de atleten positief op tekenen van gingivitis. Deze aandoening wordt veroorzaakt door een onvoldoende mondhygiëne. In dit onderzoek bleek leeftijd geen bepalende determinant voor de prevalentie van gingivitis. Deze jonge atleten gaven aan hun tanden regelmatig te poetsen; de effectiviteit van dit poetsen werd niet geëvalueerd.
4. Bij jonge Europese atleten met een mentale beperking werd een hoge graad van gingivitis, ontbrekende gebitselementen en onbehandelde cariës vastgesteld. De meerderheid van deze atleten had behoefte aan een dringende tandheelkundige behandeling.
5. Tekenen van gingivitis en onbehandelde tandbederf kunnen niet verklaard worden door leeftijd, geslacht, orale pijn, de al of niet aanwezigheid van tandverzorging

en/of frequentie van tanden poetsen. Dit betekent dat andere factoren (dieet, rookgedrag), samen met de barrières voor de toegang tot mondverzorging, een belangrijke rol zouden kunnen spelen. Beoordeling van deze factoren was niet opgenomen in de screening en werden daarom niet gecontroleerd in de model.

6. Deze thesis geeft weer dat Europese regio's geconfronteerd worden met vergelijkbare orale gezondheidsproblemen. Naast de huidige nationale en de een individuele aanpak lijkt het zinvol dat de regio's binnen Europa een belangrijk rol toebedeeld krijgen in de ontwikkeling van programma's ter bevordering van mondgezondheidspreventie.

7. Uitgebreide mondgezondheidsproblemen werden aangetoond bij atleten met een mentale beperking uit Oost-Europese, meer specifiek e noodzaak van uitgebreide behandeling (dringende en niet dringende tandheelkundige zorg).Dit geeft de uitdaging voor Roemenië, Polen en Slovenië weer om en mondgezondheidsbeleid te ontwikkelen om zodoende aan de behoeften van bevolking met mentale beperking te voldoen.

8. De mondgezondheid in België bleef vrijwel gelijk in een vergelijking 2008-2013 en dit ondanks het feit dat atleten een voorkeursstatuut naar terugbetaling genieten binnen de Belgische ziekteverzekering. Daarenboven vond deze studie geen enkel bewijs van het effect van een éénmalige mondgezondheidsvoorlichting en beveelt het de ontwikkeling van continue voorlichtingsprogramma's rond mondgezondheid aan.

9. Personen met een mentale beperking hebben recht op betere mondgezondheid en daardoor een betere levenskwaliteit.

9.3. Resúmen y conclusiones

Capítulo 1 Los pacientes con discapacidad intelectual presentan mayor riesgo de padecer enfermedades orales debido a las manifestaciones orales propias de su condición y a una higiene oral comprometida a causa sus limitaciones. Por esta razón presentan mayor necesidad de prevención y atención odontológica. Sin

embargo, estos individuos pertenecen a un grupo desatendido de la población en el campo odontológico y sus necesidades de tratamiento no han sido epidemiológicamente monitoreadas en la misma medida que en la población general. En este capítulo se presenta el marco teórico y revisión de literatura relevantes para nuestro estudio, abordando los avances de la Unión Europea en el camino hacia la igualdad de derechos para las personas con discapacidad. Posteriormente, la revisión se enfoca en los siguientes aspectos: las principales características de la salud oral de personas con discapacidad intelectual, las múltiples barreras que pueden afectar el acceso a atención dental y el rol que desempeñan los sistemas de salud. Al final del capítulo se expone el objetivo general de este proyecto, que consiste en alcanzar un mayor nivel de conocimiento y conciencia sobre el estado de salud oral y las necesidades de tratamiento de atletas con discapacidad intelectual en Europa y Eurasia.

Capítulo 2 Este trabajo fue realizado sobre una base de datos de las Olimpiadas Especiales que, a través del programa de Sonrisas Especiales, ofrece una oportunidad única para la colección de datos a gran escala sobre la salud oral de atletas con discapacidad intelectual. El protocolo utilizado para la colección de datos fue desarrollado por los Centros de Control de Enfermedades y Prevención de EEUU y su descripción se presenta en este capítulo.

Capítulo 3 En este capítulo se aborda la evaluación de la prevalencia de trauma dental en los atletas de Olimpiadas Especiales. Los sujetos estudiados participaban en disciplinas deportivas, algunas de ellas de contacto, por lo que se les atribuye un mayor riesgo de trauma, por sobre los factores de riesgo de trauma propios a su condición. Estos factores incluyen principalmente problemas de coordinación, episodios convulsivos, reflejos lentos y cierre labial limitado, además de algunas características dentales. El 13.2% de los 15,941 atletas que participaron en el estudio, pertenecientes a 49 países de Europa y Eurasia, presentaron trauma dental en incisivos maxilares o mandibulares. No se encontraron diferencias significativas entre los distintos grupos etarios, pero sí gran variación en la prevalencia de trauma entre los países, algunos de ellos presentando más de 20% de atletas afectados.

Capítulo 4 En este capítulo se explora la prevalencia de signos de enfermedad gingival y su relación con higiene oral y edad entre los atletas pertenecientes a 49

países de Europa y Eurasia. El 48.64% de los atletas presentaron signos de inflamación gingival en el área vestibular de al menos tres piezas dentarias permanentes del arco mandibular entre canino y canino. En primer lugar, no se encontraron diferencias significativas en la presencia de signos de gingivitis media entre los 3 grupos etarios estudiados. En segundo lugar, el análisis de los hábitos de higiene oral reveló que el 60.38% de los atletas limpiaba su cavidad oral al menos una vez al día, y que los atletas mayores de 26 años cepillaban sus dientes con una frecuencia significativamente menor. Los resultados indicaron que la incidencia de enfermedad periodontal no sólo aumenta en relación al tipo y severidad de la discapacidad del individuo, sino también en relación a sus hábitos de higiene oral. Por lo tanto, los atletas con dificultad de aprendizaje y ejecución de actividades de higiene oral requieren supervisión o asistencia para mantener las encías en un estado saludable.

Capítulo 5 La prevalencia de caries o enfermedad periodontal en jóvenes puede generar con los años muchas complicaciones en su calidad de vida. En este capítulo se presenta la evaluación de las necesidades de tratamiento dental de 503 atletas europeos menores de 21 años. Además, se busca determinar la capacidad predictiva de las variables explicativas para caries no tratada y signos de patología gingival, por medio de análisis de Regresión logística y Modelos Lineales Generalizados Mixtos en Multiniveles. Aunque el 87.7% de los atletas limpiaba su cavidad oral más de una vez por día, se encontró una prevalencia de signos de patología gingival de 38.7%. Un tercio de los atletas presentó caries no tratada y un cuarto de ellos había perdido al menos una pieza dental. Con respecto a los modelos estadísticos, los resultados revelaron que los atletas que no presentan caries no tratada tienen 1.9 veces más chance de tener encías saludables que aquellos que si presentan caries no tratada. Del mismo modo, los atletas que no presentan dolor en su cavidad oral tienen 2.9 más chance de no presentar caries no tratada que aquellos que presentan dolor en su cavidad oral. Sin embargo, la capacidad predictiva de las variables explicativas fue limitada y la mayor parte de la variabilidad es atribuible a la variación individual, más que a la variación de las regiones de proveniencia de los atletas.

Capítulo 6 En este capítulo se exploran las necesidades de salud oral y diferencias de sistemas de salud en Polonia, Rumania y Eslovenia. La necesidad de tratamiento fue clasificada como 'urgente' en el 20% de los atletas Rumanos y Eslovenos y en el 50% de los atletas Polacos. La necesidad de tratamiento en estos países podría ser reflejo de una falta de políticas de salud para personas con discapacidad o de falta de recursos.

Capítulo 7 En este capítulo se aborda el impacto de la educación y recomendaciones de tratamiento impartidas a través del programa Sonrisas Especiales de las Olimpiadas Especiales. La evaluación se realizó en un grupo de 132 atletas que participaron en el programa en Bélgica, en 2012 y 2013. Adicionalmente, se presentan las necesidades de tratamiento de 627 atletas que participaron en las Olimpiadas Especiales Bélgica 2013 para compararlas posteriormente con las obtenidas en 2008. El estudio arrojó preocupantes resultados que revelan una considerable necesidad de tratamiento. Tanto la prevalencia de caries no tratada (27.1%) como la prevalencia de signos de patología gingival (44.3%) muestran un aumento en comparación con 2008. Entre los años 2012 y 2013, el programa de Sonrisas Especiales no generó un impacto significativo en la salud oral de los atletas.

Capítulo 8 Este capítulo incluye la discusión general de los resultados de esta tesis doctoral. En particular, se revisa el estado de salud oral y las necesidades de tratamiento de los atletas, destacando la patología gingival como la más prevalente y la presencia de caries no tratada en la mayoría de los atletas con patología gingival. Por otro lado, se discuten las principales razones que podrían explicar la falta de atención dental y se propone la colaboración entre países como una estrategia de lucha común contra la desigualdad. Por último, se presenta un análisis de la necesidad de prevención de enfermedades orales, las limitaciones de este estudio y la recomendaciones para futuro.

Las conclusiones generales basadas en los resultados de esta tesis doctoral son las siguientes:

1. Los resultados de este estudio muestran que los problemas de salud oral son prevalentes en la población con discapacidad intelectual, por ello hay una necesidad importante de atención dental y mejoras en hábitos de higiene oral.
2. Algunos de los países estudiados presentaron alta prevalencia de trauma dental, en los cuales hay necesidad de programas de prevención de trauma dental para individuos con discapacidad intelectual, sus familiares y/o cuidadores. En especial nuestra población de estudio, que consiste en atletas, debe tomar conciencia de la necesidad del uso de protectores bucales para deportes de contacto.
3. La mitad de los atletas en mas de 20 de los 49 países estudiados presentaron signos de patología gingival, que puede ser influenciada por los hábitos de higiene oral. En este estudio la edad no fue un factor determinante para la prevalencia de patología gingival aun cuando los atletas mas jóvenes si lavaban sus dientes con mas frecuencia. Sin embargo una mayor frecuencia de cepillado no implica un adecuado control de placa dental.
4. Las patologías orales de atletas europeos jóvenes con discapacidad intelectual comprenden alta prevalencia de signos de patología gingival, dientes perdidos, caries no tratada y necesidad de tratamiento urgente.
5. La mayor parte de la variabilidad en la presencia de signos de patología gingival y caries no tratada en atletas jóvenes con discapacidad intelectual no pudo ser explicada por las variables edad, género, dolor oral, caries no tratada, sellantes de fisura o frecuencia de limpieza oral. Esto nos permite concluir que otros factores involucrados (dieta, habito de fumar, etc.) sumados a las barreras de acceso a atención dental podrían jugar un rol mas importante que las variables estudiadas, sin embargo estos factores no fueron controlados en los modelos estadísticos.
6. Esta tesis propone que las Regiones de Europa pueden ser consideradas como foco de políticas de salud relacionadas con la disminución de desigualdad en salud oral.
7. En Polonia Rumania y Eslovenia se encontraron considerables necesidades de atención dental. Como consecuencia, el desafío de estos países esta en desarrollar

y evaluar mecanismos para satisfacer las necesidades de tratamiento de la población con discapacidad intelectual.

8. En Bélgica, las necesidades de salud oral no disminuyeron desde el año 2008 al 2013. Aún cuando los individuos con discapacidad intelectual tienen acceso a un reembolso preferencial por parte del sistema de seguro de salud. Mas aún, no se encontró ninguna evidencia de impacto del programa de Sonrisas Especiales en el estado de salud de atletas, un año después de la intervención. Por esto se destaca la necesidad de programas continuos de promoción de salud oral.

9. Las personas con discapacidad intelectual tienen necesidades derecho a una mejor salud oral y mejor calidad de vida.

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Annex

Screening form

Firstname	Lastname	HAS ID _____
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Date	<input type="radio"/> Male <input type="radio"/> Female	DoB	Age (years) <input type="radio"/> Not sure
Event	Location	<input type="radio"/> Athlete <input type="radio"/> Unified partner	Sport
Delegation	SO Program		
Cell phone number	Number is <input type="radio"/> Athlete's <input type="radio"/> Parent's / Guardian's		
Providing a phone number is optional. It will be used to send a text reminder if any follow up is recommended after screening.			

Screener's name

Dental History

1. Fill out this section for each athlete even if edentulous

How often do you clean your mouth?

- Once or more a day
- 2 to 6 times per week
- Once per week
- Less than once per week
- Not sure

2. Pain inside mouth

- Yes No
- Teeth
- Other

3. Athlete refused/could not screen



Screening

4. Edentulous

- Yes (-> stop here) Exam completed
- No (answer all questions 5 thru 14)

5. Untreated decay

- Yes No
- Anterior(s)
- Premolar(s)
- Molar(s)

6. Filled teeth

- Yes No

7. Missing teeth

- Yes No
- Anterior(s)
- Molar(s)

8. Sealant(s)

- Yes No

9. Injury

- Yes No
- Injury Treated** Yes No

10. Fluorosis

- Yes No

11. Gingival signs

- Yes No

12. Treatment urgency

- Maintenance
- Non-urgent
- Urgent

13. Mouthguard recommended

- Yes No
- Mouthguard delivered

14. Fluoride Varnish recommended

- Yes No
- Fluoride Varnish delivered