Barriers in oral hygiene in children with an autism spectrum disorder of various cultural backgrounds in the Netherlands.

A qualitative study among special dental care providers

Name & student number: Roos Kooijman, 2519106
Study & Specialization: Health Sciences, International Public Health
Placement organization: Autismvriendelijke Tandheelkunde
VU supervisor: Frank Kupper, Dr.
On-site supervisor: Jan Hendrik Elhorst, Drs.
Email address on-site supervisor: jh.elhorst@quicknet.nl

01-09-2016
Acknowledgements

Children with autism are colourful
– they are often very beautiful and,
like the rainbow, they stand out.

Adele Devine

Foremost, I would like to thank all special dental care providers that offered their time to fill out the open-ended questionnaire. Especially, I would like to express my gratitude to the practitioners who participated in the interviews for sharing their personal experiences and their valuable explanations about ASD. Moreover, I wanted to thank the members of boards of the NVvK, VBTGG and NVM for their cooperation in this study.

Secondly, I’d like to sincerely thank Marije de Jong for her guidance in the first part of this internship, and Frank Kupper for his support in the final part of this internship. Furthermore, I’d like to express my appreciation to Erik Vermaire, Henk Algra and Merel van der Ploeg for their expertise and valuable feedback during the writing of this thesis.

Finally, and with special attention, I would like to warmly thank Jan Elhorst that he gave me the opportunity to conduct this study for ‘autism friendly dentistry’ and for his boundless enthusiasm, supervision and expertise.
Abstract

Introduction
Special dental care providers have indicated that oral care in children with an autism spectrum disorder (ASD) can be challenging especially when their oral hygiene is involved. To date, limited research is conducted on the barriers in oral hygiene of children with ASD. Research shows that culture can play a role in the oral hygiene of children. However, research that includes various cultural backgrounds is unavailable. This study aimed to explore the perceived barriers of special dental care providers in oral hygiene of all children with ASD.

Methods
A qualitative study, through open-ended questionnaires and semi-structured interviews, was conducted among special dental care providers in the Netherlands. A total of forty-eight oral health care providers for patients with special needs filled out the questionnaire; 15 pediatric dentists, 14 dentists specialized in dental care for disabled and 19 oral hygienists. Of this total population sample, six practitioners were selected for a semi-structured interview. A framework analysis was used.

Results
The main perceived barriers for practitioners in professional oral hygienic care in children with ASD appeared to be: Communication/Contact, Sensory perception and Cooperation. In teaching home oral care two additional barriers were identified: Add structure and Motor function. Moreover, the knowledge about ASD of the practitioners emerged as overarching barrier within the oral hygiene of the child with ASD. Additionally, the perceived cultural-related barriers in home oral care appeared to be: Nutrition & Sugar intake and Support & attitude. Additionally, Language was found to be a vital barrier in the professional oral care in children with ASD from various cultural backgrounds.

Conclusion
This study provides preliminary insights in the perceived barriers of special dental care providers in oral hygiene of children with ASD. On the basis of this study, it can be suggested that knowledge expansion of the practitioners about ASD can be the basis for potential solutions to these barriers. Further research is needed to look at the interaction between different perceived barriers. Moreover, the children’s and parents’ perceived barriers in oral care should be explored as well. All persons of this “triangle of people” are needed to achieve a proper level of oral hygiene in children. Concerning “culture”, it was found that this entails specific experienced barriers. Future research may explore cultural-related barriers in maintaining an adequate level oral hygiene in children with ASD and focus on culture in order to customize solutions for all children. Overall, it was concluded that the need is evident, but the solution is not simple.
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1. Introduction

1.1 Background

It is widely acknowledged that achieving and maintaining an adequate level of oral care to children with special needs, including an autism spectrum disorder (ASD), can be challenging. ASD includes a range of neurodevelopmental conditions which are characterized by persistent deficits in social interaction, social communication and the presence of restricted, repetitive patterns of behavior, activities and interests during lifespan. Worldwide, it is estimated that approximately 1 percent of the population has ASD. Nonetheless, differences in prevalence occur between regions and ethnic groups. The number of diagnosed individuals living with this condition on a global scale, has rapidly increased in the last decades due to improved research and diagnostics, the notoriety of ASD, as well as the expansion of the diagnostic criteria within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). In the Netherlands, thirty years ago, approximately 10,000 people were diagnosed with ASD. Nowadays this has risen to 190,000 people, which is equivalent to 1.3 in 1000 children.

Multiple studies have indicated that children with ASD have inferior levels of oral hygiene, compared to typically developing children. Hence, these children are at increased risk to develop gingivitis, caries which can lead respectively to periodontitis, pain, inflammation, abcesses and premature tooth loss. Other factors that may increase oral health problems in children with ASD are: xerostomia, reflux and damaging oral habits such as bruxism and pica. To reduce the risk on periodontal and dental diseases, proper oral care, both at home and in the dental office, is necessary to improve oral hygiene and oral health.

Oral hygiene & cultural disparities

Within oral home care, the parents’ perspectives on oral health are of major importance, since they have a pivotal role in the supervision and assistance in tooth brushing of their children. Research have revealed that attitudes and cultural beliefs towards oral hygiene vary between ethnic groups. Specifically, a study of Sundby et al. found that children from various ethnic minority groups receive less help with tooth brushing from their parents compared to indigenous children and that these parents started brushing their children’s teeth at a later age. Additionally, studies have demonstrated that children from various ethnic minority groups have a higher rate of sweet consumption and an increased risk to develop dental caries.
The perspectives, behaviors and habits of parents can be considered especially influential on children with ASD who are often completely dependent on their parents’ decisions in daily living, and on physical assistance in oral care due to difficulties in motor coordination, sensory sensitivities and uncooperative behavior.

**Special Care Dentistry**
For professional oral care, a considerable part of the total population of children with ASD in the Netherlands visit special dental care providers. Special Care Dentistry is concerned with the provision of oral care for individuals living with a disability or impairment, including children with ASD, and comprises a range of specializations, among others Dentists specialized in dental care for disabled (DD), Pediatric Dentists (PD) and they are supported by oral hygienists (OH). These practitioners are united by their specialized association: the PDs in the Dutch Society for Pediatric Dentistry (NVvK), the DDs in the Dutch Association of Special Care in Dentistry (VBTGG) and the OHs in the Dutch Society of Dental Hygienists (NVM).

**1.1.1 Main research questions**
The special dental care providers, all members of the VBTGG, NVvK or NVM, have indicated that they experience difficulties in the provision of both oral professional- and home care in children with ASD, which affects the oral hygiene of these patients. Problems in oral health, including oral hygiene, have an effect on the well-being and overall health, thus proper oral care is needed.

In 2013, the organization ‘autism friendly dentistry’, was set up by various members of the NVvK, VBTGG and NVM, to improve oral care for people with ASD. The highest priority of this organization is to enhance oral hygiene in children with ASD, as they have the greatest gains due to their young age. ‘Autism friendly dentistry’ wants to achieve more consistency in oral care for this patient group through practice and/or evidence-based research. Yet, to date, limited research is conducted on the main barriers in oral hygiene of children with ASD. Concretely, no prior studies have been executed in the Netherlands among differentiated special dental care providers. To improve oral care for children with ASD, it is important to address the main perceived problems of special dental care providers in the oral hygiene of the growing number of diagnosed children. Therefore, the objective of this study is to provide an overview of the problems in oral hygiene of children with ASD in the Netherlands, by exploring the main perceived barriers of special dental care providers in oral hygiene of all children with ASD. The following first main research question was formulated:

1. **What are the main perceived barriers to special dental care provision in oral hygiene to patients, aged 0-18 years, with an autism spectrum disorder in the Netherlands?**
Moreover, there is a lack of research which takes cultural backgrounds of children with ASD into account, as current studies mainly focusing on indigenous children with ASD\textsuperscript{5,7}. However, cultural influences may affect the oral hygiene of children\textsuperscript{25,27}. To enhance the personalized, oral care for all children with ASD and with the increasing influx of immigrants and cultures, it is important to explore the cultural-related differences in oral hygiene of children with ASD from various cultural backgrounds. Therefore, the second main research question is:

2. What are the main perceived cultural-related barriers to special dental care provision in oral hygiene to patients, aged 0-18 years, from various cultural backgrounds with an autism spectrum disorder in the Netherlands?

\subsection*{1.2 Contextual background}
As mentioned before, proper oral care to improve oral hygiene of children with ASD, can be challenging. To get a better insight into the particularities these practitioners may encounter, several factors are important. Therefore first, a detailed explanation is given of ASD and oral hygiene. Thereafter, the influence of overstimulation of sensory input, stress and anxiety related to the ASD will be described in the provision of oral care.

**Autism spectrum disorder (ASD)**
ASD is characterized by persistent deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests and activities during lifespan\textsuperscript{3}. It is a multi-factoral condition, with a hereditary explicable proportion of approximately 60 percent, though the environment also plays a role\textsuperscript{40,41}. In general, boys are 4 to 5 times more likely to be diagnosed with the condition than girls\textsuperscript{41,42}. Seventy percent of the individuals with ASD, are diagnosed with an comorbid disorder\textsuperscript{43,44}. Approximately 40-50 percent of the children with ASD have an intellectual disability\textsuperscript{45}. Formerly, ASD was an umbrella term which included a group of five pervasive developmental disorders: Autistic Disorder, Asperger Disorder, Rett syndrome, Childhood Disintegrative Disorder (CDD) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)\textsuperscript{3,46,47}. Nowadays, in the DSM-5, a ranking is made in the severity of ASD with the classification; level 1 ‘Requiring support’, level 2, ‘Requiring substantial support’ and level 3 ‘Requiring very substantial support’ (Appendix A) \textsuperscript{3}.

In people with ASD, the Central Coherence (CC), the Theory of Mind (ToM) and the Executive Function (EF) function differently compared to typically developing people. Through a weak CC, people with ASD have an inability to bring various pieces of information together to make a
meaningful whole. Deficits in ToM make that people with ASD have an inability to recognize and understand expectations, thoughts and feelings of others, as well to have empathy. Furthermore, deficits in EF enables people with ASD to plan, to be mentally flexible and to make adjustments along the way. The strict adhering to routines and the difficulty to cope with minor changes in daily life may lead to difficult behavior and diminished cooperation. Within oral care, a reduced cooperation increases the risk for the development of oral health problems, including a poor oral hygiene.

**Oral hygiene**
Oral hygiene refers to “the practice of keeping the mouth, teeth, and gums clean and healthy to prevent disease.” Tooth brushing is the basis for oral hygiene. The regular basic advice in oral hygiene for parents in typically developing children in the Netherlands, is to brush their children’s teeth until the age of ten, preferable in the evening. The aim is to brush the teeth twice a day for two minutes with a fluoride toothpaste, independent of age. Furthermore, it is advised to visit a dentist or oral hygienist twice a year. If this basic advice has insufficient results, additional measures are recommended, such as the usage of interdental brushes, toothpicks or dental floss once a day.

For individuals with ASD, the assistance in tooth brushing and dental visits will often continue after childhood, which require much patience and social support of parents. Additionally, proper oral care to enhance the oral hygiene of these children, is often complicated by various factors related to ASD which are; overstimulation of sensory input, stress and anxiety.

**Overstimulation of sensory input**
The neurological thresholds of the neuronal system responding to sensory input are often extremely high or low in children with ASD, which makes them hypo- or hypersensitive to sounds, touch, smell, sight, balance & movement, body awareness (proprioception) and taste. However, these factors often are prominently present in oral care and therefore can impede cooperation. An overstimulation from sensory input or stimuli may lead to specific behaviors to deduce oneself from the incoming stimuli in order to get a grip on the situation. This specific behavior is related to the severity of the ASD; a child with severe ASD can show self-injurious behavior such as hitting, banging or biting whereas a child with mild ASD may withdraw themself from the situation with repetitive behaviors, such as hand flapping, twirling or rocking. Overstimulation and incentives often cause stress in people with ASD.

**Stress**
Disrupted daily routines, such as dental visits, may lead to stress and chaos in children with ASD. Research has shown that in general people with ASD experience more stress and have difficulties to cope with stressors compared to people without ASD. Stress in children with ASD can be
aggravated due to their impaired social interaction and diminished communication, which as well lead to reduced cooperation during oral care\textsuperscript{52,63}. Moreover, stress is intimately intertwined with anxiety\textsuperscript{63}.

**Anxiety**

As mentioned above, seventy percent of the individuals with ASD are diagnosed with an comorbid disorder, which makes them uncooperative even in oral care basics, such as dental control or tooth brushing\textsuperscript{12,43,44,64}. In children with ASD, the most prevalent comorbid disorder are anxiety disorders, with approximately 40 percent of these children having at least one anxiety disorder\textsuperscript{44,65}. Though, it has to be noted that not all anxiety is part of the ASD, children could also have clinical anxiety which is independent of ASD\textsuperscript{66,67}. Anxiety and fear in dental care, is often related to the patients’ expectation of upcoming pain, as well as uncertainty and ignorance about oral procedures\textsuperscript{68}. Young children are more prone to dental anxiety, due to scarce coping skills to stressors and limited capabilities to understand the situation\textsuperscript{69}. An anxious child with ASD can display his or her fear in different behavioral expressions such as emotional outbursts, retreat, self-injurious behavior or attempts to escape from the dental practice\textsuperscript{46,70}.

**1.3 Theoretical background**

To understand how different factors influence the oral hygiene of children with ASD, the biopsychosocial model of health was used as a theoretical framework. Traditionally in dentistry, the biomedical model of health is used more prominently\textsuperscript{71}. Within the paradigm of the biomedical model, health and illness are strictly seen as a biological phenomena\textsuperscript{71}. However, psychological and social factors may also play an important role in health\textsuperscript{72}. The biopsychosocial model of health, introduced by the psychiatrist Engel, is a holistic approach towards the patient and takes the missing dimensions of the biomedical model into account\textsuperscript{72,73}. Despite the limited use of this model in dental research, it is especially appropriate for dental practices since most problems in oral health can be controlled through preventive measures\textsuperscript{74}. Moreover, during past years gradually there has been a shift towards a behavioral approach within special care dentistry, while in earlier days pharmacological support was frequently used to treat people with ASD, which as well makes this framework suitable\textsuperscript{75}. Additionally, the international learning approach within the special care dentistry curriculum has turned towards a holistic, patient-centered care and is no longer solely focused on the medical condition\textsuperscript{76,77}. 
1.3.1 Biopsychosocial model of Health

The biopsychosocial model consists of 3 components; the biological, psychological and social component, which are all taken into account in health or disease. The biological component deals with the anatomical, structural and molecular components of the disease and the effects on the patients’ (biological) functioning, which includes among others factors as gender, genetic vulnerability, age, medication effects, disability, physical illness and immune function\(^{78,79}\). The psychological component include psychodynamic factors, like personality, motivation, learning, behavior, coping skills and emotions as reaction to the illness\(^{78,79}\). The social component examines the cultural, familial and environmental influences on the expression of the illness, which are factors as education, family background, social support, socio-economic status and cultural traditions\(^{78,79}\).

Since this study was trying to explore the perceived barriers of special dental care providers in oral hygiene of children with ASD, as well as the perceived cultural-related barriers in oral hygiene of children from various cultural background, this study was focused on specific themes or concepts within the biopsychosocial model. In the biological component these concepts were; age and intellectual disability. The psychological factors were; learning and behavior. Moreover, the social themes were culture, social support and environment. To answer both research questions, these concepts were viewed as most relevant by the researcher. However, the theoretical framework was used by the researcher as guiding principle, to focus the research. Other important themes could as well emerge from analysis of the data. Figure 1 shows the biopsychosocial model adapted to this study. After Figure 1 is presented, the concepts that guide this study were clarified.

![Figure 1: Conceptual framework of oral hygiene, based on the biopsychosocial model of health\(^{79}\).](image-url)
**Biological component**

**Age**
Age is defined as “one of the stages of life”\(^8^0\). Moreover, it is the time within life in which certain personal capacities, rest or qualities come forward\(^7^9\). A younger age is associated with less cooperative behavior during oral screening or treatment, which hinders proper oral care\(^6^9\). Within this study, age refers to the difficulties in oral treatment of special dental care providers between age-groups in children with ASD.

**Intellectual disability**
An intellectual disability is “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior”\(^8^1\). Hereby, adaptive behavior refers to the collection of practical, social and conceptual skills that are performed in people’s daily live\(^8^1\). In addition, intellectual functioning refers to the general mental capacity (intelligence), which generally is measured with the intelligence quotient (IQ)\(^8^1\). An IQ test score of 70 to 75 (or lower than 70), indicates that the person has an intellectual disability. This boundary for an intellectual disability will also be used within this study\(^8^1,^8^2\). In this study intellectual disability refers to the influence of an intellectual disability on oral home- and professional care in children with ASD.

**Psychological component**

**Learning**
Learning is defined as “the activity or process of gaining knowledge or skill by studying, practicing, being taught, or experiencing something”\(^8^3\). It is a modification of a behavioral tendency by experience, as exposure to conditioning\(^8^3\). Within this study, learning entails the skill in tooth brushing in children with ASD after practice for oral home care and the experience to undergo oral hygienic treatment (professional oral care).

**Behavior**
Behavior is “the means and actions by which organisms adjust to their environment”\(^8^4\). Thus, the action or reaction in response to internal or external stimuli\(^8^5\). It is the way people act or conduct themselves in certain situations, especially towards others. In this study, behavior implies the means and actions of children with ASD to adjust to the environment, during professional oral care.
Social component

Culture
A culture is a system of shared ideas, rules, meanings and concepts that form the basis and are expressed in the way that people live\(^8\). Culture is dynamic and can be defined as “a set of attitudes, values, beliefs and goals, that characterizes an institution, a group or an organization” \(^7\).

Globally, there are multiple different cultures. When a person migrates from one country or area to another, cultural affiliation is important, i.e. the extent in which this person hold on to his or her cultural traditions and group identity or connects and adopts the new culture\(^8\). In this study, merely the various foreign cultural influences in the oral hygiene of children with ASD will be explored.

Social support
Social support is the assistance or help what people receive from others\(^9\). Social support is generally classified in four categories: emotional, instrumental support, appraisal and informational support\(^10\). Within this study, the focus will be solely on the instrumental social support, which comprises the actual assistance and supervision of parents (or supervisors) in professional oral care as well as oral home care, such as tooth brushing\(^10\).

Environment
Environment can be defined as “anything immediately surrounding an object and exerting a direct influence on it” \(^1\). Therefore, in this study environment refers to the surrounding that affect the children with ASD during professional care, such as the influences from within the dental practice or outside the dental practice, such as home or school.

1.3.2 Sub questions
Several sub questions were derived from the biopsychosocial approach of this study. To answer the first main question (“What are the main perceived barriers to special dental care provision in oral hygiene to patients, aged 0-18 years, with an autism spectrum disorder in the Netherlands?”), insights into the barriers of biological, psychological, and social nature was needed. Accordingly, three sub questions were formulated:

Research question 1: Sub questions
- What are the perceived barriers of special dental care providers in the oral hygiene of patients with ASD within the psychological component?
- What are the perceived barriers of special dental care providers in the oral hygiene of patients with ASD within the biological component?
- What are the perceived barriers of special dental care providers in the oral hygiene of patients with ASD within the social component?

Furthermore, to answer the second main question (”What are the main perceived cultural-related barriers to special dental care provision in oral hygiene to patients, aged 0-18 years, from various cultural backgrounds with an autism spectrum disorder in the Netherlands?”), insights into differences in home- and professional oral care were needed in children with ASD from a non-Dutch cultural background. Correspondingly, two sub questions were formulated:

**Research question 2: Sub questions**

- What are the perceived cultural-related barriers of special dental care providers in home oral care in children with ASD from various cultural backgrounds?
- What are the perceived cultural-related barriers of special dental care providers in professional oral care in children with ASD from various cultural backgrounds?

## 2. Methodology

### 2.1 Study design

This research is an exploratory, qualitative study to identify the perceived barriers to special dental care provision in oral hygiene in children with ASD from various cultural backgrounds in the Netherlands. The qualitative design enabled the practitioners to express the personal obstacles in their own words. Open-ended questionnaires about perceived barriers were filled in by the respondents. After analysis of the open-ended questionnaires, semi-structured interviews were conducted.

### 2.2 Data Collection

#### 2.2.1 Open-ended questionnaires

The data was collected by an open-ended questionnaire (Appendix B). This questionnaire was developed in February 2016 by the intern in consensus with her supervisor. In the open-ended questionnaires, the explained concepts from the biopsychosocial model of health were explored and operationalized. Several questions sought explanation about experienced problems in tooth brushing
and during oral hygienic treatment in children with ASD. Thereafter several questions were asked about experienced cultural-related barriers in oral hygiene of children with ASD from various cultural backgrounds, such as perceived differences in sugar intake and tooth brushing. Prior to the distribution of the questionnaire, a pilot study was conducted with a small group of practitioners. To obtain this in-depth data from a large amount of participants, the questionnaires were made in SurveyMonkey. The link to fill out the questionnaire was sent forward via email end March 2016 by the boards of the associations (NVvK, VBTGG and NVM), in order to establish anonymity of their members. Two weeks after the initial request, a reminder was sent by email to fill out the questionnaire.

Population & Recruitment procedure
In this study, 48 special dental care providers filled out the open-ended questionnaires completely; respectively PD (n=15), DD (n=14) and OH (n=19). A call for participation in the study (Appendix C), was sent forward by the associations in March 2016 to their members. The participants have been derived from purposive sampling; the population was specifically targeted at special dental care providers. Since this study approached all 212 special dental care providers in the Netherlands, a total population sample was used. All participants who voluntarily filled out the questionnaire were special dental care providers and member of the department of their specialization (NVvK, VBTGG or NVM). Furthermore, practitioners were currently working in a dental practice in the Netherlands or were retired within the last five years. Moreover, participants required moderate Dutch language skills, to read and answer the questionnaire. If these requirements were absent, the participant was excluded from this study.

2.2.2 Semi-structured interviews
Additionally, semi-structured interviews were conducted. The interviews were held end April and May 2016 within the dental practice, at the participant’s home or by telephone. The interviews were used as member-check to verify findings which emerged from the open-ended questionnaires. An interview script was used with specific themes to cover (Appendix D). By using interviews, the researcher gained a more in-depth understanding of the participants’ experiences, because the practitioner could elaborate face-to-face on the oral hygienic barriers within this patient group. At the start of each interview, participants signed an informed consent form (Appendix E). The practitioner who was interviewed by telephone gave verbal consent. Each interview was conducted in Dutch and lasted 55-75 minutes. The interviews were audio recorded in order to transcribe them verbatim. All participants received a box of chocolates from the researcher to thank them for their cooperation.
Population & Recruitment procedure

The semi-structured interviews were held with 6 special dental care providers; respectively three Oral Hygienists, two Pediatric Dentists and one Dentist specialized in dental care for disabled. These participants were recruited by convenience sampling, since the open-ended questionnaires were filled in anonymously. As the researcher and one supervisor used to work within the field of Special Care Dentistry, this network made it possible to recruit participants. All practitioners included in the interviews were member of the department of their specialization (NVvK, VBTGG or NVM). In advance of the interview, the participants filled out the questionnaire. Additionally, the special dental care providers were currently working in a dental practice in the Netherlands. All participants required moderate Dutch language skills, to answer the questions within the interviews. If these requirements were absent, the participant was excluded from this study.

2.3 Data Analysis

The open-ended questionnaires and semi-structured interviews were analyzed by encoding these collected data. A framework analysis was used to analyze the data. A framework analysis is a more deductive way of analyzing and is described as “a content analysis, which includes classifying and summarizing the data within a thematic framework.” The concepts from the biopsychosocial model (Figure 1) were used as guiding principles.

The first step in the framework analysis was to become familiar with the large quantity of raw data, obtained by the questionnaires and interviews. Therefore, recordings were listened carefully and the answers and transcripts were read and reread. Secondly, a thematic analysis was conducted, to develop a code scheme (Appendix F) from the first couple of collected data: the concepts from the theoretical framework became the labels for the codes. Although the themes were set a priori and gave direction within the analysis (deductive), the researcher had an open mind to other emerging themes (inductive). Thirdly, indexing took place, which is the process of applying the codes in a systematic way to the whole data set. In the fourth step, named charting, a comparison was made between the cases. Hereby, the data was rearranged by the thematic content of the experienced barriers of the practitioners. The charts contained the summary of the data by case and were rearranged according to the themes, therefore the researcher was able to explore findings under themes. The last step within the framework analysis was mapping and interpretation, which explored the relationships between encodings and themes within the charts.

The audio-recordings of the semi-structured interviews were transcribed by one researcher. Moreover, the questionnaires and interviews were encoded by one researcher. Though, encodings
and findings were discussed by two researchers. The use of the qualitative software program MAXQDA was helpful to manage and analyze the data.

### 2.4 Quality criteria

Several measures were taken for the credibility, dependability, confirmability and transferability of this study, which are legitimate validity criteria for qualitative research. The measures will be discussed below.

For the credibility within this study a range of steps and actions were taken. First, prior to the distribution of the open-ended questionnaire, a pilot study was conducted. Moreover, by using open-ended questionnaires and semi-structured interviews, methodological triangulation took place. Triangulation compensates the individual shortcomings of each used method. Open-ended questionnaire gave the respondents the opportunity to write about their personal experiences without limitations or influences from the researcher. The interviews gave an in-depth conversation and understanding around this topic. Furthermore, the semi-structured interviews were used as member-check, to verify findings. By using a total population sample there was no bias from the researcher to select participants. Additionally, the researcher had regular meetings and discussions with two supervisors to reflect on findings, which limited bias from the researcher, called investigator triangulation. Lastly, the findings were compared with scientific literature on barriers in oral hygiene in individuals with ASD.

For the dependability of this study, the research design and steps in data gathering were described in detail to allow the study to be repeated. Furthermore, the data was analyzed iteratively. Citations and quotes to support findings were selected and translated from Dutch to English and precisely edited to make them more readable without loss of meaning. Moreover, audio recordings were taken of the interviews and verbatim transcripts were made.

The optimize confirmability of this study, the research process and findings were discussed with two supervisors. Additionally, literature was searched for conflicting findings. Furthermore, the researcher described possible limitations of the study.

The findings are transferable to special dental care providers in other Western European countries with a comparative multi-cultural society as the Netherlands. Since these specialized practitioners also treat children with ASD in a similar setting and comparable context, they probably have to deal with similar experienced barriers in oral hygiene in patients with ASD.
2.5 Ethical considerations
This study was found non-WMO complicit by the Internship-coordinator and needed no further medical-ethical approval. The researcher adhered to the guidelines of good clinical practice\textsuperscript{115}. All documents were stored carefully and were (and will) not be distributed to third parties\textsuperscript{115}. The questionnaires were filled in anonymous by the participants, because the associations wanted to protect the personal data of their members. Moreover, informed consent was obtained from participants prior to the interview\textsuperscript{115}. The names of the participants or dental practices in the semi-structured interviews were not used in this study, therefore anonymity and privacy of all participants was guaranteed.

3. Results
As mentioned above, in total 48 special dental care providers filled out the open-ended questionnaire. Additionally, six practitioners were interviewed; three Oral Hygienists (OH), two Pediatric Dentists (PD) and one Dentist specialized in dental care of disabled (DD), in the age of 20-51\textsuperscript{*}. The interviewees worked in various dental practices (Table 1).

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Profession</th>
<th>Age (Years)</th>
<th>Primary workplace</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>OH</td>
<td>20 - 35</td>
<td>Institution for people with intellectual disabilities</td>
</tr>
<tr>
<td>R2</td>
<td>OH</td>
<td>36 - 51</td>
<td>Institution for people with intellectual disabilities</td>
</tr>
<tr>
<td>R3</td>
<td>PD</td>
<td>36 - 51</td>
<td>General practice or pediatric referral practice</td>
</tr>
<tr>
<td>R4</td>
<td>PD</td>
<td>51 \textsuperscript{*}</td>
<td>General practice or pediatric referral practice</td>
</tr>
<tr>
<td>R5</td>
<td>OH</td>
<td>20 - 35</td>
<td>Special Dental Care Centre</td>
</tr>
<tr>
<td>R6</td>
<td>DD</td>
<td>51 \textsuperscript{*}</td>
<td>Special Dental Care Centre</td>
</tr>
</tbody>
</table>

The main perceived barriers to special dental care provision will be discussed in this section. From the encodings, six principal barriers emerged. These appeared to be: Communication/Contact,
Sensory perception, Cooperation, Add structure, Motor function and Oral care-providing factors. Moreover, the main perceived cultural-related barriers were found to be: Nutrition & Sugar intake, Support & Attitude and Language.

First, Table 2 is showed to visualize the main barriers and the aspects which play a part, in order to answer main research question 1. Subsequently, we will elucidate on these barriers. Thereafter, Table 3 is showed to provide insights in the perceived cultural-related barriers to special dental care provision in children with ASD from various cultural backgrounds (main research question 2). We will conclude this section with an elaboration on these cultural-related barriers.

### 3.1 Main perceived barriers in oral hygiene

#### Table 2 Main perceived barriers to special dental care provision in oral hygiene of children with ASD

<table>
<thead>
<tr>
<th>Main perceived barriers</th>
<th>Biological</th>
<th>Psychological</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication/ Contact</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Sensory perception</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Cooperation</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Add structure</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Motor function</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Oral care-providing factors</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

#### 3.1.1. Communication/Contact

Both within the instruction of oral home care and the professional oral care, many special dental care providers indicated that they experience difficulties in communication, as well to make, maintain or restore contact with the child with ASD. These perceived issues in communication appeared to have psychological, biological and social aspects. Children with ASD often have a deviant perception and connect and communicate in a different way than the practitioners which makes the psychological learning process in oral care challenging. One respondent explained:
**R4: The bottleneck for me is that you don’t get the usual feedback on direct contact. So you try to make contact and you try to get response so that you can continue to the next initiative, but in people with ASD it’s often the case that you will not get the expected response and therefore you get lost in the moment. And not only you are lost as practitioner, but also the patient doesn’t understand you and that’s a big challenge.**

All respondents in the interviews emphasized the importance of communication with the patient in order to provide clarity on the oral procedures and to minimize ambiguities. Several practitioners indicated that communication can influence the behavior of the child. If oral procedures are explained in an unclear way, this will impede oral care. One respondent explained:

**R1: You often see when it’s not clear what will happen, that someone who doesn’t get all the pieces together will express himself with repetitive behavior or defensive behavior, because he is anxious since he doesn’t understand what will come**

Moreover, biological aspects such as a dual diagnosis of both an intellectual disability and ASD, makes the optimization of oral hygiene more complex for the practitioners. They experienced a greater challenge to communicate and make contact with these children, because in many cases the verbal communication of the child is limited or absent and their level of understanding is lower. Additionally, the communication and understanding of young children, aged 0-6 years, is sometimes also experienced as difficult.

Social factors appeared to be important in the communication with the child. Noises, lights, movement or other stimuli from the environment can easily distract children from a conversation or other forms of contact due to the child’s sensory sensitivity. Additionally, parents or caregivers can sometimes be a disturbing factor since these children have a great tendency towards familiar persons, which hampers the direct contact and communication of the practitioner with the child.

### 3.1.2. Sensory perception

The child’s sensitivity to stimuli is as another main barrier for the practitioners. Several respondents noted that children with ASD can be as susceptible that it hinders the instruction and provision of oral home care, for example when a child can only tolerate one brand of toothpaste due to their sensitivity to taste. Moreover, sensory perception can impede professional oral care; if a child has to
process too many or to strong stimuli, this might lead to overstimulation and can result in non cooperative reactions. One respondent tried to explain the influence of sensory processing within professional oral care:

R1: [...] actually it always involves hyper- or under sensitivity and I think that is one of the key issues that makes it difficult to treat [...]. In particular, sensitivity to certain touches, which are already of course intense in the mouth area, and flavors. But also for example the vestibular system when the dental chair moves backwards can be a problem or things you actually as ordinary person without ASD would not think about, which simply does pose a problem

Since communication with an intellectual disabled child and ASD is experienced as more complex, this factor makes it harder for practitioners to discover specific disturbing stimuli which complicates oral care within these children. Additionally, age also plays a role within sensory perception, as young children often have experienced fewer sensations than older children. Stimulus sensitivity might decrease over time, because the child is more often exposed to incentives and have learned important coping skills through life.

Although sensory perception by itself is a biological aspect which has an influence on the psychological learning process and behavior of the child, social factors are intertwined in this perceived barrier, i.e. all stimuli in sensory processing come from the environment. Within the dental setting, the multiple stimuli make that the senses of people with ASD are being exposed to numerous sudden and unusual incentives, such as the vibrations of dental equipment or talking of the parents or caregivers, which the child all has to process.

3.1.3. Cooperation

The treatability of children with ASD appeared to be also challenging for the special dental care providers. Some children show defensive behavior or resistance in the oral hygienic treatment. Additionally, children with ASD are often inpatient or have diminished attention, which hinders the provision of oral care. Due to the (psychological) uncooperative behaviors of the children, practitioners cannot fulfill oral treatment or instructions in the way they planned and are not able to clean all teeth, which affects oral hygiene. However, the majority of respondents in the interviews does not blame the child for uncooperative behavior, but sees it as the practitioners responsibility to diminish inconveniences or ambiguities which might cause these ‘undesired’ behaviors. This, because
difficulties in cooperation are often a result of the child’s sensory sensitivity or the incomprehension of the situation according to the practitioners. Behavior that hinders treatment is often a reaction on situations that are unbearable, unpredictable, unfamiliar or unclear for the child:

*R4: Someone with ASD doesn’t understand that you want to take care of his mouth and that it’s a good thing that you scratch with a scaler, with a sound-producing, rotating machinery that develops vibrations and sounds, which perhaps by someone with ASD is experienced much stronger and more exciting than average people. This person sees it as a burden not as a possible benefit. So it scares them and they find it unpleasant, therefore they will repel*

Moreover, biological aspects as well have an influence on the treatability of the child; the cooperation is often experienced less in a child with ASD and an intellectual disability. These children show more often resistant behavior, because they want to protect themselves in this unclear and unfamiliar situation, which is also the case in young children. Older children already have learned important skills through prior visits to dental care providers which sometimes facilitates oral care.

Social aspects, such as support, motivation and attitude of parents or caregivers during oral hygienic treatment also have an impact on the cooperation of the child according to the practitioners. In general, proper guidance leads to improved cooperation. Furthermore, environmental factors, for example the impressions and stimuli that the child has to process during the day might from immediate surroundings, influence the collaboration of the patient in oral care. One respondent explained:

*R3: [...] it’s the sum of things. It’s the sum of: what happened at school, what happened at home, what happens here, what happened in the waiting room, which makes ‘how well they can actually handle it today’*

### 3.1.4. Add structure

Within the instruction of home oral care, the structuring of tooth brushing appeared to be a bottleneck for practitioners as well in some cases. Difficulties were experienced to get tooth brushing within the child’s daily routine, as well to teach the child structure within the actual tooth brushing activity. Children with ASD often hold on to their own daily rhythm and routines, which can hamper any necessary changes and structures in home oral care:
R2: [...] if the children brush their teeth on their own, they often brush one side the whole time and they might skip the rest of the mouth. Also, they sometimes brush ridiculously hard until they almost end within the root canal [...]  

Additionally, children with ASD often cannot oversee the whole activity. Therefore, every action in tooth brushing need to be explained and divided in steps, otherwise the child is lost and does not know what to do next. The children often do not have the ability to be flexible and anticipate on unknown situations. Thus, social aspects play an important role within the psychological learning process: parents, caregivers and oral care providers are needed to provide clarity in tooth brushing to improve oral hygiene. One respondent shared an experience (Box 1):

**Box 1: Add structure in tooth brushing**

R1: Recently, I made a drawing for a patient with all the teeth and molars on it. Together we added darts to get it clear which sequence to maintain for not skipping any teeth in tooth brushing, because that went wrong. I drew all teeth and molars until the sevens. However, this was a patient with wisdom teeth. When he came back the next time everything was spotless! That’s the beauty of autism, if you explain something and it’s clear and they really understand it, then they will do it often extraordinary well. But in this case, the wisdom teeth were still completely covered with plaque! And I thought: ‘How is that possible?’ [...] So, together we looked at the drawing to find the answer. I showed the wisdom teeth in the mirror to him and he said: ‘Yes, but these were not on the drawing!’ Therefore, we drew two extra circles which represented the wisdom molars and the next time it was sparkling clean!

Moreover, other social aspects such as changes in environment or social support, *i.e.* when the teeth are brushed in different (dental) rooms or through different caregivers, might impedes the structuring of tooth brushing. This, because the child cannot relate one specific room or a specific person to tooth brushing, which leads to confusion and uncooperative behavior.

An aggravating factor for the practitioners appeared to add structure to the tooth brushing of children with an intellectual disability and ASD or in young children, due to their cognitive function. Moreover, within institutionalized children, assistance and support in tooth brushing of caregivers varies widely, which makes it more difficult to get tooth brushing in the daily routine and to execute
it structured by every caregiver. Thus, biological, psychological and social factors all play a part within this perceived barrier.

3.1.5. Motor function

The limited motor coordination of the child appeared to be another perceived obstacle for home oral care. Several dental care providers indicated that occasionally the children do not have the motor skills to brush their teeth properly. Due to the reduced motor function, the children are not able to clean certain parts of the dentition, especially the lingual and palatal side, which ultimately leads to problems in oral hygiene, due to plaque accumulation. However, biological factors appeared to play an important part in motor function within the psychological learning process. Several respondents emphasized that some children have excellent fine motor skills, which are often children with normal intelligence or beyond:

R2: Well the fine motor skills, is of course the last part in the development of the motor coordination to execute it properly. However, there are also very intelligent autistic people. A number of my clients are familiar with Asperger’s Syndrome and in general they have a very good oral care, so motorial they can handle it

Therefore, the perceived difficulties with the child’s motor function are more profound in children with ASD who are intellectually disabled, because their fine motor skills are often not fully developed. Moreover, the fine motor skills in young children are also still inadequate for tooth brushing.

3.1.6. Oral care-providing factors

The final perceived barrier in oral hygiene of children with ASD was found to be not a patient-related factor, but derived from the practitioners themselves in the social domain. Special dental care providers experience difficulties in the provision of oral care to children with ASD due to their own time limitations and level of knowledge about ASD. Sufficient time to treat children with ASD is considered essential, however sometimes absent. Insufficient time during an appointment has an effect on the psychological aspects in oral hygiene of the child; when instructions or treatment are executed hasty and there is no time for habituation, the cooperation of the child will diminish.
Additionally, knowledge about ASD in the oral sector is critical in the oral hygiene of the children, nevertheless this knowledge could be improved. Occasionally, general practitioners have too limited knowledge about ASD. This could lead to a late referral to specialized dental care providers and may have (harmful) consequences for treatment during lifespan. However, to provide quality customized care to these children, practitioners indicated that their own knowledge about ASD and its specifics are also sometimes substandard to create solutions for the perceived patient-related barriers:

R1: *If you have the knowledge and you take the time for it, all other things are really just preconditions. You know, within our specialist profession, there is always the spirit to do it right, therefore many things are already sufficient. But if you also can tackle those big things you can make a big step forward. And that’s ultimately in the benefit of the child.*

Knowledge of the practitioner was viewed as the basis from which can be built further to exert influence on the psychological aspects of the perceived barriers.

### 3.2 Main perceived cultural-related barriers in oral hygiene

Of the 48 respondents in total, 39 have indicated that they treat children with ASD from another cultural background than solely Dutch. The backgrounds of these children were very diverse, but the most frequently named were the Moroccan, Turkish, Surinamese and Syrian culture, however also Asiatic, African and Eastern-European cultures were mentioned. The large majority of these practitioners declared that they experience cultural-related influences which sometimes have adverse effects on the child’s oral hygiene. Table 3 shows the perceived cultural-related barriers which is located in the social component of the theoretical framework.

Table 3 Main perceived cultural-related barriers to special dental care provision in oral hygiene of children with ASD from a non-Dutch cultural background
3.2.1. Nutrition & Sugar intake

A perceived barrier in home oral care in children with ASD from a non-Dutch cultural background, is their often differing eating habits. Practitioners mentioned that these children consume more frequently snacks as well as high sugar food and that they more often have cavities compared to their Dutch peers. According to the respondents, parents sometimes have a tendency to spoil their children, especially a child with ASD because he or she is ‘different’ and ‘special’. Frequent food intake (sweets, drinks or food) during the day increases the risk to develop caries. However, in various cultures, food is viewed as a sign of hospitality and is often accessible for children:

*R5: I come from a North-African country myself and within my family it was really ‘one sweet after dinner’. However, within our culture food shows wealth and there is more sugar intake [...] throughout the entire day tea with sugar and cookies are consumed and there is no rhythm in food. If the child has hungry, he just gets food and nobody says: ‘wait, because we’ll soon eat supper’. That also has to do with parenting I think, but also culture plays a big role*

However, respondents in the interviews emphasized that this cultural-related barrier is only experienced in community-dwelling children and *not* in children with a non-Dutch cultural background who have moved from their parental home and reside in an institution. Within institutions, rules in daily rhythm and nutrition are being enforced, which diminish the perceived disparities in oral hygiene between children from Dutch and non-Dutch cultural backgrounds:

*R1: [...] On the group homes within the institution things are drastically changing, there is compliance to the rules which are imposed by the caregivers within the home [...]. Especially in children who cannot make all decisions by themselves, this often have a positive effect for example in the dental caries activity. When sugar usage is restricted, you often see that a big problem is eliminated and also that the pampering of ‘oh, that child has a disability and is special, therefore he gets a little bit of extra sugar and extra kindness and love’, changes on*
such group homes, because all the children in the house are special, so no distinctions are made. You see that this can make a big change for the children.

3.2.2. Support & Attitude

Another barrier from the majority of the practitioners in home oral care is that parents from a non-Dutch cultural background occasionally have an otherwise motivated attitude towards oral care. The respondents indicated that parents sometimes appoint less priority to tooth brushing and consider oral care as less important. Moreover, parents provide fewer support or assistance during tooth brushing compared to Dutch parents. According to the practitioners, some parents struggle to be consistent and act decisively towards children with ‘special needs’, which is sometimes needed in preventive measures to enhance oral hygiene:

R6: They think from their perspective ‘the child already has a hard time, we are not going to tease him’ [...]. And things they find complicated or more difficult they simply will not do, or do it less frequently.

Like frequent food intake, limited tooth brushing has an adverse effect on the oral health of the child. Independently, these two factors increase the risk to develop caries, which will be reinforced if they co-occur.

3.2.3. Language

Differences in language can also be a bottleneck for the practitioners. When communication in professional oral care proceeds with difficulties, it can become a problem to ask and discuss oral-related issues with the caregivers. Several respondents emphasized that especially in children with ASD, communication with the parents is of major importance:

R3: Look, if a child has ASD, it already complicates treatment and if parents don’t speak Dutch then it becomes really complicated. [...] you need a close collaboration within the treatment of the child. So if you can’t communicate with the parents, that really complicates things and also to build up a relationship with the child [...]

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As mentioned before, communication is essential to provide clarity and explain ambiguities within oral care procedures. Moreover, language and proper communication is needed to transfer knowledge about healthy habits. Additionally, language is important in the explanation of important aspects of home oral care, such as tooth brushing and the relationship between sugar intake and cavities, which is sometimes unclear for parents. Without proper knowledge transfer, frequent sugar intake is likely to maintain in these children.

4. Discussion

4.1 Principal findings

The main perceived barriers for practitioners in professional oral hygienic care in children with ASD were found to be: Communication/Contact, Sensory perception and Cooperation. In teaching home oral care two additional barriers were identified: Add structure and Motor function. Moreover, the knowledge about ASD of the practitioners emerged as overarching barrier within the oral hygiene of the child with ASD.

The perceived cultural-related barriers in home oral care appeared to be: Nutrition & Sugar intake and Support & Attitude. Additionally, Language was found to be a vital barrier in the professional oral care.

4.2 Strengths and limitations

A strength of this study was that the data was collected in different ways i.e. with open-ended questionnaires and semi-structured interviews. The interviews were used as a member check but the also gave a more in-depth understanding about important barriers and were often illustrated with the practitioners experiences. The open-ended questionnaire gave respondents the opportunity to explain their barriers anonymously and therefore to express themselves freely. Though, it might have been preferred to conduct explorative interviews prior to the questionnaire and base the final
questions on these interviews, however this was not possible within the tight schedule of this internship.

Another strength of this study was that the intern regularly discussed the ongoing analyses with her supervisor to enhance validity of the findings. Furthermore, all special dental care providers within the Netherlands who work with children with ASD were approached to fill out the questionnaire, which gave a broad perspective on the present barriers in this patient group. Additionally, the findings of this study may be relevant to other Western European countries where special dental care providers treat children with ASD in a similar setting and context, as they probably have to deal with equal barriers and a comparable multi-cultural patient population.

This study has also some limitations. The relatively small number of returned and completely filled out questionnaires (48 out of 212; a response rate of 22%) can be considered quite limited. Yet, prior to the study it was clear that these specialized practitioners have a high work load, which might have influenced response rate. Additionally, it was known that less than half of the 126 oral hygienists who received the link for SurveyMonkey to fill out the questionnaire, actually treat children with ASD. Moreover, the NVM noted that oral hygienists are often are exposed to questionnaires from students, which also could have influenced response rate. Still, the NVM rated this research of such importance that they wanted to cooperate. Moreover, some dentists appeared to be double specialized i.e. both Pediatric Dentist and Dentist specialized in dental care for disabled, meaning that these practitioners received the link to the questionnaire from both the NVvK and VBTGG. Thus, some dentists of the 212 were counted double in the beginning, because the organizations provided the number of their members independently from each other. In short; ultimately less than 150 special dental care providers (instead of 212) were the actual target population for this study. Thus, 1 in 3 approached professionals (i.e. 48 out of approximately 150) filled out the questionnaire. This remains unfortunate a relatively low response, yet this occurs more often in studies where these professions are included\textsuperscript{116,117}.

In theory, the use of convenience sampling for the interviewees could have resulted that these selectively chosen respondents were more outspoken than others about this topic. Though, since the interviews were used as member check and to gain deeper insights, it was expected that this have not been a major limitation.
4.3 Implications & Recommendations

The main perceived barriers of practitioners in oral hygienic treatment of children with ASD appeared to be: Communication/Contact, Sensory perception and Cooperation. These emerged bottlenecks were consistent with several studies.\textsuperscript{34,116,118-120} Within oral treatment, it is crucial that information from the practitioners about procedures or instructions can be transferred to patients\textsuperscript{121,122}. Moreover, literature has shown that communication plays a significant role in the child’s cooperation during oral care.\textsuperscript{123-125} To enhance communication in children with ASD, several measures are recommended. First, the practitioner needs to adapt his communication to the level that the child understands\textsuperscript{126}. Moreover, the ‘Tell-Show-Feel-Do’ approach can enhance treatment, \textit{i.e.} the dental care provider \textit{tells} the patient what is going to happen, \textit{shows} what would be done and what he or she will \textit{feel} or \textit{do}\textsuperscript{126,127}. Also ‘The Essential 5’ method, which is based on 5 basic questions: Who, What, How, Where and When, might provide clarity to the patient\textsuperscript{128}. Furthermore, visual pedagogy, which is a structured method with pictures or pictograms to clarify tooth brushing procedures or oral procedures, has proven to be effective\textsuperscript{55,129-132}.

The children’s sensory perception appeared to be another important barrier within oral care, confirming several other studies\textsuperscript{118-119}. Research has indicated that overstimulation to specific stimuli in a person with sensory processing disrupted, could lead to fight, freeze or flight behavior in order to block the stimuli and therefore affects cooperation\textsuperscript{56,118}. Some preventive measures could reduce the incentives for the child, such as allowing sunglasses or an earphone\textsuperscript{56}. Furthermore, it is important to search and detect the appropriate toothpaste for each individual patient\textsuperscript{119,120}. Moreover, stimuli within the dental setting should be diminished as much as possible. A study of Shapiro on a sensory-adapted dental environment (SADE) showed an increase in relaxation and cooperation of the patients during treatment compared to the regular dental environment, however the sample size of the study was relatively small\textsuperscript{133}. Additionally, it would be recommended that parents or caregivers fill out a questionnaire about the child. By doing this, more information is acquired and an assessment can be made about the child’s unique specifics\textsuperscript{134,135}.

The special dental care providers acknowledge their responsibility to diminish inconveniences or ambiguities which cause ‘undesired’ behaviors in children with ASD. The practitioners’ pivotal role to improve cooperation, demonstrates the shift towards a behavioral approach within dentistry.\textsuperscript{72,123,136} In contrast, formerly non cooperative behavior was primarily countered by pharmacological interventions or physical restraints of the patient\textsuperscript{137,138}. 
Structuring tooth brushing appeared to be another barrier, as well to get this activity in daily routine. Literature shows that changes in structure are often difficult for people with ASD since they often strictly adhere to their own routines. Additionally, individuals with ASD have difficulties in the transition of context; they cannot relate (the structure in) tooth brushing in the dental practice with tooth brushing at home. Therefore, it is recommended to plan a tooth brushing instruction of the practitioner within the home setting. Moreover, continuity should be pursued; treat the child as much as possible in the same dental office, with the same staff, at the same time on the same day of the week. Moreover, to get the tooth brushing practice in the daily routine, pictograms can be supportive since visual pedagogy is already a common method at schools or at home for children with ASD.

The motor function of the child is also perceived as bottleneck within home oral care. According to the practitioners, the children sometimes do not have the motor coordination to execute tooth brushing properly. A number of studies ratify that motor function can play a role in oral hygiene. To maintain or achieve a good oral hygiene, it is essential that the majority of dental plaque will be removed. A tool that helps children with deficits in motor coordination is the triple-headed toothbrush which cleans all surfaces of the teeth simultaneously and is proven to be effective.

A surprising finding in this study was that the practitioners’ time and knowledge were found to be overarching barriers in oral hygiene of children with ASD. These barriers were not previously mentioned in literature. A possible explanation for this new finding might be the qualitative nature of this study. Predominantly, in the field of oral care and ASD, quantitative studies and closed questionnaires are used, in which answers are set in advance. Thereby, respondents do not have the opportunity to express their personal bottlenecks.

The practitioners’ knowledge about ASD was identified as foundation for the level of oral hygiene in the children. Several special dental care providers indicated that occasionally the general practitioner has limited knowledge about ASD and patients with ‘special needs’ in general. Multiple studies among students and general practitioners have shown that limited time during education is spend on treating special care groups. To improve knowledge within the general practitioners, it is recommended to include education about ASD in the basic curriculum for dentists and oral hygienists. However, respondents also felt that their own knowledge about ASD is sometimes substandard, though essential to optimize care. Knowledge expansion will provide tools for perceived patient-related barriers, such as communication and sensory processing. For the differentiated oral care providers, an in-depth course could give more insights in this specific patient-related barrier.
Moreover, training courses about ASD should be provided to the whole dental team, including dental assistants to improve the team knowledge. Additionally, the expertise of behavioral specialists can be helpful to seek solutions for the perceived barriers. Above all, research about oral care in patients with ASD should be expanded, in order to exchange knowledge.

A cultural-related barrier in oral hygiene appeared to be that children with another cultural background consume more frequently snacks or food compared to their Dutch peers, which is in line with literature\textsuperscript{28,150}. Though, the Health Behaviour in School-Aged Children study showed that children from a non-Dutch cultural background eat less sweets than Dutch children\textsuperscript{151}. However, this study only included children aged 11 to 16 years, which could explain the differences. Frequency of food intake is related to dental cavities, hence to reduce the risk on cavities food intake needs to diminish\textsuperscript{152}. A recommendation for special dental care professionals is to distribute a diet diary to (the parents of) these children. A diet diary provide a clear insight about specific nutrition habits and frequency of food intake in the child\textsuperscript{153}.

Another identified cultural-related barrier was that children with another cultural background than solely Dutch, receive less support in tooth brushing and that parents sometimes have an otherwise motivated attitude towards oral care. This is consistent with literature, however differences occur between cultures or ethnic groups\textsuperscript{28,154,155}. Specifically, a study of Brugman et al. showed that Moroccan mothers were more committed towards dental visits and in brushing their children’s teeth compared to Turkish mothers\textsuperscript{156}. Tooth brushing is an important measure to prevent periodontal- and dental diseases. Since most children with ASD are not able to brush their own teeth, it is necessary that parents provide sufficient support to diminish oral health problems\textsuperscript{34,35}.

The majority of practitioners declared that children from another cultural background more often have cavities, confirming other studies\textsuperscript{28-30,32,157-160}. Additionally, the finding that oral hygienic differences disappear when a child moves to an institution, emphasizes the crucial role of culture on the child’s oral health and demonstrates that disparities can be prevented with sufficient support in tooth brushing and a decrease in frequency of sugar (food) intake.

Language barriers appeared to make it harder for the practitioner to transfer knowledge or to discuss oral-related issues. This finding is consistent with a study of Verrips et al., which showed that language fluency of parents in minority groups in the Netherlands is a risk factor for dental caries in children\textsuperscript{155}. This current study shows the necessity for practitioners to transfer information properly to all their patients. A recommendation to counteract disparities in oral hygiene and to reduce caries in children with ASD from a non-Dutch background, is to pay extra attention in explaining the relation between sugar and cavities, and the need for tooth brushing. Due to language differences, it could be
helpful to distribute supportive oral health brochures in the parents’ native language, where necessary.

It is expected that the experienced oral hygienic disparities of the specialized practitioners are present on a larger scale in children with ASD in the Netherlands. A study of Begeer et al. showed that children from Turkish or Moroccan background were half as often diagnosed with ASD than their indigenous peers. Moreover, pediatricians referred these children less often for treatment to specialized care facilities, because the social and communicative problems were frequently linked to the child’s ethnicity instead of the ASD. Furthermore it is expected that insufficiently integrated parents, probably do not know of the (free) specialized oral care within the Dutch healthcare system, which was also the case for parents with intellectually disabled children. These issues could lead that children with ASD from various cultural backgrounds will visit more often the general practitioner or no oral care provider at all due to difficulties in cooperation, which will worsen the oral hygienic situation.

5. Conclusions

5.1 Main perceived barriers in oral hygiene

This study provides preliminary insights in the perceived barriers to special dental care provision in oral hygiene of children with ASD. The identified patient-related main barriers appeared to be: Communication/Contact, Sensory perception, Cooperation, Add structure and Motor function. Biological factors, i.e. an intellectual disability and young age were found to reinforce these barriers. The social aspects were found to play an important part in the psychological oral hygienic factors of learning and behavior of the children.

The Oral care-providing factors emerged as overarching barriers in the oral hygiene of the child. Therefore, the basis for potential solutions seems to lie within the practitioners themselves; knowledge expansion about ASD will provide opportunities to enhance communication with the child, to find practical solutions for the child’s stimulus sensitivity and to add structure in tooth brushing, which all could enhance cooperation and oral care.
Further research is needed to explore the interaction and relation between the different perceived barriers. Moreover, it is important that future studies as well explore the experienced barriers of children with ASD and their parents or caregivers in oral care, as this “triangle of people” is needed to achieve a proper level of oral hygiene in children with ASD.

5.2 Main perceived cultural-related barriers in oral hygiene

It was found that culture entails specific barriers to special dental care provision. The main perceived cultural-related barriers in home oral care, respectively Nutrition & Sugar intake and the Support & Attitude of parents, often result in higher caries activity in children with ASD from various cultural backgrounds and affects their level of oral hygiene. Additionally, Language barriers complicate the communication in professional oral care; oral-related issues cannot be discussed and knowledge transfer about home oral care is difficult.

On the basis of this study, it can be concluded that the oral hygiene in children with ASD is affected by cultural habits. Therefore, it would be beneficial that practitioners pay extra attention to the factors that influence home oral care in children from non-Dutch cultural backgrounds. Autism-related research is recommended to include children of a variety of cultural backgrounds, as this represents the current patient population. Future research may explore cultural-related barriers in maintaining an adequate level of oral hygiene in children with ASD and focus on culture in order to customize solutions for all children.
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### Appendix A

**DSM-5 criteria for Autism Spectrum Disorder**

**Must meet criteria A,B,C, and D:**

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<table>
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<tbody>
<tr>
<td><strong>A.</strong></td>
<td><strong>Persistent deficits in social communication &amp; social interaction across contexts, as manifested by the following, currently or by history:</strong></td>
</tr>
<tr>
<td></td>
<td>1. Deficits in social-emotional reciprocity; Ranging, for example, from abnormal social approach &amp; failure of normal back &amp; forth conversation to reduced sharing of interests, emotions, and affect; to failure to initiate or respond to social interactions</td>
</tr>
<tr>
<td></td>
<td>2. Deficits in non-communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication</td>
</tr>
<tr>
<td></td>
<td>3. Deficits in developing, maintaining and understanding relationships, ranging, for example, from difficulties adjusting behaviors to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.</td>
</tr>
<tr>
<td><strong>B.</strong></td>
<td><strong>Restricted repetitive patterns of behaviors, interests or activities as manifested by at least two of the following, currently or by history:</strong></td>
</tr>
<tr>
<td></td>
<td>1. Stereotyped or repetitive motor movements, use of objects of speech (e.g. simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)</td>
</tr>
<tr>
<td></td>
<td>2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g. extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or at eat the same food everyday</td>
</tr>
<tr>
<td></td>
<td>3. Highly restricted, fixated interests that are abnormal in intensity of focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)</td>
</tr>
<tr>
<td></td>
<td>4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or toucing or objects, visual fascination with lights or movements</td>
</tr>
<tr>
<td><strong>C.</strong></td>
<td><strong>Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)</strong></td>
</tr>
<tr>
<td><strong>D.</strong></td>
<td><strong>Symptoms together limit and impair everyday functioning.</strong></td>
</tr>
</tbody>
</table>
A new addition to the DSM-5 is a table of severity descriptors for both the Social Communication and the Restricted Interests & Repetitive Behaviors domain:

<table>
<thead>
<tr>
<th>Severity Level for ASD</th>
<th>Social Communication</th>
<th>Restricted Interests &amp; Repetitive Behaviors (RIRBs)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level 3 - 'Requiring very substantial support'</strong></td>
<td>Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.</td>
<td>Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.</td>
</tr>
<tr>
<td><strong>Level 2 - 'Requiring substantial support'</strong></td>
<td>Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.</td>
<td>Rituals and repetitive behaviors and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when Rituals and repetitive behaviors are interrupted; difficult to redirect from fixated interest.</td>
</tr>
<tr>
<td><strong>Level 1 - 'Requiring support'</strong></td>
<td>Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.</td>
<td>Rituals and repetitive behaviors cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt rituals and repetitive behaviors or to be redirected from fixated interest.</td>
</tr>
</tbody>
</table>
Appendix B

Vragenlijst barrières mondverzorging kinderen met ASS voor mondzorgprofessionals

Geachte heer/ mevrouw,

Graag nodig ik u uit om deel te nemen aan het onderzoek naar de ervaren barrières van mondzorgverleners in de mondverzorging van kinderen met Autisme Spectrum Stoornis (ASS).

Wie voert het onderzoek uit?
Dit onderzoek wordt – als onderdeel van haar thesis voor de Master Gezondheidswetenschappen aan de Vrije Universiteit Amsterdam – uitgevoerd door Roos Kooijman. Zij was – voorafgaand aan haar huidige studie –, tandartsassistent in een instelling voor mensen met een verstandelijke beperking. De resultaten van dit onderzoek zullen verschijnen op de website van de VBTGG, NVvK en de NVM.

Aanleiding Onderzoek
In 2013 is de werkgroep ‘autisme vriendelijke tandheelkunde’ voor het eerst bij elkaar geweest. Gesteld werd dat de tandheelkundige ondersteuning en zorg voor mensen met ASS (met of zonder verstandelijke beperking) verbeterd kan worden. De zorg voor mensen met ASS is flink in beweging en daarop kan de mondzorg inspelen. Omdat er ook bij de verleners van mondzorg regelmatig sprake is van een handelingsverlegenheid, is onderhavig onderzoek opgezet. De Vereniging tot Bevordering der Tandheelkundige Gezondheid voor Gehandicapten (VBTGG), de Nederlandse Vereniging voor Kindertandheelkunde (NVvK) en de Nederlandse Vereniging van Mondhygiënisten (NVM) ondersteunen dit initiatief.

Doel van het Onderzoek
Dit onderzoek wil de barrières in de preventieve en curatieve mondzorg bij kinderen van 0-18 jaar met ASS, die worden ervaren door Tandartsen Gehandicaptenzorg, Tandarts Pedodontologen en mondhigiënisten (lid van de NVM-vakgroep Intramuraale zorgverlening).
Door het in kaart brengen van de ervaren barrières in de mondverzorging, kunnen oplossingsrichtingen gezocht worden die de mondzorg kunnen optimaliseren voor kinderen met ASS.
Vragenlijst
De vragenlijst bestaat uit open en gesloten vragen. Het invullen duurt ongeveer 20 minuten. U heeft de mogelijkheid om tussentijds te stoppen met de vragenlijst en het invullen op een later tijdstip te hervatten.
Aangezien deze vragenlijst volledig anoniem is, zullen geen van de antwoorden terug te leiden zijn naar individuen.
Het is erg waardevol voor het onderzoek om uw persoonlijke ervaringen en gedachten uitgebreid weer te geven en de werkelijkheid zo goed mogelijk te beschrijven. Er zijn geen goede of foute antwoorden.
Bij voorbaat hartelijk dank voor uw tijd en medewerking!

1. Wat is uw beroep? Er zijn meerdere antwoorden mogelijk.
   - Mondhygiënist
   - Tandarts Pedodontoloog
   - Tandarts Gehandicaptenzorg
   - Anders, namelijk...........

2. Wat is uw leeftijd?
   - 20 - 35 jaar
   - 36 - 50 jaar
   - 51 jaar en ouder

3. Ik ben hoofdzakelijk werkzaam in:
   - Reguliere praktijk of kinderverwijspraktijk
   - Instelling voor mensen met een verstandelijke beperking
   - Centrum voor Bijzondere Tandheelkunde
   - Universiteit (klinisch)
   - Universiteit (onderzoek en onderwijs)
   - Anders, namelijk.........

ASS is een breed spectrum: van mensen die zeer afwijzend zijn ten opzichte van contact tot mensen die alle aandacht claimen, van kinderen met een lage intelligentie tot kinderen die zeer intelligent zijn, van mensen die niet spreken tot mensen die voortdurend aan het praten zijn enzovoorts.
In deze vragenlijst gaat het om (uw) patiënten van bij wie officieel de diagnose ASS is gesteld en/of om patiënten van wie de ouders zeggen dat bij hun kind een vermoeden van een stoornis in het autistisch spectrum bestaat.

4. Ik behandel in de praktijk:
   - Wel kinderen met autisme spectrum stoornis (ASS)
   - Geen kinderen met ASS  -> Dank u voor uw bijdrage, u bent klaar met deze vragenlijst
Er is veel verschil in niveau van kinderen met autisme. Voor een verstandelijke beperking is de grens een IQ van 75.

5. Geef naar schatting het percentage kinderen met ASS met een verstandelijke beperking aan dat u behandelt in de praktijk.

Schatting percentage IQ < 75 ...... %

6. Wat zijn naar volgens u, de 3 grootste knelpunten bij het aanleren van tandenpoetsen bij kinderen met ASS? Gelieve uw antwoord toe te lichten.
   1. ..................
   2. ..................
   3. ..................

U zult mogelijk constateren dat het poetsen thuis niet optimaal gebeurt.

7. Wat voor soort hulpmiddelen gebruikt u om het tandenpoetsen bij kinderen met ASS in de thuissituatie te bevorderen?
   ........................................

8. Welk gedrag of gedragingen in kinderen met ASS ervaart u als meest belemmerend tijdens een mondhygiënebehandeling (zoals plaquekleuring, polijsten en/of tandsteen verwijderen) bij u in de behandelstoel?
   ........................................

9. Heeft u te maken met verbale agressie (i.e. gillen, schelden, vloeken enz.) van kinderen met ASS in of bij de behandelstoel?
   o Nooit
   o Soms
   o Vaak
   o Altijd

10. Heeft u te maken met fysieke agressie van kinderen met ASS in of bij de behandelstoel?
    o Nooit
    o Soms
    o Vaak
    o Altijd

11. Wat zijn volgens u, de 3 grootste knelpunten in de mondhygiënebehandeling (zoals plaquekleuring, polijsten en/of tandsteen verwijderen) bij kinderen met ASS in de behandelstoel? Gelieve uw antwoord toe te lichten.
    1. .....................
    2. .....................
    3. .....................
12. Wat voor soort hulpmiddelen gebruikt u om de mondhygiënebehandeling (zoals plaquenkleuring, polijsten en/of tandsteen verwijderen) bij kinderen met ASS in de behandelstoel te bevorderen?

………………………………

13. Wat voor actie(s) onderneemt u, als u vastloopt bij een mondhygiënebehandeling (zoals plaquenkleuring, polijsten en/of tandsteen verwijderen) in de behandelstoel bij een kind met ASS?

………………………………

14. Ik vind de behandeling van kinderen met ASS het moeilijkst in de leeftijdscategorie

   o Tussen 0-6 jaar, omdat........................
   o Tussen 7-12 jaar, omdat......................
   o Tussen 13-18 jaar, omdat......................
   o Ik ervaar geen verschil

15. Bij kinderen met ASS, gebruik ik in de praktijk:
   (Gelijkee een kruis te plaatsen in het vakje wat van toepassing is).

Vragenlijst bij intake specifiek voor ASS
Visuele hulpmiddelen (zoals pictogrammen, foto’s)
Distactie (afleiding), bijv. iPad mee, muziek
Voedingsdagboekje
Modeling (i.e. ‘leren door imitatie’)
Stapsgewijze gewenning
Belonen van het kind
De aanwezigheid van ouders in de behandelkamer
Ouders in de wachtkamer
Fysieke bewegingsbelemmering
Medicatie
Multidisciplinaire samenwerking

16. Ik vind de behandeling van kinderen met ASS het moeilijkst in de leeftijdscategorie:

   o Tussen 0-6 jaar, omdat......................
   o Tussen 7-12 jaar, omdat......................
   o Tussen 13-18 jaar, omdat......................
   o Geen mening

17. Hoe zelfverzekerd voelt u zich in het algemeen in het behandelen van kinderen met ASS?

   o Zelfverzekerd
   o Enigszins zelfverzekerd
   o Niet zelfverzekerd

18. Over welke kennis en vaardigheden zou u willen beschikken om de mondzorg voor kinderen met ASS te verbeteren?

………………………………………………………. 
19. Wat zijn volgens u de 3 grootste knelpunten in de totale mondzorgsector om kinderen met ASS verantwoorde mondzorg te verlenen?
   1. .....................
   2. .....................
   3. .....................

20. Welke maatregelen zouden deze genoemde knelpunten (uit voorgaande vraag) in de mondzorgsector kunnen reduceren?
   ..........................................................................................

21. Behandelt u, naast Nederlandse kinderen, ook kinderen met ASS met een andere culturele achtergrond (*i.e.* ideeën, regels, normen & waarden, overtuigingen, gedragingen en gewoonten) in de praktijk? Zo ja: uit welke culturen hebt u kinderen met ASS onder behandeling?
   o Nee, ik behandel geen kinderen met ASS met een andere culturele achtergrond dan de Nederlandse
   o Ja, ik behandel kinderen met ASS met de volgende culturele achtergrond(en):
     ..........................................................................................

22. Heeft cultuur of culturele achtergrond (*i.e.* ideeën, regels, normen & waarden, overtuigingen, gedragingen en gewoonten) volgens u invloed op de mondverzorging van het kind met ASS?
   o Ja, culturele achtergrond heeft mijns inziens invloed op de mondverzorging -> vraag 23
   o Nee, culturele achtergrond heeft mijns inziens geen invloed op de mondverzorging -> vraag 24
   o Weet ik niet -> vraag 25

23. Kunt u toelichten wat volgens u de invloed/invloeden is van cultuur of culturele achtergrond op de mondverzorging van het kind met ASS?
   .........................................................................................

24. Kunt u toelichten waarom cultuur of culturele achtergrond volgens u geen invloed heeft op de mondverzorging van het kind met ASS?

25. Kunt u toelichten waarom u voor het antwoord ‘weet ik niet’ hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..........................

Citaat: ‘Ik kom af en toe patiënten tegen die in geen jaren bij de tandarts zijn geweest. Ik dacht dan eerst aan verwaarlozing. Maar, het blijkt dat deze ouders helemaal niet beseffen dat je ook zonder pijnklacht naar de tandarts kunt gaan. In hun cultuur ga je naar de dokter als je ziek bent en naar de tandarts als je kiespijn hebt.’
26. Ervaart u invloed van cultuur of culturele achtergrond (inclusief de Nederlandse) op de frequentie van praktijkbezoek van het kind met ASS?
   o Ja, ik ervaar invloed van cultuur op de frequentie van praktijkbezoek - vraag 27
   o Nee, ik ervaar geen invloed van cultuur op de frequentie van praktijkbezoek - vraag 28
   o Weet ik niet - vraag 29

27. Kunt u voorbeelden geven van de invloed van cultuur of culturele achtergrond op de frequentie van praktijkbezoek van het kind met ASS? Gelieve ook de culturen benoemen waarover u voorbeelden geeft.
   ..........................................................

28. Kunt u uitleggen waarom volgens u cultuur of culturele achtergrond geen invloed heeft op de frequentie van praktijkbezoek van het kind met ASS?
   ..........................................................

29. Kunt u toelichten waarom u voor het antwoord ‘weet ik niet’ hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..........................

30. Heeft cultuur of culturele achtergrond (inclusief de Nederlandse) volgens u invloed op de mondhygiënebehandeling (zoals plaquekleuring, polijsten en/of tandsteen verwijderen) bij het kind met ASS?
   o Ja, culturele achtergrond heeft mijns inziens invloed - vraag 31
   o Nee, culturele achtergrond heeft mijns inziens geen invloed - vraag 32
   o Weet ik niet - vraag 33

31. Kunt u toelichten wat volgens u de invloed/invloeden van cultuur of culturele achtergrond is op de mondhygiënebehandeling bij het kind met ASS? Gelieve ook de culturen benoemen waarover u toelichting geeft.
   ..........................................................

32. Kunt u toelichten waarom volgens u cultuur of culturele achtergrond geen invloed heeft op de mondhygiënebehandeling bij het kind met ASS?
   ..........................................................

33. Kunt u toelichten waarom u voor het antwoord ‘weet ik niet’ hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..........................

34. Ervaart u verschil in de ondersteuning van ouders bij het tandenpoetsen of andere preventiemaatregelen, bij hun kind met ASS op basis van cultuur of culturele achtergrond (inclusief de Nederlandse)?
   o Ja, ik ervaar verschil - vraag 35
   o Nee, ik ervaar geen verschil - vraag 37
   o Weet ik niet - vraag 36
35. Kunt u toelichten wat voor verschil u ervaart in de ondersteuning van ouders bij het tandenpoetsen of andere preventiemaatregelen bij hun kind met ASS op basis van cultuur of culturele achtergrond? Gelieve ook de culturen benoemen waarover u toelichting geeft.

………………………………………

36. Kunt u toelichten waarom u voor het antwoord 'weet ik niet' hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..............................

37. Ervaart u verschil in houding (attitude) van ouders ten opzichte van de mondverzorging of mondzorg bij hun kind met ASS op basis van cultuur of culturele achtergrond (inclusief de Nederlandse)?
   o Ja, ik ervaar verschil --> vraag 38
   o Nee, ik ervaar geen verschil --> vraag 40
   o Weet ik niet --> vraag 39

38. Kunt u toelichten wat voor verschil u ervaart in attitude van ouders ten opzichte van de mondverzorging of mondzorg bij het kind met ASS op basis van cultuur of culturele achtergrond (inclusief de Nederlandse)? Gelieve ook de culturen benoemen waarover u toelichting geeft.

………………………………………

39. Kunt u toelichten waarom u voor het antwoord 'weet ik niet' hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..............................

40. Ervaart u verschil in zuurmomenten bij kinderen met ASS op basis van cultuur en culturele achtergrond (inclusief de Nederlandse)?
   o Ja, ik ervaar verschil --> vraag 41
   o Nee, ik ervaar geen verschil --> vraag 43
   o Weet ik niet --> vraag 42

41. Kunt u toelichten wat voor verschil u ervaart in zuurmomenten bij kinderen met ASS op basis van cultuur of culturele achtergrond (inclusief de Nederlandse)? Gelieve ook de culturen benoemen waarover u toelichting geeft.

………………………………………

42. Kunt u toelichten waarom u voor het antwoord 'weet ik niet' hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie ‘weet ik niet’ gekozen, omdat..............................

43. Ervaar u verschil in cariësactiviteit bij kinderen met ASS op basis van cultuur of culturele achtergrond (inclusief de Nederlandse)?
   o Ja, ik ervaar verschil --> vraag 44
   o Nee, ik ervaar geen verschil --> einde van de vragenlijst
   o Weet ik niet --> vraag 45
44. Kunt u toelichten wat voor verschil u ervaart in cariësactiviteit bij kinderen met ASS op basis van cultuur of culturele achtergrond? Gelieve ook de culturen benoemen waarover u toelichting geeft.

………………………….

45. Kunt u toelichten waarom u voor het antwoord 'weet ik niet' hebt gekozen bij voorgaande vraag?
   o Nee, dat kan ik niet toelichten
   o Ja, ik heb voor de optie 'weet ik niet' gekozen, omdat………………………….

Einde van de vragenlijst.

Nogmaals hartelijk dank voor uw medewerking!

Met vriendelijke groet,

Roos Kooijman
Appendix C

Oproep tot deelname onderzoek:
Barrières mondverzorging kinderen met ASS

Het is algemeen bekend dat het verlenen van mondzorg (met nadruk op preventie en mondhygiëne) bij kinderen met Autisme Spectrum Stoorz (ASS) uitdagend kan zijn. Uit wetenschappelijk onderzoek blijkt dat mondzorg bij kinderen met ASS van 0-18 jaar, met of zonder verstandelijke beperking, een handelingsverlegenheid bij mondzorgverleners kan geven. Bovendien blijkt uit onderzoek dat culturele achtergrond een rol kan spelen in de mondverzorging van een kind.

Met uw hulp wil de werkgroep ‘autismevriendelijke tandheelkunde’ de meest voorkomende, ervaren barrières van mondzorgverleners bij de mondverzorging van kinderen met ASS in kaart brengen door middel van een vragenlijst en enkele interviews. Aan de hand van de resultaten kunnen oplossingsrichtingen gezocht worden om de mondzorg te optimaliseren voor kinderen met ASS.


Voor dit onderzoek zullen vragenlijsten verstuurd worden aan alle Tandartsen Gehandicaptenzorg, Tandarts Pedodontologen en mondhygiënisten (lid van de NVM-vakgroep Intramuraale zorgverlening). De vragenlijst is (volledig anoniem) in te vullen via SurveyMonkey. U ontvangt eind maart 2016 een link via uw e-mailadres voor de vragenlijst, verzonden door het secretariaat van de VBTGG, NVvK of de NVM. De vragenlijst is in te vullen tot 24 april 2016. De bevindingen zullen, na afronding van het onderzoek, verschijnen op de website van de VBTGG, NVvK en de NVM.

Bij voorbaat hartelijk dank voor uw tijd en medewerking!

Met vriendelijke groet, Roos Kooijman (rooskooijman4@hotmail.com)
### Appendix D

<table>
<thead>
<tr>
<th><strong>Interview Design</strong></th>
<th><strong>Allereerst wil ik nogmaals zeggen dat ik erg blij ben dat u/jij deel wilt nemen aan dit onderzoek en hiervoor de tijd wilt nemen</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intro</strong></td>
<td>Dit onderzoek wil de ervaren knelpunten of barrières van 'bijzondere' mondzorgverleners in de mondhygiëne bij kinderen met een autisme spectrum stoornis in Nederland in kaart brengen. Hierdoor kunnen oplossingsrichtingen gezocht worden die de mondzorg kunnen optimaliseren bij deze doelgroep. Uit de vragenlijst die is ingevuld door de TG's, de TP's en de mondhygiënisten die lid zijn van de vakgroep Intramuraale zorgverlening zijn voorlopige conclusies getrokken over de ervaren barrières van deze mondzorgverleners. Dit interview verifieert de conclusies en geeft verdieping en verduidelijking op de antwoorden die gegeven zijn in de vragenlijst. Het gaat er dus om of u zich in de conclusies kan vinden in grote lijnen, het hoeft niet letterlijk overeen te komen met uw gegeven antwoorden in de vragenlijst. Ik zal met meerdere 'bijzondere' mondzorgverleners interviews houden uit heel Nederland. Uw/jouw kennis en ervaring met de doelgroep is erg belangrijk voor het onderzoek.</td>
</tr>
<tr>
<td><strong>Uitleg over het doel van het onderzoek</strong></td>
<td>Bij het uitwerken van de gegevens/data van het interview wordt uw/jouw naam niet genoemd. Dus dit interview is anoniem (alleen ik weet wie de respondenten zijn en mijn begeleider Jan Elhorst).</td>
</tr>
<tr>
<td><strong>Aangeven dat de gegevens anoniem en vertrouwelijk worden verwerkt</strong></td>
<td>Als je tijdens het interview besluit dat je niet meer verder wilt gaan, of als je het genoeg vindt dan kun je dat aangeven. Ik zal dan stoppen met het interview.</td>
</tr>
<tr>
<td><strong>Als de respondent wil stoppen</strong></td>
<td>Ik heb een telefoon bij mij zodat dit interview kan worden opgenomen. Dit zorgt ervoor dat ik niet zoveel op hoef te schrijven en dat ik het gesprek later terug kan luisteren. Het interview zal later door mij worden geanalyseerd. Vanuit de wet is het voorgeschreven om u/jou toestemming te vragen als ik het gesprek wil opnemen, zou dat mogen van jou/u? Zo ja, zou u dan dit formulier willen ondertekenen?</td>
</tr>
</tbody>
</table>
Heel erg bedankt! Dan zet ik nu de geluidsopname aan en dan kunnen we beginnen.

**Vraag 1**

In de vragenlijst kwam naar voren dat veel mondzorgverleners zowel bij het behandelen in de stoel als bij het aanleren van tandenpoetsen de zintuiglijke waarneming en de communicatie/contact met het kind met ASS als knelpunt ervaren. Herkent u dit? Kunt u mij dit toelichten?

**Evt. aansluitende vragen**

- Speelt het hebben van een verstandelijke beperking een rol in de mondhygiëne/mondverzorging/behandeling bij het kind met ASS? Heeft u hier ervaring mee? Kunt u voorbeelden geven/dit toelichten?
- Speelt de leeftijd van het kind met ASS een rol in de mondhygiëne/mondverzorging/behandeling?

**Vraag 2**

Ook kwam in de vragenlijst naar voren dat verminderde coöperatie van het kind met ASS als barrière wordt ervaren door de mondzorgverleners, bijv. dmv afweer, weerstand of onrust. Herkent u dit?

**Evt. aansluitende vragen**

- Speelt het hebben van een verstandelijke beperking een rol in de coöperatie van het kind met ASS?
- Speelt leeftijd een rol in de coöperatie van het kind met ASS?
- Wat mij intrigeert is dat aandacht/concentratie van het kind ook vaak werd benoemd. Herkent u dat? Is dit bij alle kinderen zo of hoort dit specifiek bij kinderen met ASS? Kunt u mij dit toelichten?

**Vraag 3**

Verder kwam uit de vragenlijst naar voren dat het aanleren en toepassen van tandenpoetsen niet altijd als gemakkelijk wordt ervaren (dus bijvoorbeeld om structuur te krijgen in het tandenpoetsen of om het tandenpoetsen in het dagelijks ritme/routine te krijgen van de kinderen met ASS). Herkent u dit? Kunt u dit toelichten?

**Evt. aansluitende vragen**

- Ook werd de motoriek van het kind vaak benoemd als knelpunt bij het aanleren van tandenpoetsen. Herkent u dit? Is de motoriek ASS specifiek of heeft dit meer te maken dat het kind een verstandelijke beperking heeft of een jongere leeftijd bijvoorbeeld? Kunt u dit toelichten?
| Vraag 4 | Verder kwam naar voren dat niet alleen knelpunten worden ervaren vanuit de patiënt/het kind zelf, maar ook dat de omgeving een grote rol speelt tijdens de mhbehandeling of het tandenpoetsen thuis), omdat er veel prikkels zijn. Herkent u dit?  
- Kunt u dit toelichten? |
| Vraag 5 | Ook werden ouders/begeleiders benoemd in de vragenlijst, omdat het hen soms ontbreekt aan motivatie of kennis. Herkent u dit? Kunt u hiervan een voorbeeld geven/een ervaring delen? |
| Vraag 6 | Ook blijkt dat de factor 'tijd' als belangrijk knelpunt wordt gezien bij de mondzorgverleners. Herkent u dit?  
- Kunt u toelichten?  
- Wat voor invloed heeft 'tijd' van de mondzorgverlener op de mondhygiëne van het kind.  
Verder is door de mondzorgverleners benoemd dat kennis en ervaring van de mondzorgverleners zelf een knelpunt kan zijn in de mondverzorging van het kind met ASS. Herkent u dit? Kunt u zich dit voorstellen? Kunt u dit voor mij toelichten? |
| Vraag 7 | Dan gaan we nu naar de voorlopige resultaten van de invloed van cultuur of culturele achtergrond op de mondverzorging of mondhygiëne van het kind met ASS. Het merendeel van de respondenten heeft beantwoord dat culturele achtergrond invloed heeft op de mondverzorging van het kind bij ASS, Herkent u dit? Heeft u hier zelf ervaring mee? Kunt u dit toelichten?  
- De respondenten hebben aangegeven dat ze over het algemeen ervaren dat kinderen met ASS met een Arabische achtergrond (voornamelijk Turkse of Marokkaanse) maar ook Aziatische achtergrond meer zuurmomenten/zoetmomenten hebben op een dag doordat de ouders de kinderen minder ontzeggen en dat er minder prioriteit ligt bij de mondverzorging/poetsen. Herkent u dit?  
- Kunt u zich dit voorstellen?  
- Kunt u toelichten hoe het komt dat er verdeeldheid is over of culturele achtergrond van invloed is op de frequentie van praktijkbezoek of op de mhbehandeling? Wat is uw ervaring |
<table>
<thead>
<tr>
<th>hiermee?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ik denk dat dit het zo was. Heeft u nog dingen toe te voegen die niet aan bod zijn gekomen? Heel erg bedankt!</td>
</tr>
</tbody>
</table>
Appendix E
Toestemmingsverklaringformulier (informed consent)

Titel onderzoek: 
Verantwoordelijke onderzoeker:

*In te vullen door de deelnemer*

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en [indien aanwezig] de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

[indien van toepassing] Ik begrijp dat de geluidsopname uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: ..............................................................

Datum: ............. Handtekening deelnemer: ..............................

*In te vullen door de uitvoerende onderzoeker*

Ik heb een mondelinge toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: ..............................................................

Datum: ............. Handtekening onderzoeker: ..............................
Appendix F

Main barriers in oral hygiene of children with ASD

Learning

Communication / Contact
- Making contact
- Communication Problems
  - Language Level
  - Incomprehension
  - Instruction Treatment
- Reachability
  ➔ Aggravating factor: intellectual disability and age

Sensory perception
- Stimulus processing
- Stimulus sensitivity
  - Taste Sounds Smell Touch Light
  - Direct contact Mirror Vibration
- Sensitivity of the head/mouth
  ➔ Aggravating factor: intellectual disability

Cooperation
- Defense
- Resistance
- Flight
- Avoid
- Movement
- Anxiety
  ➔ Aggravating factor: intellectual disability and age

Add structure
- Routine
- Difficult in changing patterns
- Restructure tooth brushing
  - Skipping parts of dentition
  - Brushing habits
- Build in daily structure
  ➔ Aggravating factor: intellectual disability

Motor function
- Motor skills
- Technique
- Eye-hand coordination
- Difficulty of activity
  ➔ Aggravating factor: intellectual disability and age

Behavior
Non-cooperative behavior
- Defense
- Resistance
- Flight
- Avoidance
- Movement
- Anxiety
  ➔ Aggravating factor: intellectual disability and age

Diminished attention and concentration
- Short attention span
- Little attention
- Restless
- Impatience
- Distracted
  ➔ Aggravating factor: intellectual disability and age

Environment
Dental setting
- Incentives instruments
  Noises
  Water
  Vibrations
  Light
  Taste
  Smell
- Incentives devices
- People
  Touch
  Talk
  Contact
Immediate surroundings
- Incentives work
- Incentives school
- Incentives parents/caregivers
- Incentives waiting area
- Incentives traffic

Social support

Knowledge
- Tooth brushing skills
- Knowledge oral health

Motivation
- Priority home oral care
- Motivation for oral care
- Support in tooth brushing
- Support in professional oral care

Oral care-providing factors

Knowledge
- General practitioners
  - Lack of knowledge ASD
  - Late referral
  - Understanding the patient
- Special dental care providers
  - Little knowledge about ASD background
  - Little knowledge about communication
  - Limited experience with ASD

Time
- Lack of time
- Time-pressure
- Extended treatment
- Limited specialists
- Reimbursement
- Many treatments in short intervals
Cultural-related barriers in oral hygiene of children with ASD

Support & Attitude
- Assistance tooth brushing
- Prioritize tooth brushing
- Attitude towards oral health
- Acting decisively
- Attitude towards tooth brushing
  ➔ cavities

Nutrition & Sugar intake
- Sugar
  Amount
  Frequency
  Sweets
  Spoiling
  Soft drinks
  Snacks
  Cookies
  Tea with sugar
- Eating pattern
- Different nutrition
  ➔ cavities

Language & communication
- Do not speak Dutch
- Do not speak English
- Miscommunication
- Do not understand instructions
- No knowledge transfer
- Importance of oral care

Visits to the practice
- Frequency of visits
  Acute problems
  Pain
  Referral practice
- Cancellations
- ‘No-shows’