Is Severe Early Childhood Caries Associated with Dental Caries in Adulthood?
~A Pilot Project~

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science

Graduate Department of Dentistry
University of Toronto

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Master of Science, 2011  
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Abstract

Dental caries in the primary dentition is a risk factor for dental caries in the permanent dentition. The aim of this pilot project was to establish if high levels of dental caries very early in life translate into increased levels of dental caries in adulthood. Our objective was to determine the mean DMFT score of individuals with a history of severe early childhood caries (S-ECC) and compare it with the mean DMFT score of individuals who were caries-free in the primary dentition. The results of our analyses indicate that adults who experienced S-ECC manifest significantly higher levels of dental caries in their adulthood. The best predictor for dental caries in adulthood was caries experience in primary dentition. This preliminary study, the first of its kind, suggests that early childhood caries might indeed be associated with dental caries in adulthood.
Acknowledgements

First and foremost I would like to thank my principal supervisor, Dr. Gajanan (Kiran) Kulkarni for his tremendous support and excellent supervision in carrying out this project. His knowledge, direction and input were invaluable, creating a great learning and intellectual development experience.

In the completion of the project I would like to recognize the most valuable contributions of the scientific advisory committee members, Dr. Michael J. Casas and Dr. Peter Judd, from The Hospital for Sick Children. Their patience and concern with the project allowed for the important logistic support needed for such an operation; their help and advice regarding the scientific part were treasured.

I would like to express my gratitude to Dr. Maltz, who has helped enrolling the participants for the control group, through his clinic in Brampton. His kind support and consistent contribution were essential to the project.

A thought of gratitude goes to Dr. Amir Azarpazhooh for accepting to become part of the project’s committee.

As the present project involved a very large amount of paperwork, I would like to offer a warm thank you to Ms. Helen Cheung and Ms. Elizabeth Brussolo from The Hospital for Sick Children. Helen’s meticulous endeavour in printing and managing the correspondence and Elizabeth’s excellent support with the file boxes are highly appreciated and deserve gratitude.
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<td>AAPD</td>
<td>American Academy of Paediatric Dentistry</td>
</tr>
<tr>
<td>CDA</td>
<td>Canadian Dental Association</td>
</tr>
<tr>
<td>dmft</td>
<td>decayed missing filled teeth (in primary dentition)</td>
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<td>DMFT</td>
<td>Decayed Missing Filled Teeth (in permanent dentition)</td>
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<td>ECC</td>
<td>Early Childhood Caries</td>
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<tr>
<td>ER</td>
<td>Emergency Rooms</td>
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<td>ETS</td>
<td>Environmental Tobacco Smoke</td>
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<td>GA</td>
<td>General Anesthesia</td>
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<tr>
<td>HSHP</td>
<td>The Healthy Smiles Happy Child Program</td>
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<tr>
<td>NHANES III</td>
<td>The Third National Health and Nutrition Examination Survey</td>
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<tr>
<td>OHRQoL</td>
<td>Oral Health-Related Quality of Life</td>
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<td>S-ECC</td>
<td>Severe Early Childhood Caries</td>
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<tr>
<td>SSC</td>
<td>Stainless Steel Crown</td>
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1. Introduction

Dental caries is a preventable, multifactorial, progressive, infectious, chronic disease. The disease is cumulative and progresses at various rates, depending on numerous individual and environmental factors.

The relationship between dental caries in primary and permanent dentition has been investigated extensively. However, to the best of our knowledge, no study inquired into the long-term oral health implications of adults with a history of high levels of disease in the primary dentition. This study explores the possible link between S-ECC and adult oral health.

2. Background

2.1. Definition

The American Academy of Paediatric Dentistry defines the disease of early childhood caries (ECC) as the presence of 1 or more decayed (noncavitated or cavitated lesions), missing (due to caries), or filled tooth surfaces (dmfs) in any primary tooth in a child 71 months of age or younger. In children younger than three years of age, any sign of smooth-surface caries is indicative of severe early childhood caries (S-ECC). From ages three through five, a dmfs of one or more in primary maxillary anterior teeth or a decayed, missing or filled (dmft) score of ≥4 (age 3), ≥5 (age 4), or ≥6 (age 5) constitutes S-ECC (1).

2.2. Etiology

ECC is a complex and multifactorial chronic disease that is heavily influenced by numerous biomedical factors (e.g., bacteria, host, genetics, and diet) and by social determinants of health (2). Some of the factors influencing the onset and progression of the disease are mentioned below.
2.2.1 Bacteria

Dental caries is a disease that results from a disturbance in the balance of homeostatic mechanisms between the teeth and the existing oral flora present in biofilms. Those sites where biofilms are allowed to mature favour new caries development (3).

Oral microbiota associated with health is more diverse and complex than the oral microbiota associated with dental caries (4). *Streptococcus mutans* (*S.mutans*) is the major microbial species associated with S-ECC. It can colonize the mouths of predentate infants (5) and is commonly acquired from the child's primary caregiver, most often the mother, via infected saliva. While the sources or the origins of the organisms are sometimes untraceable, the known mechanisms of transmission may include kissing, sharing of utensils or food, poor oral hygiene and/or open carious lesions in the primary caregiver (6, 7).

Initially caries-free children with high salivary *S. mutans* levels are at greater risk for caries at any given time than caries-free children who had low salivary *S. mutans* levels at baseline (8). In children with S-ECC *S. mutans* regularly exceed 30% of the cultivable plaque flora but typically constitutes less than 0.1% of the plaque flora in children with minimal to no caries activity (5). Other microbial species associated with S-ECC include *Streptococcus mutans, Scardovia wiggsiae, Veillonella parvula, Streptococcus cristatus* and *Actinomyces gerensceriae* (9). Children with multiple species have higher numbers of total streptococci and a tendency to higher caries prevalence than children with only *S. mutans* (10).

The earlier a tooth decays prior to normal exfoliation, the greater the risk of developing higher levels of disease and the greater the likelihood of pain (11). In other words, an earlier onset is related to a greater burden of disease. The most critical period for plaque accumulation is the time from tooth emergence to full occlusion. This coincides with the period when the tooth has a limited participation in the mechanical oral function. As caries is a plaque induced disease, the potential for caries development in children with poor oral
hygiene during tooth eruption is consequently high. Therefore, the first two years of life are of critical importance in the onset of dental disease (12).

In young children (i.e., 2 to 5 years of age) operative procedures under general anaesthesia (GA) significantly decrease the concentration and the amount of *S. mutans* for at least three months. After three months, saliva concentrations and plaque numbers of *S. mutans* increase significantly in relation to one week post-operatively but do not reach the pre-treatment levels (13). At 12 months post-therapy children without new carious lesions show lower levels of *S. mutans* than children with new caries lesions at follow-up (14).

There are several important differences between the variety and dynamics of bacterial flora associated with primary and permanent dentitions. The bacterial flora of healthy sites in primary teeth is less varied than the bacterial flora of healthy sites in permanent teeth. The bacterial profiles during the initiation of caries are more complex than those in established caries lesions, and distinct bacterial profiles are present at each stage of caries progression. There is an overall greater microbial diversity associated with caries in permanent teeth. Bacterial profiles of caries in the permanent dentition vary from subject to subject, and the role of *S. mutans* in rampant caries in permanent teeth is less prominent than in rampant caries in primary teeth (15).

These observations illustrate the concept that ECC is an infectious disease and that *S. mutans* is most likely the infectious agent. The long-term changes in the dynamics of oral flora in S-ECC patients following comprehensive restorative treatment under GA are unknown. Therefore, strategies for the prevention of dental caries should include timely control of colonization of the cariogenic bacteria in the mouths of young children.

### 2.2.2 Enamel Defects

Enamel defects are a risk factor for dental caries. Low structural integrity, low acid resistance, developmental defects on tooth structure, porosity and high sensitivity to brushing allow for additional plaque accumulation and increase the risk of caries (16).
Enamel hypoplasia is one of the enamel defects frequently associated with dental caries in primary dentition. It may occur as a result of developmental disturbances related to pregnancy, such as preterm births, low birth weight or maternal smoking, and complications during the pre- or postnatal period including illness, infection or malnutrition (6).

Enamel and dentin of primary teeth are inherently thinner and caries progression can more rapidly involve the pulp. In addition, teeth emerge with immature enamel that continues to mature throughout eruption by incorporating intra-oral minerals and ions, one of which is fluoride. Thus, newly erupted teeth are at an increased risk of caries until complete maturation occurs (6).

As discussed in section 2.2.1, S-ECC patients acquire cariogenic bacteria at an early age, have multiple species of cariogenic bacteria and higher numbers of total streptococci. These factors can influence the onset and severity of dental caries. The presence of enamel defects further increase the risk of dental caries. Whether the preventive measures can overcome the influence of these risk factors, and downplay their impact on adult oral health status has not been established.

2.2.3. Dietary and Feeding Habits
Diet and feeding habits play an important role in the pathology of early childhood caries. Fermentable carbohydrates lower the pH intra-orally. Repeated exposure to fermentable carbohydrates for prolonged periods of time increases the risk of dental caries. Children who consume more soft drinks, relative to milk and 100 percent fruit juice, are at a greater risk of developing dental caries (17). *Ad libitum* feedings, frequent consumption of any liquid containing fermentable carbohydrates, and frequent snacking should be avoided. Of particular concern is the significant risk associated with feedings when the child wakes up during the night. After the child returns to sleep, the salivary flow decreases. Consequently, any food or liquid present in the mouth remains in prolonged contact with the tooth structure. In the presence of *S. mutans*, this feeding habit may increase the risk for dental
caries (17). More importantly, when practiced over a long period of time, these dietary and feeding habits may become established, and may lead to unfavourable oral health outcomes in both the primary and permanent dentition.

Prolonged bottle feeding is also considered a risk factor for ECC. The mothers’ main motivation for prolonged bottle feeding can be conceptualized as ‘buying time’. The feeding bottle buys time away from crying children by silencing them but also buys extra time with the child. These insights are important as they bring about an understanding of the time and behavioural concerns that many mothers experience when caring for their babies, and the reasons for prolonged bottle feeding (18).

The literature on dietary and feeding habits indicates that these habits are adopted for a number of reasons and serve certain purposes. If the pattern of poor diet and feeding habits continued through childhood into adulthood, it is possible that the risk of dental disease may have remained unchanged. Therefore, in some cases the pattern of adult dental disease might be nothing more than a reflection of the individual’s dietary and feeding habits established in early childhood. Whether these habits remain fairly constant over time and pose the same risk on the permanent teeth remains to be proven.

2.2.4. Genetics

There is a significant body of evidence that genetic factors are important determinants of diseases. Although caries studies in humans are complex, evidence for a genetic contribution to dental caries has existed for years. The strongest evidence to date of the influence of genetics on caries incidence comes from studies where genetically similar individuals are separated at birth and brought up under different environmental conditions. Monozygotic but not dizygotic adult twins who were separated early in life and reared apart showed a highly significant relationship in terms of the number of teeth present and the percentage of teeth/surfaces restored. Similarities in dental caries experience between monozygotic twins held true for both an increase and decrease in dental caries. A statistically significant resemblance in dental caries status, despite being exposed to
different environmental factors was observed, and thus ascribed to their shared genetic information (19).

Investigations on how genetics may affect primary and permanent teeth demonstrated that both primary and permanent caries scores were significantly related to genetic inheritance. In addition, a higher heritability estimate (54-70%) in the primary dentition and a lower but significant heritability in the permanent dentition (35-55%) was observed. Inclusion of non-cavitated white spot lesions further increased the strength of heritability. Although genetics appears to be a factor in caries development, the genes affecting susceptibility to caries in the primary dentition may differ from those in the permanent dentition (20).

It appears that dental disease has a genetic component (20) whose influence is greater in primary dentition. Associations between S-ECC and adult dental disease if established in future research, might point to an underlying genetic predisposition. However, studies to date have not identified genes or gene profiles that are good predictors of caries.

2.2.5. Passive Smoking

Passive smoking is a risk factor for dental caries in primary dentition. Passive smoking or environmental tobacco smoke (ETS) has immunosuppressive properties and is a known risk factor for infections of the head and neck organs. Thus, it is not surprising that it would be a risk factor for caries development, which is an oral infectious disease. In addition, ETS is associated with decreased serum vitamin C levels in children, which are associated with growth of cariogenic bacteria. Also, it is possible that ETS may reduce the protective properties of saliva. Environmental tobacco smoke is known to increase inflammation of the respiratory tract, producing symptoms of various clinical conditions, including allergic rhinitis, which frequently cause mouth breathing and thus result in xerostomia (e.g., an effective decrease in saliva). In early childhood, when the immune system is generally less mature, the saliva is known to be different from that of adults with respect to IgA concentrations; in addition, salivary flow rate is lower. Young children may thus be particularly vulnerable to the harmful effects of ETS on the immune system and saliva.
flow. Nicotine has been shown to promote the growth of cariogenic bacteria in vitro; thus, mothers who smoke may be more likely than nonsmokers to harbour higher levels of cariogenic bacteria and transmit these germs to their children (21).

Bacteria, enamel defects, poor dietary and feeding habits, genetics, and passive smoking influence the onset, progression and the severity of early childhood caries. Whether the comprehensive restorative treatment and the preventive measures were able to overcome the impact of these risk factors in S-ECC patients is not known.

3. Treatment Options, Outcomes and Follow-up
The treatment for S-ECC can be rendered under general anesthesia or under local anesthesia and conscious sedation. Eidelman et al. reported that the quality of treatment performed under GA exceeded the one performed under conscious sedation. Parameters such as marginal adaptation and superior anatomic form were better for all types of restorations placed under GA. These improved parameters lower secondary caries rates (22).

Treatment of S-ECC under GA is sometimes required because of the level of cooperative behaviour of babies and young preschool children. In such instances, the treatment is usually restricted to restoration or extraction of carious teeth coupled with recommendations to extinguish decay-promoting feeding behaviours. However, dental surgery has minimal long-term impact on oral caries-promoting bacteria, and counselling parents about unhealthy feeding behaviours has low success rates (23).

Clinical outcomes for treatment of ECC are less than ideal (24). Despite the aggressive treatment of ECC, more than half the patients have new caries lesions within 2 years (25) and 13% of them return for an emergency visit within 3 years of their GA experience (26). The majority of ECC children who do not develop further carious lesions have more aggressive restorative approaches performed during comprehensive dental treatment (e.g., stainless steel crowns (SSC)) (27, 28).
Although the immediate follow-up visits after comprehensive treatment under GA have been recognized as a protective factor in the development of new caries (25), slightly more than half of patients return for a postoperative visit, and only 13% of them present for the 6-month recall (26).

To summarize, the quality of treatment performed under GA is superior to that performed under conscious sedation. Children diagnosed with S-ECC and treated under GA remain at risk to develop new dental lesions (23, 26, 27). The relapse rate is higher in children who fail to attend their immediate follow-up session. Also, the relapse rate is associated with the type of restorative treatment performed (e.g., SSC versus composite/amalgam restorations). The impact of these risk factors on the adult oral health is unknown.

4. Dental Caries and Socio-Economic Status

Dental caries is a multifactorial, infectious, chronic disease. The role of the primary caregiver (e.g., the mother) in the pathology of the ECC has been acknowledged. The role of mothers as facilitators of oral hygiene in early childhood was thoroughly investigated. Clean teeth are more likely in children of mothers who themselves have a higher toothbrushing frequency. In order to improve oral hygiene in early childhood, more emphasis should be placed on mothers’ own toothbrushing and their skills in their children's oral cleaning (29).

The child’s toothbrushing frequency, and the prevalence and severity of dental caries are influenced by maternal background (e.g., age, education, occupation), maternal dental attendance pattern (30), number of missing teeth, active decay (31, 32), maternal high S. mutans levels and maternal sugar consumption (33). The regular toothbrushing is associated with the use of fluoride tablets, while occasional toothbrushing is associated with the addition of sugar to the diet and frequent use of sweets (34).
The maternal influence is not restricted to childhood. Shearer et al. investigated the long-term effects of poor maternal oral health on their children’s caries status in adulthood at the age 32. The results showed that maternal oral health and an unfavorable maternal self-rated oral health when children are young should be regarded as a risk indicator for poor oral health among offspring as they reach adulthood (35).

Family characteristics such as parental control and support, family values, culture and relationships are associated with young people’s health and health behaviour, and health in adulthood. The family context sets the stage for long-term health outcomes. Unlike other behaviours, oral health care is carried out almost exclusively in the home, usually before going to bed and on waking. Since toothbrushing behaviour is formed at an early age, parental influence plays an essential role in the initiation and shaping of adequate and appropriate oral health practices. Toothbrushing is a routine. In addition, one routine is likely to reinforce a second. An investigation into the relationship between oral health practices and family context found that the best predictor of twice-a-day toothbrushing for both boys and girls was eating breakfast. Higher family socioeconomic status, family structure and home environment were also found to be associated with optimal toothbrushing frequency (36).

Dental caries in early childhood is influenced by a number of factors. Among these, mother’s age, education, oral hygiene practices, oral health status and pattern of dental services utilization are just a few. Other factors include family structure and access to dental services. The long-term implications of these early influences on the adult dentition are difficult to quantify.

5. The Relationship between ECC/S-ECC and Permanent Dentition

The relationship between dental caries in the primary dentition and dental caries in the permanent dentition was thoroughly investigated by many researchers in a variety of settings. Thus, it was established that dental plaque on primary central incisors and infrequent brushing at the age of 3 years is associated with a high caries experience at the
age of 15 years (37). In children 5 years of age, more than two surfaces with caries in primary second molars is a clinically useful predictor for future caries development in the permanent dentition at 10 years of age (3). In children 6 to 12 years of age, the first permanent molar is 15 times more likely to be carious when the distal surface of the second primary molar had dental lesions confined to enamel than when it did not display radiographic evidence of caries. In addition, presence or absence of approximal caries in the distal surface of the first primary molars and/or the mesial surface of the second primary molars at the time of eruption is also related to the caries rate for the first permanent molars (38). Children 3 to 5 years of age having dental caries in their primary teeth are three times more likely to develop caries in their permanent teeth at 11 to 13 years of age (39). Caries experience in primary molars and canines at 8 years of age correlates with caries experience in the permanent dentition at 16 years of age. This correlation remains fairly constant in spite of the changes in caries prevalence and in the criteria for restorative treatment over a 20-year period (from 1950 to 1970) (40).

According to the literature, dental caries in the primary dentition is a risk factor for dental caries in the permanent dentition. If the magnitude of this risk changes over long periods of time, at various ages and stages in one’s life in not known.

6. ECC/S-ECC and General Health
ECC, the most common childhood disease, is often accompanied by acute and/or chronic pain, an interference with the eating, sleeping and proper growth of the child, compromised general health, tooth loss, malocclusion and increased expenses for dental care throughout life. In rare instances, untreated carious lesions can lead to life threatening infections and death (41).

Dental problems in early childhood have been shown to have a negative impact on growth and cognitive development by interfering with nutrition, concentration and school participation (42). Sheiham found that three-year-olds with at least one pulpally involved tooth weighed about 1 kg less than caries-free children of the same age. Children with
rampant caries can weigh up to 80% less than of ideal weight when compared to the controls without caries, and are significantly lighter and shorter than the latter. However, following therapeutic dental treatment the children with ECC have increased growth velocities. Thus, after the treatment there was no difference in age adjusted weights between the ECC group and the control group (43).

There are several mechanisms for how dental caries may be associated with poor growth in children. A high sugar intake can be detrimental to teeth and nutrition. Untreated caries and the associated infection can cause pain, discomfort and reduce the intake of foods which translates into failure to thrive. Severe caries can affect children’s quality of life by causing irritability and disturbed sleeping habits. In addition, disturbed sleep may affect glucocorticoid production and growth. Chronic inflammation (i.e., pulpitis and/or dental abscesses) negatively impacts growth via metabolic pathways, where cytokines affect erythropoiesis. Furthermore, the depressed erythrocyte production in the bone marrow leads to anaemia (43).

S-ECC was shown to be a risk marker for malnourishment in young children. In addition, a high proportion of S-ECC patients showed iron depletion, iron deficiency, or iron deficiency anemia. These findings are of clinical concern because in such a young population such disorders have the potential to cause impairment of body function. Research into the effects of iron deficiency has found that physical growth, behavioral development, and activity are impaired with low iron. Chronic iron deficiency is associated with impaired brain development and function. Population studies suggest that chronic iron deficiency can have permanent ill effects as neither cognitive scores nor behavior improve after iron supplement therapy (44).

Casamassimo et al. reported that dental pain is one of the leading pediatric admission symptoms to Emergency Rooms (ER). In most cases, ER dental interventions are limited to management of pain and infection, leaving the source untreated. Some ER admissions become prolonged hospitalizations for management of facial cellulites with a length of stay of five days or longer and a significant cost of care. In a study of pediatric patients with
facial cellulitis, researchers found that ER physicians were more likely to order computed tomographic imaging than were pediatric dentists, with no difference in treatment outcome. This finding is most relevant because a growing body of literature suggests that head and neck computed tomographic imaging is responsible for an increase in thyroid cancer incidence in children (45).

S-ECC can impact general health through a variety of mechanisms and with various consequences. While some of these consequences disappear over time, others do not. Their role on the adult oral and general health is unknown.

7. ECC/S-ECC and the Oral Health-Related Quality of Life

The concept of oral health-related quality of life (OHRQoL) refers to the impact that oral health or disease has on the individual’s daily functioning, well-being or quality of life. ECC has negative repercussions on the OHRQoL of children and of their parents’ (46).

Casamassimo et al. found that the effect of ECC-related pain on distraction from learning and school performance was significant. In the U.S., school systems that serve a significant low income population report that dental problems contribute to learning difficulties, loss of sleep, inability to concentrate in school, and absences from school. It is estimated that about 9.3 % of the children younger than 5 years experienced “restricted activity days” because of dental problems (45).

The treatment of S-ECC under GA has demonstrated significant improvement in reported OHRQoL scores. A systematic review investigating this issue revealed that all articles included in the analysis stated the same results: dental treatment under GA led to improvement in the quality of life of the child in all the aspects considered. In addition, the parents pointed out the child's better physical condition, better sleep, appetite, and absence of toothache. The quality of life also improved in psychological and social aspects: parents noted more smiles, better results at school and increased interaction with others (47).
The quality of life is diminished not only for the children affected with S-ECC but also for their families. In today’s chaotic economy, employee absenteeism and associated loss of income for time spent taking a child to multiple dental appointments, the cost of transportation, the time took to find a willing dentist and financial aspects of the treatment are significant issues for these families. These issues can cause parents to delay care as the child’s condition continues to worsen until it becomes so acute as to demand intervention regardless of the effect on the family’s resources. When these families finally gain access to care, they encounter significant delays, because the available treatment resources are far outstripped by the need and demand for them (45).

S-ECC has consequences at multiple levels. These consequences are suffered by the child and also by the family. The treatment of the condition leads to an improvement in the social functioning and psychological well-being of the child and of the family.

8. Dental Caries from a Life-Course Perspective

Dental caries in children and adults is a multifactorial, insidious disease that develops over time. Some of the risk factors for dental caries include harmful health- and oral health-related behaviours (i.e., irregular toothbrushing, frequent consumption of sweets). In addition, behaviours tend to be stable. When an attempt is made to alter them, temporary improvements are noted and lapses occur before the final pattern of behaviour is established. Therefore, in order to improve behaviours, children need to receive constant family support in their daily environment.

A Finnish population study of 5th and 6th graders described the individual stability and stage transitions for behaviors among children exposed to oral health promotion. Over half of the children had stable behaviors throughout the 3.4-year study. For those children whose behaviors changed, the behavior was more likely to improve than to worsen. For most behaviors, good behavior at baseline was associated with the ability to maintain the achieved good behavior and to recover from lapses to poor behaviors. The study concluded that in childhood, good behaviours are rather stable. Therefore, if healthy behaviors are learned young, lapses into poor behaviors, for instance during the teens, are likely to be
temporary rather than permanent (48). During the period of transition into adolescence, many students develop fatalistic beliefs regarding oral diseases, along with a decrease in their individual sense of value, self-esteem and sociability. Pre-adolescents brushed their teeth more often and consumed less sweet snacks than adolescents (49).

Health in adulthood is influenced by many factors. Adult health may be affected by socioeconomic status during different periods in the life course. Three models of life course socioeconomic status (i.e., critical period, accumulation of risk, and social mobility) were used to predict unsound teeth in adulthood (at 24 years of age) among a Brazilian cohort born in 1982. Individuals who experienced poverty around the time of their birth had high proportions of unsound teeth as adults, regardless of their family income in adolescence and adulthood. Variations in socioeconomic status from birth to adulthood influenced the proportion of unsound teeth in adulthood. The explanations for these findings are related to patterns of both dental care and preventive measures (e.g., access to and use of dental services, poor hygiene and improper diet) (50).

Dental caries is a multifactorial disease. Adult dental disease may be seen as a result of the interplay between biological and socioeconomic factors. Therefore, it is best tested from a life course perspective.

9. S-ECC from a Public Health Perspective

Paediatric dental surgery is the most common surgical daycare procedure at most hospitals in Canada. More than 2,000 preschool-aged children undergo dental surgery in Manitoba hospitals annually for the treatment of ECC, while many more receive treatment in private surgical centers. Approximately $3.5-$ 4 million per annum is paid out in federal supported dental fee remuneration for Manitoba children (51).

There is a lack of evidence, communication and agreement between pediatric dentists, public health dentists, general dentists, dental hygienists and allied health professionals, including general practitioners, pediatricians and family doctors, as to the most appropriate methods to reduce a child’s risk of early childhood caries (2).
Currently, no central information bank containing evidence-based information about early childhood caries is available to professionals and the public. There are insufficient community-based initiatives to target the disease and those that do exist occur in relative isolation and are not widely known. These multidisciplinary programs need to be identified, recognized, supported and leveraged to implement successful strategies across many populations by a variety of health care professionals (2).

10. Statement of the Problem

Dental caries is a multifactorial, progressive, infectious chronic disease that also affects general health and the quality of life. Dental caries in the primary dentition is a risk factor for dental caries in the permanent dentition. Continuation of this elevated risk factor into adulthood has not been investigated in those with a history S-ECC.

According to our knowledge, the longest follow-up study of ECC patients took place in the U.S. In this study the time interval (from 1998 until 2002) elapsed from the GA varied between 5 to 9 years (26).

According to our knowledge no such study has been conducted in Canada.

11. Hypothesis

Former S-ECC patients retain a higher risk to develop new dental caries in adulthood when compared to individuals who were caries-free in early childhood.

12. Aim and Objectives

The broad aim of this research was to establish if high levels of dental caries very early in life translate into increased levels of dental caries in adulthood.

Our objectives were to determine the DMFT scores of healthy individuals diagnosed with S-ECC who received comprehensive restorative treatment under GA at The Hospital for Sick Children between 1980 and 1989, to determine the DMFT scores of adults who were
caries-free in early childhood, and to compare the level of caries experience between these two groups.

13. Methodology
This pilot project was a retrospective cohort study. Approval for this investigation was obtained from the Faculty of Dentistry Ethics Committees and The Hospital for Sick Children Research Ethics Board. One hundred twenty five boxes of dental charts of the individuals who received comprehensive restorative dental treatment under GA for the treatment of S-ECC at The Hospital for Sick Children between 1980 and 1989 were retrieved from hospital archives. These records were shipped to The Hospital for Sick Children in five instalments of 25 boxes each, over a period of 6 months during which time they were stored in a locked room.

Approximately 10,000 charts were reviewed to identify those subjects who met the following inclusion criteria: children 71 months of age or younger in good general health who received comprehensive restorative dental treatment under GA for S-ECC between 1980 and 1989. The dental charts of the potential study participants who met the inclusion criteria were scanned and the information saved on USB keys that were also stored in secure rooms at The Hospital for Sick Children.

Based on the personal contact information available in the charts, the former S-ECC patients were contacted by mail, and invited to participate in the study. Those who accepted were invited to the Faculty of Dentistry, University of Toronto (between March and November 2011) for a free dental examination and to fill in a questionnaire. Each participant received token compensation of $40 in cash at the time of their appointment.

The comparison group of individuals with no history of early childhood caries was recruited from an established pediatric dental practice in the community. Although the individuals were adults, they had been in the care of the same pediatric dental specialist since early childhood. Dental radiographs from patients’ childhood served to identify
sixteen potential participants as former caries-free individuals and eligible for this study. These potential participants were informed about the nature of the study by their dentist and agreed to be contacted by the principal investigator. Those who consented to participate were seen in their dentist’s office for an oral examination and to fill in the questionnaire. At that time, they also received the token compensation of $40 in cash. Some of the participants in this group were seen at the time of their regular dental hygiene appointment while others consented to come in response to our invitation to participate.

Sample size calculation and power
Sample size calculation was based on DMFT scores of Canadian adult population reported by the World Health Organization (WHO). According to WHO, Canadian adults aged 35 to 44 years of age had a mean DMFT score of 20 as of 1994-1995, and was based on a study conducted by Brodeur et al. in Quebec (52). Since this source did not provide a standard deviation we used the standard deviation available from The Oral Health of our Aging Population survey (TOHAP) conducted in Nova Scotia in 2008 that targeted adults 45 years of age and older (53). Therefore, we assumed the S-ECC group would have a mean DMFT score of 20 and the comparison group would have a mean DMFT score of 10. This was done in order to ensure that a difference of at least 10 between the mean DMFT scores of the two groups could be detected. The sample size calculation for two independent samples:

\[ \mu_1 = 20 \text{ and } \mu_2 = 10 \]

Standard deviation \( \sigma = 7.24 \text{ (TOHAP Study, 2010)} \)

\( \alpha = 0.05 \)

Power= 80%

Sample size = \( 2 \times \sigma^2 (1.96 + \frac{0.84}{2})^2 / (\mu_1 - \mu_2)^2 = (104.8 \times 7.84) / (20 - 10)^2 = 821.6 / 100 \approx 8 \)

individuals per group.
Dependent and Independent Variables

The DMFT score was the outcome or dependent variable. The dmft score, socio-demographic factors, income, dental insurance, medication, self-perceived oral health, oral hygiene habits and smoking history were the independent variables.

Statistical analysis

The difference in mean DMFT scores between the groups was tested using the Independent Samples Mann-Whitney U Test (non-parametric test) and the Independent Samples T-Test (parametric test). Other tests included Fisher’s Exact Test and Linear Regression Analysis. The Fisher’s Exact Test is a statistical significance test used in the analysis of 2x2 contingency tables where sample sizes are small. The Linear Regression model can be used to identify the relationship between one or more predictor variables and the response variable (outcome). The $R^2$ as determined by the Linear Regression model indicates how much of the outcome (e.g., DMFT) can be accounted for by the selected predictor variable. The non-parametric test and the regression analysis are suited for the situations where the data set does not follow a normal distribution (54). All statistical tests were conducted using SPSS version 20 (SPSS Inc., Chicago, U.S.A.) Significance level was set at $p < 0.05$ and the tests were two-tailed. For the linear regression model, the entry point was set at 0.05 and the removal point at 0.10.
14. Results

14.1. Response Rate and Power Analysis

More than 10,000 charts of all the dental patients treated at The Hospital for Sick Children were reviewed, 714 met the inclusion criteria (326F:388M). Twenty seven charts were excluded because of incomplete or illegible contact information. Letters of invitation were sent to 687 individuals with 176 letters returned as undeliverable. Individuals who at the time of their GA resided in a house as opposed to an apartment building received two more additional letters. None of the participants were contacted by phone since this approach was not approved by the Research Ethics Board of The Hospital for Sick Children.

A total of 19 individuals contacted us either by e-mail or by telephone. Of these, 11 accepted to participate in this study (10 from Toronto and area, and 1 from British Columbia). The 10 participants from Toronto and area were assessed at the Faculty of Dentistry. The participant from British Columbia was assessed by his dentist.

There were 16 potential participants (i.e., 5 females and 11 males) identified as former caries-free children, and eligible for the comparison group. All of them were contacted and invited to participate in this study. Of these, 10 consented (i.e., 5 females and 5 males).

The response rate was 1.6% in the S-ECC group and 62.5% in the comparison group. This project achieved a statistical power of 92%.

14.2. Descriptive Statistics

The participants in the S-ECC group had a mean age of 2.87 years at the time of treatment, range 1.7-4.93 years. The mean wait time for GA from the time of diagnosis was 3.1 months (range 1 day-11.04 months). At the time of GA, the parents of eight children had dental insurance, one had social services dental coverage, one had no insurance, and in one case the insurance status was unknown.

Characteristics of the two groups are summarized in the tables below. The data were dichotomized so that the results highlight the differences between the two groups.
### Table 1 - Socio-Demographic Characteristics and Smoking

<table>
<thead>
<tr>
<th>SOCIO-DEMOGRAPHIC CHARACTERISTICS</th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
<th>Fisher’s Exact Test (n)</th>
<th>Fisher’s Exact Test (n)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7/11</td>
<td>5/10</td>
<td></td>
<td></td>
<td>.650</td>
</tr>
<tr>
<td>Male</td>
<td>4/11</td>
<td>5/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Place of Birth</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>11/11</td>
<td>10/10</td>
<td></td>
<td></td>
<td>----</td>
</tr>
<tr>
<td><strong>Siblings</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One sibling or less</td>
<td>6/11</td>
<td>9/10</td>
<td></td>
<td></td>
<td>.149</td>
</tr>
<tr>
<td>Two siblings or more</td>
<td>5/11</td>
<td>1/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family Structure Change</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2/11</td>
<td>0/10</td>
<td></td>
<td></td>
<td>.476</td>
</tr>
<tr>
<td>No</td>
<td>9/11</td>
<td>10/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family Problems in Childhood</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2/11</td>
<td>1/10</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>No</td>
<td>9/11</td>
<td>9/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school/ Post-Secondary</td>
<td>1/11</td>
<td>0/10</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Some college or university - Post Grad. Studies</td>
<td>10/11</td>
<td>10/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Are you currently attending school?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3/11</td>
<td>4/10</td>
<td></td>
<td></td>
<td>.659</td>
</tr>
<tr>
<td>No</td>
<td>8/11</td>
<td>6/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>By yourself/ With your roommate</td>
<td>5/11</td>
<td>1/10</td>
<td></td>
<td></td>
<td>.149</td>
</tr>
<tr>
<td>With your parents/ Spouse, children/ Parents, spouse, children</td>
<td>6/11</td>
<td>9/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or Living Common Law</td>
<td>3/11</td>
<td>4/10</td>
<td></td>
<td></td>
<td>.659</td>
</tr>
<tr>
<td>Single</td>
<td>8/11</td>
<td>6/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Do you have any children?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0/11</td>
<td>1/10</td>
<td></td>
<td></td>
<td>.476</td>
</tr>
<tr>
<td>No</td>
<td>11/11</td>
<td>9/10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SMOKING</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes-Daily</td>
<td>2/11</td>
<td>0/10</td>
<td></td>
<td></td>
<td>.476</td>
</tr>
<tr>
<td>Not at all</td>
<td>9/11</td>
<td>10/10</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The differences noticed between the two groups in terms of age and gender distribution, family problems experienced in childhood, events that changed the family structure in childhood, education, living arrangements, marital status, offspring, and smoking did not achieve statistical significance. All participants were born in Canada. The age characteristics between the two groups are available in Table 5, Appendix 1.

**Table 2 - Insurance Coverage, Income and Labour Force Activity**

<table>
<thead>
<tr>
<th>INSURANCE COVERAGE, INCOME AND LABOUR FORCE ACTIVITY</th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
<th>Fisher’s Exact Test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n)</td>
<td>(n)</td>
<td>p-value</td>
</tr>
<tr>
<td>Dental Insurance</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Yes</td>
<td>9/11</td>
<td>9/10</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2/11</td>
<td>1/10</td>
<td></td>
</tr>
<tr>
<td>Total Household Income</td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Less than $50,000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5/9*</td>
<td>2/5*</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4/9*</td>
<td>3/5*</td>
<td></td>
</tr>
<tr>
<td>More than 50,000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10/11</td>
<td>8/10</td>
<td>.586</td>
</tr>
<tr>
<td>No</td>
<td>1/11</td>
<td>2/10</td>
<td></td>
</tr>
</tbody>
</table>

* -Missing data

The differences between the two groups in terms of dental insurance status, total household income, and employment status were not statistically significant. One third of all respondents declined to provide information about the total household income. Table 15 located in Appendix 1 provides more details in this respect.
<table>
<thead>
<tr>
<th>ORAL HEALTH</th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
<th>Fisher’s Exact Test</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Perceived Dental Needs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevention</td>
<td>4/11</td>
<td>9/10</td>
<td>.024</td>
</tr>
<tr>
<td>Esthetics, TMJ, Ortho, Perio, Surgery, Fillings</td>
<td>7/11</td>
<td>1/10</td>
<td></td>
</tr>
<tr>
<td><strong>Oral Health Rating</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent, Very Good</td>
<td>5/11</td>
<td>8/10</td>
<td>.183</td>
</tr>
<tr>
<td>Good, Fair</td>
<td>6/11</td>
<td>2/10</td>
<td></td>
</tr>
<tr>
<td><strong>Oral Health Satisfaction</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Satisfied, Satisfied</td>
<td>8/11</td>
<td>10/10</td>
<td>.214</td>
</tr>
<tr>
<td>Neither Satisfied nor Dissatisfied</td>
<td>3/11</td>
<td>0/10</td>
<td></td>
</tr>
<tr>
<td><strong>Dental Pain within the Last Month</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0/11</td>
<td>0/10</td>
<td>-----</td>
</tr>
<tr>
<td>No</td>
<td>11/11</td>
<td>10/10</td>
<td></td>
</tr>
<tr>
<td><strong>Tooth Brushing Frequency</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Twice a day or more/Twice a day</td>
<td>8/11</td>
<td>10/10</td>
<td>.214</td>
</tr>
<tr>
<td>Less than once a day</td>
<td>3/11</td>
<td>0/10</td>
<td></td>
</tr>
<tr>
<td><strong>Dental Flossing Frequency</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once a day or more/Once a day</td>
<td>3/11</td>
<td>5/10</td>
<td>.387</td>
</tr>
<tr>
<td>Less than once a day</td>
<td>8/11</td>
<td>5/10</td>
<td></td>
</tr>
<tr>
<td><strong>Dental Visits Frequency</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than once a year</td>
<td>6/11</td>
<td>7/10</td>
<td>.659</td>
</tr>
<tr>
<td>About once a year or less</td>
<td>5/11</td>
<td>3/10</td>
<td></td>
</tr>
<tr>
<td><strong>Last Time Visiting the Dentist</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year ago</td>
<td>9/11</td>
<td>8/10</td>
<td>1.00</td>
</tr>
<tr>
<td>One year to less than 2 years ago</td>
<td>2/11</td>
<td>2/10</td>
<td></td>
</tr>
<tr>
<td><strong>Avoid Professional Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4/11</td>
<td>0/10</td>
<td>.090</td>
</tr>
<tr>
<td>No</td>
<td>7/11</td>
<td>10/10</td>
<td></td>
</tr>
<tr>
<td><strong>Dental Care Spending</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $500</td>
<td>5/11</td>
<td>7/10</td>
<td>.387</td>
</tr>
<tr>
<td>More than $500</td>
<td>6/11</td>
<td>3/10</td>
<td></td>
</tr>
<tr>
<td><strong>Caries Experience in the Primary Dentition</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dmft=0</td>
<td>0/11</td>
<td>10/10</td>
<td>.000</td>
</tr>
<tr>
<td>dmft≠0</td>
<td>11/11</td>
<td>0/10</td>
<td></td>
</tr>
</tbody>
</table>
Participants in the S-ECC group had statistically significant greater levels of dental disease in primary teeth than participants in the comparison group. Participants in the S-ECC group had statistically significant more perceived dental needs when compared to participants who were caries-free in childhood. The differences between the two groups in terms of oral health rating, oral health satisfaction, toothbrushing and dental flossing frequencies, frequency of dental treatments/check-ups, time elapsed from the last visit to the dentist, avoidance of getting professional dental treatment, and dental care spending did not achieve statistical significance. None of the participants in either of the two groups experienced dental pain within the previous year. More detailed information is available in Tables 10, 11, 12, 13 and 14, Appendix 1.

14.3. Relationship between dmft and DMFT
The S-ECC group had a mean dmft score of 10.1 (range 6-14) and median score of 11.0 (13.0, 75th percentile) at the time of their GA. The males had a mean dmft score of 8.75 (range 6-14) and a median of 7.5 (12.5, 75th percentile), while the females had a mean dmft score of 10.86 (range 6-14) and a median of 12.0 (13.0, 75th percentile).

As adults, the S-ECC group had a mean DMFT score of 7.1 (range 2-13) and a median of 7.0 (9.0, 75th percentile). Males had a mean DMFT score of 4.75 (range 2-7) and a median of 5.0 (7.0, 75th percentile). Females had a mean DMFT score of 8.58 (range 5-13) and a median 9.0 (10.0, 75th percentile).
Fig. 1 - The individual dmft and DMFT scores for the S-ECC group. In general, the level of dental disease in adulthood is lower than the level of disease in childhood. This observation holds true for the entire group with the exception of participant #11. This individual received dental treatment under GA on 2 occasions approximately one year apart.

At the time of study, all participants in the S-ECC group experienced dental caries in their permanent dentition. Of these, 54.5% presented with active carious lesions while the remaining 45.5% experienced dental caries at some point in time but they were treated. None of the participants in the S-ECC group had missing teeth due to caries. The chart below (Fig. 2) illustrates the DMFT composition for the S-ECC group.
All participants in this group experienced dental caries in their permanent dentition and more than half of them had active decay at the time of study.

The comparison group had a mean dmft score of 0.0 and a mean DMFT score of 1.2 (range 0-4); median 0.5 (2.5, 75th percentile). Half of the participants in the comparison group never experienced dental caries (Fig. 3). The remaining 50% experienced dental decay at some point in time but they were treated. At the time of the study, none of the participants in the comparison group presented with active caries lesions or had missing teeth due to caries.
Fig. 3 - All participants in this group were caries free in childhood. At the time of study, half of them had experienced dental caries but they treated. The remaining half never experienced dental caries.

Fig. 4 - The mean DMFT score for the S-ECC group was 7.1 ±3.12; the mean DMFT score for the comparison group was 1.2 ±1.62.
The difference in caries experience between the S-ECC and comparison groups as measured by the DMFT Index was statistically significant in both the non-parametric (i.e., Mann-Whitney U Test) and the parametric tests (i.e., Independent Samples T-Test) (Appendix 1, Tables 8 and 9).

The results of the Mann-Whitney U Test indicate statistically significant differences for the following variables: the DMFT score (p=0.000), the Decayed component of the DMFT (p=0.036) and the Filled component of the DMFT (p=0.000). There were no teeth missing due to caries in either of the two groups (p=1.00).

The results of the Independent Samples T-Test indicate statistically significant differences for the mean DMFT score (p=0.000), and its Decayed (p=0.016) and Filled (p=0.000) components. There were no teeth missing due to caries in either of the two groups (p=1.00). More information is available in Tables 7 and 8, Appendix 1.

The mean DMFT score and standard deviation for the two groups combined was 4.33±3.92; median 4.0 (7.0, 75th percentile). Minimum and maximum scores are shown in Table 9, Appendix 1.

The correlation analysis indicates a weak positive association between age and dental caries in adulthood in the comparison group (i.e., $R^2=0.34$, $p=0.076$). In the S-ECC group there was little or no association between age and dental caries in adulthood ($R^2=0.002$, $p=0.9$).

According to the linear regression analysis, 67% of the variation in the level of adult dental disease (i.e., DMFT score) can be accounted for by caries experience in the primary dentition (i.e. dmft score) ($R^2 = 0.6677$, $p<0.001$). The results of this analysis are presented in Fig. 5.
Fig. 5 - Linear Regression Analysis (the DMFT score as outcome and dmft score as predictor).

This chart indicates that individuals who were caries-free in childhood will have a DMFT score of 1.3155. The intercept of the curve approximates the mean DMFT score in the comparison group (i.e., 1.3155 vs. 1.2).
15. Discussion

A cohort is a group of people who have something in common when they are first assembled. In a retrospective cohort study, medical records of groups of individuals who are alike in a number of ways but differ by a certain characteristic (i.e., S-ECC experience) are compared for a particular outcome (i.e., adult dental disease). In a retrospective cohort study, all the events/exposure of interest, latent period and the outcome have already occurred; subsequently, the data are collected and the risk or association relationship of developing a disease if exposed to a particular risk factor is established. Retrospective cohort studies are quick and relatively inexpensive, are good for studying multiple outcomes, and require smaller sample sizes when compared to prospective cohort studies. However, in retrospective cohort studies, temporal relationship is difficult to determine, and comparability between exposed and non-exposed is difficult to achieve (e.g., continuity of dental care) (55).

This was a retrospective cohort study that examined and compared two groups: individuals who experienced S-ECC and individuals who were caries-free in early childhood. These two groups were identified from past records and followed forward from early childhood up to the present time of the study. For discussion purposes, all study participants will be referred to using masculine pronouns.

Despite receiving comprehensive restorative treatment under ideal conditions, most of the children with S-ECC remained at risk to develop dental caries in adulthood. This is because the restorative treatment, whether performed under GA or not, does not hold the potential to address the other determinants of dental disease (e.g., bacteria, saliva quality and quantity, oral hygiene practices, fluoride exposure, diet) (27).

The S-ECC group had a mean DMFT score 5.9 times higher than the mean DMFT score of the comparison group, and a median value 14 times higher. The expression of the results as a mean has the advantage that it is well suited for mathematical manipulation. However, it is skewed by extreme values. The median has the advantage that it is not easily influenced by extreme values. However, it is not well suited for mathematical manipulation (55). For the
S-ECC group the mean and median values were very similar (7.1 vs. 7.0) while for the comparison group the mean was 2.4 times higher than the median (1.2 vs. 0.5). This difference in the mean and median values for the comparison group could stem from the fact that at the time of the study half of the participants in this group had a DMFT score of 0.

A number of studies suggest that caries experience in primary dentition is a good indicator for caries experience in the young permanent dentition (3, 38-40). For instance, in children 6 to 12 years of age, the first permanent molar is 15 times more likely to be carious when the distal surface of the second primary molar had dental lesions confined to enamel than when it did not display radiographic evidence of caries (38). In children 5 years of age, more than two surfaces with caries in primary second molars is a clinically useful predictor for future caries development in the permanent dentition at 10 years of age (3). Children 3 to 5 years of age having dental caries in their primary teeth are three times more likely to develop caries in their permanent teeth at 11 to 13 years of age (39). Caries experience in primary molars and canines at 8 years of age correlates with caries experience in the permanent dentition at 16 years of age (40). The results of this pilot project suggest that adults who experienced S-ECC might have remained at a higher risk to develop carious lesions than individuals who were caries-free in childhood.

It was previously estimated that about one fifth of the children who undergo comprehensive treatment for S-ECC under GA require additional treatment within two years (27). In our study group, one participant required additional treatment for dental caries. The additional treatment was performed under GA. The two GA appointments were set approximately one year apart. This participant was also the only one who had a DMFT score larger than his dmft score (i.e., 13 vs. 8). At the time of GA his parents had insurance that could have facilitated timely access to adequate dental care. At the time of the study this participant had no longer dental insurance, mentioning he had lost it recently. This participant was concerned about getting dental caries easily, while having no effective means to decrease his risk.

The correlation between age and DMFT achieved borderline significance (i.e., p= 0.07) for the participants in the comparison group; this could suggest that in adults with no history of
dental caries in their primary dentition, the dental disease follows a trajectory close to its natural course.

The participants in the S-ECC group rated their oral health as Excellent/Very Good less often, were less satisfied with the appearance of their teeth, were committed to a lesser degree to good oral health practices, visited the dentist less often, avoided getting the care they needed for reasons that also included dental pain and fear, and spent more on dental care than the participants in the comparison group, but these differences were not statistically significant.

None of the participants in the comparison group but 2 of 11 participants in the S-ECC group took prescription medications. For one of these two participants, the medications taken (i.e., Clonazepam and Cipralex) could have side effects that included xerostomia, a condition that increases the risk for dental caries (56).

Recruiting an appropriate sample size of participants from 20-30 years ago is a major challenge. Many former S-ECC patients and their families had moved. A number of letters that were returned to The Hospital for Sick Children bore short explanatory notes such as: “Moved 10 years ago”, “Moved 19 years ago, and “Moved 28 years ago.” This study had a response rate of 1.6% and a sample of 11 participants for the S-ECC group. A similar study conducted in the U.S.A. reported a response rate of 7% (16 participants) at 5 to 9 years from the intervention performed under GA (26).

More than 10,000 charts were reviewed for this pilot project. Of these, 714 met the inclusion criteria. The discussion section of this material would not be complete if the issue of the remaining charts was not addressed. Most of these children were dental patients with medical comorbidities. Others were cleft lip and palate patients. Some of the children presented with trauma. Some of the healthy children diagnosed with S-ECC never received the treatment because their parents failed repeatedly to show-up for the appointments while others received their treatment under local anesthesia. The severity of the disease in those who declined treatment or those with medical comorbidities is not known. One may speculate that over time and into adulthood the burden of disease in some of these children might have been and remained higher.
Although at least 176 of the potential participants could not be contacted, it is possible that many of them still live at the same address as 22 to 31 years ago. Therefore, the low response rate could be attributed to factors that include: lack of interest in the project, lack of time, other priorities, embarrassment in regards to the oral health status at the time of the study and unpleasant memories associated with dental treatment or dental care providers.

It is possible that participants in the S-ECC group self-selected in such a way that only the ones who valued oral health consented to participate. For instance, 4 of 11 participants in this group were working in health care or were in health-related study programs. Therefore, potential participants who didn’t have good oral health or didn’t have good experiences in respect to dental care might have declined to participate. The geographical proximity might have been an important enabler. This was confirmed by the fact that almost all participants in the S-ECC group were residing, working or studying in downtown Toronto, close to the Faculty of Dentistry.

Therefore, the small number of participants who consented to take part in this pilot project may not be considered a true representation of their cohort (former S-ECC patients treated under GA between 1980 and 1989). Nonetheless, their participation constitutes a good starting point in understanding some of the challenges experienced by this population.

**Limitations**

This study was intended as a pilot project. Random selection of the children with S-ECC who met the inclusion criteria was considered in the initial stages of the project. However, it soon became evident that such an approach would not yield meaningful results in a timely manner. Therefore, letters of invitation were sent to all potential participants who met the inclusion criteria (i.e., children with S-ECC treated under GA between 1980 and 1989 who were in good general health at the time of treatment). If random selection had been performed, it is likely that repeated rounds of randomization would have led to a similar response rate but over a longer period of time.
All participants in the comparison group came from one dental practice and had the same dental care provider for their entire lives. In contrast, participants in the S-ECC group were treated by different dental care providers. To what extent that might have influenced their oral health status and attitude towards oral health cannot be determined.

One of the participants in the S-ECC group was from British Columbia. His oral health status was evaluated by his dentist. This participant had a DMFT score of 9 (1D: 8F). The inter-examiner reliability regarding the measurement of the “D” component of the DMFT could not be established.

The majority of questions in the survey tool demonstrated face validity and provided us with information that may be valuable in future study design of this at risk group. The question about household income might have been regarded as sensitive since one third of the participants declined to answer it. In order to get a better understanding of the role played by other risk factors, questions about dietary habits might be added to the questionnaire.

This pilot project was designed as a retrospective cohort study. One of the limitations pertaining to this study design is that it cannot account for former exposure to risk and protection variables. In the case of this specific project some of these risk and protection variables include: diet and dietary habits, fluoride exposure, oral hygiene practices, dental visits and smoking.

**Future research considerations: prospective vs. retrospective cohort studies**

Dental caries is a common chronic disease caused by several risk factors acting together. For chronic diseases, the contact with the risk factors occurs over a long period of time, and changes in exposure to the risk factors can influence the level of disease. Therefore, dental caries would be best investigated through a prospective study. Such an approach would lead to a better understanding of the relationship between the risk factors and their effects at various ages and stages in the life of an individual.
In order to determine whether a factor is independently related to risk or prognosis, it is ideal to compare cohorts with and without the factor (e.g., prior history of S-ECC), everything else being equal (55).

Therefore, a prospective cohort study would be more suitable than a retrospective study to answer the research question of this pilot project. The study group would comprise healthy children with S-ECC treated under GA, and who are under the care of a dentist. The comparison group would comprise healthy children with no history of dental caries in the primary dentition. These caries-free children should originate from the same dental practices as the children with S-ECC. A potential alternative to ensure longitudinal follow-up would be to establish a practice-based research network.

Ideally the participants in the S-ECC group would be matched with participants in the comparison group. When matching the two groups, variables such as age, gender, parental education and family income could be considered. Still, it is difficult to match for more than a few variables because of practical difficulties in finding patients who meet all the above mentioned matching criteria.

Based on the difference in the mean DMFT scores and standard deviation determined by this pilot project (i.e., Table 9), the power analysis indicates that a sample of 7 participants would be required for a prospective cohort study (i.e., sample size= $2\times\sigma^2 (1.96+ 0.84)^2/(\mu_1-\mu_2)^2 = (30.42\times7.84)/(7.1-1.2)^2 =6.85 \approx 7$). However, many more individuals must be enrolled because long-term prospective studies experience high drop-out rates. If the sample size calculation is based on the data provided by the Canadian Health Measures Survey (57), the most recent nation-wide survey, a sample of 5 participants would be sufficient (i.e., sample size= $2\times\sigma^2 (1.96+ 0.84)^2/(\mu_1-\mu_2)^2 = (30.42\times7.84)/(6.85)^2 = 5.08$).

Such a study would require effort and money to keep track of the people enrolled. The problem is compounded by the need to match experimental participants (i.e., children with S-ECC) with caries-free children originating from the same dental clinic.

Ideally, the groups would be followed until adulthood, with data collection on an annual basis. The data collection phase would consist of a questionnaire and an oral examination. The questionnaire should provide information on variables such as: parental place of birth
(Canada vs. outside Canada), parental education, family income, family size, parental oral hygiene practices and oral health status, utilization pattern of dental services, child place of birth (Canada vs. outside Canada), language, child oral hygiene practices, fluoride exposure, diet, feeding practices, child general health conditions and medication, child exposure to second hand smoking, saliva quality and quantity, \( S. mutans \) counts and enamel defects. Initially, the questionnaire would be answered by the parents/caregivers. With time, the questionnaire would be modified and the children themselves would fill it in.

Compared to prospective cohort studies, retrospective cohort studies require less time to complete, are less expensive and have a smaller scale. However, in retrospective cohort studies, such as this pilot project, the temporal relationship is difficult to determine, and comparability between exposed and non-exposed is difficult to achieve. Therefore, the ideal future study would be a prospective cohort study or a retrospective cohort study with an improved methodology.

If a retrospective study was to be conducted, some of the following improvements should be considered. The letter of invitation sent to potential participants may be modified to state this is a one-time study. Some potential participants might think that a long-term follow-up study implies participation over a long period of time. The type and value of the token compensation should be clearly stated so that potential participants could make an informed decision without contacting the research team for further information. Three letters should be sent to each participant.

Most of the participants in the S-ECC group had no recollection of their past experience at The Hospital for Sick Children. Therefore, the letter of invitation could specify that the potential study participants were not chosen by chance alone.

Some of the participants in the S-ECC group were concerned about their contact information being released to advertising companies. The information available in the letter of invitation should clarify this issue as well. Although these suggestions for improvement could be beneficial, they must be approved by The Hospital for Sick Children Research Ethics Board.
Researchers aiming to replicate this project could also consider recruiting the participants for the comparison group from a larger number of dental clinics in the community. If possible, these clinics should include general dental practices and not only pediatric dental clinics. A potential alternative would be to establish a practice-based research network.

Some of the children with S-ECC were under the care of a dentist at the time of their treatment at The Hospital for Sick Children. A number of them remained under the care of the same dentist for a long time. Therefore, adults with a history of S-ECC could be matched with adults who were caries-free in early childhood and were treated by the same dentists. Although this approach might yield little or no success, it is worth mentioning.

Significance
To the best of our knowledge, this is the longest follow-up study of adults who experienced S-ECC and adults who were caries-free in early childhood.

If validated by other studies, the results of this pilot project suggest that the best way to decrease the burden of disease in adulthood may be by preventing and controlling the disease in early childhood. Since children with S-ECC remain at greater risk for dental caries in adulthood, preventive resources should preferentially be directed at very young children.

Identification of children who are likely to be at high risk for S-ECC based on genetic markers, even prior to the onset of environmental factors is now considered an important research priority. Determining the genetic predisposition to dental caries will help target preventive and clinical resources to at-risk individuals, right from birth, thereby influencing the rising incidence of ECC and changing the disease trajectory of adult disease.

16. Conclusions
Former S-ECC patients experience significantly higher levels of dental caries in adulthood and report more perceived unmet dental needs compared to adults who were caries-free in childhood. Dental caries experience in early childhood appears to be the best predictor for dental caries in adulthood.
17. Appendices

17.1. Appendix 1 - Tables and Figures

Table 4 - Age at the time of GA (years)

<table>
<thead>
<tr>
<th>S-ECC Group</th>
<th>Mean age (years)</th>
<th>N</th>
<th>Std. Deviation (years)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.87</td>
<td>11</td>
<td>.98</td>
<td></td>
<td>1.71</td>
<td>4.93</td>
</tr>
</tbody>
</table>

Table 5 - Age at the Time of Study

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean (years)</th>
<th>Std. Deviation (years)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>S-ECC Group</td>
<td>11</td>
<td>25.7</td>
<td>1.73</td>
<td>23</td>
<td>29</td>
</tr>
<tr>
<td>Comparison Group</td>
<td>10</td>
<td>26.3</td>
<td>4.85</td>
<td>20</td>
<td>33</td>
</tr>
</tbody>
</table>

Table 6 - Mean and Median dmft Scores at the Time of GA (S-ECC Group)

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Median</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.09</td>
<td>11</td>
<td>11</td>
<td>11</td>
<td>3.14</td>
<td>6.00</td>
<td>14.00</td>
</tr>
</tbody>
</table>

Table 7 - Comparison of DMFT Scores between the Two Groups - Independent Samples Mann-Whitney U Test

<table>
<thead>
<tr>
<th>Null Hypothesis</th>
<th>Test</th>
<th>Sig.</th>
<th>Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Distribution of DMFT is the same across both groups</td>
<td>Independent Samples Mann-Whitney U Test</td>
<td>0.000</td>
<td>Reject the Null Hypothesis</td>
</tr>
<tr>
<td>The Distribution Decay is the same across both groups</td>
<td>Independent Samples Mann-Whitney U Test</td>
<td>0.036</td>
<td>Reject the Null Hypothesis</td>
</tr>
<tr>
<td>The Distribution of Missing is the same across both groups</td>
<td>Independent Samples Mann-Whitney U Test</td>
<td>1.000</td>
<td>Retain the Null Hypothesis</td>
</tr>
<tr>
<td>The Distribution of Filled is the same across both groups</td>
<td>Independent Samples Mann-Whitney U Test</td>
<td>0.000</td>
<td>Reject the Null Hypothesis</td>
</tr>
</tbody>
</table>
Table 8 - Comparison of DMFT Scores between the Two Groups - Independent Samples T-Test

<table>
<thead>
<tr>
<th>Groups</th>
<th>n</th>
<th>Mean</th>
<th>Std. Dev.</th>
<th>Std. Err. Mean</th>
<th>p-value</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fillings*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S-ECC</td>
<td>11</td>
<td>6.09</td>
<td>2.98</td>
<td>0.89</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td>10</td>
<td>1.20</td>
<td>1.62</td>
<td>0.51</td>
<td>0.000</td>
<td>2.66</td>
<td>7.11</td>
</tr>
<tr>
<td>Decay*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S-ECC</td>
<td>11</td>
<td>1.09</td>
<td>1.30</td>
<td>0.39</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td>10</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.016</td>
<td>0.23</td>
<td>1.95</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S-ECC</td>
<td>11</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td>10</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>----</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMFT*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S-ECC</td>
<td>11</td>
<td>7.18</td>
<td>3.12</td>
<td>0.94</td>
<td>0.000</td>
<td>3.67</td>
<td>8.29</td>
</tr>
<tr>
<td>Comparison</td>
<td>10</td>
<td>1.20</td>
<td>1.61</td>
<td>0.51</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* - statistically significant results

Table 9 - Mean and Median DMFT Scores for the S-ECC and Comparison Groups Combined

<table>
<thead>
<tr>
<th>Mean</th>
<th>Median</th>
<th>N</th>
<th>Std. Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.33</td>
<td>4.00</td>
<td>21</td>
<td>3.92</td>
<td>0.00</td>
<td>13.00</td>
</tr>
</tbody>
</table>

Table 10 - Oral Health Rating

<table>
<thead>
<tr>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>Excellent</td>
<td>2/11</td>
</tr>
<tr>
<td>Very good</td>
<td>3/11</td>
</tr>
<tr>
<td>Good</td>
<td>4/11</td>
</tr>
<tr>
<td>Fair</td>
<td>2/11</td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
</tr>
</tbody>
</table>
### Table 11 - Frequency of Dental Visits

<table>
<thead>
<tr>
<th></th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than once a year</td>
<td>6/11</td>
<td>7/10</td>
</tr>
<tr>
<td>check-ups/ cleaning.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>About once a year</td>
<td>3/11</td>
<td>3/10</td>
</tr>
<tr>
<td>check-ups/ treatments/</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cleaning.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than once a year</td>
<td>2/11</td>
<td>0/10</td>
</tr>
<tr>
<td>check-ups/treatment/cleanings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
<td>10/10</td>
</tr>
</tbody>
</table>

### Table 12 - Tooth Brushing Frequency

<table>
<thead>
<tr>
<th></th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Twice a day or more</td>
<td>4/11</td>
<td>4/10</td>
</tr>
<tr>
<td>Twice a day</td>
<td>4/11</td>
<td>6/10</td>
</tr>
<tr>
<td>Once a day or more</td>
<td>3/11</td>
<td>0/10</td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
<td>10/10</td>
</tr>
</tbody>
</table>

### Table 13 - Tooth Flossing Frequency

<table>
<thead>
<tr>
<th></th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a day or more</td>
<td>0/11</td>
<td>2/10</td>
</tr>
<tr>
<td>Once a day</td>
<td>3/11</td>
<td>3/10</td>
</tr>
<tr>
<td>Less than once a day</td>
<td>7/11</td>
<td>5/10</td>
</tr>
<tr>
<td>Don't know/ Refuse to answer</td>
<td>1/11</td>
<td>0/10</td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
<td>10/10</td>
</tr>
</tbody>
</table>
Table 14 - Expenditures for Dental Care by Both Groups within the Last Year

<table>
<thead>
<tr>
<th></th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>Less than $ 500</td>
<td>5/11</td>
<td>7/10</td>
</tr>
<tr>
<td>$500-1,000</td>
<td>1/11</td>
<td>1/10</td>
</tr>
<tr>
<td>$ 1,000- 1,500</td>
<td>1/11</td>
<td>0/10</td>
</tr>
<tr>
<td>More than $ 1,500.</td>
<td>1/11</td>
<td>0/10</td>
</tr>
<tr>
<td>Don't know/ Refuse to answer</td>
<td>3/11</td>
<td>2/10</td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
<td>10/10</td>
</tr>
</tbody>
</table>

Table 15 - Total Household Income from All Sources in the Past 12 Months

<table>
<thead>
<tr>
<th></th>
<th>S-ECC Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>$10,000 to less than 20,000</td>
<td>1/11</td>
<td>0/10</td>
</tr>
<tr>
<td>$ 20,000 to less than 30,000</td>
<td>1/11</td>
<td>1/10</td>
</tr>
<tr>
<td>$ 30,000 to less than $ 40,000</td>
<td>2/11</td>
<td>1/10</td>
</tr>
<tr>
<td>$ 40,000 to less than $ 50,000.</td>
<td>1/11</td>
<td>0/10</td>
</tr>
<tr>
<td>$80,000 to less than $ 100,000.</td>
<td>2/11</td>
<td>2/10</td>
</tr>
<tr>
<td>$ 100,000 or more</td>
<td>2/11</td>
<td>1/10</td>
</tr>
<tr>
<td>Don't know/ Refuse to answer.</td>
<td>2/11</td>
<td>5/10</td>
</tr>
<tr>
<td>Total</td>
<td>11/11</td>
<td>10/10</td>
</tr>
</tbody>
</table>
Figure 6 - The Frequency Distribution of DMFT Scores for the S-ECC and Comparison Groups
The Distribution of DMFT Scores for the S-ECC and Comparison Groups Combined
17.2. Appendix 2 – Questionnaire

DATA COLLECTION SHEET

QUESTIONNAIRE

Date:   M  /  D  /  Y

Study Identifier Code: ____________________

ORAL HEALTH

Q1. What kind of dental treatment(s) do you think you need?  

   Instruction: Mark all that apply.

   2. Fillings of dental cavities
   3. Temporomandibular joint disorder (jaw pain or clicking)
   4. Surgery (tooth extraction)
   5. Periodontics (gum disease)
   6. Esthetics (the appearance of your teeth)
   7. Endodontics (root canal treatment)
   8. Orthodontics (teeth alignment)
   9. Prosthetics (replacement of missing or severely damaged teeth)
   10. Other – Specify:__________________
   11. Don’t know/ Refuse to answer

Q2. In general would you say that the health of your mouth is:

   1. Excellent
   2. Very Good
   3. Good
   4. Fair
   5. Poor
   6. Don’t know/Refuse to answer
Q3. How satisfied are you with the appearance of your teeth and/or dentures?
   1. Very satisfied.
   2. Satisfied.
   3. Neither satisfied nor dissatisfied.
   4. Dissatisfied.
   5. Very dissatisfied.
   6. Don’t know/ Refuse to answer

Q4. In the past month, that is, from [date last month] to yesterday, have you had a toothache?
   1. Yes
   2. No
   3. Don’t know/ Refuse to answer

Q5. How often do you usually brush your teeth and/or clean your dentures?
   1. twice a day or more
   2. twice a day
   3. once a day or more
   4. less than once a day
   5. Don’t know/ refuse to answer

Q6. How often do you usually floss your teeth?
   1. Once a day or more
   2. Once a day
   3. Less than once a day
   4. Don’t know/ Refuse to answer

Q7. How often do you usually see a dental professional?
   1. More than once a year for check-ups and/or cleaning
   2. About once a year for check-ups/ treatment/ cleaning
3. Less than once a year for check-ups or treatments/cleaning
4. Only for emergency care
5. Never
6. Don’t know/Refuse to answer

Q8. When was the last time that you went to a dentist?
   1. Less than 1 year ago.
   2. 1 year to less than 2 years ago
   3. 2 years to less than 3 years ago
   4. 3 years to less than 4 years ago
   5. 4 years to less than 5 years ago
   6. 5 or more years ago
   7. Never
   8. Don’t know/Refuse to answer

Q9. In the past 12 months, have you avoided having professional treatment for some or all of your dental/oral problems?
   1. Yes
   2. No
   3. Don’t Know/Refuse to Answer

Q10. Why have you avoided professional treatment? *(Select all that apply).*
    1. Cannot get an appointment
    2. Don’t have dental insurance
    3. Cannot afford it
    4. Cannot get to the dentist
    5. Previous treatment hasn’t helped
    6. Treatment is too painful
    7. Too afraid
    8. Too far to travel
    9. Too busy
10. Don’t want to upset my mouth
11. Cannot be bothered
12. Too sick to go
13. Not important
14. Other
15. Don’t Know/Refuse to Answer

Q11. How much did you spend on dental care last year?
   1. Less than $ 500
   2. $ 500-1,000
   3. $ 1,000-1,500
   4. More than $ 1,500
   5. Don’t know/Refuse to answer

DIABETES AND PRESCRIBED MEDICATION

Q12. Have you ever been diagnosed with diabetes?
   1. Yes       If "Yes": How old were you at that time?___________
   2. No.
   3. Don’t know/ Refuse to answer

Q13. In the past month, that is, from [date last month] to yesterday, did you take any prescription medications? Prescribed medication could also include things such as insulin and nicotine patches (pills, patches or injections).
   1. Yes       If “Yes”: How many different types? ___________
   2. No
   3. Don’t know/ Refuse to answer

Q14. Do you remember the names of your medications?
   1. Yes.
   2. No.
   3. Don’t know/ Refuse to answer
If “Yes”, please indicate the name(s) of your medication(s):

______________________________________________

__________________________________

INSURANCE COVERAGE

Q15. At present, do you have insurance that covers all or part of your dental expenses?

1. Yes
2. No
3. Don’t know/Refuse to answer

Q16. If you have insurance that covers all or part of your dental expenses is it a:

(mark all that apply)

1. …a government-sponsored plan?
2. …an employer-sponsored plan?
3. …a private-sponsored plan?
4. Don’t know/Refuse to answer

INCOME

Q17. What was the total household income from all sources in the past 12 months?

1. Less than $10,000.
2. $10,000 to less than $20,000
3. $20,000 to less than $30,000
4. $30,000 to less than $40,000
5. $40,000 to less than $50,000
6. $50,000 to less than $60,000
7. $60,000 to less than $80,000
8. $80,000 to less than $100,000
9. $100,000 or more
10. Don’t know/Refuse to answer
LABOUR FORCE ACTIVITY
Q18. Are you currently employed?
   1. Yes- Full Time
   2. Yes- Part Time
   3. Self-employed
   4. Sick leave
   5. Maternity leave
   6. No- Unemployed
   7. Permanently Unable
   8. Don’t know/ Refuse to answer

SOCIO-DEMOGRAPHIC CHARACTERISTICS
Q19. What is your place of birth?
   1. Canada
   2. Outside Canada
   3. Don’t know/ Refuse to answer

Q20. How many siblings do you have (brothers, sisters)? ____________

Q21. As you grew up, was there a specific event that changed the structure of your family?
   (E.g., your parents got a divorce or one of them left or passed away)
   1. Yes
   2. No
   3. Don’t know/ Refuse to answer

Q22. Did either of your parents drink or use drugs or smoke so often that it caused problems for the family?
   1. Yes
   2. No
   3. Don’t know/ Refuse to answer
Q23. What is the highest level of education you have completed?
   1. Less than High School
   2. Completed High School
   3. Post-secondary Technical School
   4. Some College or University
   5. Completed College Diploma
   6. Completed University Degree
   7. Completed Post-Graduate Degree (M.A., Ph.D.)
   8. Refuse to answer

Q24. Are you currently attending a school, college or university?
   1. Yes  If “Yes”: Full-time or Part-time?
   2. No
   3. Refuse to answer

Q25. Are you living:
   1. By yourself?
   2. With your roommate?
   3. With your parents?
   4. With your spouse/children?
   5. With your spouse/children/parents?
   6. Refuse to answer

Q26. What is your current marital status?
   1. Married
   2. Living common-law
   3. Widowed
   4. Separated
   5. Divorced
   6. Single, never married
   7. Refuse to Answer
Q27. Do you have children?
   1. Yes  If “Yes”: How many? ____
   2. No
   3. Refuse to Answer

SMOKING
Q28. At the present time, do you smoke cigarettes daily, occasionally or not at all?
   1. Daily
   2. Occasionally
   3. Not at all
   4. Don’t know/ Refuse to answer

THANK YOU!
17.3. Appendix 3 - Letter of Invitation

Date:

Dear Mr./Ms._________________________________________,

We are contacting you on behalf of the Hospital of Sick Children.

The hospital is conducting a long-term follow-up study about the relationship between the oral health of children and that of adults and is inviting you to participate.

If you are interested, in finding out more about this initiative please contact Dr. Alexandra Nicolae at telephone no. (416)-540-0866/e-mail address alexandra.nicolae@utoronto.ca or Dr. Gajanan Kulkarni at telephone no. (416)-979-4926 ext. 4460 or e-mail address: G.Kulkarni@dentistry.utoronto.ca.

You will be compensated for your time.

Thank you for your consideration.

Peter Judd, BSc, DDS, D.Paed., MSc., FRCD(C)  Michael J. Casas, DDS, MSc, FRCD(C)
Dentist-in-Chief  Director of Clinics
Department of Dentistry  Department of Dentistry
The Hospital for Sick Children  Project Director (Research Institute)
Associate Professor  The Hospital for Sick Children
University of Toronto  Associate Professor

Dr. Gajanan Kulkarni  University of Toronto
Gajanan (Kiran) Kulkarni  BDS, LLB, MSc, D Paed Dent, PhD, FRCD(C)
Diplomate, American Board of Pediatric Dentistry  Associate Professor, Pediatric and Preventive Dentistry
Faculty of Dentistry  University of Toronto

Dr. Alexandra Nicolae, DDS, MSc DPH (Candidate)
Dental Public Health  7-April-2011
Faculty of Dentistry
University of Toronto

University of Toronto
Clinical investigation:
A longitudinal clinical study designed to investigate if experience of dental disease in early childhood predicts the presence of oral disease in adulthood.

Principal Investigator:
Dr. Alexandra Nicolae, M.Sc. - Dental Public Health (candidate).

Supervisor:
Dr. Gajanan Kulkarni, Associate Professor, Pediatric and Preventive Dentistry. Tel: 416-979-4929 ext.4460.

Co-investigators:
Dr. Michael Casas
Dr. Peter Judd

Purpose:
To investigate if the treatment for Severe- Early Childhood Caries (S-ECC) under General Anesthesia (GA) predicts the presence of oral disease in adulthood.

Description:
A dental examination similar to a regular check-up at the dentist will be conducted. We will examine your teeth and take 2-4 radiographs (X-rays). In addition, you will need to fill out a questionnaire.

Potential harms, injuries or inconvenience:
There is no foreseeable harm or injury as a result of participating in this study. The inconvenience lies in having to come to the Faculty of Dentistry for the examination to be conducted and the time spent in collecting the needed information.
**Potential benefits:**
A dental examination has the potential benefit of early detection of dental disease which may be managed thereafter at the Faculty of Dentistry or any other dental clinic. You will get copies of the X-rays if you wish. Should any oral or dental problems be identified by the examiner, you will be notified of your options regarding follow up and treatments. Also, you will be compensated for your travel expenses with $40 in cash.

**Duration of study:**
Only a one-time participation is required to complete the clinical examination which should not take more than 1 hour.

**Confidentiality:**
Confidentiality will be respected and no information that discloses your identity will be released or published without consent unless required by law. In order to ensure the proper safe-guard of the information, all the data will be encrypted. For your information, the research consent form will be inserted in the patient health record.

**Participation:**
Participation in this study is completely voluntary. You may choose to withdraw from this study at any point of time without provision of a reason.

**Consent:**
I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction.

I have been informed of the right not to participate and the right to withdraw from this study at any given point of time without provision of a reason.
The potential harms and discomforts have been explained to me. I understand the benefits (if any) of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or the research procedures.

I have been assured that records collected in this study will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law.

I, ____________________________, hereby consent to participate in the study.

_______________________________________
Signature / Date

________________________________________
Name / Signature of person who obtained consent
Title of Research Project:
*Is the Pattern of Adult Dental Disease Set in Early Childhood?*

Principal Investigator:
Dr. Gajanan Kulkarni, Associate Professor, Pediatric and Preventive Dentistry.
Tel: 416-979-4929 ext.4460

Co-investigators:
Dr. Michael Casas   Tel: 416-813-6018
Dr. Peter Judd   Tel: 416- 813-6008
Dr. Alexandra Nicolae, M.Sc. - Dental Public Health (candidate) supervised by Dr. Gajanan Kulkarni, the Principal Investigator. Tel: 416- 540-0866/ 416- 979-4900 ext. 4670.

Purpose of the Research:
A longitudinal clinical study designed to investigate if experience of severe dental disease in early childhood predicts the presence of oral disease in adulthood.

Description:
Upon arriving at the Faculty of Dentistry, University of Toronto, a dental examination will be conducted which would be similar to a regular check-up at any dental office. We will examine your teeth and take 2-4 radiographs (X-rays). In addition, you will be invited to fill out a short questionnaire.
There will be no subsequent use of the research data beyond the current study. All the research data are to be destroyed after the study is complete.
Potential Harms, Discomforts or Inconvenience
There is no foreseeable harm or injury as a result of participating in this study. The inconvenience lies in having to come to the Faculty of Dentistry for the examination to be conducted and the time spent filling out the questionnaire.

Duration of study:
Only a one-time participation is required to complete the clinical examination which should not take more than 1 hour.

Potential Benefits to Individual Subjects
A dental examination has the potential benefit of early detection of dental disease which may be managed thereafter at the Faculty of Dentistry or any other dental clinic. You will receive copies of your dental X-rays if you wish. Should any oral or dental problems be identified by the examiner, you will be notified of your options regarding follow up and treatments. Also, should you desire, you will be informed about the results of the research study.

Potential Benefits to Society
Our expectation is that the results of the study will lead to improved oral health promotion and preventive programs that will help young children obtain and maintain good oral health right from early childhood, which in turn will lead to better oral health when they are adults.

Confidentiality:
We will respect your privacy and confidentiality. No information about who you are will be given to anyone or be published without your permission, unless required by law. For example, the law could make us give information about you if a child has been abused, if you have an illness that could spread to others, if you or someone else talks about suicide (killing themselves), or if the court orders us to give them the study papers.

Sick Kids Clinical Research Monitors, employees of the University of Toronto, or the regulator of the study may see your health record to check on the study. By signing this consent form, you agree to let these people look at your records. We will put a copy of this research consent form in your patient health record and give you a copy as well.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. This could include external research team members. In order to ensure the proper safe-guard of the information, all the data will be encrypted. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.
**Reimbursement:**
We will also provide you with a one-time compensation of $40 in cash in recognition of your time and effort.

**Participation:**
Participation in this study is completely voluntary. You may choose to withdraw from this study at any point of time without provision of a reason.

The care your children (should you have any) will not be affected in any way by whether you take part in this study or not.

If you become ill or are harmed because of study participation, we will treat you for free. Your signing this consent form does not interfere with your legal rights in any way. The staff of the study, any people who gave money for the study, or the Faculty of Dentistry are still responsible, legally and professionally, for what they do.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

**Sponsorship:**
The sponsor/funder of this research is Faculty of Dentistry, University of Toronto.

**Conflict of Interest:**
The Principal Investigator, Dr. Kulkarni, and the other research team members have no conflict of interest to declare.

**Consent:**
By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect the health care (of my children, should I have any) at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.
I have read and understood pages 1 to 5 of this consent form. I agree, or consent to take part in this study.

________________________________        _______________________________
Printed Name of Subject & Age                  Subject’s signature & date

________________________________
Printed Name of person who explained consent

Signature of Person who explained consent & date

______________________________________      _______________________________
Printed Name of person who explained consent      Subject’s signature & date

___________________________
Printed Witness’ name (if the subject does not read English)

Witness’ signature & date

If you have any questions about this study, please call Dr. Alexandra Nicolae at: telephone number (416)-540-0866 or Dr. Gajanan Kulkarni at telephone number 416-979-4929 ext.4460.

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.
18. References


