CAREGIVER'S PERCEPTIONS OF ORAL HEALTH RELATED QUALITY OF LIFE AMONG CHILDREN WITH SPECIAL NEEDS IN JOHANNESBURG.

Cathrine Batseba Nqcobo

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DECLARATION

I, **Cathrine Batseba Nqcobo**, declare that this research report is my own work. It is being submitted in partial fulfilment for the degree of Master of Dentistry at the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted for any other degree or examination at this university or any other university.

Dr CB Nqcobo_____

Signed at _Wits_____ (place) on the_20th_____day of___November___in the year 2015.

School of Oral Health Sciences

University of the Witwatersrand

DEDICATION

This is dedicated to my mother,

Mokgadi Regina Malau, whose love,

Support and encouragement made this research report possible.

And to husband Kenneth and my sons

Quincy and Kamogelo Nqcobo

For your unconditional love and understanding during my studies.

ABSTRACT

This study **aims** to assess Oral Health-Related Quality of Life among children with special needs, from the caregiver's perspective. The **objectives** of the study were: (i) To describe the demographic profile of the caregivers in terms of age, gender and socio-economic status,(ii) To assess the dental caries status of children with special needs,(iii) To establish the caregivers' perceived Oral Health-Related Quality of Life of the children with special needs using the short-form Parent-Caregiver Perception Questionnaire, (iv) To assess the impact of the dental caries status on the families of children with special needs using the Family Impact Scale questionnaire. **Results:** The study consisted of 150 caregiver child pairs, the mean age of the caregivers was 39.52 years (SD 9.26) and mean age of children was 8.72 years (SD 6.07). There was a high prevalence of untreated caries regardless of the type of disability. The highest caries prevalence in both the primary and permanent dentition was found in the Epilepsy and the Autism groups (75%-83%) while the lowest was found among Down syndrome and Cerebral palsy groups (30%-47%).All the caregivers expressed impact on the Oral Health-Related Quality of Life.The mean Parent-Caregiver Perception Questionnaire score was 12.88 (SD 12.14) while the mean Family Impact score was 6.05 (SD 6.77). The highest Parent-Caregiver Perception score of 20.5 (SD 11.07) was found in the complex disability group followed by the Down syndrome group 15.87 (SD 13.87). The highest scores were found in the oral symptoms, functional limitation and emotional wellbeing domains which contributed more to the parent perception score. **Conclusion:** Caregivers of children with special needs in the current study experienced a negative impact on Oral Health-Related Quality of Life. Caries experience of the children with special needs was slightly lower than in the general population irrespective of disabilities and had no impact on the FIS and overall global rating-well-being.

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ABBREVIATIONS AND ACRONYMS

BDI: Beck Depression Inventory

COHRQoL: Child oral health related quality of life

CSNs: Children with Special Needs

DSA: Down Syndrome Association

FHC-OHRQoL: Franciscan Hospital for Children Oral Health Related Quality of Life questionnaire

FIS: Family Impact Scale

ID: Intellectual Disability

NCOHS: National Children's Oral Health Survey

OHRQoL: Oral Health Related Quality of Life

P-CPQ: Caregiver Perception Questionnaire

QoL: Oral Health-Related Quality of Life

QRS: Questionnaire of Resources and Stress

CHAPTER 1: INTRODUCTION

1.1 Introduction and Background

Caregivers of Children with Special Needs (CSNs) face an increased burden due to the demands of taking care of their children. The huge burden related to the general health concerns of these children often results in neglect regarding their oral health as this is not regarded as a priority (1). It is also challenging for the oral health care providers to provide effective and efficient oral health care for CSNs because of cognitive limitations, behavioural concerns, oral-motor limitations of the CSNs which restrict intraoral access and impact on the diagnostic and preventative procedures (2).Other limitations like motor, sensory and intellectual disabilities also lead to the CSNs having difficulties in communicating their oral health needs and as a result they depend on their caregivers for general care including oral hygiene (3).

Over a billion people (15% of the world's population) are estimated to live with some form of disability and this estimate is on the rise (4). According to census data of 2011, approximately 7.5% of the population in South Africa are living with disabilities, of which Gauteng province has the lowest prevalence of disabilities at 5% (5). There is a higher prevalence of disabilities among females (8.3%) compared to males (6.5%). Data shows that 2.1 million (11.2% of the total child population) children in South Africa are categorised as CSNs. Of the total child population with special needs, 28% is in the 0-4 year old group and 10% is in the 5-9 year old group (5).

These children are the neglected segment of the population in terms of access to services like education, however, there is no up-to-date data which indicates their general health status and their use of health services (6). The census data shows that attendance of early childhood

development centres/schools among children aged 5–6 years, with disabilities was lower compared to those who did not have disabilities (4). Previous studies have shown high levels of untreated caries in CSNs (7) and that they have poor access to oral health care services. This could be attributed to the different perceptions of the caregivers to their oral health needs. The caregivers perceptions of their child's oral health status and Oral Health Related Quality of Life (OHRQoL) influences their oral health care seeking behaviour and motivates them to access oral health services (8, 9). Children with Special Needs are more susceptible to poor oral health which has a significant effect on their quality of life. This can cause difficulty with eating, speech, pain, sleep disturbances and missed days at school (10). Additionally, poor oral health may compromise the family welfare because the parents feel guilty for their children's problems and have work absenteeism and expenditures associated with dental treatment (11). Due to the inherent difficulties in communication among CSNs, the caregiver and/or parental perception of the children's oral health is often used as proxy measure (12, 13). Locker reported that personal and environmental variables such as household income and level of education of the caregiver mediated the relationship between clinical oral disease and OHRQoL (14).

Caregivers are mostly mothers to the children as a result they bear most of the burden in caring for their CSNs and this can have a detrimental impact on family life (15). A study which focused on the caregivers of children with Cerebral palsy reported that caregivers had a low quality of life, due to the difficult tasks of caring for their children and preventing oral diseases (16). They also face many barriers in fulfilling their role in helping their CSNs with oral hygiene such as the problems with manual dexterity, difficulty with motor sensory movement, etc. (17).

1.2 Rationale and significance of the study

Young children are the prime target group of oral health care service in many countries including South Africa. This research report gives an account of a study that was conducted with the aim to assess the OHRQoL of CSNs, because it has been shown that the impact of oral disease on OHRQoL of children can be used in health service planning and priority setting (18). Studies have recommended that people with a negative impact on their OHRQoL should be prioritised and receive treatment first (19). Hence this vulnerable group of children needs to be prioritised in the planning of health services and oral health care programs. The programmes need to be informed by the needs of the caregivers together with their children (18).

CHAPTER 2: LITERATURE REVIEW

This chapter is based on an electronic search of data bases and the search used key words that pertained to the objectives of the study. A literature review was conducted in this study and definition of terms, oral health status and CSNs as well as caregiver perceptions are outlined in this chapter.

PUBMED, EBSCO host, Scopus and various other databases were searched for journal articles. This review of the published literature explored the perceptions of OHRQoL for children with special needs and its impact on their quality of life during the period of 2005 to 2015. Some important studies which were dated prior to 2005 were also included. The search terms that were used included “oral health”, “Quality of Life”, “Oral Health Related Quality of Life”, “Parent Perceptions”, “Caregiver Perceptions” and “Children with Special Needs”.

2.1 Definition of terms

According to the WHO, Quality of Life is defined “as the individual’s perceptions of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (20).

Oral Health-Related Quality of Life (OHRQoL) is defined as “The impact of oral diseases and disorders on aspects of everyday life that a patient or person values, that are of sufficient magnitude, in terms of frequency, severity or duration to affect their experience and perception of their life overall”(21). Malden *et al.,* explained that the definition of OHRQoL relates to “the impact that oral health or disease has on the individual’s daily functioning and

well-being" (22). It takes into account the individual's perceptions of their oral health status as well as the psychological and social impact of oral disease (18).

Children with Special Health Care Needs (CSHCN) are defined as "those children who have an increased risk for a chronic physical, developmental, behavioural, or emotional condition and require health and related services of a type or amount beyond that required by children generally"(23). The term: Children with Special Health Care Needs and Children with Special Needs are used interchangeably. For the purpose of this study, the term Children with Special Needs is used (CSNs). The types of disabilities that were included in this study were Down syndrome, Cerebral palsy, Autism and Epilepsy. For the purpose of the study, all the severe disabilities were grouped together under the label of complex disabilities. These included conditions like myotonic dystrophy (24), severe physical disability and syndromes like Noonan syndrome (25) and Cornelia de Lange syndrome (26).

In this study, caregivers were defined as all the parents, legal guardians or relatives who attend to the needs of a dependent (27).

2.2 The OHRQoL measurement tool

Oral Health Related Quality of Life is measured by using the OHRQoL instrument and some of the questionnaires used for children include: Child Oral Health Related Quality of Life questionnaire (COHRQoL) (28) (29), Child Oral Health Impact Profile (COHIP) (30) the Child-Oral Impacts on Daily Performances (Child-OIDP) (19), the Michigan OHRQoL scale (31) and Early Childhood Oral Health Impact Scale (ECOHIS) (32). One of the most commonly used questionnaires in children is the COHRQoL.

The COHRQoL is a set of scales measuring the negative impact of oral diseases on the well-being of children and their families. This questionnaire has three components which include Child Perceptions Questionnaire (CPQ), the Parental-Caregiver Perceptions Questionnaire (P-CPQ) and the Family Impact Scale (FIS). However, this current study has used only two of the three components i.e. P-CPQ and the FIS in their short form because the CPQ could not be used on children with special needs.

The first component i.e. P-CPQ is a measure of parental/caregiver perception of the OHRQoL of the children especially those who have special needs or may be too young to answer questions pertaining to oral health related quality of life (28, 29). The questionnaire was developed firstly because parents/caregivers are closely involved in the health and health care of their children. Secondly, the questionnaire was also developed because the referral for treatment of children's oral health problems is likely to be influenced by parental perceptions of a child's needs (33).

The development of the (COHRQoL) questionnaire involved a review of child health questionnaires and interviews with parents/caregivers of children with paedodontic, orthodontic, and orofacial conditions (34).From the review of the questionnaires, a pool of 47 items was developed. These included questions on the oral conditions and their impact on quality of life. These items were later used in an item impact study which included 208 parents/caregivers who provided information on the frequency and importance of items in the item pool. Thirty-one items were the most frequent and important, and were then selected for the final questionnaire called the Parent Caregiver Perception Questionnaire (P-CPQ) (34).

A convenience sample of parents/caregivers of paediatric dentistry patients, orthodontic patients, and patients with orofacial conditions (predominantly cleft lip or palate) was used to validate the P-CPQ. The setting for the study was six sites which included the Faculty of

Dentistry, University of Toronto, the Craniofacial Unit, Hospital for Sick Children, Toronto, and Toronto Public Health Dental Clinics (34).

Locker *et al*., later developed and evaluated the FIS questionnaire in a study which involved 93 caregivers (59% were mothers) of children aged between 6 and 14 years. The most common impacts reported were the child requiring more attention, financial difficulties, taking time off work, parents feeling guilty, worried and upset about the child's condition (29). These results give evidence that oral conditions affect parent and family activities, impact on parental emotions and can result in conflict in the family (29). Caregivers for CSNs are often responsible for essential oral health practices such as feeding practices, oral hygiene and seeking dental care (35).

The original P-CPQ has 34 items which are divided into four subscales/domains: Oral Symptoms (OS) with five items, Functional Limitations (FL) with nine items, Emotional Wellbeing and Social Wellbeing (SWB) with eight and twelve items, respectively. The questions on the domains refer to the frequency of events in the previous 3 months and the items are scored on a 5 point Likert type scale with options from "never" to "almost every day". The score is calculated by the adding all the scores in each domain and the sum of the three domain scores make up the individual P-CPQ score 0-148. A high score indicates a poor quality of life.

The second component of the tool is the Family Impact Scale (FIS) which was developed by Locker *et al*., (29). This scale is regarded as an essential component of the child OHRQoL measure (29) because it recognises the central role played by the family in child health as well as the impact of the child's chronic illness on the family. The FIS scale was developed on the basis that that parental reports of a child's health may be influenced by the degree to which the

parent is physically or emotionally affected by the child's condition (29). The FIS is composed of 14 items that measure the impact of the oral condition on the Quality of Life of the family and is measured across four domains: parental and family activities, parental emotions, family conflict, and family finances (29). The total score range is 0-56 which is calculated separately but in the same way as described above for the P-CPQ. The original P-CPQ and FIS OHRQoL questionnaires had limited routine use in research because they were long, hence Thomson *et al*., developed the short form versions (36).

An OHRQoL questionnaire is evaluated by the presence of global rating questions (21). These are summary indicators which consist of single questions that provide a summary of how people perceive their health (37). They are widely used in health services research and for testing the construct validity of measures of Health Related Quality of Life as well as OHRQoL (38, 39) . The first question requires the participants to rate their children's overall oral health status using a five-point Likert scale and the response options are from "excellent" to "poor". The second question focuses on how the overall wellbeing of the child is affected by the oral health status using a Likert scale ranging from "not at all" to "very much" (38). In this study, the two global rating questions were included in addition to the two components (P-CPQ and FIS) of the Child Oral Health Related Quality of Life questionnaire.

2.3 Oral health status of CSNs and impact on Oral Health Related Quality of Life.

There are variations in the results concerning caries prevalence among CSNs. Some studies reported a higher burden of oral disease and unmet treatment needs while others reported a lower burden when compared to children in the general population. One study was conducted in the Limpopo province, South Africa which assessed the dental caries prevalence among disabled children attending special needs schools (40).The study involved 629 children and

pupils aged between 0 and 19 years. The overall caries prevalence was reported as 80% and the mean dmft/DMFT score was 5.51 (SD 2.1) and 7.38 (SD 3.22) respectively. The authors concluded that the children with special needs had higher caries prevalence and unmet dental needs compared to the general population in the same age groups (40).

Nqcobo *et al*., reported on a cross-sectional study among 3-21 year olds (n=882) from Johannesburg, South Africa that sought to determine the caries prevalence among children with Cerebral palsy, Hearing impaired, Learning disability and Mental disability (7). The caries prevalence was found to be 27% and 33% in primary dentition and permanent dentition respectively. This was lower than the prevalence in the general population as reported in the National Children's Oral Health Survey (NCOHS) (41). There were high unmet treatment needs which ranged between 55%-100% among the different disabilities (7).

The oral health of CSNs is of great importance because these children represent a high risk group for oral diseases such as dental caries, periodontal diseases, gingivitis, halitosis, malocclusion and enamel opacities (3). The oral health status of an individual with special health care needs is influenced by various sociodemographic factors such as age, living conditions, severity of impairment, special diets and the type of medication taken daily (3).

Children are a major focus of public health programmes as part of achieving the millennium development goals (MDGs) (42) and four of the goals are relevant to child health. These four goals relate to i) eradication of extreme poverty, (ii) achieving universal primary education, (iii) reducing child mortality and (iv) improving maternal mortality. Hence measures of OHRQoL are important to make sure that impact of oral disease on children, especially those with special health needs are well captured and understood (28). This is of importance when it comes to the planning of oral health services for this vulnerable population group.

In an attempt to measure this impact of oral diseases in children, Cohen and Jago first advocated the development of "socio-dental" indicators in 1976 to record the social aspects of oral disease (43), because the normative oral health assessment provides limited understanding of the impact of oral disease (18).

A cross sectional study in India was conducted which sought to determine prevalence of dental caries, oral health status, and periodontal needs in individuals with disabilities. The study population comprised of 258 participants aged between 6 and 40 years who were divided into five groups of disabilities namely: Mental disability, Autistic disorder, Down syndrome, Cerebral palsy and others. The overall caries prevalence was 76%. Among the groups, Down syndrome had the highest DMFT score (3.6 (SD 2.63) followed by Cerebral palsy (3.5 (SD 3.51)), Mental disability (3.54 (SD 4.22)) and Autism had the lowest score (2.25 (SD 1.39). These differences were not significant (p=0.856). The authors explained that the results (high caries prevalence and DMFT scores) were related to the limitation in the physical abilities of the participants, problems in communicating oral health needs as well as dependence on caregivers for oral hygiene practices (44).

Butani *et al.*, conducted a study in the USA with the aim of comparing the parental perceptions of the oral health status and access to dental services. The study involved children in 34 special education classes and 16 mainstream public schools using a self-administered questionnaire. the results indicated that that compared to mainstream schools, parents of learners in special education classes were twice as likely to report their children to have worse oral health (OR=2.4, CI 1.54-3.67) and have missed school days due to oral health problems (OR=2.5, CI 1.55-4.17). Nearly 60% of the parents of children in special education viewed their children as having less than excellent oral health compared to 40% of the mainstream parents (p=0.001). Far fewer (48%) parents of the special education group reported their

children as having excellent overall health compared to 82% of the mainstream parents. There were differences between the two groups in parental perceptions of their children's oral health status with special education children having worse oral health and less frequent dental care compared to the main stream children (45).

Parental perceptions on oral health status and children's OHRQoL was assessed in India by Yashoda and Puranik using only the P-CPQ. The study was a comparative cross sectional study which comprised of 4-15 year old children (n=135) with Autism compared with those without Autism. The result indicated that those with Autism had significantly higher dmft/DMFT scores (1.40 (SD 2.48) and 0.86 (SD 1.22) respectively) compared to those without Autism (0.59 (SD 1.28) and 0.46 (SD 1.06)) $p<0.01$ (46).

The children with Autism had higher caries experience in the primary dentition possibly due to the difficulties that the parents encounter when they need to brush the children's teeth. The P-CPQ score for the Autistic children was significantly higher (29.95 (SD 17.98)) than the score for the non-Autistic children (25.24 (SD 17.22)).The functional limitation and social wellbeing domain scores were reported to be statistically higher ($p<0.05$) in the Autistic children (8.86 (SD 5.65) and 9.27 (SD 8.25) respectively) than the non-autistic children (6.66 (SD 4.07) and 7.51 (SD 6.47) respectively). The significantly higher functional limitation domain scores in the Autism group were related to the self-inflicting habits of the Autistic children (46). The study also found a significant correlation between the DMFT and the oral symptoms domain in the children with Autism. All except the social wellbeing domain showed a significant correlation with dmft (Pearson's correlation coefficient significant at 0.01). The authors did not use the COHRQoL in its entirety as it was developed by Jokovic *et al*., (28).

A study was conducted by Pani *et al*., in Saudi Arabia to determine parental perceptions on the OHRQoL of Autistic children and to explore the effects of different sociodemographic variables on parents' perceptions of their children's quality of life. The study followed a cross sectional comparative design whereby a total of 59 families of Autistic children aged 8-13 years, who had unaffected siblings, were cross matched by age and gender of the affected child with families with no Autistic children. The study results showed that the majority of parents who participated were mothers and the instrument that was used was the P-CPQ and FIS. The results showed that the Autistic children had poor OHRQoL compared to their siblings as the overall P-CPQ scores for the Autistic children were significantly higher (37.05 (SD 18.60)) ($p<0.001$) than those of their siblings (21.02 (SD 18.14)) (13).

When the domain scores in the P-CPQ were compared, there were significantly higher scores reported in the functional limitation (9.51 (SD 5.77)), social wellbeing (11.95 (SD 6)) and emotional well-being (10.56 (SD 5.29)) domains of children with Autism compared to their siblings. The sibling scores were 3.83 (SD 4.57), 6.32 (SD 5.72) and 6.78 (SD 5.85) for functional limitation, social wellbeing and emotional wellbeing respectively. The authors explained that the parents of Autistic children were more inclined to be sympathetic towards the disability than to the oral status, hence the results of lower perception scores in the oral symptom and higher scores in the functional limitation, emotional wellbeing and social wellbeing domains were reported. Significantly higher family impact domain scores were found in families with autistic children compared to those without autistic children. These were found in parental emotions (4.98 (SD 3.7) vs 3.26 (SD 3.05)) and family finances domains (0.97 (SD 1.1) vs 0.41 (SD 0.9)). The differences in the scores was statistically significant ($p<0.001$) (13).

Results from a regression analysis established that maternal age had a significant positive influence on the P-CPQ score which indicated that older mothers had more concerns about children's oral health. The level of education had a positive influence on the FIS. Maternal education played a role in FIS whereby an inverse relationship between the FIS and family finances was observed in the results (13). The authors concluded that the Autism condition resulted in poor OHRQoL for both the affected child and their families. This study only focused on Autistic children and no dental caries status was assessed, hence the relationship between oral health status and the age of the mother could not be assessed (13).

Another study which highlighted the influence of maternal age and level of education on the caregivers' perception of OHRQoL was conducted by Baghdadi and Muhajarine in Saudi Arabia(12). The study sought to determine the effects of dental treatment under general anaesthetic on children's OHRQoL. The authors reported that maternal age was a significant factor that influenced the P-CPQ scores because older mothers had greater concerns about their children's oral health. Mother's education had a major influence in determining the positive effect of dental treatment on quality of life. Higher level of education was shown to have led to a higher score change from pre- to post- treatment OHRQoL scores (12).

A study was conducted in Brazil by Abanto *et al*., with the aim of investigating the impact of oral diseases and disorders on the OHRQoL of children with Cerebral palsy aged between 6-11 years (n=60) (47). Their caregivers (n=60) responded to questions of the P-CPQ and the FIS questionnaire. The dental caries prevalence was found to be 55% and the dmft and DMFT scores were 2.00 and 0.43 respectively. The mean overall P-CPQ score was 17.28 (SD 13.25) and the presence of dental caries was associated with a negative impact on the OHRQoL

[caries: RR = 1.75, CI 95% = 1.29–2.36, $p < 0.001$] .When each domain was evaluated, high scores were found in the oral symptoms (6.05 (SD 4.17)) and functional limitation domains (5.62 (SD 4.07)) which indicated that the presence of dental caries had a negative impact on the OHRQoL. High scores in the above mentioned domains could be due to severe dental caries which caused pain and difficulty to eat. About 43% of the parents reported that the overall wellbeing of their children was not affected by oral conditions and the authors explained that this result could have occurred because the children's overall wellbeing was mostly affected by the severity of the disability, rather than by the oral condition (47). Another possible explanation of the result could be that the parents knew very little about oral health and did not even consider oral health as important.

Piovesan *et al.,* conducted a study to assess the relationship of child OHRQoL with socio-economic status and clinical factors (dental caries, occlusion and trauma)(48). A total of 792 school children aged 12 years completed the Brazilian version of the Child Perceptions Questionnaire ($CPQ_{11–14}$), their parents or caregivers answered questions on socio-economic status. A dental examination was conducted to provide information on the caries prevalence, dental trauma and occlusion. The dental caries prevalence was found to be 39.3% but the dmft/DMFT scores were not reported. The mean overall CPQ score was 20.9 (SD 14.8). The authors found that children who presented with untreated dental caries had higher impacts on OHRQoL (RR = 1.2; 95% CI 1.07–1.35). The children whose mothers had not completed primary education (RR = 1.3; 95% CI 1.17–1.44) and those with lower household income (RR = 1.13; 95% CI 1.02–1.26) were found to have a poor OHRQoL. The authors concluded that poor socio-economic status and poor oral health status had a negative impact on the Child Oral Health Related Quality (48).

OHRQoL tools are also used to evaluate treatment. The next three studies (one conducted USA and two conducted in Saudi Arabia) involved participants who were scheduled for treatment under general anaesthesia (GA).

Baens-Ferrer and colleagues (2) conducted a study in Boston, USA with the aim of describing the symptoms, daily life problems and parental concerns related to dental general anaesthesia for CSNs. Caregivers of 107 children completed an OHRQoL survey questionnaire called the Franciscan Hospital for Children Oral Health Related Quality of Life questionnaire (FHC-OHRQOL).This questionnaire was designed specifically for the study and had three sections i.e. oral symptoms, daily life and parental concerns which were measured on a Likert scale. The children had several disabilities like Cerebral palsy, hydrocephalus, Autism, Epilepsy, developmental delay, etc. The results showed that the most frequent oral symptom reported by the caregivers was spontaneous toothache when exposed to hot/cold temperatures. Difficulty when eating, lack of sleeping and nourishment were the most frequently reported daily life problems. The study revealed that oral rehabilitation under GA was effective at improving OHRQoL for children with special needs and the quality of life of their families. The children could have had severe oral conditions prior to undergoing dental treatment under GA, hence the improved OHRQoL. The study used a different OHRQoL measuring tool, therefore, it was difficult to compare the results with other studies.

Baghdadi and Muhajarine (12) and Baghdadi (49) in Saudi Arabia reported on data from the same sample which was 66 parents and their children aged 3-10 years who were affected by severe early childhood caries and required treatment under GA. These studies excluded children with special needs. The studies sought to determine the effects of dental treatment under general anaesthetic on children's oral health related quality of life. Both studies applied

a pre- and post- cross sectional design using the original version of the P-CPQ (33 items) (used by Baghdadi and Muhajarine (12)) and the short form version of the questionnaire (16 items) used by Baghdadi (49).

When the two studies are compared, Baghdadi and Muhajarine found that the mean dmft/DMFT was 9.76 (SD 3.07) and 3.25 (SD 2.04) respectively. The pre-treatment P-CPQ was found to be 33.37 (SD 18.72) and FIS was 15.20 (SD 8.85). The high scores were found in the oral symptom (9.69 (SD 4.79)), functional limitation (10.03 (SD 7.45)) and emotional well-being (9.72 (SD 6.86)) domains. This result emphasised the negative impact of dental caries on the OHRQoL and the authors reported that caregivers' assessment of their child's OHRQoL correlated significantly with dmft scores following dental treatment (12). Baghdadi (49) found slightly lower scores when compared to Baghdadi and Muhajarine (12) i.e. P-CPQ score was 19.41 (SD 10.25) and FIS score was 10.60 (SD 5.41). Regarding domain scores, oral symptom and functional limitation had high scores (7.46 (SD 3.66) and 5.73 (SD 3.89) respectively).The results in both studies (12, 49) suggest that early childhood caries had a significant negative impact on the P-CPQ score and treatment under general anaesthetic improved the oral health related quality (12, 49).

In summary, Table 2.1 below describes the instruments used in the quoted studies from the literature review that reported on OHRQoL studies. The review indicates that there was a variation in the use of the COHROL instrument as some studies used only the P-CPQ, however, some studies used the short form and others used to original long version of the P-CPQ. Some of the studies did not use the FIS e.g. Baens-Ferrer *et al*., developed the FHC-OHRQOL questionnaire specifically for their study (2). Abanto *et al*., reported the overall OHRQoL as a sum of the scores from P-CPQ, FIS and global ratings while all the others

reported the overall score as the total P-CPQ (47). In general, the domains that showed high scores were the functional limitations, oral symptoms and emotional well-being. There was a variation in the reported FIS scores whereby some studies reported lower scores (47) and others reported very high scores (12).

Table 2.1: Instruments that were used in the quoted studies from the literature review and reported on Oral health related quality of life

Author, Year, Study design	**Country**	**Disability & Instruments used**	**P-CPQ and domains**	**FIS and Domains**	**dmft/DMFT**
Abanto *et al*., (47). Cross sectional design	Brazil	Cerebral palsy P-CPQ	P-CPQ 17.28 (SD 13.25) Oral symptoms 6.05 (SD 4.17) Functional limitation 5.62 (SD 4.07)	FIS = 3.32 (SD 4.76)	Prevalence 55% dmft = 2.00 DMFT = 0.43
Pani *et al*., (13) Comparative cross sectional design	Saudi Arabia	Autism P-CPQ and FIS	P-CPQ = 37.05 (SD18.6) Functional limitation = 9.51 (SD 5.77) Social wellbeing = 11.95 (SD 6.) Emotional wellbeing = 10.56 (SD 5.29)	Parental emotions = 4.98 (SD 3.7)	Oral health status not assessed
Yashoda and Puranik (46) Comparative cross sectional design	India	Autism P-CPQ	P-CPQ = 29.95 (SD17.98) Functional limitation = 9.27 (SD 8.25) Social wellbeing = 8.86 (SD 5.65)	Not used FIS	Dmft = 1.4 (SD 2.48) DMFT = 0.86 (SD 1.22)
Baghdadi and Muhajarine (12) Pre-test post-test cross sectional design	Saudi Arabia	No disability (only severe dental caries) P-CPQ and FIS	P-CPQ = 33.37 (SD 18.72) Oral symptoms = 9.69 (SD 4.79), Functional limitation =10.03 (SD 7.45) Emotional wellbeing = 9.72 (SD6.86)	FIS =15.2 (SD 8.85)	dmft/ DMFT was 9.76 (SD 3.07) and 3.25 (SD 2.04) respectively.
Baghdadi (49) Pre-test post-test cross sectional design	Saudi Arabia	No disability (only severe dental caries) **Short form version** P-CPQ and FIS	P-CPQ = 19.41 (SD 10.25) Oral symptoms = 7.46 (SD 3.66) Functional limitation = 5.73 (SD 3.89)	FIS =10.6 (SD 5.41)	Oral health status not reported
Abanto *et al*., (50) Cross sectional design	Brazil	Cerebral palsy P-CPQ and FIS	Overall score = P-CPQ+FIS+ Global rating scores = 17.28 (SD 13.25) Oral symptoms = 1.02 (SD 0.56) Functional limitation = 0.75 (SD 0.56) Emotional wellbeing = 0.15 (SD 0.32)	FIS = 0.24 (SD 0.34)	DMFT/ dmft scores were not reported in the study
Piovesan *et al*., (48) Cross sectional design	Brazil	$CPQ_{(11–14)}$	CPQ score = 20.9 (SD 14.8) Oral symptom = 6.08 (SD 3.6) Functional limitation = 6. (SD 3.9)	Not used FIS	DMFT /dmft scores not reported in the study

2.4 Factors that determine the caregiver perceptions on child's OHRQoL

It is important to consider factors that may influence the caregivers' OHRQoL perceptions of their children. Caregivers' views of their children's OHRQoL may be affected by the burden of caregiving and their own mental health and wellbeing (51). Mothers of CSNs were found to be at increased risk of developing psychiatric illness and stress compared to mothers of non-disabled children (52). An assessment of the determinants of physical and psychological health of adult caregivers of children with Cerebral palsy was conducted by Raina *et al*., in Canada. The study involved 468 families of children with Cerebral palsy using self-completed parent questionnaires as well as a face-to-face home interview (53). The study found that the majority of caregivers were females and mothers to the children in the study. The results showed that child behaviour, caregiving demands, and family function were the most important predictors of caregivers' wellbeing. A higher level of behaviour problems of children was associated with lower levels of both psychological and physical health of the caregivers, whereas fewer child behaviour problems were associated with higher self-perception and a greater ability to manage stress. Less caregiving demands were associated with better physical and psychological wellbeing of caregivers. The authors concluded that the psychological and physical health of caregivers was strongly influenced by child behaviour and caregiving demands. Caregiving demands contributed directly to both the psychological and the physical health of the caregivers (53).

Another study was conducted in Sweden by Olsson and Hwang to assess the prevalence and severity of parental depression in families of children with intellectual disability (54). Parental depression was assessed using the Beck Depression Inventory (BDI) among 216 families of children with Autism and/or Intellectual Disability (ID) and in 214 control families. The authors found that mothers of children with Autism had higher mean depression scores (mean = 11.8)

than mothers of children with ID without Autism (mean = 9.2). They also had higher depression scores than fathers of children with Autism (mean = 6.2). The authors concluded that mothers of children with disabilities are at a significant increased risk of suffering from psychological distress and depression (54).

A study by Dabrowska and Pisula in Poland sought to assess the profile of stress in two groups of mothers and fathers of young children with developmental disabilities i.e. Autism (n=51) and Down syndrome (n=54) and to compare their perceptions of parenting stress with those of mothers and fathers of children with no disabilities (n=57) (55). The parents filled in a Holroyd's Questionnaire of Resources and Stress (QRS) for Families with Chronically Ill or Handicapped Members. This is a 66 item short form version of the questionnaire to measure parental stress. The results indicated higher levels of stress in parents of children with Autism than in parents of children with Down syndrome and non-disabled children. There was also a higher level of stress in parents of children with Autism and the mothers scored higher than fathers in parental stress (55).

Caregivers may have limited knowledge about their child's OHRQoL when they have to report on their children status. A study by Jokovic *et al*., sought to assess the parental knowledge of their children's OHRQoL (33). One of their objectives was to determine the level of agreement between parental and child reports on their OHRQoL. The study involved 63 pairs of parents and their children (11-14 years old) who answered questions from the P-CPQ and child perception questionnaire ($CPQ_{11–14}$). The study results confirmed that some parents may have limited knowledge concerning their OHRQoL particularly the impact on social and emotional wellbeing of their children (33). This was confirmed by the number of "don't know" responses to the

questionnaire. The mean number of "don't know" responses given by parents of older children (age 11-14yrs) was twice that for the younger children (age 6-10yrs) (33).

Parental gender was also found to be a predictor of the number of "don't know" responses for oral symptoms, with fathers having more such responses than mothers ($p < 0.01$) (33). The above results are supported by a study that was conducted in Saudi Arabia by Pani *et al*., which sought to compare differences in perceptions between fathers and mothers (56) . The study showed that mothers were more appropriate proxies than fathers in the assessment of OHRQoL (56). This result was expected as mothers tend to be more closely related to childcare activities than the fathers (56). The study also used self-reporting from children without disabilities, hence, it is difficult to compare with studies focusing on CSNs. This study emphasises the limitation of using proxy reporting.

The relationship between oral disease and OHRQoL is mediated by personal and environmental variables. This was confirmed when Locker (21) assessed the socio-economic inequalities in OHRQoL of 370 Canadian children aged between 11-14 years old using a self-administered short form version of the CPQ_{11-14}. The mean DMFT was 0.79 (SD1.21) and the results indicated that children from low income households had a high overall CPQ $_{11-14}$ score of 15 compared to those from high income households who had a CPQ $_{11-14}$ score of 12. The highest scores (17.8) were found in those children living in households that received welfare or disability support income. The author concluded that household income was a predictor of OHRQoL amongst the children with high scores (21).

Piovesan *et al*., (48) corroborate the results of the above study by Locker (21). Poor OHRQoL was shown to be reported by the children whose mothers had a lower household income (RR 1.13; 95% CI 1.02–1.26). Both studies showed that poor socio-economic status has a negative

impact on the child's OHRQoL. These studies cannot be compared with the current study because the children were self-reporting on quality of life scores and the parent only answered questions relating to sociodemographic variables. In the current study, caregivers are reporting on behalf of the children with special needs.

Studies have also established the influence of maternal age and level of education on the perception of OHRQoL (12, 13). Abanto *et al*., (47) also found that the level of education of the mother, household crowding and low family income were associated with a low OHRQoL, while a higher family income had a positive impact on OHRQoL. On the contrary, Piovesan *et al*., (48) found that the maternal low level of education had a negative impact on the OHRQoL.

There is an association between the type and severity of disability with the perceived OHRQoL. A population study in Europe was conducted to determine the influence of the severity and type of the child's motor and associated impairments, as well as the socio-economic factors and parental stress on the child's OHRQoL (57). The study included children with Cerebral palsy (n=818) with a mean age of 10 years. The quality of life questionnaire that was used in this study was the generic health related quality of life questionnaire called Kidscreen. It is a health related quality of life questionnaire for children aged 8-18. This instrument has a parent/proxy version which has 52 items in 10 domains. Some of the domains are physical wellbeing, psychological wellbeing and social environment etc. All the items are scored in a Likert scale and the range of scores is 1-100. The results showed that children with severe impaired motor function were more likely to have poor quality of life in physical wellbeing and parents with higher levels of stress were more likely to report poor quality of life of their children (57).

Abanto *et al*.,(50)conducted a study in Brazil with the aim of assessing the impact of impairments (type of CP, communication ability, gross motor function), the severity of dental caries, seizures and socio-economic conditions on the OHRQoL of children with CP using their parental perceptions. The study involved parents of 60 children with CP aged between 6-14 years. The instrument used was the P-CPQ and FIS and the overall OHRQOL score was reported to be 17.28 (SD 13.25). This score was made up of a sum of P-CPQ, FIS and global ratings. The authors found that the reduction of communication ability and dental caries severity (dmft = 2.06) had a negative impact on the overall OHRQoL score ($p < 0.05$). The severity of the type of CP and decline in the ability to communicate showed a negative impact on oral symptoms and functional limitations domains ($p < 0.05$). Seizures had a negative impact on the oral symptoms domain ($p = 0.006$). The severity of dental caries, communication ability and low family income were negatively associated with the impact on OHRQoL ($p <0.001$) and the authors concluded that the severity of dental caries, communication ability, and family income are strongly associated with a negative impact on OHRQoL of children with CP (50).

These sections revealed that mothers know more about the oral health conditions of their children and were more likely to more appropriate proxies when assessing oral health related quality of life of their children, than fathers. The determinants which were associated with increased caregiver perception of OHRQoL were female gender, maternal age and education as well as household income.

Concluding Remarks

An analysis of the literature in this section suggests that there were consistencies in the reported findings and the following generalisations can be made:

1. The reviewed studies have shown that CSNs had high dental caries levels and poor OHRQoL as reported by the caregivers, and that untreated dental caries was associated with a negative impact on OHRQoL.
2. In the parent caregiver perception questionnaire the domains that showed high scores were the functional limitations, oral symptoms and emotional wellbeing.
3. The components of the OHRQoL questionnaire were applied differently in the different studies. Some studies reported only on the caregiver perception questionnaire scores while some reported on its combination with the family impact scale.
4. Studies have shown that most caregivers are mothers who bear the most caregiver burden and this may influence the perception of the OHRQoL.
5. A range of factors impacted on the caregiver perception of OHRQoL i.e. caregiver sociodemographic factors like gender, monthly family income, mother's education, family structure and increased caregiver stress (12, 13, 21).

In South Africa, there is a paucity of studies that report on the impact of dental caries on OHRQoL of CSN, which makes this research particularly important.

AIMS AND OBJECTIVES OF THE STUDY

AIM

To assess OHRQoL among Children with Special Needs, from the caregiver's perspective.

OBJECTIVES

1. To describe the demographic profile of the caregivers participating in this study.
2. To assess the dental caries status of CSNs.
3. To establish the caregivers' perceived OHRQoL of the CSNs using the short-form P-CPQ.
4. To assess the impact of dental caries on the families of CSNs using the FIS questionnaire.

CHAPTER 3: METHODOLOGY

This chapter describes the research methodology used to conduct this study. Methods used for conducting the study, ethical considerations and analytic techniques pertaining to this study are also discussed with in this chapter.

3.1 Study Design

A cross-sectional analytical study design was used to ascertain the dental caries status and its impact on Oral Health-Related Quality of Life in CSNs. A cross-sectional study is usually conducted to generate hypothesis around the outcome of interest for a given population which in this case is OHRQoL and the related factors. The study design can yield useful information needed for the purposes of public health planning (18).

3.2 Study Population

The study population included all caregivers paired with their children with special health care needs who attended the support group meetings in the outreach sites of the Down Syndrome Association in Johannesburg (DSA, Johannesburg) and a special needs school in Johannesburg.

Inclusion criteria

All the caregivers above the age of 18 who attended the outreach sites of the Down Syndrome Association in Johannesburg, as well as all those who attended the parents open day at the special needs school were included.

3.3 Study Sample

The DSA in Johannesburg outreach sites cater for children with several types of disabilities including Cerebral palsy, hydrocephalus, Autism, Epilepsy and developmental delays. The association schedules and facilitates support group meetings for the caregivers of children with Down syndrome and other disabilities. These meetings are held at the outreach sites which are located at different district hospitals and community health centres in Johannesburg, and are co-facilitated by the association's outreach coordinator together with a team of physiotherapists, occupational therapists and speech therapists. During the group meetings, the caregivers have facilitated group discussions and peer group education sessions whereby several topics are discussed e.g. caring for a child with Down syndrome and other disabilities and how to stimulate children with disabilities. All the caregivers attending the support group meetings were invited to participate in the study.

When calculating the appropriate sample size, the following variables were considered: hypothesised mean of 17 (SD 20) (47), alpha of 0.05 and 80% power. According to the STATA 12 statistical sample size calculator (58), the sample size was calculated to be 150 caregiver-child pairs including the 20% attrition effect.

A convenient sampling method was used as it was not feasible to sample randomly for participants, hence, all the caregivers attending the facilities were invited to participate and those who agreed to participate formed part of the sample. At the end of a four month period of data collection only 37% (n=56) of the sample size was collected. Thus resulting in a decision to purposively recruit the caregivers from a special needs school in Johannesburg. The researchers attended a parent's open day at the school where all the caregivers were invited to participate in the study.

3.4 Study Instruments

3.4.1 Data collection and the study instrument

The study instrument used in this study was divided in the following sections: demographic data collection section (Appendix I), P-CPQ (Appendix II), FIS (Appendix III) and a clinical assessment form (Appendix IV).

3.4.2 OHRQoL assessment

This study used the short-form P-CPQ and FIS (36). These are components of the child OHRQoL questionnaire which aims to assess parental perceptions of their children's OHRQoL and its effects on the family (34). Both the P-CPQ and the FIS components of the questionnaire have been validated in English as well as been recommended for use in health service research (36).

The short-form P-CPQ (Appendix II) consisted of 16 items (closed-ended questions) which were grouped into four subscales/domains: Oral symptoms items, Functional limitations items, Emotional wellbeing and Social wellbeing each with four items, respectively. The questionnaire used a 5-point Likert scale and all the scores in each domain were added separately to give a domain score. The sum of the four domain scores made up the total P-CPQ score for each individual participant. The scores ranged from 0 to 64, and the lower scores represented a high OHRQoL.

The FIS (Appendix III) was made up of 8 items that measured the effect of a child's oral condition across three domains: parental and family activities, parental emotions, family conflict. Scoring of the FIS also used a 5-point Likert scale which had scores ranging between 0-56, calculated in the same manner as the P-CPQ scores (34).

The questionnaires also had a "don't know" response option which is essential in studies in which participants report their perceptions of the health or quality of life of another individual (34).

These study instruments could not be translated into African languages as the process required psychometric testing to validate whether translation did not change the dimensions of the questionnaires, and therefore translation was beyond the scope of this study. However, questionnaires were administered by a trained interviewer who explained and gave clarifications to the caregivers. Training was essential to ensure the uniformity of the data by reducing interviewer error. The participants were encouraged to ask for clarifications during the interview.

The caregivers also answered two additional questions which related to the child's OHRQoL global rating score. This score summarizes how the caregivers perceive the children's oral health related quality of life using two questions and is often used to test for construct validity. The first question asks the caregivers to rate their children's overall oral health status (health of the teeth, lips, jaws and mouth) using a five-point Likert scale and the response options are from "excellent" to "poor". The second question focuses on how the overall wellbeing of the child is affected by the oral health status using a Likert scale ranging from "not at all" to "very much" (38). When the global rating score correlates well with the perceived quality of life score, it proves that the OHRQoL perception score is valid.

Clinical examination of the children

In addition to the caregivers interviews using the P-CPQ and FIS questionnaires, data was also collected by clinical examination and recorded using the child oral assessment form (see appendix IV). The form has been adapted from the one which was used on previous research

projects by the Community Oral Health Outreach Programme (COHOP) in the Department of Community Dentistry at the University of the Witwatersrand, Johannesburg.

The assessment form was also used to collect information on the sociodemographic status of the child namely: age, gender, type of disability and as well as information on clinical oral examination findings (see Appendix IV). Two calibrated examiners conducted the clinical examination and both had undergone a calibration exercise to standardise clinical criteria for diagnosis of caries. Inter- and intra-examiner reliability scores were assessed using the Cohen Kappa scores which were found to be 0.9 for diagnosis of dental caries.

3.4.3 Dental caries examination

The children were examined in a seated position on site under natural light using a mouth mirror according to the modified World Health Organisation guidelines (59). Dental caries was measured using the decayed, missing and filled (dmft) index for primary and decayed, missing and filled (DMFT) for permanent dentition. Dental caries prevalence was defined as a DMFT/ dmft score ≥1.This study reports on the primary and secondary dentition only.

3.5 Data and Statistical Analysis

Data from the questionnaires was captured on Microsoft Excel and analyzed using the statistical package for social sciences version (SPSS) 16 (60). The predictor variables were the demographic variables (caregiver age and gender), socio-economic condition (household income, caregivers' education level and employment status) and clinical status (prevalence of untreated dental caries and dmft/DMFT scores). Explanatory variable were the OHRQoL outcomes as determined by the P-CPQ overall total and domain scores as well as the FIS.

Descriptive statistics was used to describe the demographic profile of the caregivers and the children using means, standard deviations, frequency and ranges of the total and domain scores. The T-test, Mann-Whitney and One way Analysis of Variance (ANOVA) tests were carried out to assess the group differences between means. The Games-Howell post-hoc tests were also used to identify group differences. The statistical significance level was set at $p < 0.05$ and estimates were reported at the 95% confidence interval (CI). Odds ratios (OR) were calculated to assess the association between the caregiver sociodemographic characteristics and the disability of the child. The groups were collapsed in order to dichotomize the variables.

3.5.1 Analysis by objective

Objective 1: To describe the demographic profile of the caregivers in terms of age, gender and socio-economic status.

The profile of the study population was described using proportions for categorical variables. Means and standard deviations (SD) were used to describe continuous variables. Frequency tables, bar charts and pie charts were used to present the variables.

Objective 2: To assess the dental caries status of children with special health care needs.

Mean dmft/DMFT scores were calculated and an independent sample T-test was used to evaluate the difference between two mean scores. Analysis of variance (ANOVA) was applied to compare more than two means.

Objective 3: To establish the caregivers' perceived OHRQoL of the CSNs.

The total individual P-CPQ and domain mean scores were calculated by adding all the scores in each domain and the sum of the domain scores were added to make up the total individual P-CPQ scores. To quantify the impact on OHRQoL in this study, any impact P-CPQ score greater

than 0 was regarded as a negative impact. The P-CPQ and FIS were dichotomized into negative impact (scores=1 and above) and no impact (scores=0) for ease of reporting caregiver perceptions.

The independent sample T-test was used to evaluate the difference between two means and ANOVA was applied to compare more than two mean scores. The association between the dental caries status (dmft/DMFT scores) and P-CPQ scores was assessed using the Spearman's correlation coefficient. The Spearman correlation is a nonparametric test which measures the strength and direction of association between two variables that are measured on an ordinal or continuous scale. The correlation coefficient was also used to measure the association between the P-CPQ scores with the global rating scores. Linear regression analysis was performed to analyse the factors which were most likely to independently influence the perceived OHRQoL outcomes.

Objective 4: To assess the impact of dental caries on the families using the FIS questionnaire.

The total individual FIS and domain mean scores were calculated by adding all the scores in each domain and the sum of the domain scores were added to make up the total individual FIS score. Independent sample T-test was used to evaluate the difference in two mean scores between and ANOVA was applied to compare more than two means. The association between the dental caries status (dmft/DMFT scores) and FIS was assessed using the Spearman's correlation coefficient.

Management of "don't know" and "never" responses

To calculate P-CPQ scores for each individual, mean item scores were calculated based on only those items that had responses other than "don't know" and "never" (33). All "don't know" and "never" responses were given the value of zero to calculate the proportions. Thereafter all the

"don't know" and "never" responses were excluded from the calculation of the P-CPQ and FIS individual scores (33).

3.6 Ethical Considerations

Permission to undertake the current study was granted by the University of Witwatersrand Ethics Committee and the ethics clearance certificate is attached as Appendix VII (Ethics Clearance Certificate number M140438). Permission was also obtained from the Department of Education (Appendix VIII). The caregiver of each participant was given an information sheet (see Appendix V) and a written consent form for obtaining their permission to allow their children to participate in the study (see Appendix VI), which they had to sign.

CHAPTER 4: RESULTS

This chapter focuses on the findings of the study and results will be presented according to: i) Sociodemographic characteristics of the caregiver ii) Characteristics of the children by age, gender and disability iii) Relationship between child disability and caregiver demographic variables iv) Dental caries status of the children and v) The OHRQoL

4.1 Socio-demographic characteristics of the caregivers

4.1.1 Distribution by age

The total study population consisted of 150 caregiver child pairs (one child per caregiver) and the mean age of the caregivers was 39.52 yrs. (SD 9.26). The profile of the caregivers by age groups is shown in Figure 4.1 which indicates that the majority (42%) of the caregivers were between 40-49 years, followed by 32% which were in the 30-39 year age group.

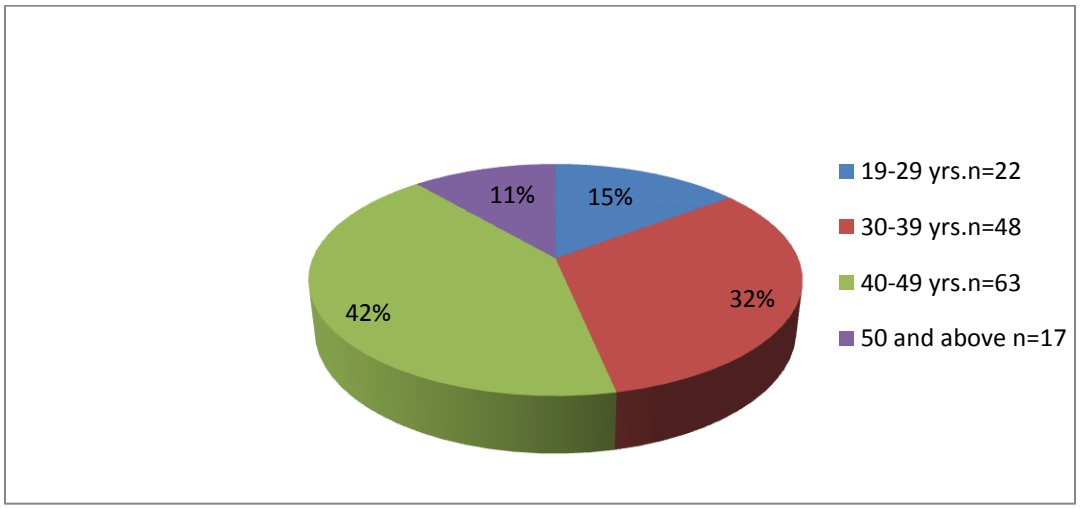

Figure 4.1: Frequency and percentage of caregivers by age group

The distribution of the relationship of caregivers to the CSNs is described in Figure 4.2 and it shows that the majority of the caregivers were the biological mothers (86.7%). In total, 92.7% of the caregivers were parents. Only 2.7% was in the "other" category which was made up of family friends, relatives and neighbours.

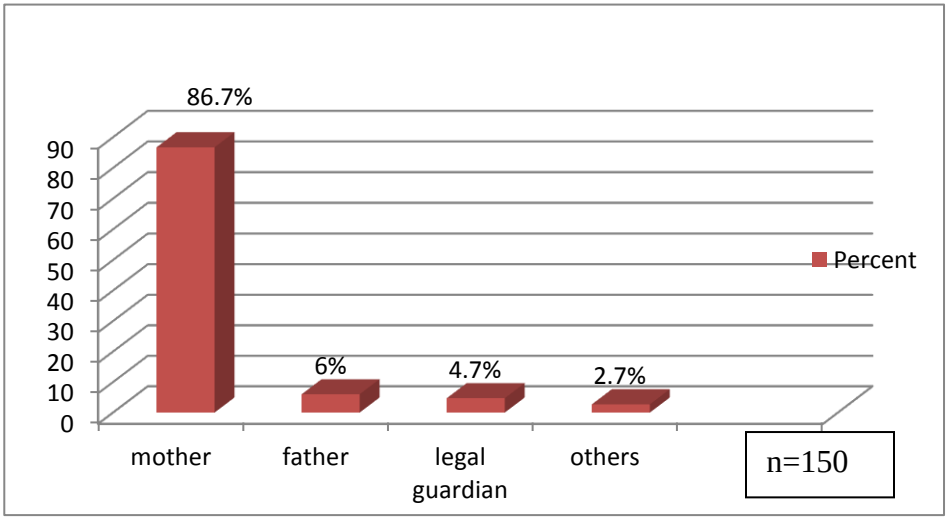

Figure 4.2 Relationship of caregivers to children with special needs.

4.1.2 Distribution of caregivers by gender.

Figure 4.3 provides information on the gender split among the caregivers and the predominant gender was female who made up 94.7% of the total sample.

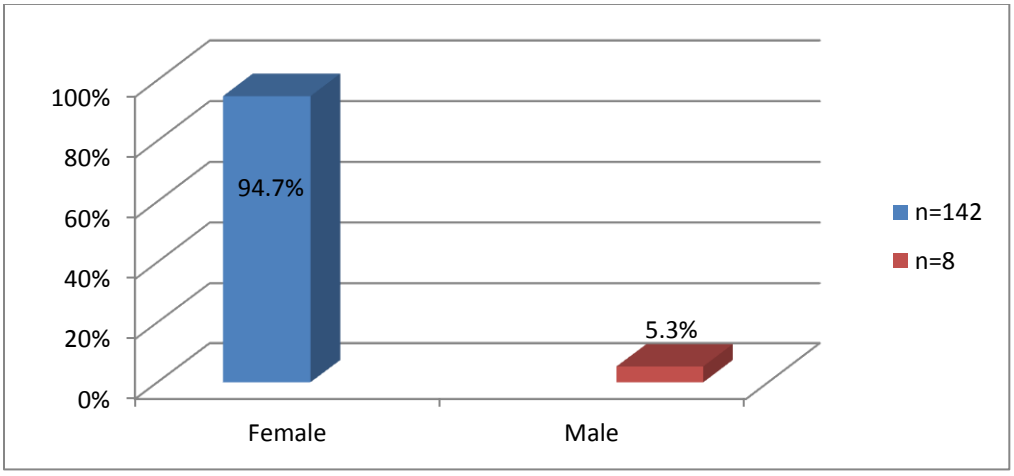

Figure 4.3: Number and percentage of participants by gender.

Table 4.1 describes the socio-economic characteristics of the caregivers by level of education, employment status and source of income. The result shows that 1.3% had no form of formal education and about 48% of the caregivers had reached high school level education while only 22.7% reached college level. The majority of the caregivers were employed (52.7%) and 40% were unemployed. The analysis of source of income indicated that the majority of the caregivers (64%) earned a salary while 27.3% received disability grants for their children.

Table 4.1: Frequency and percentage of caregivers by sociodemographic characteristics

	n	**%**
Level of education	**n = 150**	**100%**
No schooling	2	1.3
Primary (Grades 1 to 7)	14	9.3
High school (Grades 8-12	72	48
College	34	22.7
University	25	16.7
Others	3	2
Employment status	**n = 150**	**100%**
Not employed	60	40
Employed	79	52.7
Self employed	5	3.3
other	6	4
Source of income	**n = 150**	**100%**
Salary	96	64
Disability grant	41	27.3
Pension grant	1	0.7
Child grant	12	8

4.2 Demographic characteristics of the children with special needs.

4.2.1 Distribution by age and gender.

A total of 150 children participated in the study and the mean age was 8.72 years (SD 6.07). Table 4.2 describes the distribution of the child participants in the study by gender and age group. The males were the predominant gender (59.3%) compared to females (40.7%). In terms of age groups, the majority of the children were in the 6 months to 4 year old group, and the other three age groups were evenly distributed in a range between (20-22%).

Table 4.2: Frequency and percentage of children by gender and age group

Gender	**n = 150**	**%**
female	61	40.7
male	89	59.3
Age group	**n** = 150	100%
6 months-4 yrs.	52	34.7
5-9 yrs.	34	22.7
10-14 yrs.	30	20
15-20 yrs.	34	22
Total	**150**	**100**

4.2.2 Distribution by disability.

Figure 4.4 provides information about the percentage distribution of the child participants in the study according to type of disability. Of the total of 150 children, two had no final diagnosis of the type of disability. The majority of children (40.7%) had Down syndrome followed by Cerebral palsy (28.0%). About 10% of the children had disabilities which are grouped as complex disabilities due to their severity. These include conditions like myotonic dystrophy (n=5), severe physical disability (n=6) and syndromes like Noonan syndrome (n=2) and Cornelia de Lange syndrome (n=2).

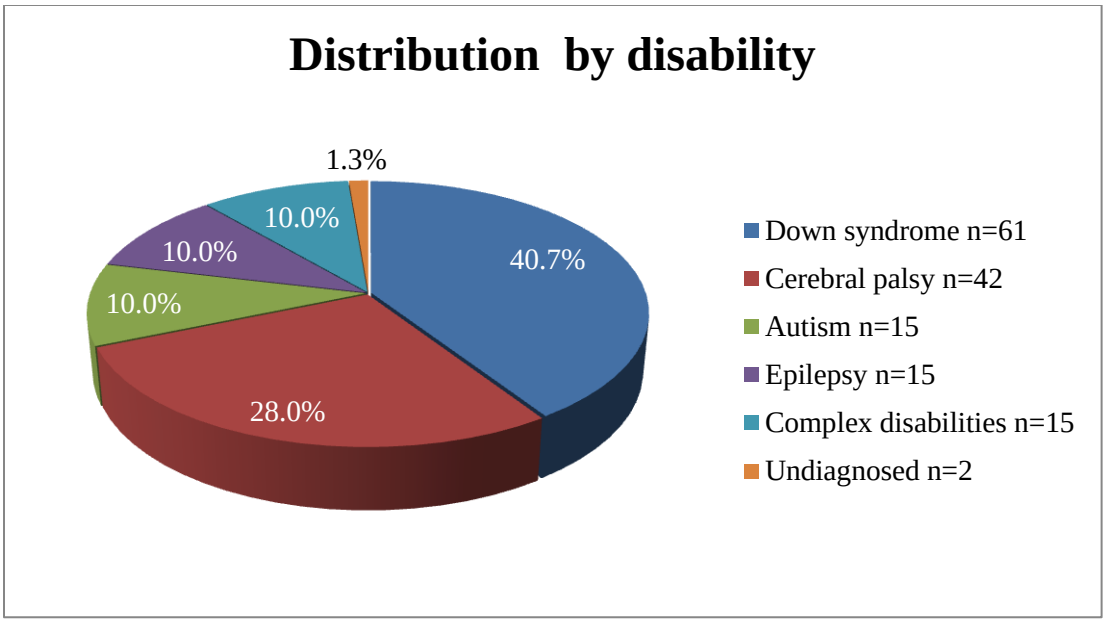

Figure 4.4: Number and percentage of children by type of disability

4.3 Distribution of child disability according to sociodemographic profile of caregiver.

An analysis was undertaken to assess the relationship between disability and some sociodemographic variables of the caregiver such as age, relationship, level of education, employment status and source of income. Table 4.3 describes the distribution of the child disability by the age group of the caregiver. Caregivers within the age group 40-49 accounted for the majority irrespective of the type of the disability of the child.

Table 4.3: Distribution of child disability by the age group of caregiver

Disability		Age group of caregiver				Total
		19-29	30-39	40-49	≥ 50	
Down syndrome	n	7	22	25	7	61
	%	4.7	14.9	16.9	4.7	41.2
Cerebral palsy	n	11	14	15	2	42
	%	7.4	9.5	10.1	1.4	28.4
Autism	n	1	6	6	2	15
	%	0.7	4.1	4.1	1.4	10.1
Epilepsy	n	2	3	7	3	15
	%	1.4	2	4.7	2	10.1
Other	n	1	3	9	2	15
	%	0.7	2.0	6.1	1.4	10.1
Total	n	22	48	62	16	148
	%	14.9	32.4	41.9	10.8	100

Table 4.4 Describes the relationship of the caregivers to their children and regardless of the type of disability, mothers were mainly the caregiver ($p < 0.05$).

Table 4.4: Distribution of the child disability by the relationship of the caregiver

		Relationship				
Disability		mother	father	legal guardian	others	Total
Down syndrome	n	60	1	0	0	61
	%	40.5	0.7	0	0	41.2
Cerebral Palsy	n	34	3	4	1	42
	%	23.0	2	2.7	0.7	28.4
Autism	n	11	2	1	1	15
	%	7.4	1.4	0.7	0.7	10.1
Epilepsy	n	13	0	1	1	15
	%	8.8	0	0.7	0.7	10.1
other	n	10	3	1	1	15
	%	6.8	2	0.7	0.7	10.1
Total	n	128	9	7	4	148
	%	86.5	6.1	4.7	2.7	100

Table 4.5 describes the distribution of the disabilities by the level of education of the caregiver. The results showed that there was a significant difference between the levels of education of caregivers among the different disabilities ($p=0.02$).About 18.9% of caregivers whose children had Down syndrome had a high school level of education compared to 15.5% of the Cerebral palsy group.

Table 4.5: Relationship of disability of the children and the level of education of the caregiver

Disability		Level of education						
		No school	primary	high school	college	University	others	Total
Down syndrome	n	1	6	28	20	4	2	61
	%	0.7	4.1	18.9	13.5	2.7	1.4	41.2
Cerebral Palsy	n	1	6	23	7	5	0	42
	%	0.7	4.1	15.5	4.7	3.4	0	28.4
Autism	n	0	1	4	2	8	0	15
	%	0	0.7	2.7	1.4	5.4	0	10.1
Epilepsy	n	0	0	8	4	2	1	15
	%	0	0	5.4	2.7	1.4	0.7	10.1
other	n	0	1	8	1	5	0	15
	%	0	0.7	5.4	0.7	3.4	0	10.1
Total	n	2	14	71	34	24	3	148
	%	1.4	9.5	48	23	16.2	2	100

Table 4.6 describes the relationship of the caregiver employment status and the type of disability of the children. The majority of the caregivers were employed (52%) opposed to 40% who were unemployed. A significant association was noted between the type of disability and the employment status of the caregiver ($p<0.001$). The majority of the unemployed caregivers (18.2%) cared for children with Cerebral palsy group compared to the (15.5%) in the Down syndrome group ($p<0.001$).

Table 4.6: Distribution of the children by employment status of the caregivers

Disability		Employment				Total
		No	yes	self employed	other	
Down syndrome	n	23	37	1	0	61
	%	15.5	25.0	0.7	0	41.2
Cerebral Palsy	n	27	14	0	1	42
	%	18.2	9.5	0	0.7	28.4
Autism	n	2	13	0	0	15
	%	1.4	8.8	0	0	10.1
Epilepsy	n	4	8	0	3	15
	%	2.7	5.4	0	2	10.1
other	n	4	6	3	2	15
	%	2.7	4.1	2	1.4	10.1
Total	n	60	78	4	6	148
	%	40.5	52.7	2.7	4.1	100

Table 4.7 describes the distribution of the disability by source of income. Although the majority was earning a salary, there was no significant distribution of the CSNs and the employment status of their caregivers.

Table 4.7: Distribution of disability of children with special needs by the income status of the caregiver

Disability		Source of income				Total
		salary	disability grant	pension grant	child grant	
Down syndrome	n	38	18	0	5	61
	%	25.7	12.2	0	3.4	41.2
Cerebral Palsy	n	25	11	1	5	42
	%	16.9	7.4	0.7	3.4	28.4
Autism	n	14	1	0	0	15
	%	9.5	0	0	0	10.1
Epilepsy	n	7	8	0	0	15
	%	4.7	5.4	0	0	10.1
other	n	11	2	0	2	15
	%	7.4	1.4	0	1.4	10.1
Total	n	95	40	1	12	148
	%	64.2	27.0	0.7	8.1	100

4.4 Results of odds ratio analysis (Tables 4.3, 4.6, 4.7)

Odd ratio analysis was done to determine the association between the age group, employment status and source of income of the caregivers and the type of disability cared for. The variables were dichotomized and one of the disabilities was referenced against the other types of disability.

The younger age group was defined as below 39 years and the older age group was the 40 years old and above. The results showed that the younger caregivers (< 40 years old) were almost twice as likely to be caring for children with Cerebral palsy as compared to older caregivers (> 40 years old [OR = 2.20: CI 1.32- 3.67] and this result was statistically significant (p=0.001)

The OR (p value) scores for younger and older caregivers caring for children with Down syndrome was [OR = 1.25: CI 0.77-2.03]; p=0.34 which implies no significant difference. Similar non-significant relationships with respect to age of the caregiver (younger and older < 40 & > 40) and type of disability were found in the Autistic, Epileptic and Complex disabilities groups.

The caregivers' employment status was dichotomized into unemployed and employed. When assessing the association between the employment status of the caregiver and the disability of the children, significant associations were noted only for caregivers of children with Cerebral palsy who were four times more likely to be unemployed compared to the other disabilities [OR = 3.98: CI 1.87-8.45]; p<0.001.

To assess the association between source of income and disability, the odds ratio was calculated for the caregivers who were caring for a child with disabilities while receiving a salary or social grants. The child, pension and disability grants were collapsed into one group (social grant). The results established that the caregivers who received a salary were less likely to care for the children with Down syndrome compared to those who received a social grant [OR = 0.87: CI

0.44-1.72] but this relationship was not significant. Similar non-significant relationships between source of income of the caregiver and the disability of the child were found in the Epileptic, Cerebral palsy and Complex disabilities groups. Significant associations were only noted for caregivers who were earning a salary as they were eight times more likely to care for children with Autism [OR = 8.98: CI 1.14-70.40] p=0.000 compared to the caregivers who received social grants.

4.5 Dental Caries Status

The overall caries prevalence for the total child participants was 42%. This section reports on the primary (n = 97) and permanent dentition (n = 68) caries status for the children who participated in the study respectively. The caries prevalence was shown to be higher in the permanent dentition than in the primary dentition (figure 4.5). However, the difference was not significant (p > 0.05).

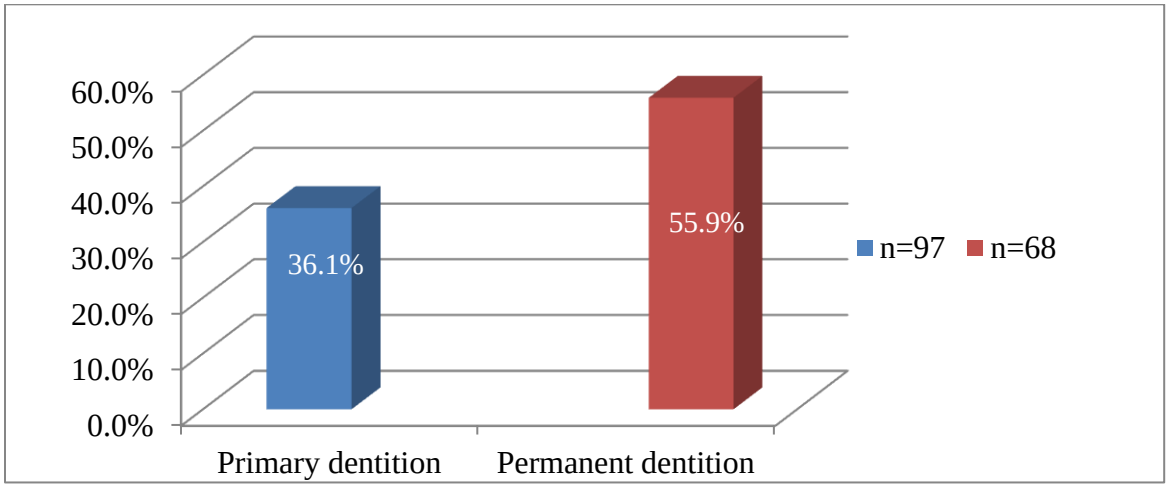

Figure 4.5: Dental caries prevalence in permanent and primary dentition

4.5.1 Caries status in primary dentition.

Dental caries prevalence was defined as a DMFT/dmft score ≥1. Regarding caries in primary dentition, females had a higher prevalence (44.44%, n = 45) than males (28.85%, n = 52), however, the difference in the prevalence was not significant. Figure 4.6 provides information on the caries prevalence and untreated caries in the primary dentition of the participants in each of the disabilities. The highest caries prevalence was found in the Epilepsy (83.3%) and the Autism groups (75%) compared to Down syndrome and Cerebral palsy. The untreated caries remained high across all the disabilities regardless of the caries prevalence.However the results need to be interpreted with caution due to the small sample in other disabilities.

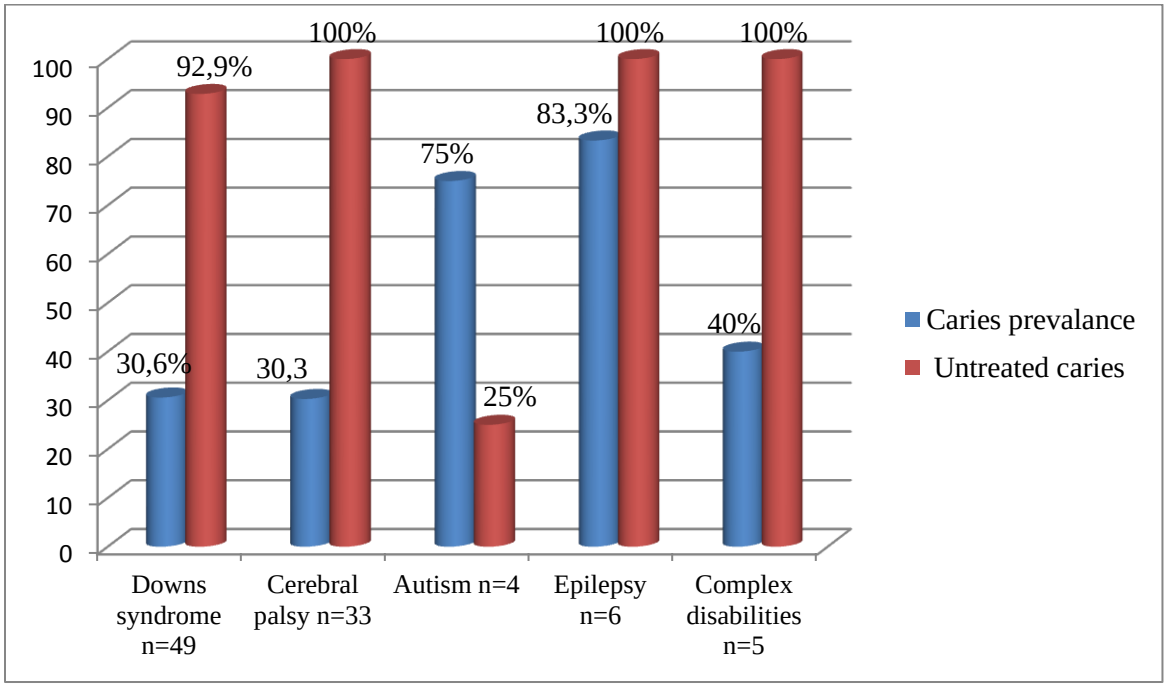

Figure 4.6: Dental caries prevalence and untreated caries in primary dentition by disability

Table 4.8 describes the dmft status in the primary dentition by disability and the results show that the highest dmft scores were found in the complex disabilities (3.2 (SD 4.38)) followed by equal

scores in the Epilepsy and Autism groups. The Autism group had a significantly higher number of missing teeth than the other disabilities groups ($p = 0.001$). All the disabilities had an overall score of zero on the fillings component of the dmft score. When comparing dmft scores by gender, no significant difference was found between males and females ($p > 0.05$).

Table 4.8: Mean d, m, f and dmft scores by disability (n=97)

Disability	d	SD	m	SD	f	SD	dmft	SD
Downs syndrome n=49	1.04	2.17	0.08	0.57	0	0	1.12	2.21
Cerebral palsy n=33	1.58	2.88	0	0	0	0	1.58	2.88
Autism n=4	0.50	0.57	1.50	3	0	0	2	2.7
Epilepsy n=6	2.00	1.67	0	0	0	0	2	1.67
Complex disabilities n=5	3.20	4.38	0	0	0	0	3.2	4.38

Figure 4.7 describes the mean d, m, f and dmft scores in the primary dentition by age group. The 5-9 year age group had the highest dmft scores (2.75 (SD 3.19)) compared to the other age groups. The decayed component contributed 93% to the total dmft score in the 5-9 year olds and the missing component contributed 45% to the total score. The dmft scores in the 15-20 year olds indicated the scores of the retained primary dentition.

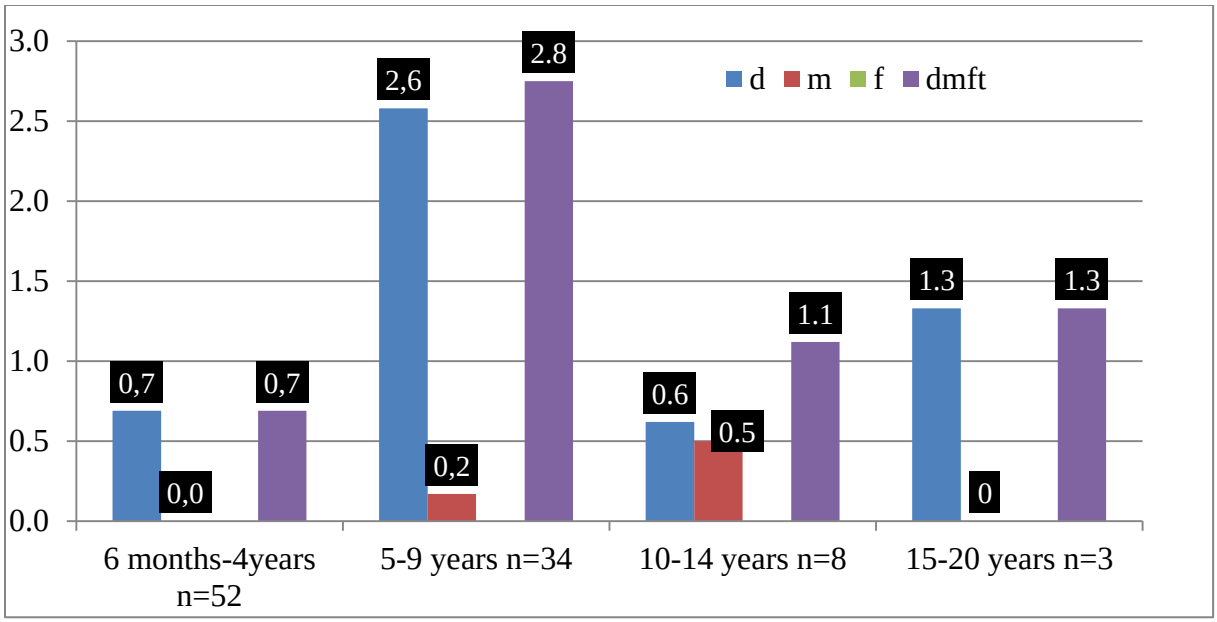

Figure 4.7: Mean d, m, f and dmft scores by age group (primary dentition)

4.5.2 Caries status in permanent dentition.

The results on overall caries prevalence by gender showed that males had more (57.45%, n = 47) caries in the permanent dentition than females (52.38%, n=21) however the difference was not significant (p=0.697). Figure 4.8 describes the caries prevalence and untreated caries per disability. The highest caries prevalence was found in the Autism group (75%) and the lowest was found in the Cerebral palsy group (45.5%). There was also a high prevalence of untreated caries regardless of the type of disability.

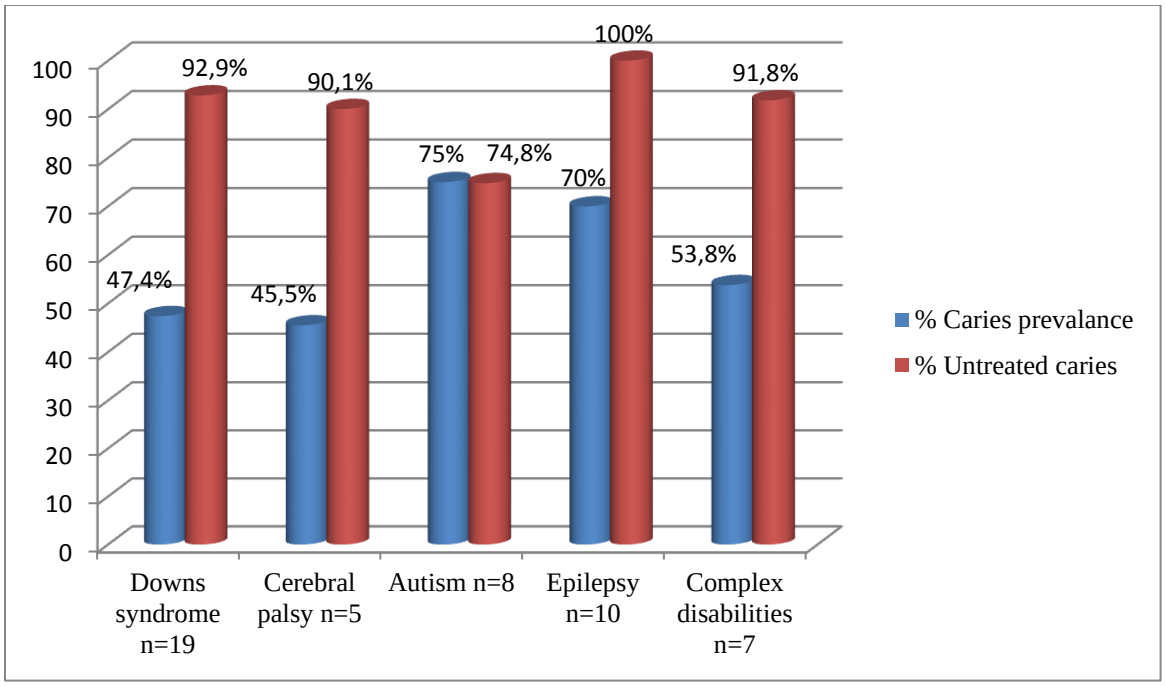

Figure 4.8: Dental caries prevalence and untreated caries in permanent dentition by disability.

Figure 4.9 provides information on the DMFT scores of the participants in the different disabilities. It is clear that the Cerebral palsy and Complex disabilities groups had the highest mean DMFT scores (1.81 (SD 2.48)) and (1.83 (SD 2.03)) respectively, compared to 1.20 (SD 1.13) and 1.22 (SD 1.36) respectively found in the Epilepsy and Autism disability groups.

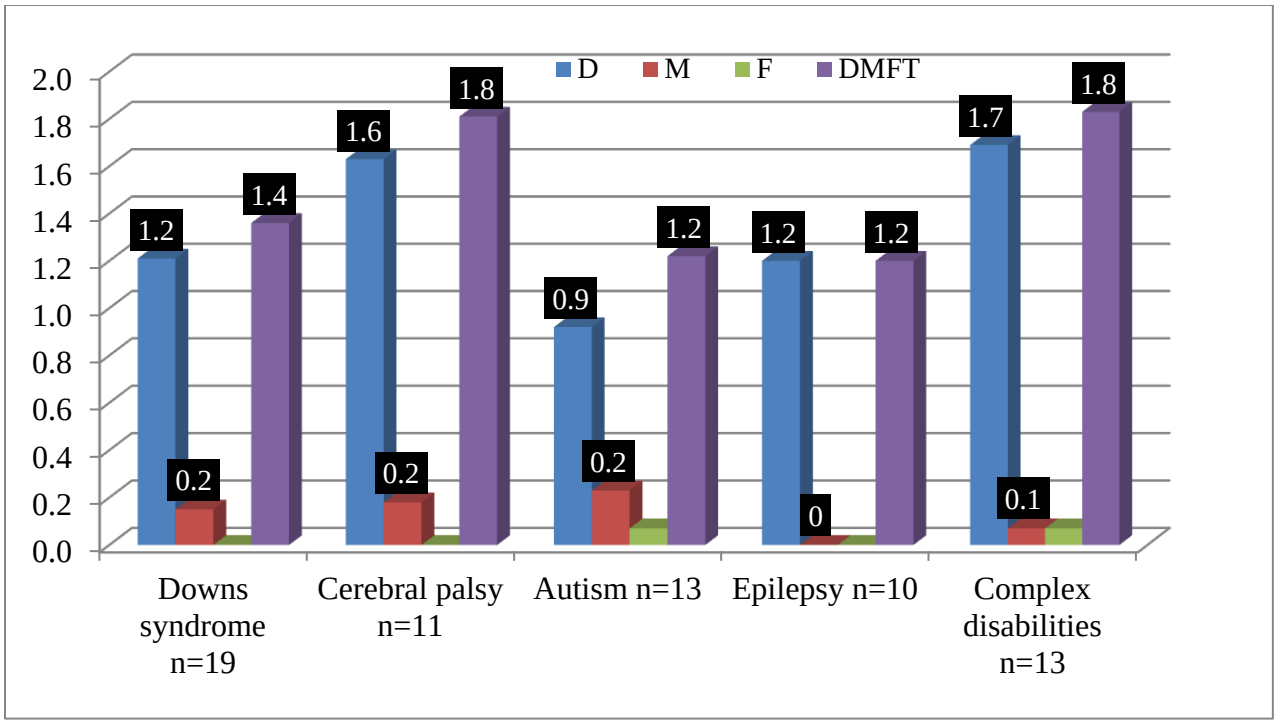

Figure 4.9: Mean D, M, F and DMFT scores by disability

Figure 4.10 provides information about the DMFT status by age categories of the participants and it shows that the mean DMFT scores increased with age. The 15-20 year age group had a higher filled component of the DMFT score compared to the other age groups.

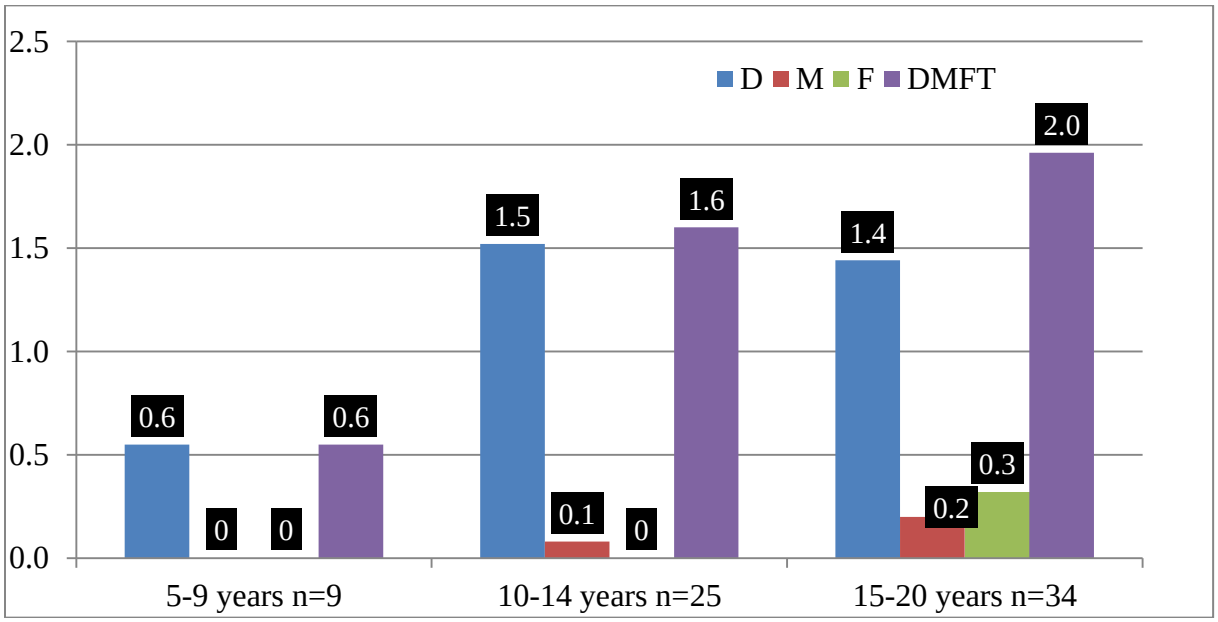

Figure 4.10: Mean D, M, F and DMFT scores by age group

Figure 4.11 depicts the caries prevalence by different age groups and dentition. The caries prevalence in the permanent dentition increased with age, and the 15-20 year olds had the highest prevalence of caries in the permanent dentition (70.59%). Again in the primary dentition, caries prevalence increased with age and peaked at the 5-9 year age with a prevalence of 64, 71%. These results mirrored the dmft/DMFT scores shown in Figures 4.7 and 4.9.

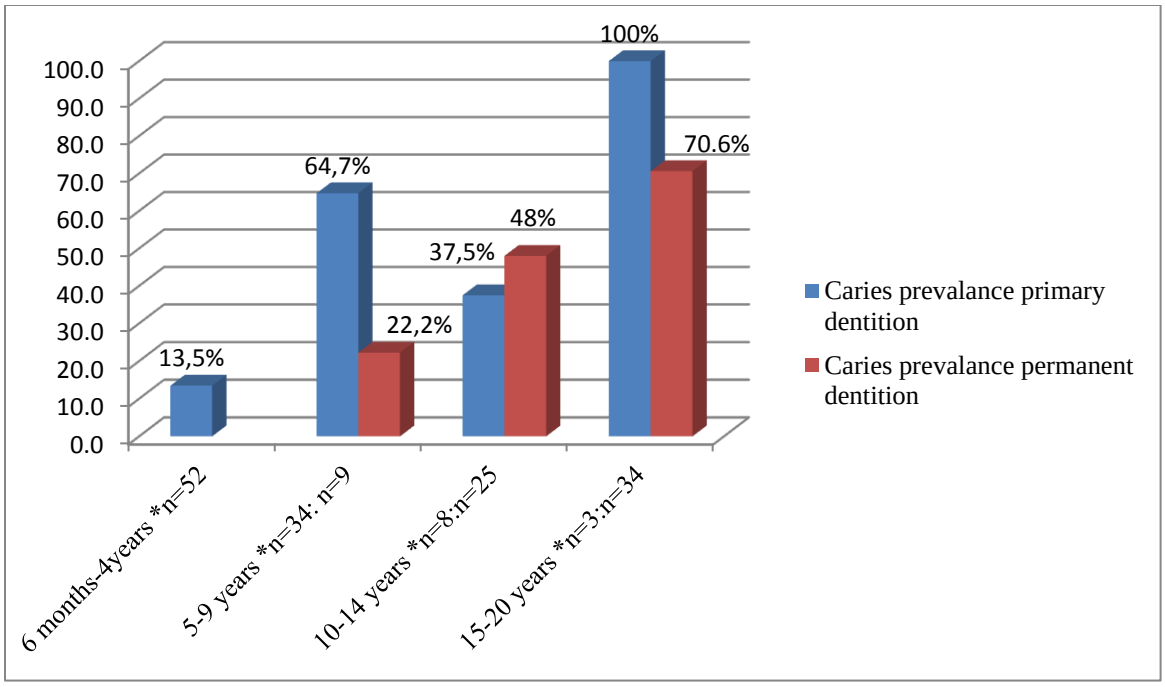

Figure 4.11: Percentage of caries prevalence by age group and dentition
*Three of the 15-20 year old had retained primary dentition

4.6 Oral health related quality of life (OHRQoL)

The data for the OHRQoL will be reported based on the overall as well as domain scores of the P-CPQ and FIS.

4.6.1 Parent caregiver perception questionnaire scores (P-CPQ)

Table 4.9 illustrates the mean P-CPQ and domain scores of the study population and the mean score was 12.88 (SD 12.14). This score is regarded as relatively lower when compared to the

expected P-CPQ range of scores (0-64).High domain scores of 4.62 (SD3.91) and 4.38 (SD 4.06) were observed in the oral symptoms and functional limitations domain respectively. The lowest scores were found in the social wellbeing domain (2.23 (SD3.00)). The highest proportion of the "don't know" responses was in the oral symptom domain (n = 58) followed by the social wellbeing domain (n = 46). There was no significant difference in the mean P-CPQ scores when compared among the different disabilities.

Table 4.9: Mean, standard deviations, ranges and number of don't know and total parent caregiver perception (P-CPQ) scores.

Domains and overall P-CPQscores	Mean (SD)	Expected range	Observed range	Don't know
Oral symptoms	4.62 (3.91)	0-16	0-16	58
Functional limitations	4.38 (4.06)	0-16	0-14	30
Emotional wellbeing	3.95 (4.02)	0-16	0-16	30
Social wellbeing	2.23 (3.00)	0-16	0-11	46
P- CPQ	12.88 (12.14)	0-64	0-44	85

Tables 4.10 to Table 4.13 and Figure 4.12 present the comparison of the mean responses in all the domains and the overall quality of life by caregivers' age group, gender, level of education, employment status and types of disability of their children using the student T-test and ANOVA where appropriate.

Table 4.10 indicate that when the responses of all the age groups were compared using ANOVA, there was no significant variation in their mean scores in all the domains and the overall quality of life as reported by caregivers of children with different disabilities ($p > 0.05$ respectively).

Table 4.10: Comparison of perceived mean score of the domains and overall quality of life (P-CPQ) of children by the age group of the caregivers

Domain and Total P-CPQ	Age group	Sum of Squares	df	F	p
Oral symptoms	Between Groups	5.4	3	0.15	0.932
	Within Groups	1791.6	146		
	Total	1796.99	149		
Functional limitation	Between Groups	17.53	3	0.38	0.767
	Within Groups	2238.67	146		
	Total	2256.19	149		
Emotional wellbeing	Between Groups	15.92	3	0.34	0.795
	Within Groups	2268.08	146		
	Total	2284	149		
Social wellbeing	Between Groups	4.67	3	0.20	0.899
	Within Groups	1162.33	146		
	Total	1166.99	149		
P- CPQ	Between Groups	46.34	3	0.13	0.94
	Within Groups	16944.66	146		
	Total	16990.99	149		

The mean scores of the domains and the overall OHRQoL were compared by gender using the student T-test. There were no significant differences between the perceived score of the domains ($p > 0.05$) and overall quality of life ($p > 0.05$) by males and females caregivers (Table 4.11).

Table 4.11: Comparison of perceived mean score of the domains and overall quality of life of children with special needs by caregivers' gender

Domain and Total P-CPQ	Gender	n	Mean	SD	t	p
Oral symptoms	Female	142	4.43	3.51	1.53	0.127
	Male	8	2.5	2.14		
Functional limitation	Female	142	4.04	3.88	-0.5	0.615
	Male	8	4.75	4.37		
Emotional wellbeing	Female	142	3.65	3.89	0.63	0.53
	Male	8	2.75	4.5		
Social wellbeing	Female	141	2.01	2.84	0.01	0.994
	Male	8	2	2.2		
P- CPQ	Female	141	14.05	10.78	0.53	0.6
	Male	8	12	9.44		

Figure 4.12 describes the total mean and domain scores of P-CPQ by disability and the results showed that the highest P-CPQ scores were found in the complex disability group (20.50 (SD 11.07)) followed by the Down syndrome group (15.87 (SD 13.87)). The results also showed that the oral symptoms, functional limitation and emotional wellbeing domains generally had high scores which contributed more to the caregiver perception score. Regarding scores in the different disabilities, high impact scores were reported in the oral symptom (5.71 (SD 4.27)) and emotional wellbeing (5.42 (SD 3.97)) in the complex disability group as well as oral symptoms (4.21 (SD 4.02)) and functional limitation (4.83 (SD 4.24)) in the Down syndrome group. The Cerebral palsy group also had high scores in the oral symptoms and functional limitation domain (4.74 (SD 3.75) and 4.25 (SD 4.27) respectively). There was no significant difference noted when mean scores were compared among the different disabilities and among the sociodemographic factors ($p > 0.05$).

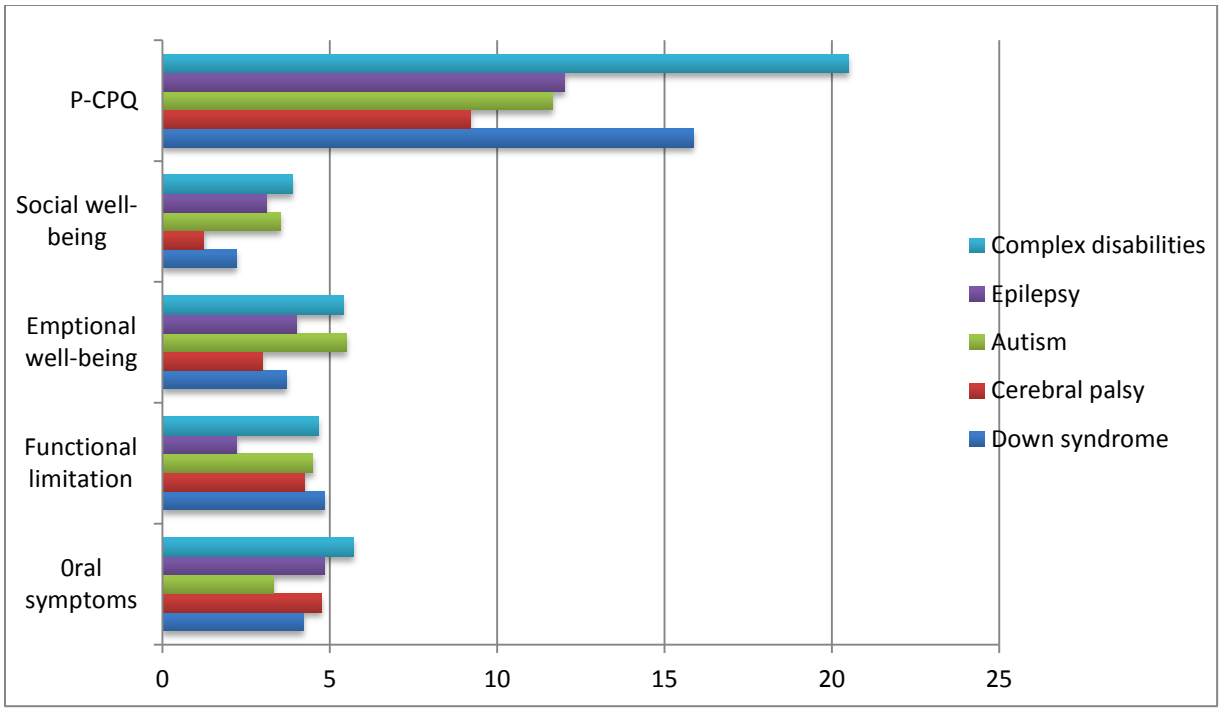

Figure 4.12: Total and domain mean of P-CPQ by disability

Furthermore, One-way ANOVA was conducted to compare the mean score of all the domains and overall quality of life of CSNs by the level of education of the caregivers in Table 4.12. Only the social wellbeing domain showed significant variation in the perceived mean score by the type of disability of the CSNs ($p < 0.05$), Post-hoc analysis by Games Howell multiple comparison of means showed that caregivers with high school ($p < 0.05$), college ($p < 0.05$) or University level education ($p < 0.05$) expressed significant negative impact in the social wellbeing domain when compared with other levels of education such as Primary school.

Table 4.12: Comparison of perceived mean score of the domains and overall quality of life by caregivers' level of education

Domain and Total P-CPQ scores	level of education	Sum of Squares	df	Mean Square	F	p
Oral symptoms	Between Groups	47.89	5	9.58	0.79	0.559
	Within Groups	1749.1	144	12.15		
	Total	1796.99	149			
Functional limitation	Between Groups	129.01	5	25.8	1.75	0.128
	Within Groups	2127.18	144	14.77		
	Total	2256.19	149			
Emotional wellbeing	Between Groups	122.48	5	24.5	1.63	0.155
	Within Groups	2161.52	144	15.01		
	Total	2284	149			
Social wellbeing	Between Groups	88.99	5	17.8	2.37	0.042
	Within Groups	1074	143	7.51		
	Total	1162.99	148			
P- CPQ score	Between Groups	1182.08	5	236.42	2.15	0.063
	Within Groups	15744.37	143	110.1		
	Total	16926.46	148			

Table of ANOVA (Table 4.13 and) showed no significant variations in the perceived mean score of the caregivers in all the domains and overall quality of life of the CSNs (employment status: $p > 0.05$).

Table 4.13: Comparison of perceived mean score of the domains and overall quality of life by caregivers' employment status

Domains	Employment status	Sum of Squares	df	F	p
Oral symptoms	Between Groups	15.48	3	0.42	0.737
	Within Groups	1781.52	146		
	Total	1796.99	149		
Functional limitation	Between Groups	5.69	3	0.12	0.946
	Within Groups	2250.5	146		
	Total	2256.19	149		
Emotional wellbeing	Between Groups	7.45	3	0.16	0.924
	Within Groups	2276.56	146		
	Total	2284	149		
Social wellbeing	Between Groups	49.79	3	2.16	0.095
	Within Groups	1113.2	145		
	Total	1162.99	148		
P- CPQ score	Between Groups	47.82	3	0.14	0.938
	Within Groups	16878.64	145		
	Total	16926.46	148		

Tables 4.14 and 4.15 showed the influence of caries status in the primary and permanent dentition on the quality of life of the children with disability as perceived by the caregivers.

Table 4.14 showed that there were significant differences in the oral symptom, functional limitation domain and overall quality of life in those with caries in primary dentition expressing significant negative impact on their quality of life.

Table 4.14: Comparison of Quality of life scores by the caries status in primary dentition

Domains	caries prevalence primary dentition	n	Mean	SD	t	p
Oral symptoms	Caries free	62	3.44	3.37	-2.35	0.021
	Caries present	35	5.14	3.57		
Functional limitation	Caries free	62	2.9	3.46	-2.27	0.025
	Caries present	35	4.66	3.96		
Emotional wellbeing	Caries free	62	2.65	3.97	-0.37	0.715
	Caries present	35	2.94	3.6		
Social wellbeing	Caries free	61	1.05	2.5	-1.15	0.253
	Caries present	35	1.63	2.14		
P- CPQ score	Caries free	61	9.82	10.4	-2.13	0.035
	Caries present	35	14.37	9.42		

Table 4.15 showed that there was a significant difference in the mean scores of the oral symptom domain only with those with caries in permanent dentition expressing significant impact on this domain ($p<0.05$). There were no significant differences in the mean scores in other domains and overall quality of life in individuals without caries and those with caries in permanent dentition ($p>0.05$) respectively.

Table 4.15: Comparison of quality of life scores by the caries status in permanent dentition

Domains	Caries prevalence permanent dentition	n	Mean	SD	t	p
Oral symptoms	Caries free	30	3.17	2.63	-2.29	0.026
	Caries present	38	5.05	3.87		
Functional limitation	Caries free	30	3.33	3.17	-1.39	0.169
	Caries present	38	4.55	3.89		
Emotional wellbeing	Caries free	30	3.27	2.95	-1.12	0.267
	Caries present	38	4.26	4.11		
Social wellbeing	Caries free	30	2.67	2.94	1.76	0.083
	Caries present	37	1.57	2.17		
P- CPQ score	Caries free	30	12.43	8.19	-1.26	0.212
	Caries present	37	15.22	9.57		

4.6.2 Family impact scores (FIS)

The data for the FIS will also be reported based on the overall as well as domain scores of the FIS.

Table 4.16 illustrates the mean FIS and domain scores of the study population. The mean FIS score was 6.05 (SD 6.77). The results showed that the high domain scores were found in the parental emotion symptoms (4 (SD 4.36)) followed by the parental activity domain (2.1 (SD 2.36)). The lowest scores were found in the family conflict domain (0.67 (SD 1.26)). The highest proportion of the "don't know" responses was in the family conflict domain (n = 27) followed by the parental emotion domain (n = 26).

Table 4.16: Mean, standard deviations, ranges and number of "don't know" responses of the domain and total FIS score

Domains and overall scores	Mean (SD)	Expected range	Observed range	"Don't know"
Parental activity	2.1 (2.36)	0-8	0-8	19
Parental emotions	4. (4.36)	0-16	0-16	26
Family conflict	0.67 (1.26)	0-8	0-6	27
Family impact scale	6.05 (6.77)	0-32	0-27	41

Table 4.17 shows the mean score of the domains and the overall FIS as expressed by the caregivers. A statistically significant difference was noted in the domain of parental emotions between males and females, with the females showing more parental emotions than their male counterparts ($p < 0.05$).However the results should be interpreted with caution as there were few male caregivers.

Table 4.17: Comparison of the domain and overall family impact scale scores by gender

Domains and Total family impact	Gender	n	Mean	SD	t	p
Parental activity	Female	142	3.83	4.3	-0.27	0.788
	Male	8	4.25	3.73		
Parental emotions	Female	142	1.95	2.34	2.891	0.014
	Male	8	0.75	1.04		
Family conflict	Female	142	0.56	1.19	-0.143	0.886
	Male	8	0.63	0.92		
FIS	Female	142	6.35	6.78	0.295	0.768
	Male	8	5.63	4.96		

Tables 4.18 and 4.19 describe the mean scores of the FIS and its domains, and analysis of variance by disability. The caregivers of the Autistic children reported high family impact followed by Epilepsy and Down syndrome children. Across all the disabilities, caregivers expressed high scores in the parental activity domain.

Table 4.18: Total and domain mean and standard deviations of FIS by disability

Domains	Down syndrome (n=61)	Cerebral palsy (n=42)	Autism (n=15)	Epilepsy (n=15)	Complex disabilities (n=15)	p
Parental activity	4.21 (4.43)	3 (4.41)	4.75 (4.15)	4.42 (4.2)	3.7 (2.79)	> 0.05
Parental emotions	2.36 (2.57)	1.43 (2.24)	2.5 (2.24)	2.33 (1.92)	1.91 (1.88)	> 0.05
Family conflict	0.68 (1.36)	0.29 (0.97)	1 (1.29)	1 (1.27)	0.69 (0.85)	> 0.05
Family impact scale	6.35 (6.79)	4.2 (6.32)	8.63 (7.00)	6.66 (6.46)	5.33 (4.00)	> 0.05

However, analysis of variance showed no significant variation in the mean score of the domains and overall FIS expressed by the caregivers irrespective of the type of disability of their children ($p > 0.05$) (Table 4.19).

Table 4.19: Analysis of variance of the mean scores of all the domains and overall FIS by disability

Domains and Total family impact	Disability	Sum of Squares	df	F	p
Parental activity	Between Groups	65.13	4	0.941	0.442
	Within Groups	2474.79	143		
	Total	2539.92	147		
Parental emotions	Between Groups	28.59	4	1.377	0.245
	Within Groups	741.97	143		
	Total	770.56	147		
Family conflict	Between Groups	6.65	4	1.32	0.265
	Within Groups	180.11	143		
	Total	186.76	147		
FIS	Between Groups	235.44	4	1.412	0.233
	Within Groups	5961.06	143		
	Total	6196.51	147		

In Table 4.20 significant variations were noted in the parental activity and overall FIS ($p < 0.05$) respectively. Post-hoc analysis showed that university graduates expressed a significantly higher negative impact than high school leavers in the domain of parental activities and the overall FIS ($p < 0.05$) respectively.

Table 4.20: Comparison of perceived mean score of the domains and overall FIS by caregivers' level of education

Domains and Total family impact	Level of Education	Sum of Squares	df	F	p
Parental activity	Between Groups	306.15	5	3.68	0.004
	Within Groups	2396.63	144		
	Total	2702.77	149		
Parental emotions	Between Groups	29.36	5	1.11	0.358
	Within Groups	761.72	144		
	Total	791.07	149		
Family conflict	Between Groups	7.9	5	1.14	0.34
	Within Groups	198.93	144		
	Total	206.83	149		
FIS	Between Groups	566.51	5	2.68	0.024
	Within Groups	6099.38	144		
	Total	6665.89	149		

Table 4.21 showed that there were significant variations in the parental activity and family conflict domains ($p < 0.05$ respectively) as shown in the table of ANOVA below. However, Post-hoc analysis did not show any significant difference when comparing means of the overall and domain FIS scores by their employment status ($p > 0.05$) respectively.

Table 4.21: Comparison of perceived mean score of the domains and overall quality of life by caregivers' employment status

Domains	Employment status	Sum of Squares	df	F	p
Parental activity	Between Groups	147.993	3	2.812	0.041
	Within Groups	2554.781	146		
	Total	2702.773	149		
Parental emotions	Between Groups	2.559	3	0.156	0.924
	Within Groups	788.514	146		
	Total	791.073	149		
Family conflict	Between Groups	11.59	3	2.89	0.038
	Within Groups	195.243	146		
	Total	206.833	149		
FIS	Between Groups	251.384	3	1.91	0.131
	Within Groups	6414.51	146		
	Total	6665.893	149		

Tables 4.22 and 4.23 showed the influence of caries status in the primary and permanent dentition on the family of the CSNs using the FIS. No significant differences were noted in all the domains and the overall FIS by the caries status of both the primary and permanent dentitions.

Table 4.22: Comparison of family impact scores by the caries status in primary dentition

Domains	caries prevalence primary dentition	n	Mean	SD	t	p
Parental activity	Caries free	62	2.66	4.12	-0.97	0.335
	Caries present	35	3.49	3.85		
Parental emotions	Caries free	62	1.29	1.99	-1.93	0.057
	Caries present	35	2.17	2.44		
Family conflict	Caries free	62	0.31	1	-0.96	0.34
	Caries present	35	0.51	1.07		
FIS	Caries free	62	4.26	6.04	-1.48	0.143
	Caries present	35	6.17	6.29		

Table 4.23: Comparison of family impact scores by the caries status in permanent dentition

Domain	Caries status in permanent dentition	N	Mean	SD	t	p
Parental activity	Caries free	30	4.8	4.29	0.53	0.596
	Caries present	38	4.26	3.99		
Parental emotions	Caries free	30	2.6	2.43	1.06	0.295
	Caries present	38	2.03	2.05		
Family conflict	Caries free	30	0.63	0.96	0.11	0.915
	caries present	38	0.61	1.15		
FIS	Caries free	30	8.03	6.41	0.75	0.454
	Caries present	38	6.9	6.01		

In summary, table 4.24 reported the proportions of caregivers who indicated a negative impact or no impact by disabilities of their children on the P-CPQ and FIS. The majority of the caregivers (85-100%) reported a negative impact on the oral health related quality of life of their children. All the caregivers of children with Epilepsy and Complex disability reported negative impact on OHRQoL. A high proportion of caregivers of children with Autism (n = 13; 86%) reported an impact on family life followed by the complex disability group (n = 12; 80%) while only 50% of the Down syndrome group caregivers reported an impact on their families.

Table 4.24: Summary of the proportion of caregivers who reported impact or no impact on the quality of life and family impact scale by the disability

Disability	OHRQoL		Family Impact scale		
	Impact n (%)	No impact n (%)	Impact n (%)	No impact n (%)	Total
Downs syndrome	52 (85.2%)	9 (14.8%)	31 (50.08%)	30 (49.2%)	n=61
Cerebral palsy	39 (92.9%)	3 (7.1%)	27 (64.3%)	15 (35.7%)	n=42
Autism	14 (93.3%)	1 (6.7%)	13 (86.7%)	2 (13.3%)	n=15
Epilepsy	15 (100%)	*	10 (66.7%)	5 (33.3%)	n=10
Complex disabilities	15 (100%)	*	12 (80%)	3 (20%)	n=15

*No impact reported

About 95% the caregivers of the children who had dental caries in the primary dentition, reported a negative impact on their perceived OHRQoL and similarly, about 90% of the caregivers of those who had caries in the permanent dentition reported a negative impact.

4.6.3 Global rating scores and construct validity testing

The data from the global rating scores indicated that 31.3% (n = 47) of the caregivers rated their children's oral health as excellent and only 12% (n =18) rated the oral health as being poor. A total of 60.7% (n=91) caregivers reported that their children's overall wellbeing was not affected by the oral conditions.

Spearman Rho correlation coefficient was used to assess the construct validity of the study instrument (questionnaire).There was a strong correlation between the P-CPQ scores and the global rating of overall wellbeing scores (ρ=0.56; p=<0.001) and global rating of oral health score (ρ=0.653; p<0.001) respectively.

4.6.4 Correlations and Regression models

Based on the literature review and the perusal of the different analyses of variables undertaken, we reported on the following as a means of comparing our findings with that in the published literature:

1. Spearman Rho correlation

2. Linear Regression analysis

Spearman's correlation coefficient was used to measure the extent of the linear relationship between dental caries, caregiver perception scores, FIS and global rating scores and the results are displayed in Table 4.25

Primary dentition caries correlated significantly with oral symptoms, functional limitation and social wellbeing domains. However, the strength of association was mild (ρ coefficient ranged between 0.23-0.25). Dental caries was also found to be moderately associated with the global rating score on the overall oral health rating and the association was moderate (ρ =0.349: p=0.005). There was no association between the caries index scores and the FIS scores.

Table 4.25: Correlation between dmft, DMFT, domains and total P-CPQ scores

Variable	**dmft**		**DMFT**	
	ρ**	p-value	ρ**	p-value
Oral Symptoms	0.246	0.034*	0.051	0.793
Functional Limitation	0.231	0.041*	-0.091	0.511
Emotional Well being	0.078	0.494	0.054	0.692
Social Well being	0.252	0.038*	-0.24	0.103
P-CPQ	0.154	0.273	-0.256	0.261
Parental Activity	0.165	0.14	-0.209	0.124
Parental emotion	0.204	0.058	-0.167	0.209
Family Conflict	0.205	0.697	0.099	0.456
Family Impact Scale	0.137	0.247	-0.128	0.3893
Global rating-oral health	0.349	0.005*	0.349	0*
Global rating-overall well being	0.02	0.84	0.117	0.339

*significant at p<0.05** Spearman's correlation coefficient

The linear regression model was used to evaluate the impact of the sociodemographic factors of the caregiver, the caries status of the children on Oral Health Related Quality of Life Family Impact core. The dependent variables used in the regression model were P-CPQ and FIS. The independent variables such as age group, relationship, the gender, level of education and employment status of the caregivers as well as dmft and DMFT of the children were added into the equation in a stepwise form. The results are displayed on Tables 4.26 and 4.27.

Table 4.26 showed that there was no significant relationship between all the variables entered into the regression model and the P-CPQ scores as expressed by the caregivers.

Table 4.26: Linear regression of sociodemographic variables of the caregiver, dmft and DMFT of the children and P-CPQ

Model	Variables	*B*	Std. Error	t	p	Confidence interval	
						low	upper
	(Constant)	-1.46	17.78	-0.08	0.94	-43.5	40.57
1	Caregiver Age group	0.52	3.27	0.16	0.88	-7.21	8.26
2	Relationship	-3.99	4.17	-0.96	0.37	-13.85	5.87
3	Disability	1.1	2.13	0.52	0.62	-3.93	6.13
4	Level of education	8.4	4.47	1.88	0.10	-2.17	18.98
5	Employment	-5.48	4	-1.37	0.21	-14.94	3.98
6	dmft	-0.4	1.08	-0.37	0.72	-2.96	2.16
7	DMFT	4.81	3.50	1.38	0.21	-3.47	13.09

Table 4.27 showed that there was no significant relationship between all the variables entered into the regression model and the FIS scores as expressed by the caregivers.

Table 4.27: Linear regression of sociodemographic variables of the caregiver, dmft and DMFT of the children and FIS

Model	Variables	B	Std. Error	t	p	Confidence interval	
						low	upper
	(Constant)	-4.34	12.72	-0.34	0.74	-34.41	25.74
1	Age group of caregiver	-1.55	2.34	-0.66	0.53	-7.09	3.98
2	Relationship	-6.12	2.98	-2.05	0.08	-13.18	0.94
3	Disability	1.29	1.52	0.85	0.42	-2.31	4.89
4	Level of education	7.11	3.2	2.22	0.06	-0.45	14.68
5	Employment	0.47	2.86	0.17	0.87	-6.3	7.24
6	dmft	0.95	0.78	1.22	0.26	-0.88	2.78
7	DMFT	0.97	2.51	0.39	0.71	-4.95	6.9

CHAPTER 5: DISCUSSION

Children with special needs are faced with the daily burden of dealing with the negative impact of their individual disabilities, and more specifically, the effect of these disabilities on oral health. The practice of sustaining good oral health is difficult among people with disabilities because of limitations due to poor neuromuscular coordination, lack of access to health care and competing demands. Poor oral hygiene is a risk factor in the development of dental caries and oral diseases in neurologically challenged individuals (61).Oral health related quality of life measures have been used to measure the impact of oral disease on their quality of life and these subjective measurements use self-reports from patients regarding the impact of oral disease on their quality of life. Parent/caregiver and child OHRQoL instruments should measure the same condition in order to enable comparisons between self and proxy reports. For young children, especially those with special needs, a parent/caregiver proxy report may be needed. Even when children are able to self-report, caregiver proxy reports should be considered to complement the child's report (62). The impact of dental caries in this South African population of CSN is not known in the current setting and in the country as a whole; hence, caregiver reporting was used in this cross sectional study with the aim of assessing OHRQoL among CSN, from the caregiver's perspective.

5.1 Demographics

5.1.1 Caregiver demographics

The total study population consisted of 150 caregiver child pairs and the mean age of the caregivers was 39.52 (SD 9.26). Females were the predominant caregiver and this is consistent with other studies that reported on caregivers' perceptions on OHRQoL, which reported to have more females as the caregivers (13, 47). The females were mothers, grandmothers or relatives.

This is due to the worldwide societal norm, including South Africa, where females are regarded as primary caregivers (63, 64). The majority of the female caregivers in this study were mothers (86%). This is similar to many studies in the published literature that report that the majority of the mothers are the ones who care for the children with special health care needs (15, 63, 64).

Most of the caregivers were in the age group between 19-49 years. This age bracket is usually the childbearing age in this society. However, grandmothers or relatives may be involved in the care of these children if the mothers are not alive or due to work commitment or marital problems (65). When the age of the caregivers was dichotomized into below 40 years and above, there was a significant association between the age of the caregiver and the disability of the child. Those caregivers below age 40 were twice as likely to care for children with Cerebral palsy compared to the older caregivers (p=0.001). This is similar to the study by Byrne *et al.*, where they found the younger caregivers were more likely to care for children with Cerebral palsy (66). Children with Cerebral palsy have problems with neuro muscular coordination and are quite difficult to care for, hence, they need caregivers who are young and physically active to cope with the stress of caring for this group of children (67).

In addition, a large percentage of the caregivers were unemployed with the majority of these (18.2%) in the Cerebral palsy group, and they were about 4 times more likely to care for this group of disabled children compared to the employed. This could be related to the challenges of caring for the children with disabilities, especially children with Cerebral palsy, since they may need constant care and supervision (16). Furthermore, the lack of access to special needs day care centers could lead parents to decide to stay home or couples to decide that one partner should stay at home to care for the child (6).

5.1.2 Child demographics

The mean age of the child participants was found to be 8.72 years (SD 6.07) and there were more males (59.30%) than females (40.70%). These findings are consistent with other studies on special needs children that have also shown significant differences in gender proportions. Studies of CSNs in India (44), Saudi Arabia (13) and USA (45) also had more males as the majority participants. A possible reason for the male predominance in the CSNs could be that boys are genetically predisposed to having one form or another of disabilities opposed to females (68).

The majority of the CSNs in this study had Down syndrome (40%) followed by children with Cerebral palsy (28%). This distribution is not the true reflection of the prevalence of the disabilities in South Africa (69). Our study sample was mainly collected from one special needs school and from the Down syndrome association outreach site which also catered for children with other disabilities as well.

5.2 Caries status

Dental caries is a major public health problem in South Africa. Several reports have shown the prevalence of dental caries to be higher in children with disabilities compared to the general populations (40, 70) (71). The overall caries prevalence in this cohort was 42%. This is lower than when compared to the prevalence (76%) reported by Shukla *et al,.* in India (44) and (55%) by Abanto *et al,.* in Brazil(47) . The reason for the lower prevalence in this cohort studied could be that this cohort had a daily tooth brushing routine after lunch which was established at the special needs school for more than a year. Indeed, the prevalence reported in this study was lower than the National Children's Oral Health Survey (NCOHS) prevalence reported by Van

Wyk, (41). An earlier study done by Nqcobo *et al*., also found caries prevalence to be lower in the CSNs than in the general population of Johannesburg (7).

This is similar to the present study where the prevalence of caries was found to be lower in primary and permanent dentition in the CSNs (36.1% and 55.9%) respectively, compared to the general population (50.6% and 60.3% respectively). 0ne of the reasons for this could be that the diet in these children is more controlled and there is controlled brushing and oral health care programs which children in the general population may not be exposed to.

Dental caries was found to be more severe in the primary dentition than in the permanent dentition. This is consistent with the National Oral Health Survey which has also reported dental caries to have been more severe in the primary than in the permanent dentition (41). The results are also consistent with the findings of Begramian *et al,*. in their review of dental caries prevalence in developing countries, which found an alarming increases in dental caries in the primary dentition (72).

The report of the NCOHS which excluded CSNs showed that the mean national caries prevalence in 4-5 year olds was 50.6% while it was 60.3% in 6 year olds (41). Gauteng Province also showed the same level of caries as the mean national estimates. The current study has shown that when caries prevalence was compared by age groups, the 4-5 year olds in the current study had a lower caries prevalence (42%) compared to the 4-5 year olds in the NCOHS (50.6%) (41). One would have expected the caries prevalence to be higher in the disability group however the controlled diet and brushing programs could be the reason for the low caries prevalence in this cohort. Another reason could be that the caregivers who regularly attend support groups meetings and are frequently visited by the oral health team have acquired skills and knowledge on how to take care of the oral health of their children.

5.2.1 Caries prevalence by disability

The highest caries prevalence was found in the Epilepsy group (83.3%) followed by the Autism group (75%). Similarly, Gurbuz and Tan found the caries prevalence in children with Epilepsy to be high (96.7%) (73). The reason for the high prevalence among this group may be as a result of medications which predispose them to gingival hyperplasia and dry mouth. This in turn accelerates plaque retention and ultimately increases the risk for dental caries. The prevalence of caries in the Autism group was also found to be high (75%) in the current study. This is similar to the findings by Jaber *et al*., (74). The reason for this high prevalence could be that children with Autism have multiple medical and behavioural problems, which make their oral hygiene care extremely difficult. In general, children with Autism prefer soft and sweetened foods and they tend to pouch food inside the mouth instead of swallowing it due to poor tongue coordination, thus increasing the susceptibility to caries (75).

In contrast to the prevalence obtained for the Epilepsy and Autistic groups, caries prevalence was low in the Down syndrome and Cerebral palsy groups. Controversies exist regarding the caries susceptibility in individuals with Down's syndrome. Caries prevalence has been reported to be both higher (70, 74), and lower in patients with Down's syndrome (71) compared to individuals with other mental disabilities. One expects the caries prevalence to be higher in the Downs syndrome and Cerebral palsy groups because of the associated muscle weakness and inadequate muscle coordination which prevents proper daily hygiene procedures. Caution needs to be exercised when interpreting the high prevalence recorded for Epilepsy and Autistic groups due to the small sample sizes reported. Of interest is that determinants of dental caries risk in these

individuals, such as less frequent brushing, and some sociodemographic factors, may be important in this cohort.

5.2.2 Untreated Caries

In keeping with other studies (70), the prevalence of untreated caries among disabilities such as Down syndrome, Cerebral palsy, Epilepsy and other complex disabilities was high, ranging from 75-100% except in the Autistic group (25%). In contrast, a study by Jaber *et al*., (74) found 77% of untreated caries among Autistic children in United Arab Emirates. The reason for the low figure recorded in this study's Autism cohort could be because, the majority of the caregivers of Autistic children had higher levels education (college and university) compared to other caregivers, thus improving the access of this group of children to oral health care services.

Untreated dental caries in South Africa according to the NCOHS was reported to be 46.6% in the 4-5 year olds and 55.1% in the 6 year olds (41). In contrast the current study has shown untreated caries to be much higher in the same age groups (100%). These results are also higher than the results reported earlier by Nqcobo *et al*., which ranged between 57%-68% (7). The reason for this high untreated caries among CSNs may be due to the lack of access to oral health services, long waiting lists for general anaesthesia and the caregiver's perception of oral health care as not being a priority over general health problems.

5.2.3 DMFT /dmft by disability

There seems to be consensus among various authors that the dmft and DMFT of children with disability is usually higher than that of the general population. Two studies (40) (7) showed that CSNs had significantly higher dmft/DMFT scores compared to those reported in the NCOHS. The findings of this current study showed lower dmft scores compared to the national dmft scores and previous studies (40) (7), except in children with complex disabilities who had a

higher dmft of 3.2 (SD 4.38). The lower dmft score may be due to factors previously as explained, which include that the study participants have been visited many times by oral health workers for preventive care. The higher dmft in children with complex disabilities may be due to a greater handicap experienced by the children in this group in maintaining good oral health.

When compared to other Autistic children, the findings of this study was higher than those reported by Yashoda and Puranik (46) (1.46 (SD 0.86)) in India and by Yengopal *et al*., in South Africa (76) (1.57 (SD 2.5)). This high score could be due to the effect of the high "missing" teeth component (1.00 (SD 3.00)) on the overall dmft score. This indicated that the children with Autism in this cohort had received more extractions. This finding is unexpected as there is anecdotal evidence that Autistic children have difficulties in adapting to new environments like a dental clinic. A possible explanation was that the children received treatments under general anaesthesia while the initial clinical examinations were conducted at school, which is a familiar environment. Yashoda and Puranik, (46) have reported that children with Autism are more inclined to be co-operative during a clinical exam if it is conducted in a familiar environment like at school. The dmft score of children with Cerebral palsy was found to be lower (1.58 (SD 2.88)) than in the study reported on Brazilian children by Abanto *et al*., The reason could be due to different factors like access to fluoridated tooth paste and oral health services, bruxism and differences in tooth morphology (47).

The DMFT scores in this study ranged from 1.2 to 1.83 which is similar to the findings of the NCOHS (41) which was 1.1 to 1.9. It must be pointed out that the children with disabilities have delayed eruption when compared with other children without disabilities (77). Hence, the teeth have less exposure time in the mouth compared to children without disabilities. Therefore, this might have accounted for the slightly lower DMFT in the current study. The present study also

revealed that the mean DMFT scores in Down syndrome, Cerebral palsy and Autism were lower compared to those reported by Shukla *et al*., (44) and Nqcobo *et al*., (7). The reason for this might be due to differences in populations sampled as the current cohort had brushing programs for a year.

5.3 Perceptions of OHRQoL

OHRQoL is usually assessed by a questionnaire using a Likert scale format. This specifically asks respondents questions about the impact of oral diseases on activities such as chewing, pain, psychosocial functions and social wellbeing. When the respondents are young children and those with special needs, the caregivers usually serve as proxy (12). This method was used in the determination of the OHRQoL of CSNs in the present study. This same method has been justified in several studies as reliable and a valid measure of OHRQoL in CSNs (13) (31)

Studies have shown that the OHRQoL of CSNs are significantly compromised by oral diseases because of their disability status (50). Our study showed that the majority of the caregivers of CSNs have reported that oral diseases had a negative impact on the OHRQoL. However, the level of the impact was relatively low. Other studies in literature have reported higher impact of oral diseases on the OHRQoL. Abanto *et al*., (50)and Pani *et al*., (13)showed a negative impact of oral diseases on OHRQoL of children with Cerebral palsy and Autism as perceived by their caregivers. The burden of oral diseases is high in this group of children because they are at higher risk of developing dental caries and periodontal diseases. Untreated caries that has progressed into the pulp and periapical tissues results in severe pain, which could impact on

feeding and sleeping. Hence, these are perceived as negative impacts on the quality of life of the children.

Studies (50) (57) have shown that the severity of a disability is a predictor of a poor quality of life. Abanto *et al*., reported that the presence of seizures was a positive predictor of poor OHRQoL as the presence of seizures was associated with a negative impact on the oral symptom domain (50). Seizures are common in Cerebral palsy and in those with Epilepsy and thus as a result these groups are at risk of poor OHRQoL. The reason for this increased risk is that the seizures are associated with generalized pains due to muscle spasms and there can be referred pains which can be perceived as tooth ache. Although all the caregivers expressed a negative impact of oral diseases on the quality of life of their children in the present study, there was no significant effect of the type of disability on the perception of the caregivers. The reason for this finding could be that the concern is not the severity of the disability itself but the effect of the disability on oral health, which is usually the same, regardless of the type of disability. Hence, parents may express the same negative impact on the quality of life of their children. Another reason could be the small and uneven numbers of the participants in the different disabilities.

5.3.1 Sociodemographic factors and OHRQoL

The influence of sociodemographic factors of the caregivers on the OHRQoL has been studied by many authors. De Paula *et al*., (78) and Baghdadi and Muhajarine (12) studied the influence of some sociodemographic variables such as the age of the children, age of the caregivers, gender, mother's education, source of income and family structure on the perception of OHRQoL of children. Their results showed a significant influence of these sociodemographic variables on the perception of the OHRQoL of the children. Importantly, these findings were from children without special needs.

Pani *et al*., conducted a study on Autistic children and their caregivers and found that only the age of the mothers significantly influenced the perception of the OHRQoL of their children (13). The present study determined the influence of gender of the caregivers, employment status, age of caregivers, their level of education and source of income on the perception of the caregivers on the OHRQoL of their children.

5.3.2 Gender of caregivers

Pani *et al*., reported that mothers are primary caregivers in many populations and are a good proxy for questionnaire based studies relating to their children (13). A literature review also showed that mothers as caregivers influenced the perception of OHRQoL due to the increased caregiver burden as the children required additional care due to their disabilities (79). However, in a study by Baghdadi and Muhajarine, no significant difference was found between the responses of the fathers and mothers with regard to their accurate knowledge of the OHRQoL of their children. In the present study, there was no significant difference in the proportions of the males and females with regard to the accurate knowledge of the OHRQoL of the children based on "don't know" responses (12).

A study conducted by Pani *et al.,* (56) in Saudi Arabia showed a significant difference in the perception of caregiver gender, with mothers reporting more impact than fathers. He then concluded that mothers are more appropriate proxies than fathers in the assessment of OHRQoL. However, the current study does not show any significant difference in the perception of the caregiver gender in all the domains and overall P-CPQ scores when compared using the student T-test followed by linear logistic regression analysis. Other categories of caregivers did not show significant difference in the domains and overall CPQ scores when compared to the mothers as caregivers. This was in agreement with the findings of Scarpelli *et al*., (80) and Wong *et al.*,

(81), who found no difference in OHRQoL scores in children who were taken care of by their mothers and those whose caregivers were other family members. However, in contrast to this current study, these studies were conducted on caregivers whose children had no disabilities.

5.3.3 Age of the caregivers

Several published studies (13, 81, 82), have reported on the effect of parent's age on children's OHRQoL. Abanto *et al*., (83) and Baker *et al*., (84) found no significant relationship between parent's age and children's OHRQoL. Similarly, the current study found no significant influence of the caregiver age on the perception of OHRQoL in all the domains and overall scores of P-CPQ. Other studies reported that mother's or caregiver's age was inversely related to children's OHRQoL (94) and (91). Pani *et al*., suggested that the reason for older caregivers to have a negative perception of the OHRQoL of their children is that they have greater concerns about oral hygiene than the younger caregivers (13).

5.3.4 Level education of caregivers

Mixed results have been published on the influence of caregiver's level of education and perception of the quality of life of their wards. Several studies showed that the education level of both the parents and the mothers education was found not to be related to children's OHRQoL (83) (85) (86).However, Baker *et al*., (84), and Papaioannou *et al*.,(87) showed that the level of education of caregivers was significantly related to the perception of the OHRQoL only in the social wellbeing domain. Post-hoc analysis in this current study showed that, primary and university levels of education were positive predictors of perception of negative impact of oral disease on the social wellbeing domain. The reason could be that the disability limits the social interaction of the children with their peers.

5.3.5 Employment status

Few studies evaluated the employment status in relation to perception of OHRQoL of caregivers of CSNs. Nonetheless, many studies have been done on children without special needs (88). Papaioannou *et al*., (87) reported an insignificant association between employment status and the perception of the caregivers on the OHRQoL of their children. This current study found similar results. The reason for the similar perception between those who are employed and those who are not employed may be that the unemployed voluntarily stay at home to care for their children with special needs. More so, that there are few day-care centres that care for these children in South Africa.

5.3.6 Dental Caries and OHRQoL

Abanto *at al*., reported that dental caries experience has a negative impact on the overall quality of life score especially in the emotional wellbeing domain (47). In contrast Yashoda and Puranik, found that functional limitation domain was significantly impacted (negatively) in children with Autism (46). They are of the opinion that it could be related to self-inflicting habits, and eating disorders which are predominantly seen in these groups. The current study found no significant difference between the type of disabilities and the impact of the caries experience on any of the domains and the overall OHRQoL using regression analysis on both primary and permanent dentition. Furthermore, all the caregivers irrespective of the disabilities reported a negative impact on the oral symptoms, functional limitations and overall quality of life in primary dentition only, while only the oral symptom domain was shown to significantly impact the OHRQoL in permanent dentition. This could be due to the consequences of untreated caries

which leads to discomfort and the children may not be able to eat. The children may also be complaining/show signs of discomfort, which may alert the caregiver of the extent of pain.

5.4 Family impact scale (FIS)

Few studies have been done on the effect of gender, age of caregiver and some sociodemographic characteristics on the FIS in Autistic children. Extensive search of the literature yielded no result of similar studies on children with Down syndrome. Caregivers of Autistic children expressed the highest mean FIS score of 8.0. But regression analysis and ANOVA showed no significant influence of any type of disability on the FIS score. Hence, we can infer that there was no significant variation in the mean FIS score by disability. This study reported low overall FIS mean score of 6.0 on a scale range of 0-36. In contrast, Abanto *et al.*, reported a lower FIS mean score of 3.0 in Cerebral palsy children (47). The reason for the difference in the scores may be due to population differences. Furthermore, a study by Pani *et al*., reported a higher impact on the parental emotion domains than on any other domains on the FIS (13). Similarly this study reported significantly higher parental emotion compared to other domains. Many parents are affected emotionally by the multitude of problems they deal with in caring for these children. Parents may be worried about oral health problems especially when they lead to pain, inability to eat and disturbed sleep. The caregivers get frustrated because of the inability of their children to express feelings of pain and discomfort (51).

5.4.1 Gender of caregivers and family impact scale (FIS)

Most studies reviewed did not compare the gender of the caregivers with respect to their FIS. This present study showed a significant gender difference in the parental emotional domain, with

the females expressing higher impact scores than their male counterparts. This is because the females have been shown to carry more caregiving burden than the males.

5.4.2 Effect of age of caregivers on family impact scale

Pani *et al*., investigated the influence of maternal age on FIS and the authors reported a significant positive influence on FIS (13). Older mothers were reported to express more concern about the oral health of their children (13). In contrast, the present study showed no significant association between caregiver age and the perceived FIS. The reason for the difference is not clear but it could be due to the cultural differences in the population sampled, sample sizes and selection methods.

5.4.3 Level of education of caregivers and family impact scale (FIS)

In addition, Pani *et al*, investigated the influence of the level of education of caregivers on FIS (13). It is reported that the maternal level of education positively influenced FIS. However they did not report on the influence of education level on the specific FIS domains. The current study showed a significant variation in the overall and the various domains of FIS scores by level of education. The university graduates expressed a significantly higher negative impact than high school leavers in the domain of parental activities and the overall FIS. This could be due to the fact that social activities of the family may be negatively impacted by the challenges of caring for a child with special needs. The caregivers may be forced to arrange for temporary helpers to care for the special needs child when they need to attend social events.

5.4.4 Employment of caregivers and family impact scale (FIS)

Studies evaluated did not compare employment status of the caregivers in relation to their FIS. The present study showed significant variations in the parental activity and family conflict domains in the ANOVA analysis. However, post-hoc analysis did not show any significant direction in the variation. Linear regression analysis did not show any significant influence of caregiver employment status on the FIS. The similar perception between those who are employed and those not employed may be due to the fact that many of those who are unemployed voluntarily stay at home to care for children with special needs.

5.5 Dental caries and family impact scale (FIS)

The current study showed no significant difference between the type of disabilities and the impact of the caries experience on all the domains and the overall FIS, using regression analysis in both primary and permanent dentition. Furthermore, all the caregivers, irrespective of the disabilities, reported no family impact on all the domains and the overall FIS in primary dentition. Anecdotal reports, especially in the developing world, show that oral health is not a priority. Indeed, the prevailing poor knowledge on oral health and its importance to general health in this environment, further contributes to less attention given to oral health care. There are no reports from similar developing countries to corroborate the findings of the current study.

5.6 Global rating score

A global rating score is important in evaluating an OHRQoL questionnaire and the construct validity results have showed that the overall OHRQoL score in the study is valid. This was demonstrated by the strong correlation between the global rating scores and the P-CPQ scores.

When the caregivers assessed the oral health of their children, the majority (61%) of the caregivers reported that their children's overall wellbeing was not affected by the oral conditions. In contrast, Abanto *et al.*, found a lower proportion of caregivers who rated their children's oral health as excellent (50). Correlation analysis also showed that the global rating of the overall wellbeing of the children in this current study was not significantly affected by the oral diseases. The reason could be that the overall wellbeing of the children is mostly perceived by caregivers to be affected by the severity of the disability rather than the oral condition. These findings may account for the non- significant contribution of the variables studied in the regression analysis and ANOVA tables. Oral health is not considered as life threatening by most population groups, and not considered important to overall wellbeing, especially when oral health diseases co-exist with some debilitating illness or disabilities. It is important that policy makers and health educators begin to make concerted efforts to educate the growing population of caregivers on the importance of oral health to general health. Pani *et al.,* also supports this assertion. Few studies exist to further compare these findings, hence, more studies are needed to corroborate these present findings.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Within the limitations of the study i.e. convenient sampling method used because results cannot be generalised beyond the study cohort, the following conclusions can be made:

- Mostly females and mothers are primary caregivers, although there was no influence of gender on the perception of the OHRQoL and FIS. Caregivers expressed similar perceptions of OHRQoL and FIS irrespective of their socio-economic status.
- The caries experience of the CSNs as determined by the DMFT/dmft is slightly lower than that obtained from the general population.
- Overall, CSNs in the current study experienced a lower impact on OHRQoL and the type of disabilities did not influence the impact on OHRQoL. Caregivers only expressed the impact on the oral symptoms, functional limitations and social well-being domains on P-CPQ in the primary dentition. Caregivers did not express the impact of dental caries in either primary or permanent dentition on the families.

6.2 Recommendations

- Many of the outreach sites visited in this study provided caregiver support in terms of oral hygiene (peer group education), and teacher training on oral health has been planned for the school that participated in the study. It is thus recommended that the caregiver's education of oral health should be expanded in all special needs schools.

- Oral health education and promotion, especially designed for individual disabilities, and proven preventive methods such as the use of fissure sealants in six to seven year olds are recommend to be implemented in this age group of children.

- In terms of future research, more studies focused on the OHRQoL and determinants of the parent/caregiver perception of CSNs should be conducted in South Africa in order to facilitate translation, validation and standardisation of questionnaires.

- Public-private partnerships need to be strengthened to ensure that services are available to members of the population who do not have access to oral health services.

- In many of the outreach sites that were visited, the caregivers expressed a need for improved access to early learning centres for CSNs which is in line with implementation of the policy on integrated learning (CSNs to be integrated in to mainstream education). It is thus recommended that affordable/subsidised early learning centres be made available through public-private partnerships.

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APPENDICES

APPENDIX I: PARENT-CAREGIVER DEMOGRAPHIC AND SOCIO-ECONOMIC DETAILS

Ref No: ____

Tell us about yourself,

1. What is your Age? _____ Years

Place a cross in the box that best describes your response

2. What is your gender? ☐Male ☐Female ☐Other_____

3. What is your relationship to the child? ☐ Mother ☐Father ☐Legal guardian ☐Other (specify) _____

4. What is the disability of the child? ☐Down's syndrome ☐Cerebral Palsy ☐Autism ☐Epilepsy ☐Other (specify) _____

5. Socioeconomic details

a) What is your level of education?

☐No school ☐Primary school ☐High School ☐College/ ☐University ☐Other, specify_____

b) Where do you and your family stay?

☐Own a house ☐ Rented room ☐Own shack ☐ Rented shack ☐Other, specify_____

6. Employment status

☐ Yes ☐ No ☐ Self-employed ☐Other, please explain_____

7. What is your source of Household income?

☐ Salary ☐Disability grant ☐ Pension grant ☐Child grant

8. What is the scale of the combined income in your household?

☐<R1 000☐ R1 000 - R1 500 ☐ R1 500 – R2 500 ☐ R2 500 – R3 000☐>R3 000

APPENDIX II: PARENT-CAREGIVER PERCEPTION QUESTIONNAIRE

In the past 3 months, how often has your child ... (had/been) ... because of their teeth/mouth?

Place a cross in the box that best describes your response

		Never 0	Once or twice 1	Sometimes 2	Often 3	Every day/ almost everyday 4	Don't Know 0
	Oral symptoms						
1.	Bad breath	☐	☐	☐	☐	☐	☐
2.	Pain in teeth/mouth/lips jaw	☐	☐	☐	☐	☐	☐
3.	Food stuck to roof of the mouth	☐	☐	☐	☐	☐	☐
4.	Food caught in or between teeth	☐	☐	☐	☐	☐	☐
	Functional limitations						
5.	Difficulty chewing firm foods	☐	☐	☐	☐	☐	☐
6.	Breathing through the mouth	☐	☐	☐	☐	☐	☐
7.	Slow eating/taking longer than others to eat a meal	☐	☐	☐	☐	☐	☐
8.	Trouble sleeping	☐	☐	☐	☐	☐	☐
	Emotional well-being						
9.	Irritable/frustrated	☐	☐	☐	☐	☐	☐
10.	Upset	☐	☐	☐	☐	☐	☐
11.	Nervous/afraid/anxious	☐	☐	☐	☐	☐	☐
12.	Shy/embarrassed	☐	☐	☐	☐	☐	☐
	Social well-being						
13.	Missed school	☐	☐	☐	☐	☐	☐
14.	Avoided smiling when around other children	☐	☐	☐	☐	☐	☐
15.	Had a hard time paying attention in school	☐	☐	☐	☐	☐	☐
16.	Not wanted to talk with other children	☐	☐	☐	☐	☐	☐

Please answer the questions below by placing a tick in the appropriate box

Global rating	Excellent=0	Above average	average	Below average	Poor=4
How would you rate the health of your child's teeth, lips, jaws and mouth?					
	Not at all=0	Above average	Average	Below average	Very Much=4
How much is your child's overall well-being affected by the condition of his/her teeth, lips, jaws or mouth?					

APPENDIX III: FAMILY IMPACT SCALE

During the past 3 months, how often . . . Never Once or twice Sometimes Often/everyday
Place a cross in the box that best describes your response

		Never 0	Once or twice 1	Sometimes 2	Often 3	Every day/ almost everyday 4	Don't know 0
	Parental/family activity	☐	☐	☐	☐	☐	☐
1.	Have you or the other parent taken time off work?	☐	☐	☐	☐	☐	☐
2.	Has your child required more attention from you or the other parent?	☐	☐	☐	☐	☐	☐
3.	Have you or the other parent had less time for yourselves or other family members?	☐	☐	☐	☐	☐	☐
4.	Has your sleep or that of the other parent been disrupted?	☐	☐	☐	☐	☐	☐
	Parental emotions						
5.	Have you or the other parent been upset?	☐	☐	☐	☐	☐	☐
6.	Have you or the other parent felt guilty?	☐	☐	☐	☐	☐	☐
	Family conflict						
7.	Has your child argued with you or the other parent?	☐	☐	☐	☐	☐	☐
8.	Has your child blamed you or the other parent?	☐	☐	☐	☐	☐	☐

APPENDIX IV: ASSESSMENT FORM

GENERAL INFORMATION

Name of Outreach site: _____
Child's Name: _____ Date of birth :_____(YYYY/MM/DD)
Sex: M/F _____ Date of examination :_____(YYYY/MM/DD)
Type of disability_____
Place a cross in the box that best describes your response
Communication ability: ☐ Normal ☐Mild disability (some difficulty noted)
☐Moderate disability (using non speech forms) ☐Severe disability (no formal communication)
Parental consent: ☐YES ☐NO

CLINICAL ASSESSMENT

Extra-oral assessment	YES	NO
Normal appearance		
Ulceration, sores, erosions (head and neck)		
Cancrum oris		
Abnormalities of upper and lower lips		
Swellings of the face		
Other (specify)		

Intra-oral assessment	YES	NO
No abnormal condition		
Ulceration (Apthous, Herpetic, Traumatic)		
Candidiasis		
Abscess		
Other (specify)		

DENTITION STATUS AND TREATMENT NEEDED

Primary teeth

	55	54	53	52	51	61	62	63	64	65
Status										
Treatment										
	85	84	83	82	81	71	72	73	74	75
Status										
Treatment										

Permanent teeth

	18	17	16	15	14	13	12	11	21	22	23	24	25	26	27	28
Status																
Treatment																
	48	47	46	45	44	43	42	41	31	32	33	34	35	36	37	38
Status																
Treatment																

STATUS:
0 = Sound
1 = Decayed
2 = Filled and Decayed
3 = Filled, no decay
4 = Missing due to caries
5 = Missing for other reasons
6 = Sealant/varnish
7 = Bridge abutment/special crown
8 = Un-erupted tooth
9 = Excluded tooth

TREATMENT:
0 = None
1 = Caries arresting or sealant care
2 = One surface filling
3 = Two or more surface filling
4 = Crown and bridge abutment
5 = Bridge element
6 = Pulp care
7 = Extraction
8 = Need for other care ……

Summary of dental status: D/d – decayed, M/m – missing - F/f-filled

D/d	
M/m	
F/f	
DMFT/dmft	

APPENDIX V: INFORMATION DOCUMENT

Study title: Caregiver's perceptions of Oral Health Related Quality of Life among children with special needs in Johannesburg.

Good day:
Introduction:

We, from Department of Community Dentistry at University of Witwatersrand, are doing research on *Caregiver's perceptions of Oral Health Related Quality of Life among children with special needs*.Research is a way of trying to learn information and answers to important questions. This is a study involving research and no routine dental care will be provided during the research period. In this study we want to learn about the oral health related quality of life of children with special needs.

The purpose of the study is to determine the extent to which oral health affects quality of life of children with special needs in order to make sure that the service that our outreach programme renders can be prioritised accordingly.
We are requesting your permission to ask you questions about yourself and your child as well as to include your child in the research study.

What is involved in the study?
You will be requested to answer questions during a short interview (about 10 minutes) and your child will be examined where information about the health of their teeth will be recorded.
The study follows is a cross sectional analytical study design whereby about 110 children will take part in the study. The children will have their mouths examined by a hand held mouth mirror and the examination will take about 10 minutes.

Risks of being involved in the study,
There are no foreseeable risks associated with the study. The examination is pain-free and is performed under strict universal infection control measures.

Benefits of being in the study,
Your child will benefit from the examination and diagnosis of dental problems during the study and will be treated by the Community Oral Health Outreach team from Department of community Dentistry. Your child will be referred for treatment where it is not feasible to do the treatment at the outreach clinic.

Participation is voluntary,
Your refusal for you and your child to participate in the study will involve no penalty or loss of benefits to which the child is otherwise entitled, and that you may withdraw your child from the study at any time.

Reimbursements
There will be no compensation for participating in the study.

Confidentiality,
Efforts will be made to keep personal information confidential and please be assured that the information recorded is kept confidential in a secure locked office.

Contact details of researcher:
If you have any queries or would like more information about the study please contact Dr Nqcobo at Department of Community Dentistry, University of Witwatersrand on (011)717-2005, cathrine.nqcobo@wits.ac.za

For reporting of complaints / problems, you are welcome to contact the Chairperson of the Wits Research Ethics Committee, Prof P Cleaton -Jones through his secretary Ms Anisa Keshav on (011) 717-1234.
Your cooperation in this regard will be appreciated
Dr C Nqcobo

APPENDIX VI: CONSENT FORM

Parental Consent Form:

I understand that I am free to withdraw my child and my participation in project. I also understand that I am free to withdraw my consent and discontinue my child participation in this project at any time. I have been informed as to the procedures to be followed in this project. Further I understand that should I have any questions regarding this project I can contact Dr Nqcobo on (011)717-2005, cathrine.nqcobo@wits.ac.za

In signing this consent form, I allow myself to be interviewed and my child to have his or her mouth examined.
Name of the Child:.....
Name of Outreach site:.....
Guardia/Parent Signature:.....
Date:.....

APPENDIX VII: ASSENT FORM

Assent Form for Children

Hi, my name is (name of operator)
I am a dentists/dental therapist (choose appropriate title) from the University of Witwatersrand Department of Community Dentistry and I am here to examine your teeth.
I need to examine if there is anything wrong with your teeth, if there is any problem that I see then I will give you a letter to give to your parents to request for their permission to treat you. I'm just going to place a mirror in your mouth to examine; there will be no injections, no discomfort, and no pain.

The purpose of the study is to find out the extent to which oral health affects your day to day living and activities in order to make sure that the service that our outreach programme renders can be prioritised accordingly.

I want to ask your permission to examine your mouth. You are free to say "yes" or "no" and if you are not sure, you can ask me any questions.

Your parent(s) are aware of what I am doing and have also given me permission to look into your mouth, but I will not do this if you do not want me to.
Would you like me to start?
Yes No
(Circle the response given by the child)
Child's name: _____
Name of Outreach site: _____
Age: _____
Date: _____
Name of Operator who administered assent: _____

APPENDIX VIII: ETHICS APPROVAL LETTER

R14/49 Dr Cathrine Nqcobo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140438

NAME: (Principal Investigator)	Dr Cathrine Nqcobo
DEPARTMENT:	Community Dentistry Gauteng Down syndrome Association Outreach Sites
PROJECT TITLE:	Caregiver's Perceptions of Oral Health Related Quality of Life among Children with Special Needs in Johannesburg
DATE CONSIDERED:	25/04/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Yolanda Kolisa and Prof Veerasamy Yengopal
APPROVED BY:	Professor P Cleaton-Jones, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	06/06/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX IX: DEPARTMENT OF EDUCATION APPROVAL LETTER

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

For administrative use:
Reference no: D2015 / 297

GDE RESEARCH APPROVAL LETTER

Date:	**16 September 2014**
Validity of Research Approval:	**16 September 2014 to 3 October 2014**
Name of Researcher:	**Dr C.B. Nqcobo**
Address of Researcher:	**31 Engelwood Crescent**
	Klipoortjie
	Germiston
	1401
Telephone Number:	**011 717 2005; 079 404 3332**
Fax number:	**011 717 2625**
Email address:	**Cathrine.nqcobo@wits.ac.za**
Research Topic:	**Caregiver's perceptions of oral health related quality of life among children with special needs in Johannesburg**
Number and type of schools:	**ONE LSEN School**
District/s/HO	**Johannesburg North**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved. A separate copy of this letter must be presented to the Principal, SGB and the relevant District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted. However participation is VOLUNTARY.

The following conditions apply to GDE research. The researcher has agreed to and may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted: 1

Making education a societal priority

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za