

AN ASSESSMENT OF ORAL HEALTH CARE DELIVERY TO CHILDREN WITH SPECIAL NEEDS AT DENTAL SCHOOLS IN SOUTH AFRICA

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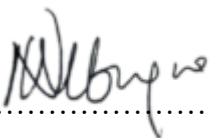
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DECLARATION

I, Nancy Njoroge, declare that this thesis titled ‘Assessment of oral healthcare delivery for children with special healthcare needs at academic dental hospitals, SA’ is my own work.

It is submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. This work has not been submitted previously at any university for a degree or examination purposes.

I confirm that this is my own work except where indicated through the appropriate references.

Signature 

15th August 2025

DEDICATION

To my parents:

For ensuring that all your children got an education despite the many challenges you faced.
Thank you for your sacrificial love

To my parents' in-law:

For your example of faith, love, integrity and hard work. Your legacy continues

To my husband: Njoroge

Thank you for your love and support through every season in life. I thank God for the gift of a supportive spouse.

To my children: Wairimu and Njeri Njoroge

Thank you for your love and encouragement. I thank God for the gift of loving children

To the Almighty God

Thank you for your steadfast love and faithfulness.

'For His compassions never fail. They are new every morning, great is your faithfulness'

Lamentations 3:22-23

PRESENTATIONS AND PUBLICATIONS ARISING FROM THIS THESIS

Oral Presentations

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Peer reviewed publications

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ABSTRACT

Background: Children with special healthcare needs (CSHCN) including adolescents may experience disproportionately poorer oral health and greater access barriers to dental care than those with no special care need (NSHCN). There is limited knowledge pertaining to the oral health status and delivery of dental care to CSHCN in South Africa (SA).

Objective: The aim of the study was to assess oral healthcare delivery to CSHCN at academic dental hospitals (ADHs) in SA. The specific objectives were to: - compare the dental treatment provided to CSHCN and NSHCN at ADHs, describe the dental care services provided for CSHCN at ADHs, explore the perceptions of oral health professionals (OHPs) towards provision of dental care to CSHCN at ADHs and identify factors influencing the delivery of oral healthcare to CSHCN at ADHs in SA from the perspectives of OHPs.

Methods: A sequential mixed methods study design was utilised. The inter-related methodological components to answer the research objectives included the quantitative phase of a narrative of literature review (2002-2023) on the oral health status of CSHCN in SA; a record review (2017-2023) of dental treatment provided under general anaesthetic (GA) to CSHCN and NSHCN aged 1-16 years at ADHs; a cross-sectional online survey conducted among OHPs at ADHs to assess their perceptions towards provision of dental care for CSHCN. The qualitative arm involved in depth interviews with clinical heads in Paediatric Dentistry at ADHs and a focus group discussion with OHPs from some respondents of the survey. Quantitative data was presented using frequencies and percentages. The Chi-square test and Fischer exact test were used for statistical analyses, and all tests were done at 95% confidence level. Thematic framework analyses were used to assess the qualitative data.

Results: Twenty-six articles were retrieved for the narrative literature review and six studies that met the eligibility criteria were analysed. A total of 2,402 CSHCN were included in the review, 59.7% (n=1,433) of whom were male and 40.3% (n=969) were female. The age of the children ranged between 0 and 20 years. The types of CSHCN varied across the studies, and included, inter alia, intellectual/mental disability, cerebral palsy, learning disabilities, autism spectrum disorders, hearing impaired, physical disabilities, Down Syndrome, epilepsy, 'complex/multiple disabilities' and other health disorders. The prevalence of dental caries ranged from 22.5% to 85.2% and 68%-100% of the caries was untreated.

Four hundred records were retrieved from the ADHs for the record review study. Of the children treated under GA, 29% were CSHCN and 71% were NSHCN. The median age at assessment was 5 years (IQR: 3-6.5). The medical conditions of CSHCN who presented for dental treatment under GA included inter alia, cerebral palsy, various chronic medical conditions, craniofacial anomalies and other developmental disorders. The CSHCN were older than NSHCN, ($p < 0.001$). More CSHCN (52.6%) compared to NSHCN (25.4%) were referred from primary health care centres (PHC), ($p < 0.001$). Caries was the main dental diagnosis. Overall, both groups received mainly extractions (43.5%), while 20% had restorative care and <10% had preventative care.

Fifty OHPs completed the survey, and eight participated in the interviews. The majority of the OHPs were female ($n=36$; 72%), above 35 years ($n=40$; 80%) and two-thirds had more than 10 years of clinical experience ($n=33$; 66%). Furthermore, the dental services provided to CSHCN comprised mainly of basic tooth extractions, restorative care, fissure sealants and oral prophylaxis. Oral surgery and orthodontics were the limited specialty services for children with cleft lip and palate. Four themes emerged from the perceptions of OHPs towards provision of dental care for CSHCN: - service provision, resource constraints, patient affordability and organisational factors. Other challenges experienced by OHPs at ADHs included inadequate infrastructure, theatre and sedation facilities, inadequate resources such as time, dental assistants, limited inter-disciplinary collaborations, and challenges with the children's medical/behavioural problems. However, the OHPs felt positive and found their work fulfilling. They suggested proposals to alleviate the challenges they faced.

Conclusions: The study findings revealed that CSHCN in SA were a diverse and heterogeneous group. Poor oral health and high unmet treatment needs were prevalent among these children from the limited data available. Patients who received dental treatment under GA at ADHs in SA were CSHCN or NSHCN typically under the age of 6 years, presenting with extensive caries. The treatment provided consisted mainly of extractions with little restorative and preventative treatment. The OHPs at ADHs experienced challenges related to service provision, resource constraints, low patient affordability and organisational factors that in turn affected the availability of quality dental services for CSHCN. These challenges can be addressed by advocating for enhanced multi-disciplinary collaborations, creation of more public-private partnerships, increasing training opportunities for OHPs especially in PHC settings, properly

equipping the PHC facilities to be able to provide basic dental services for CSHCN; thus, the travelling costs of patients and referral load to ADHs would be alleviated. Recognition of paediatric dentistry as a specialty in SA is long overdue so that the specialists can support the general dentists in the dental management of CSHCN and hence improve access to dental care.

Keywords: Oral health, children, special healthcare needs, dental treatment, Academic dental hospitals, oral health professionals, healthcare challenges, South Africa

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'My grace is sufficient for you, for my power is made perfect in weakness.' 2 Corinthians 12:9 NIV

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ABBREVIATIONS and ACRONYMS

AAPD	American Academy of Paediatric Dentistry
ADHD	Attention deficit hyperactivity disorder
ADHs	Academic dental hospitals
ASD	Autism spectrum disorder
CLP	Cleft lip and palate
CP	Cerebral palsy
CSHCN	Children with special healthcare needs
DD	Developmental disabilities
DET	Data extraction tool
DMFT/dmft	Decayed, missing, filled teeth (permanent/primary dentition)
DS	Down syndrome
EP	Epilepsy
FDI	World Dental Federation
FGD	Focus group discussion
GA	General anaesthesia
GBD	Global Burden of Disease
HCP	Healthcare professionals
HCU	Head of clinical unit
HI	Hearing impaired
HREC	Human research ethics committee
ICF	International Classification of Functioning, Disability, and Health
ICU	Intensive care unit
ID	Intellectual disability
IQR	Interquartile range
ISHPs	Integrated school health programmes
IV	Intravenous
KPA	Knowledge, perceptions, attitude
LA	Local anaesthetic
LMICs	Low-and middle-income countries
MCH	Maternal and child health
MDC	Multi-disciplinary clinic

MDT	Multi-disciplinary team
MM	Mpho Molete
MMR	Mixed methods research
NCD	Non-communicable diseases
NDoH	National department of health
Non-GA	Sedation, local anaesthetic
NHI	National Health Insurance
NN	Nancy Njoroge
NCOHS	National children's oral health survey
NOHP	National Oral Health Policy
NSHCN	Children without special healthcare needs
Non-OHPs	Other health providers
OHPs	Oral health providers
OHRQoL	Oral health related quality of life
PH	Phumzile Hlongwa
PHC	Primary health care
PhD	Doctor of Philosophy
PI	Principal investigator
QL	Qualitative
QT	Quantitative
SA	South Africa
SDGs	Sustainable Development Goals
SHCN	Special healthcare needs
TDI	Traumatic dental injuries
UHC	Universal health care
UN	United Nations
UTNs	Unmet treatment needs
US	United States
VI	Visual impairment
WHO	World Health Organisation

CHAPTER 1

Introduction

1.1 BACKGROUND

Children with special healthcare needs (CWSHCN or CSHCN) are a diverse group comprising of children and youth ‘with or at risk of chronic physical, developmental, behavioural or emotional conditions.’¹ For the purpose of this study the acronym ‘CSHCN’ will be used. The CSHCN include, inter alia, intellectual disability (ID), cerebral palsy (CP), learning disability (LD), autism spectrum disorder (ASD), hearing impairment (HI), Down Syndrome (DS), physical disabilities (PD), visual impairments (VI), epilepsy (EP) and attention deficit disorders (ADD). These children often require the use of additional and complex healthcare services compared to healthy children.¹

Globally, about 1.3 billion people or about 16.7% experience significant disability.² This is an increase from the 2011 world disability report based on the Global Burden of Disease estimates of 2004 to date, where an estimated 15.3% of the global population lived with disabilities.³ In the report, compared with developed countries, the prevalence of disability was higher in developing countries. Approximately 5.1% (93 million) children between 0-14 years and 19.4% (892 million) above 15 years had a moderate to severe disability.³ In South Africa (SA), the census report of 2011 showed that over half a million children between 5-14 years experienced some disability.⁴ However, this report is not current.

Childhood disability is difficult to evaluate as parents are often used as proxy to report disability of their children, leading to possible under-reporting.⁵ Other reasons for the inaccurate estimates include the constant change of development in children, and variations between country specific and world health surveys due to disability definitions and survey questions.³ To overcome these disparities, the International Classification of Functioning, Disability, and Health (ICF) has been used to help standardise approaches towards estimating disability prevalence.⁶ Although this classification incorporates the environmental/contextual factors that affect disability, individuals with mild forms of disability that may not cause functional impairment may be under-represented.³

Oral health is important for everyone as poor oral health may negatively impact general health.⁷ Good oral health in children assists in the child's growth and development,⁸ and other functions such as swallowing, speech and social interaction. Studies have shown that CSHCN have poorer oral health compared to their healthy peers.^{9, 10} It has been reported that dental caries and gingival/periodontal diseases are more common in CSHCN, partly due to the consumption of free sugars which are fermentable, and inadequate oral hygiene practices.¹¹ Despite dental caries being easily preventable through a healthy diet and good oral hygiene, CSHCN have a high burden of unmet dental care needs due to untreated caries,¹² which may progress to dental pain and/or sepsis, or adverse dental complications requiring emergency dental care. However, whether symptomatic or asymptomatic, dental caries in all children require dental care. Thus, CSHCN may experience more oral health problems compared to unaffected children without special healthcare needs despite receiving more preventative services.¹³

In SA, poor oral health and high unmet dental treatment needs among CSHCN have been reported in the few epidemiological studies available.¹⁴⁻¹⁸ Furthermore, CSHCN often present late for dental treatment resulting in the need to relieve pain such as dental extractions.¹⁹ The high unmet dental treatment needs and limited treatment options may impact their oral health quality of life.²⁰

Dental care is the most common unmet health care need among CSHCN in the United States (US).²¹ In addition, these children had more needs for non-preventative compared to preventative care.²¹ Furthermore, CSHCN who were older (teens), from poorer backgrounds and with more severe disabilities were likely to have higher unmet dental care needs.²¹ Regional differences in unmet dental care needs among CSHCN have been reported in the US.¹² Unmet needs were greater in areas with a shortage of professionals and greater poverty.¹² There are limited comparable studies in SA among CSHCN from different socio-economic backgrounds.^{17, 18}

Provision of dental care in routine dental settings may not be practical for some of the CSHCN, therefore, dental treatment under general anaesthetic (GA) may be required.²² Nonetheless, dental treatment under GA is costly to provide and has additional associated risks in CSHCN.²³ Some of the costs attributed to GA treatment for all patients include financial resources to provide theatre facilities, supplies, anaesthetists, professional nurses and oral health providers.

These resources are often limited in developing countries such as SA and may impact the ability to provide dental care for CSHCN.

Children with intellectual disabilities face barriers when accessing dental care.^{24, 25} In a study of 149 general dental practitioners in Kerala, India, a lack of specialised facilities and equipment, physical inaccessibility, provider training and communication were the major barriers to dental care access.²⁶ A 2020 SA study in a low socio-economic neighbourhood, reported that financial burden, poor referral networks, stigma and opportunity costs were cited as barriers to access services for children with intellectual disability.²⁷ Therefore, there is need to explore and understand some of the barriers, facilitators and gaps in the provision of dental care to CSHCN in SA. This would contribute to improving access to oral healthcare services for CSHCN within the public health sector of SA as the country moves towards universal health care (UHC).²⁸

1.2 PROBLEM STATEMENT

The focus of this study was to examine the provision of dental care for CSHCN at academic dental hospitals (ADHs) in SA. In particular, the existing ambiguity in the provision of oral healthcare to CSHCN will be explored in this study. The limited SA studies have suggested that dental care for CSHCN consists mainly of pain relief extractions,¹⁹ with limited restorative,²⁹ and rehabilitative care.³⁰ Consequently, one of the research questions sought to compare the dental treatment provided to CSHCN and children with no special healthcare need (NSHCN) at ADHs in SA.

Inequalities in health including oral health has persisted among individuals with disabilities in SA despite significant socio-economic reforms.³¹ Individuals with disabilities may be more negatively impacted by poverty and socio-economic inequalities such as unemployment, low literacy, and inadequate access to healthcare in SA.³² Furthermore, access to basic services such as health and education is significantly challenging for children with disabilities from low resource settings in SA.^{27, 33} Thus, one of the study objectives will be to describe the dental care services provided for CSHCN at ADHs.

Children and especially CSHCN may be more likely to experience poor oral health compared to healthy children,¹³ unmet dental care needs and limited dental care.^{21, 34} Oral health needs

and dental care for CSHCN are not prioritised by parents and health care workers.³⁵ The majority of parents of CSHCN face extra burden in caring for the child while oral health needs are not given much attention. Thus, CSHCN present late for dental treatment with pain and oral health providers prioritise pain relief such as dental extractions. One study that evaluated the public health facilities in the Free State of SA, cited that staff shortages and limited finances adversely impacted service delivery.³⁶ Thus, the perspectives of the oral health providers towards dental care for CSHCN will be explored in this study.

1.3 STUDY RATIONALE

Access to quality health care is a key agenda both globally and in SA. The Sustainable Development Goal (SDGs) number 3 of 2030 is to ‘ensure healthy lives and promote well-being for all at all ages.’³⁷ In line with the SDGs, SA, through the recently passed NHI Bill seeks to provide access to quality, affordable healthcare services for all its citizens based on their health needs and regardless of their socio-economic status to achieve UHC.²⁸ In addition, the constitution of SA prioritises the wellbeing of all children by putting children first.³⁸

Oral healthcare for children in SA has not been given priority as the burden of childhood caries remains above 50%.³⁹ The burden of unmet treatment needs among CSHCN remains high (68-100%) attributed to untreated dental caries.⁴⁰ Delivery of oral healthcare programs in schools for CSHCN are adversely affected by lack of resources and support from parents, oral health professionals and the provincial government.⁴¹ The implementation of school oral health programs has been hampered by inadequate policy implementation due to inadequate planning, resources and key stakeholder support.⁴² Thus, the rationale of this study is outlined below as follows:

- There are limited data on the dental care provided to CSHCN at ADHs. In addition, there is a lack of studies on the perspectives of oral health providers towards provision of dental care for these children.
- There is dearth of reports on the public health system delivery of dental care for CSHCN in Africa.
- The study may assist in identifying some of the factors influencing the delivery of oral health care to CSHCN which may inform practice and policy formulation.

There is limited understanding of the complex issues related to delivery of oral healthcare services in the public health sector of SA and its effect on outcomes.⁴³ Thus, this mixed method study will explore some of the issues affecting the delivery of oral healthcare services for CSHCN at ADHs. This could provide insights that may be helpful to inform service delivery, and provision of integrated holistic care for CSHCN.

1.4 RESEARCH QUESTIONS

1. What dental treatments are provided to CSHCN compared to NSHCN at ADHs?
2. What are the characteristics of dental services available for CSHCN at ADHs?
3. How do oral health professionals perceive and experience providing dental care to CSHCN?
4. What factors influence the delivery of oral healthcare to CSHCN at ADHs?

1.5 AIM OF THE STUDY

To assess oral healthcare delivery to CSHCN at ADHs in SA. This study hopes to uncover some of the oral healthcare service provision gaps for CSHCN at ADHs which could inform strategies for improvement.

1.6 OBJECTIVES OF THE STUDY

1. To compare the dental treatment provided to CSHCN and NSHCN at ADHs in SA.
2. To describe the dental care services provided for CSHCN at ADHs in SA.
3. To explore the perceptions of oral health professionals (OHPs) towards provision of dental care to CSHCN at ADHs in SA.
4. To identify factors influencing the delivery of oral healthcare to CSHCN at ADHs in SA from the perspectives of OHPs.

1.7 OUTLINE OF THE THESIS

Chapter 1: Introduction- This first chapter has provided a brief background of the research area, defining the CSHCN, their oral health needs and provision of dental care.

Subsequently, the problem statement, the rationale of the study and the aim and objectives are outlined.

Chapter 2: Literature Review- This chapter provides an over-view of the relevant literature on the status of oral health and provision of oral healthcare to CSHCN.

Chapter 3: Methodology- This chapter describes the methods that were used in this study, highlighting the study design, study setting, study population, sampling process, data collection methodology, data analysis and the ethical considerations followed for the study.

Chapters 4-6: Results- These chapters will provide the thesis findings, presented in publication format:

- **Chapter 4:** Oral health in children and adolescents with special healthcare needs in South Africa: A narrative review.⁴⁰
- **Chapter 5:** Comparative analysis of dental treatment for children with and without special needs in SA academic hospitals.⁴⁴
- **Chapter 6:** Perspectives and experiences of oral health professionals in the provision of dental care for CSHCN at academic hospitals in SA.

Chapter 7: Discussion- an integrated discussion of the overall study is presented. The chapter also includes the conclusions, scholarly contributions of the study and the recommendations for future research.

CHAPTER 2

Literature Review

This chapter provides an overview of the literature pertinent to this study. In this section, I have described disability in children, the oral health and prevalence of dental caries among CSHCN and the risk factors for caries in these children. Subsequently, I have discussed the oral healthcare for CSHCN, the delivery of dental care for CSHCN in SA, some of the health system challenges and those faced by the oral health providers. The section concludes with a summary of the literature reviewed, and some of the gaps identified.

The sources of literature reviewed were primarily online databases (Google Scholar and PubMed). Key words from the title were used to conduct the search for relevant abstracts and published articles. One limitation of this strategy was the omission of unpublished work.

2.1 DEFINITION OF TERMS

Children with special healthcare needs

The Maternal & Child Health Bureau in the United States (US) has defined CSHCN as ‘children living with or at greater risk for chronic physical, developmental, behavioural or emotional conditions and also demand greater and more complex health care services compared to healthy children.’¹ The American Academy of Paediatric Dentistry (AAPD) has defined special health care need (SHCN) as, ‘any physical, developmental, mental, sensory, behavioural, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention and/or use of specialised services programs.’²² In South Africa, CSHCN are individuals under the age of 18 years living with various disabilities or chronic health conditions such as intellectual disability (ID), Down syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP), epilepsy (EP), and attention deficit hyperactivity disorder (ADHD).⁴⁵ The AAPD definition has been used throughout the thesis and includes children with chronic and debilitating medical conditions.

Children with special healthcare needs suffer from a broad range of medical conditions such as epilepsy, metabolic, cardiac, renal, cancer, haematological and infectious conditions. Other

types of conditions include craniofacial anomalies for example cleft lip and/or palate. Sensory deficits include hearing and visual impairments. Cognitive and developmental disorders include ID, ASD, DS, developmental delay, speech and learning disabilities, and behavioural disorders such as attention deficit hyperactivity disorder (ADHD).

The various conditions may be congenital, developmental, or acquired through disease, trauma or environment, and may impact ability for daily self-care or important life activity.³ Furthermore, some of these conditions or disabilities impact ability to maintain good oral hygiene or make it difficult to access dental services due to anxiety or communication difficulties with the dental provider.

The term disability refers to any reduction of an individual's activity that has resulted from an acute or chronic health condition and affects motor, sensory or mental functions.⁴⁶ Thus, disability is a broad term which includes impairments, activity limitations and participation restrictions arising due to the interactions between health, environmental and individual factors.⁶ The varied understanding of disability may result in inconsistent research outcomes which in the SA context could affect oral health-related service provision and priority setting.

2.2 DISABILITY IN CHILDREN

2.2.1 Prevalence

Globally, about 1.3 billion people experience significant disability.² Currently, an estimated 240 million children aged 0-17 years suffer some form of disability.⁴⁷ The figure is higher than previous estimates due to the broader understanding of disability which includes psychosocial well-being and functional domains based on the International Classification of Functioning, Disability and Health (ICF).⁶ In contrast, the Global Burden of Disease (GBD) 2019 study estimated that 291.3 million children younger than 20 years of age had mild-to-severe disabilities.⁴⁸ According to the UNICEF report, Sub-Saharan Africa (29.6% or 69.9 million) and South Asia (27.3% or 64.4%) together accounted for more than half of the children with disabilities.⁴⁹ Unlike the GBD study, the UNICEF study excluded children aged 18 and 19 years and children with mild disabilities in all age categories, thus resulting in slightly lower global prevalence estimates.⁴⁹

In SA, there are no current data on the number of children with disabilities due to the outdated census report of 2011 which estimated that over half a million children between the ages of 5-14 years had a disability.⁵⁰ The number by now is likely to be much higher and this negatively impacts the public health system. However, a report on persons with disabilities (2011-2022) in SA has revealed a decrease in the prevalence of disabilities among children aged 5 to 9 years.⁵¹ This could be related to the nature of disability inquiries and highlights the importance of using standardised approaches.

The rising numbers of children with disabilities especially in low-income countries⁵² call for healthcare systems to recognise this challenge by providing appropriate healthcare services that include oral health care.

2.2.2 Epidemiology of disabilities in children

According to one report based on the 2011 SA census, the prevalence of specific disabilities among persons aged five years and above were as follows; sight (11%), cognitive (4.2%), hearing (3.6%) while others had difficulties such as communication, walking or self-care.⁵⁰ Some of these conditions which greatly impact oral health are described below.

Cerebral palsy

Cerebral palsy (CP) is a common cause of motor disability in children.⁵³ The condition is attributed to developmental disorders of movement and posture causing activity limitations. The condition varies widely in aetiology and clinical presentation. According to European data, the frequency of CP is 2.08 per 1000 live births.⁵⁴ In rural SA, the prevalence of CP has been estimated to be as high as 10/1 000 live births.⁵⁵ Some of the risk factors for CP include low birthweight, infections during pregnancy and multiple gestation. Birth prematurity is an important risk factor in CP.⁵⁶ Other conditions that co-exist in CP patients include epilepsy and intellectual disability.⁵⁷⁻⁵⁹ The majority of children with CP have feeding difficulties contributing to malnutrition and a risk of growth failure.⁶⁰

Intellectual disability

The term intellectual disability (ID) refers to subaverage intellectual function before the age of 18 years, with an intelligent quotient (IQ) of less than 70.⁶¹ The severity of the cognitive

disability ranges from mild ID (IQ 70-85) to severe ID (IQ 0-19) based on the IQ scores.⁴⁹ Other impairment in children with ID include life skills such as communication, social or interpersonal skills and self-care. The aetiology of ID include genetic disorders, traumatic injuries, and prenatal causes such as maternal infection or alcohol exposure.⁶² Children with ID experience poorer oral health such as dental caries and gingivitis compared to healthy children.⁶³

Down syndrome (DS) or Trisomy 21, is the most common genetic cause of intellectual disability globally.⁶⁴ The incidence of DS according to the World Health Organisation ranges from 1:1000 to 1:1,100 live births.⁶⁴ Clinical features include learning disabilities, cardiac anomalies and an altered immune system.⁶⁵ Oral health problems include periodontal disease which is partly attributed to among other factors, a low immune response, malocclusion, and dental caries.⁶⁶ Nevertheless, a recent systematic review reported a lower incidence of dental caries in children with DS compared to their healthy peers, partly due to their saliva being more alkaline.⁶⁷

Autism spectrum disorder

Autism spectrum disorder (ASD) is a group of developmental disabilities characterised by impairments in communication and behaviour.⁴⁵ The condition varies in severity ranging from mild symptoms to severe symptoms.⁴⁵ The World Health Organisation (WHO) estimates the prevalence of ASD globally as 1:160 persons.⁶⁸ The figure does not include Sub-Saharan Africa due to a lack of epidemiological surveys of the condition in the region.⁶⁹ Thus, the WHO global estimates are used in SA. Children and adolescents with ASD are at high risk of oral disease and more specifically poor oral hygiene, gingival and/or periodontal health compared their healthy counterparts.⁷⁰ Other challenges among children with ASD include diet restrictions due to sensory sensitivities such as taste, texture, and smell.⁷¹ Maintaining good oral hygiene such as tooth brushing is a challenge due to uncooperative behaviour. Moreover, dental care for children with ASD is often unpleasant for the patient due to difficulties in social interaction and communication. These factors contribute to high unmet oral health needs.⁷⁰

Attention-deficit/hyperactivity disorder

Attention-deficit/hyperactivity disorder (ADHD) is characterised by disruptive behaviour, lack of attention and impulsivity.⁷² The condition affects relationships with family and peers and academic performance due to learning disabilities.^{73 74} In a Hong Kong study, children with ADHD showed poorer oral hygiene and negative oral health behaviours compared to non-affected children.⁷⁵ A systematic review and meta-analysis indicated that compared to non-affected peers, children with ADHD had a higher risk for caries and dental trauma.⁷⁶

2.3 ORAL HEALTH AND PREVALENCE OF DENTAL CARIES IN CSHCN

2.3.1 Oral health in CSHCN

Health is ‘a state of complete physical, mental and social well-being, rather than solely an absence of disease.’⁷⁷ The term oral health according to the World Dental Federation has different aspects which includes ‘the ability to speak, smile, smell, taste, chew, swallow and the use of facial expressions without pain or discomfort attributed to diseases of the craniofacial complex.’⁷⁸ Thus, good oral health is essential for general health and wellbeing as it promotes quality of life in all persons. Good oral health is particularly important in children with disabilities as their underlying medical and/or behavioural condition could increase the risk of dental diseases compared to those with no special healthcare needs (NSHCN).⁷⁹

Oral diseases such as dental caries and gingivitis/periodontitis are common in all individuals,⁸⁰ yet these conditions are preventable with adequate oral hygiene and good nutrition. Disability and poor oral health are often interrelated issues especially in children, as physical or cognitive disabilities may for example affect the ability of children to brush their teeth.⁹ This is further demonstrated by the fact that compared to their healthy peers, children and adolescents with developmental disabilities such as ID are more at risk of poor oral health.⁸¹ Dental caries in CSHCN adversely affects their oral health related-quality of life.²⁰

2.3.2 Prevalence of dental caries in CSHCN

Dental caries is one of the most common diseases globally with significant costs associated with treatment.⁸⁰ Despite the improvements in oral health marked by a general decline in dental caries prevalence in children in developed countries, the problem persists, especially in disadvantaged children from both developed and developing countries.⁸² Worldwide, dental

caries is associated with unhealthy lifestyles such as diet, nutrition and poor oral hygiene.⁸³ The preventable lifestyle-related factors such as frequent and excessive consumption of sugars and poor oral hygiene are common in CSHCN, and children from disadvantaged and minority communities.⁸⁴

The prevalence of dental caries in CSHCN is reported to vary widely globally, as shown in Figure 2.1. The prevalence is lower in more developed regions such as the US (16.7%) and Australia (21%).^{85, 86} In developing countries, the prevalence has been reported to vary from 33.5% in China, 38% in India, 54.9% in Malaysia to 60% in Brazil.⁸⁷⁻⁹⁰ In Africa, the prevalence varies from 23% in Tanzania, 33% in Nigeria, 44.7% in Kenya to 63.3% in Uganda.⁹¹⁻⁹⁴ In SA, the limited studies available have reported caries prevalence rates of between 34% and 85.2% among CSHCN.¹⁴⁻¹⁸ The studies were mainly conducted in urban areas of SA except for one study that was done in a rural area of Limpopo more than a decade ago¹⁵ where access to dental care was limited.



Figure 2.1 Prevalence of dental caries among CSHCN in different countries

Map source⁹⁵

2.3.3 Other oral health conditions among CSHCN

Other commonly occurring health conditions in CSHCN are tooth eruption disorders, developmental anomalies of the dentition, craniofacial anomalies such as cleft lip and/or palate, traumatic dental injuries (TDI), malocclusion and gingival enlargement.^{82, 88, 92, 96, 97} These conditions may impact ability to perform daily oral hygiene and increase the need for dental care.

Tooth eruption disorders commonly affect CSHCN. Delayed eruption of teeth has been reported in children with DS.⁹⁶ Hearing impaired children in India have been found to show delayed eruption of permanent teeth.⁸⁸ Over-retained primary teeth delay the eruption of permanent successor teeth and require intervention by the dentist and close monitoring of the developing dentition.⁹⁸

Other oral health problems among CSHCN include developmental disorders of the dentition such as disorders of enamel and dentine, anomalies related to size, morphology and number of teeth, and birth defects such as cleft lip and/or palate.⁸² Developmental defects of the dentition are dependent on multiple genes that regulate cellular activities and are liable to environmental changes.⁹⁹ Anomalies in shape, size and number affect children with ectodermal dysplasia, DS, cleidocranial dysplasia and other craniofacial anomalies.¹⁰⁰ These conditions in CSHCN often require multidisciplinary dental care for optimal oral health outcomes.

Skeletal malocclusion occurs commonly in CSHCN with intellectual and developmental disabilities.⁹² In a study in Tanzania, the prevalence of malocclusion among 384 children with disabilities aged between 6-17 years was 69%.¹⁰¹ In the study, children with neurodevelopmental disorders (ID, DS, ASD and ADHD) were more affected by malocclusion (75.9%) than other disability groups (physical and sensory disabilities). Apart from aesthetic concerns, malocclusion has been associated with poor self-esteem, bullying and sleep disorders such as sleep apnoea.^{102, 103} Orthodontic treatment for skeletal malocclusion in these patients is a challenge for the providers.

Cleft lip and palate (CLP) are one of the most common craniofacial anomalies. The condition affects growth and development of the face and the dental alveolar complex predisposing the patient to malocclusion.¹⁰⁴ In addition, these children have been found to experience dental caries. One study in Brazil among 156 children with and without CLP aged 5-18 years reported

that affected children had a greater burden of caries than unaffected children.¹⁰⁵ Therefore, children with CLP require comprehensive dental care to improve their oral health.¹⁰⁶

Traumatic dental injuries are common among certain groups of CSHCN. In a study conducted on CSHCN (n=959) and healthy children (n=1010) in Jordan, the prevalence of TDI was twice as high (8.7%) among CSHCN compared to healthy children (4.1%).¹⁰⁷ Children with multiple disabilities, ID and CP were more affected, and the risk factors for TDI included increased over-jet and incompetent lips.¹⁰⁷ Other CSHCN at risk of TDI include children with ADHD, learning difficulties and physical limitations.¹⁰⁸ Timely interventions of TDI in children are important for improved treatment outcomes,¹⁰⁹ while delays in obtaining appropriate care negatively affects prognosis of TDI.

The CSHCN with spastic CP are prone to parafunctional habits such as bruxism.¹¹⁰ In a study among 180 patients with cognitive impairments (DS and CP) and healthy children, the overall prevalence of bruxism was 23%.¹¹¹ There was no difference in the prevalence between the patients with cognitive disabilities and healthy individuals. Notably, the healthy group was selected from patients waiting for orthodontic treatment and not from the general population. Dental erosion is another disorder that causes tooth wear. This condition commonly affects CSHCN with gastroesophageal disorders compared to healthy children,¹¹² which results in dentine exposure predisposing to tooth sensitivity and/or caries.

Gingival enlargement/hyperplasia has been shown to occur in patients taking anti-epileptic medications.⁹⁷ In a group of 60 children with epilepsy, increased gingival hyperplasia was associated with sodium valproate, a common anti-epileptic medication.⁹⁷ Other medications such as calcium channel blockers (nifedipine) and cyclosporin A also cause gingival hyperplasia.¹¹³ Maintaining good oral hygiene becomes more difficult and predisposes the patient to gingivitis.¹¹³ Dental care involves good oral hygiene for the child, assisted by the caregiver and regular preventative scaling and polishing.

In the SA context, some of the oral health challenges reported in two recent studies among CSHCN include dental caries, gingivitis and soft tissue trauma.^{17, 18}

2.4 DETERMINANTS OF DENTAL CARIES IN CHILDREN

2.4.1 Risk factors for dental caries

Dental caries occurs due to an interplay between biological, social, behavioural and environmental/contextual factors as depicted in Figure 2.2.¹¹⁴ The risk factors for childhood caries are the presence of *Streptococcus mutans* bacteria, a diet high in fermentable carbohydrates, suboptimal oral hygiene, inadequate fluoride exposure and enamel defects.¹¹⁵ Other factors such as poverty, minority status and low birthweight have also been documented to increase the risk of childhood caries.¹¹⁶ CSHCN have a greater burden of caries and caries risk compared to non-SHCN, with the caries risk varying among categories of children with disabilities.¹¹⁷ The caries incidence rate per year was 0.049 for CSHCN compared to 0.033 for the healthy children.¹¹⁷

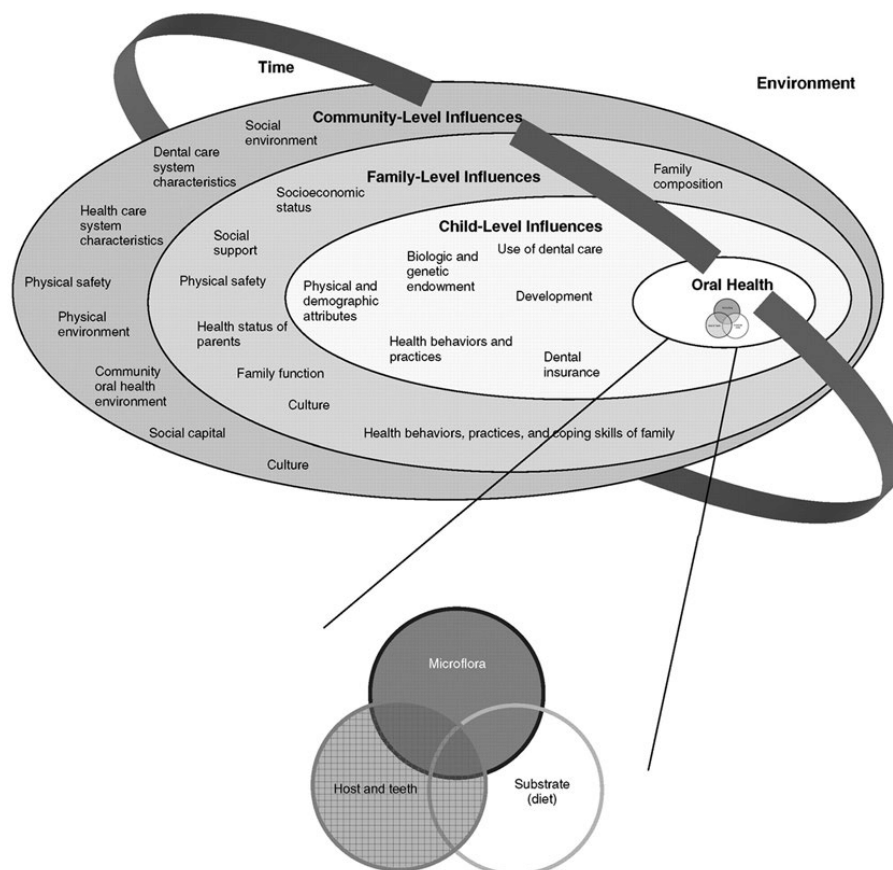


Figure 2.2 Child, family, and community influences on oral health outcomes of children

Source¹¹⁴

Socio-demographic factors of the family may influence oral health in children including CSHCN. The type of preschool (public or private), household income, birth order of the child impacted preschool children in Brazil.¹¹⁸ In a US study based on the data from the 2016-2018 National survey of children's health, CSHCN, children from poorer households and those with multiple health problems had more unmet dental care needs.¹¹⁹ In SA, in a systematic review of the determinants of childhood caries, it was reported that factors such as parental income and education level negatively influenced oral health in their children.¹²⁰ Children from low-income families had a higher caries prevalence compared to those from higher-income families.¹²⁰ However, the meta-analysis revealed that children whose parents had a tertiary education had a 0.77-fold increase in the odds of caries compared to those with high school education.

Behavioural factors such as child's nutrition, oral hygiene practices impact their oral health. Dietary factors especially high consumption of free sugars increased the risk of dental caries in children with disabilities in Rwanda.¹¹ The risk was nearly six times higher in children who consumed more sugary snacks while the risk was low for children with a good oral hygiene status.

Biological and genetic factors are important individual child-level factors that contribute to the development of dental caries.¹¹⁴ For example, reduced salivary flow, high levels of cariogenic bacteria (*Streptococcus mutans*), tooth morphological defects and special health care needs are associated with caries.^{84, 121} To demonstrate this relationship, a study comprising dental records of 89 children aged 10-71 months previously screened for *S mutans* showed that the probability of detectable caries was associated with higher levels of *S mutans*, and sub-optimal levels of fluoride in drinking water.¹²¹ In a meta-analysis of 22 studies that investigated the relationship between preterm, low birthweight and childhood caries,¹²² there was a 0.59-fold increase in odds for caries in preterm children when compared to full-term children. However, low birth weight was not a risk factor for childhood caries.¹²²

Environmental factors at the community level also play a role in the oral health of children including CSHCN.¹¹⁴ These include factors such as availability of optimally fluoridated water, community oral health programs and the availability of dental services. The community cultural influences such as knowledge and attitude towards oral health affect health seeking behaviours and dietary practices of the child.¹¹⁴

Although the factors mentioned above affect all children, some of the factors affect CSHCN to a greater extent compared to healthy children.⁸⁵ For example, CSHCN from poor families, with no insurance or with greater disability were more likely to have oral health needs than healthy children.⁸⁵ Poor oral health among children with intellectual disabilities is attributed to inability for selfcare including oral hygiene maintenance.⁷⁹ Children with ASD in Egypt had poorer oral hygiene and gingival health compared to healthy children and greater challenges accessing dental care.¹²³ In another study among 100 children with epilepsy and 80 healthy peers, the former experienced worse gingival health compared to healthy subjects, due to chronic medication.¹²⁴ In addition, children with epilepsy had a greater burden of caries in the deciduous dentition contributing to poorer oral health compared to their healthy peers.¹²⁴

Family characteristics, community level influences, the child's individual biological health status and behavioural factors such as diet and oral hygiene contribute to oral health of children. In SA, these factors affect all children, especially those with SHCN from lower social economic backgrounds who mostly utilise public health services and thus have a greater risk of poor oral health.

2.4.2 Consequences of poor oral health in CSHCN and NSHCN

Poor oral health has the potential to adversely impact children and their families.^{20, 118, 125} In Brazil, a study that assessed the impact of dental caries on OHRQoL of children and their families reported that a perception of poor oral health by the parent and presence of dental caries in the child significantly impacted the OHRQoL.¹¹⁸ Other negative consequences of childhood caries in both CSHCN and healthy peers include pain and discomfort arising from untreated dental caries when eating, disruption of sleep, tooth loss and impact on growth and development of the child.¹²⁵ A study conducted in 2019 in Johannesburg, SA found that dental caries adversely affected the OHRQoL of CSHCN.²⁰

In a study conducted in Romania among 35 children with life-threatening immunosuppressive diseases, dental caries, gingival inflammation and recurrent viral and fungal infections were reported.¹²⁶ All the 35 children required dental consultation for dental caries and gingival disease due to the complex medical conditions and/or medication. Other conditions such as difficulties in swallowing and xerostomia adversely affected the nutrition in these children at a

palliative care centre. This emphasises the importance of good oral health and the need for dental care for children with chronic health conditions.

Dental care for some CSHCN who may not be able to cooperate adequately during treatment has to be done under general anaesthetic (GA).²² Treatment under GA requires more time and cost to provide,¹²⁷ and puts a strain on the health care system. In addition, dental care has an added economic burden on the families of CSHCN,⁸⁰ and even more so considering their increased healthcare needs. Thus, the potential consequences of poor oral health in CSHCN have implications not only on the child but also on the family and the healthcare system. Prioritising oral health education, preventative, restorative and rehabilitative dental care for CSHCN improves their quality of life.

In this section, the prevalence of dental caries in CSHCN, risk factors and some of the consequences of poor oral health especially among CSHCN was reviewed. Dental caries is common among CSHCN, with differences in the caries prevalence varying according to geographical region, country, and type of disability in the child. Very few studies have been conducted in SA, resulting in a lack of epidemiological data on the oral health of CSHCN. Dental caries negatively impacts the child, the family, and the health system; therefore, prioritising oral healthcare for CSHCN is important.

2.5 ORAL HEALTHCARE FOR CSHCN

Oral healthcare encompasses promotive, preventative, curative and rehabilitative services to enable proper functioning of the oral cavity. The family, community and dental facilities play an important role in ensuring good oral health and general health for all children including CSHCN.

2.5.1 Home environment

The home environment plays an important role in the maintenance of good oral health for CSHCN. Children with severe developmental disabilities experience poor oral health and require the support of caregivers for daily oral hygiene. A recent systematic review found that dental caries in CSHCN was significantly impacted by family influences.¹²⁸ The parents' knowledge of oral health, their socio-economic status and dietary habits were among the factors reported to influence oral health of CSHCN.¹²⁸ Family influences were significantly associated

with dental caries in the child. Children of parents with skilled occupations had a lower caries prevalence than those of unskilled parents. Children who brushed their teeth without parental assistance had more caries than those who received assistance. In addition, children who received sweets often from caregivers had significantly more caries compared to others who did not.¹²⁸ Therefore, these family influences point to the role of the family in caries predisposition of the CSHCN under their care. Yet, oral health is often not prioritised by families and caregivers of CSHCN, perhaps because the caregivers are burdened by other healthcare needs of the child. For example, coordinators at long-term care facilities in the eThekweni district of SA noted that there was a lack of oral health initiatives or prioritisation at the facilities.¹²⁹

2.5.2 Routine dental clinic

Dental anxiety is common in all children; however, children with disabilities often exhibit increased anxiety and resistant behaviours during dental treatment compared to healthy children.¹³⁰ The use of protective stabilisation such as papoose boards and physical restraints is indicated, but in accordance with the guidelines at each setting. When other non-pharmacological behavioural modifications techniques are not adequate to provide dental treatment effectively, sedation or GA is necessary.²² Dental care under GA for some CSHCN who have complex medical conditions, requires to be done preferably in a hospital setting with adequate facilities and human resources. This reduces the risk of GA complications such as airway obstruction, aspiration in CP patients or oversedation.

2.5.3 Dental treatment under general anaesthetic

Dental care provision for CSHCN may require specialised provider training. This includes the use of conscious sedation and the ability to adapt the clinical setting to suit the needs of the child.²² Children with mild disabilities can receive dental care in routine dental settings with the appropriate behaviour management techniques. When this is not practical, sedation or treatment under general anaesthesia (GA) is the only choice to provide dental care safely. This enables provision of dental treatment in a single sitting making it efficient, despite the increased cost on the public health system. Dental treatment under GA has other risks involved including airway obstruction, chronic aspiration in CP patients or oversedation.²³

2.5.4 School-based dental care programs

Schools are key in promoting health for children, families and the entire community.¹³¹ In SA, the National Oral Health Policy and Strategy document emphasises the need to integrate oral health with other sectors such as education.¹³² In addition, the National Oral Health Policy (page 7) provides preventative guidelines related to school-based oral health programs under the Integrated School Health Programmes (ISHPs) which include special needs schools.¹³³ Two recent studies have documented the presence of school-based oral health programs activities at special needs schools in eThekweni District, KwaZulu-Natal.^{41, 134} Despite governments efforts, these programs have faced challenges. For example, challenges of inadequate resources and a lack of support in the implementation of the school programs in Tshwane, SA have been reported.⁴² These challenges are likely to have an impact on the effectiveness of the programs in promoting oral health among school children including children with disabilities. Nonetheless, community outreach programs are provided by ADHs as part of ISHPs to schools including special needs schools.¹³³ Despite these initiatives, CSHCN in SA continue to suffer poor oral health and high treatment needs due to caries,⁴⁰ perhaps due to other access barriers to dental care.

2.5.5 Barriers to dental care access for CSHCN

Children with disabilities face both environmental/dental care system and non-environmental/child and family barriers to access dental care. In a systematic review examining the barriers to utilisation of dental care services, caregivers in all the studies included mentioned financial constraints, uncooperative behaviour of the child and dentists who were reluctant to treat CSHCN as barriers encountered when accessing dental care.¹³⁵ Other barriers to dental care were related to the child's medical diagnosis,^{24, 136-139} caregiver knowledge and attitude towards oral health,^{26, 35, 140} OHP training and experience^{25, 26, 141} and physical accessibility to dental care services.^{26, 142}

Type of disability

The type of disability has been shown to be a barrier to dental care for some CSHCN,²⁴ ; however, in SA, there is a dearth of studies that have reported this association. A US study has reported that children with specific disabilities such as CP, ASD, DS, and developmental delay

experienced more barriers to dental care owing to their medical conditions and behaviour.²⁴ The inability to obtain dental care for CSHCN has been linked to a lack of access to medical care as demonstrated in another US study.¹³⁶

The nature and severity of the underlying medical condition may impact the ability of the OHPs to provide dental care. Dental professionals in India reported that the medical condition of CSHCN was a barrier to dental care.¹³⁷ This concern could be partly attributed to inability to obtain accurate medical details for their patients. For example, in Australia, OHPs had difficulties obtaining patient information such as the medical history and medications,¹³⁸ which are important in making decisions regarding appropriate dental care for the patient and ultimately affect access to care.

The child's behaviour in the dental setting impacts the ability to obtain dental care.²⁵ Dental professionals in India reported that a lack of patient cooperation was as a barrier to dental care for CSHCN.¹³⁷ In another study, a lack of patient cooperation resulted in more dental extractions provided to patients with mental disabilities by OHPs in Trinidad and Tobago.¹³⁹ There are no similar studies in SA. Therefore, this thesis will investigate the types of dental treatments provided to CSHCN at ADHs.

Caregiver knowledge and attitude

The parental/caregiver oral health knowledge and attitude towards oral health impacts the child's oral health status. Other factors include the parental level of education, socio economic status of the family. Positive parental attitudes towards oral health for children with ASD in Eastern Saudi Arabia was associated with lower sugars consumption in their children.¹⁴⁰ In the same study, better gingival health and less plaque accumulation was reported among parents who were better at providing routine oral hygiene. A study in Nigeria comprising 109 CSHCN and 134 healthy individuals between the age of 5 and 19 years reported poor oral health knowledge among caregivers.¹⁴³ In addition, inadequate use of dental facilities was noted among CSHCN and those from lower socio-economic backgrounds.¹⁴³ Similarly, in the US, caregivers of CSHCN had low oral health awareness,³⁵ while in India, a lack of motivation among caregivers was reported as a major barrier to dental care for CSHCN.²⁶

There are only a few studies from SA on caregiver knowledge and attitude towards their children's oral health. One study among caregivers of CSHCN in Johannesburg had inconclusive findings on the relationship between caregivers knowledge and their child's oral health status.²⁰ In another SA study, child care workers of CSHCN reported inadequate knowledge in caring for these children.¹⁴⁴

Oral Health Provider training and experience

The level of training and experience of the oral health providers (OHPs) in the dental management of CSHCN is a barrier to dental care for CSHCN.^{25, 26, 141} For example, among a group of 149 dentists in India, 57% did not feel comfortable treating CSHCN.²⁶ Some of the barriers they faced included their level of training (38.5%), communication challenges with the patient and low motivation among parents.²⁶ A previous US study had reported similar findings among dentists.¹⁴¹ Notably, dentists who reported better undergraduate dental education training were also more likely to treat special needs patients.¹⁴¹ In another US study, challenges related to finding a dentist with experience in managing persons with disabilities was a key barrier to lack of dental care for ASD children.²⁵ However, there is a lack of studies in SA on OHPs in both private and public health sectors even though they are involved in the management of individuals with disabilities. This thesis will identify some of the challenges facing OHPs in the dental care for CSHCN at ADHs to suggest some of the mitigation strategies for enhancing delivery of services.

Physical inaccessibility

The location of the health facilities influences access to dental care for CSHCN. A study in India among dentists reported that the location of the clinic (not on the ground floor of the building), lack of lifts or ramp facilities were key barriers to dental care for CSHCN.²⁶ Also, most of the clinics reported not having specialised facilities such as sedation equipment needed to manage CSHCN. Similarly, in a study in Jordan, the long distance to the dental office, inaccessible parking and lack of wheelchair access were key barriers among individuals with ASD.¹⁴²

In SA, limited studies have reported on the barriers to dental care access faced by CSHCN. One study noted that resource constraints and limited finances were potential barriers to oral

health promotion initiatives at special needs schools in eThekweni District of KwaZulu-Natal.

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In this section, the oral healthcare for CSHCN including some of the barriers to dental care faced by these children were described briefly. Barriers to accessing dental care for CSHCN are broad ranging from the nature and severity of the child's disability, the family status, training of OHPs, and the ability to access dental care. Thus, the next section reviews the SA healthcare system, and delivery of dental care for CSHCN.

2.6 DELIVERY OF DENTAL CARE to CSHCN IN SA

2.6.1 Healthcare system in SA

South Africa has a dual health care system consisting of a well-functioning and resourced private sector and an under-resourced public service.¹⁴⁵ Approximately 80% of SA health professionals (medical and dental) work in the private sector and serve the needs of about 15% of the population.¹⁴⁶ In SA, the human resources involved in the delivery of oral health care services include oral hygienists, dental therapists, dentists, and dental specialists. Other non-clinical personnel are dental technicians and dental assistants. The majority of OHPs are dentists (77%), oral hygienists (15%) and dental therapists.¹⁴⁷ The various OHPs provide a variety of dental care services in both the private and public sectors. However, the majority of the oral health professionals work in urban centres.¹⁴⁷ This maldistribution of OHP between urban and rural areas occurs not only in SA, but also in other low income countries of Africa.¹⁴⁸ The scenario is likely to perpetuate further oral health inequalities among CSHCN.

The National Department of Health guided by the National Health Act of 2003 provides the policy framework for healthcare services in SA.¹⁴⁹ Provincial governments are responsible for the delivery of health services in the public sector. Within the provinces, the sector is organised by districts with a total of 52 health districts, but not all provide oral health services.¹⁵⁰ Health services are delivered through primary clinics, secondary and tertiary hospitals. The delivery of healthcare services is done mainly through the primary health care system (PHC) which includes district hospitals and community health centres.

2.6.2 Delivery of dental care services in SA

Dental care is provided through the larger health care system in the country as guided by the National Oral Health Policy framework based on the 1990 National Health policy. The services include primary, secondary, and tertiary level services. At the primary health care level, preventative and basic oral health services such as oral examinations, radiography and extractions are provided. At the secondary level, OHPs such as dentists and dental therapists provide curative services such as restorations. Specialty services, available at ADHs, comprise mainly of rehabilitative services provided through the various specialties such as orthodontics, maxillofacial surgery and prosthodontics.¹⁴⁷

Dental services in Africa, including SA mainly focus on curative approach primarily through the alleviation of dental pain, with less emphasis on promotive and preventative care.¹⁵¹ Dental treatment under GA is also used for the management of childhood dental caries and is performed predominantly at ADHs.^{29, 152} Similarly, dental treatment for CSHCN comprises mainly of pain relief extractions done under GA as demonstrated in a previous study conducted in Cape Town, while there was limited restorative treatment.¹⁹

The focus of oral health for CSHCN should be the provision of individualised preventative care based on caries-risk assessment. This is best done in a primary healthcare (PHC) setting such as the one suggested by Gallagher and Fiske, where persons with mild/moderate disabilities access dental care at PHC provided by dentists and supported by specialists.¹⁵³ In addition, this setting has a wide range of PHC workers able to provide an integrated approach to manage general and oral health for persons with special needs. However, this requires an efficient referral healthcare system.¹⁵³ In SA, a policy to integrate maternal general and child oral health as a way of reducing the burden of dental caries among children has been proposed.¹⁵⁴ It is important for this policy to include CSHCN who would benefit from multi-disciplinary integration at PHC.

Access to comprehensive, affordable, and quality healthcare for all is a key government agenda. The National Health Insurance bill (NHI) was signed into law marking a major step towards the goal of universal health care.¹⁵⁵ This is an important step in addressing the inequalities that persist in healthcare in SA.

2.6.3 Access to healthcare

Access to healthcare is an important aspect of service delivery, yet complex due to various interpretations.¹⁵⁶ Within healthcare, access refers to the ability to use a service or reach a provider or institution.¹⁵⁶ Access has been conceptualised in different ways to denote the characteristics of the users and providers with emphasis on the characteristics of health care resources that impact both production of services and consumption.¹⁵⁷ Aday and Andersen, Andersen conceptualised utilisation as realised access based on population characteristics (predisposing, enabling, need) and health systems characteristics such as policy, resources, and organisation.^{158, 159} Some of the demographic and clinical characteristics of CSHCN utilising oral health care services at ADHs, and health system characteristics will be explored in this thesis.

2.6.4 Quality of healthcare

Another important aspect of access to health care is quality. Figure 2.3 shows the Donabedian model for the assessment of quality of care.¹⁶⁰ The structure component of the model depicts the way care is delivered including facilities, equipment, and human resources. The process indicates the interaction between the patients and the providers, in this case OHPs that provide oral health care services to CSHCN. The outcomes are the effects of health care such as improved oral health for CSHCN, reduced treatment needs due to caries and improvement in the OHRQoL. This thesis will look at some structural and process factors in the health system that impact delivery of dental care services for CSHCN in SA.

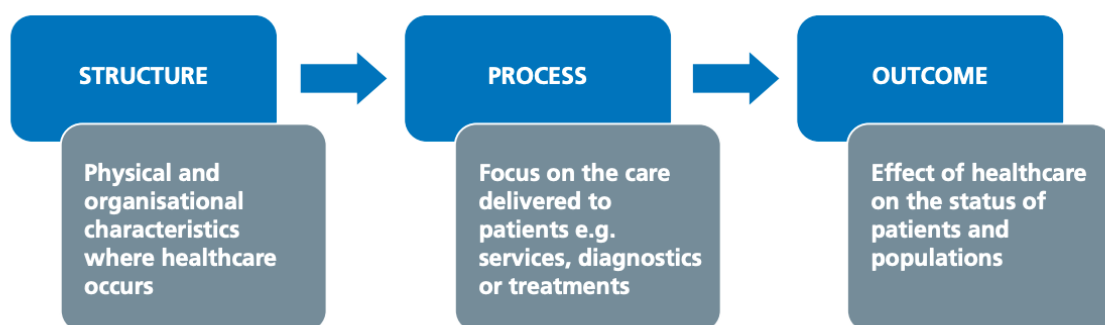


Figure 2.3 The Donabedian model for quality of care

Source¹⁶¹

This section has provided a brief overview of the healthcare system in SA, and the organisation of dental care services. Health care in SA is decentralised to the provincial governments. Dental care services are delivered through the public health facilities and consist primarily of curative services such as dental extractions. The PHC facilities in SA face challenges such as human resource constraints and facilities that impact delivery of dental care to CSHCN.

2.7 HEALTH SYSTEM CHALLENGES IN SA

The health system in SA faces multiple challenges which negatively impact the delivery of health care.¹⁶² Among the key challenges is a lack of adequate resources such as staff shortages, limited finances,³⁶ leading to poor service delivery. The challenges of limited human and financial resources for health affect not just SA, but the broader African region.¹⁶³ Other challenges specific to the oral health care services in SA include a lack of dedicated oral health budget,¹⁵¹ limited number of dental specialists and low oral health prioritisation.⁴¹ These factors negatively affect the delivery of dental care services to CSHCN.

2.7.1 Limited financial resources and low priority for oral health

Adequate financial resources are key to the delivery of health care services including oral health. A study in the Free State of SA reported that cash flow was a challenge to public health services delivery.³⁶ In Limpopo province in SA, a lack of financial support attributed to a lack of a dedicated budget for oral health was reported in public facilities.¹⁵¹ Despite the lack of adequate financial support from the government, in the 2018/19 financial year, the SA government spent about R200 billion on the public health system.¹⁶⁴ In this budget, there was no defined allocation for oral health care services which was grouped with non-communicable diseases (NCDs).¹⁶⁵ This lack of budgetary allocation specifically for oral healthcare services adversely affects delivery of services. In a study conducted among coordinators at long-term care facilities in eThekweni there was limited funding for oral health services at the facilities.¹²⁹ The coordinators who were mainly professional nurses stated that those facilities received general funding with no dedicated funds for oral health.¹²⁹ Comparable findings were noted in the US where limited financial resources was one of the major barriers to provision of preventative dental care to CSHCN in community-based organisations.³⁵ Despite the US study having been conducted in a higher economic context compared to the SA setting, limited

financial resources for oral health services was reported and highlights the lack of priority towards oral health.

Oral health is generally not prioritised in most health care systems especially in developing countries,¹⁴⁸ possibly due to the low morbidity and mortality associated with dental diseases such as dental caries. Resource constraints and more pressing social issues such as hunger, unemployment, management of infectious and NCDs are other possible reasons for low government prioritisation of oral health. As a result of this low prioritisation, CSHCN face challenges obtaining dental care.¹²⁹ Similarly, other system-level barriers to preventative dental care for CSHCN were identified at community-based organisations in the US.³⁵

2.7.2 Limited specialists and lack of expertise

Children with SHCN often have complex health and dental needs that require the services of diverse healthcare providers including dental specialists. These specialists are limited in number in public health facilities and are mainly found at ADHs in SA. In Limpopo, a shortage of OHPs, especially dental specialists, affected the delivery of oral health services.¹⁵¹ In the US, coordinators at community-based organisations found that only a few dentists were willing to accept referrals of CSHCN from their organisations.³⁵ In another US study, caregivers of CSHCN had difficulties finding dental providers willing to treat their children.³⁴ There are no comparable SA studies as paediatric dentists are few due to a lack of specialty training.

2.7.3 Impact of Covid-19 pandemic

The coronavirus disease (COVID-19) global pandemic caused major disruptions of health care services including dental care. Provision of dental care services was markedly reduced during the lockdown periods imposed by governments to reduce transmission of the virus. Provision of hospital dental care for children, especially those with disabilities, who often require dental treatment under GA was limited during this period, contributing to oral health inequalities.¹⁶⁶ In SA, CSHCN were also unable to access specialty dental care provided through the multidisciplinary clinics for patients with craniofacial anomalies. Although most of the services have resumed, facility managers in eThekweni noted that since the Covid-19 pandemic, PHC initiatives around oral health screening had stopped.¹²⁹ Therefore, this lack of screening implies

that dental disease may not be recognised in time to institute prevention and dental treatment, pointing to the lack of oral healthcare priority.

In this section, I have reviewed some of the health system challenges in SA. A lack of resources and low oral health prioritisation were among the key challenges facing the delivery of dental care services. There is a lack of studies focusing on challenges facing delivery of dental care to CSHCN in SA, including those faced by OHPs.

2.8 ORAL HEALTH PROVIDERS' CHALLENGES

Oral health providers (OHPs) face multiple barriers in providing routine dental care to CSHCN. Common barriers are the need for training in the management of CSHCN, inadequate facilities, patient safety concerns, and low oral health priority among caregivers and other medical professionals. These factors are discussed below.

2.8.1 Lack of training

The level of OHPs training could influence their ability to manage CSHCN. A study among Australian OHPs providing dental care at primary health facilities revealed that inadequate training and experience were barriers in managing patients with special needs.¹³⁸ In Trinidad, health care professionals, including OHPs, lacked the necessary knowledge or equipment to safely provide treatment for individuals with special needs at public or private facilities.¹³⁹ Similar findings were reported in India where the inadequate level of training among dental practitioners in private facilities was an important barrier to providing dental care for CSHCN.²⁶ In an Australian study, access to ongoing education in 'Special Needs Dentistry' and better training were some of the suggested support mechanisms to enhance dental care for individuals with SHCN.¹⁶⁷ However, at the time of writing this thesis there were no SA studies that had assessed training of OHPs in the management of SHCN.

2.8.2 Inadequate providers and high workload

In SA, there is a huge mal distribution of the OHP workforce between the private and public sectors.¹⁴⁷ In 2015, about 6,125 dentists were registered with the Health Professionals Council of SA with one dentist to a population of 8,900,¹⁶⁸ and only 7% of the dentists were registered in the public service category which serves 80% of the population.¹⁶⁸ A high provider to patient

ratio increases the workload and compromises the delivery of dental care. In SA, little is known about how the limited number of OHPs in the public health sector affects the delivery of dental care for CSHCN, an aspect explored in this thesis.

2.8.3 Inadequate specialised facilities

Dental treatment for some CSHCN usually requires theatre facilities for GA or sedation. The facilities are available in hospitals settings or specialised clinics. There is limited knowledge on the availability of specialised facilities for dental treatment of CSHCN in SA. However, a previous study in SA at an ADH noted the average waiting time to obtain treatment under GA for children was about 5 months, suggesting limited facilities.²⁹

2.8.4 Lack of interdisciplinary and health system support

The lack of support from other medical health professionals who provide routine medical care such as doctors, physicians, specialists has been cited as a barrier to providing dental care for children and adults with SHCN. For example, among OHPs in Australia, inadequate support such as inability to obtain patient medical or drug history from primary medical care doctors was reported as a barrier to dental care among these adult patients.¹⁶⁷ In addition, they reported that a more supportive clinical environment with less pressure on productivity could assist clinician willingness and capacity to provide treatment for patients with special needs.¹⁶⁷ In SA, clinical managers in long-term care facilities reported that there was inadequate support from the local health department for their residents' oral healthcare needs.¹²⁹

Health system support and understanding of the importance of good oral health for CSHCN is essential. In Australia, a general lack of oral health understanding among medical health professionals was reported as a barrier to dental care for individuals with special needs within the public health system.¹³⁸ In SA, OHPs in Limpopo Province reported a lack of oral health priority and inadequate support from health managers to enable the delivery of dental care services in the area.¹⁵¹ Thus, it appears that SA and Australia though contextually different have comparable challenges of poor systemic support for delivery of dental care to patients including CSHCN.

There are multiple factors that influence OHPs management of CSHCN. These include inadequate provider training, limited specialised facilities, human resources and inadequate

support from other medical professionals. There are limited SA studies that have explored these barriers from the OHPs perspective. Further studies are essential to improve delivery of dental care to CSHCN at SA public health facilities.

2.9 SUMMARY OF LITERATURE REVIEW AND KNOWLEDGE GAPS

A few issues become apparent from the literature review. A summary of some of the knowledge available, the gaps identified, and the contribution of this thesis towards addressing some of the gaps are presented in Table 2.2. Firstly, there is a lack of current epidemiological data regarding the status of oral health among children including CSHCN in SA. The last National Children's Oral Health Survey in SA was conducted two decades ago. Furthermore, only a few studies on oral healthcare for CSHCN have been conducted within SA despite the global call to improve access to healthcare for vulnerable groups. Secondly, from the literature reviewed, dental caries is prevalent among CSHCN globally with the rates varying by country and type of disability. In SA, from the few studies reported, there are high unmet treatment needs attributed to untreated caries among CSHCN, pointing to inadequate access to dental care. Thirdly, dental care services are not prioritised within the public health system of SA with low budgetary allocation and limited human resources despite serving most of the population. At the time of writing this thesis, there were no studies conducted in SA investigating factors influencing the delivery of dental care for CSHCN which has been explored in this study. Lastly, although several gaps were revealed in this literature review, not all were explored in the study as they were beyond the scope envisioned in the study protocol.

Table 2.1 Summary of literature review

Study objective	Knowledge available	Knowledge gaps	Thesis contribution
To compare the dental treatment provided to CSHCN and NSHCN at ADHs	• CSHCN both globally and in SA generally have poor oral health • CSHCN in SA have greater unmet dental care needs	• Current epidemiological data for oral health of CSHCN in SA is lacking • Dearth of studies on the dental treatment provided for CSHCN at public health facilities	Retrospective review of patient records conducted to compare dental treatment provided for CSHCN and NSHCN at ADHs in SA
To describe the dental care services provided to CSHCN at ADHs To identify factors influencing the delivery of oral healthcare to CSHCN at ADHs	• Dental care services focus on pain relief • Dental treatment under GA for management of caries in childhood is a burden • Lack of integrated and comprehensive oral healthcare for CSHCN • Challenges of inadequate resources for oral health	• Dearth of studies on oral healthcare for CSHCN at ADHs and issues affecting service delivery	In-depth interviews of OHPs at ADHs conducted to describe dental care services provided to CSHCN and factors influencing the delivery of services
To explore the perceptions of OHPs towards provision of dental care to CSHCN at ADHs	• OHP reported inadequate training, • limited specialised facilities • resources constraints adversely impacted delivery of dental care for CSHCN	• Limited studies focusing on the perspectives of OHPs providing treatment for CSHCN in SA	Survey conducted among OHPs at ADHs to describe their perceptions towards dental care provision for CSHCN

CHAPTER 3

Methodology

This Chapter describes the methods used in the study to achieve the aim and objectives outlined in Chapter 1 Sections 1.4 and 1.5. The conceptual framework for my study is described in Section 3.1. In section 3.2, I have presented the general methodological features common across the study (the study setting and the study population). Section 3.3 presents an overview of the specific study methods for each study objective, and the respective manuscripts that were envisaged to emanate from this thesis. The ethical considerations are summarised in Section 3.4. Some of the limitations and potential biases in the study are addressed in Section 3.5.

This study assessed the delivery of oral healthcare to CSHCN at academic dental hospitals (ADHs) in SA, as well as the perspectives of oral health professionals (OHPs) rendering the services. The study utilised a sequential mixed methods design in which the quantitative component was first conducted followed by the qualitative section. Three interlinked but separate study components were used to answer the research objectives. The first study component described the characteristics and status of oral health among children and adolescents with special healthcare needs in SA. The second study component compared the dental treatment provided to children with and without special healthcare needs at the ADHs in SA. The final study component explored the perceptions, and experiences of oral health professionals regarding the provision of dental services for CSHCN at the ADHs in SA.

In the sequential mixed method approach, the principal investigator (PI) first collected and analysed the quantitative (QT) data. This was followed by collection and analysis of the qualitative (QL) data which were used to explain the results of the quantitative phase.¹⁶⁹ The rationale of the MMR is to combine the strengths of each approach, triangulate the research findings, and gather a comprehensive understanding of the phenomena of interest.^{170, 171}

3.1 CONCEPTUAL FRAMEWORK FOR THE STUDY

My PhD conceptual framework was adapted from the WHO framework¹⁷² on integrated people-centred health services. The model proposes a broad range of health services such as health promotion, prevention to treatment and rehabilitation. The services should be provided based on the patient needs and at various levels within the health system. Among the objectives of this study is the need to improve access to underserved groups such as CSHCN through

the PHC. In the proposed framework, there is a shift in the care model towards community, coordination of services between different providers and sectors. In addition, the framework requires an enabling environment with adequate financial resources and training of health providers.

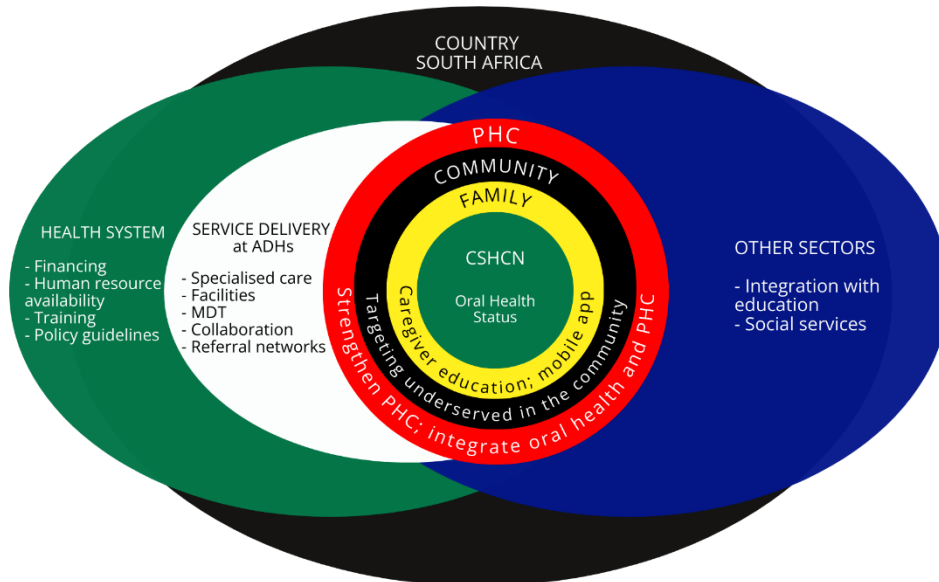


Figure 3.1 Conceptual Framework for Oral Healthcare of CSHCN

Source¹⁷²

This model was chosen for the study which focused on the delivery of oral healthcare for CSHCN in SA public health facilities, specifically ADHs where most of these children are referred for dental care. Thus, in this study, the key focus is on CSHCN placed at the centre of the model and their oral health status. The caregiver of the CSHCN is the person within the family responsible for taking care of the CSHCN surrounded by the community in which these children live, grow and function. Access to integrated health services at PHC is essential for CSHCN who often require care coordination across different providers and organisations.¹⁷³ The providers at PHC include professional nurses, community health workers, social workers, physiotherapists and sometimes OHPs such as dentists and oral hygienists. Access to other specialty health services at tertiary level hospitals such as dental treatment under GA or CLP management through multidisciplinary teams at ADHs is made through referrals from PHC. Additionally, the health services on the left are integrated with those on the right such as access to basic education and social services for CSHCN (Figure 3.1). Service delivery occurs in the

context of the overall health system and available resources of each country which in the context of this thesis is SA.

Integrating oral health care into PHC has the potential to improve oral health in Africa.¹⁷⁴ In order to promote oral health in Africa, the basic package of oral care framework was developed for resource constrained areas aimed at integrating oral healthcare into PHC and includes promotion of the use of fluoride toothpaste, emergency oral pain relief and the use of atraumatic restorative treatment for caries management. Due to the limited availability of dentists at PHC, other non-OHPs could be utilised to provide preventative dental care such as fluoride varnish for CSHCN.

Social justice is a concept where all members of society participate fully in society and where resources are balanced. Other key aspects of social justice include health systems, organisations, processes and policies that ensure health equity.¹⁷⁵ This concept has relevance in this study which focused on oral healthcare provision of a vulnerable group (CSHCN) in a resource limited setting. This is key in ensuring that CSHCN are not relegated to the fringes of oral health service provision.

3.2 GENERAL METHODOLOGICAL COMPONENTS

3.2.1 Study setting

The study was limited to the SA public health sector which provides health care services to nearly 83% of the population.¹⁷⁶ The study settings consisted of all the five ADHs in SA which are located in three of the nine provinces of SA as shown in Figure 3.2. Three ADHs are in the Gauteng province and one each in the Western Cape and KwaZulu-Natal provinces. The ADHs included are the University of the Witwatersrand Oral Health Centre, the University of Pretoria Dental Hospital, Medunsa Oral Health Centre at the Sefako Makgatho Health Sciences University, Tygerberg Dental Hospital of the University of the Western Cape and King Dinuzulu Hospital Dental Clinic. The study settings have subsequently not been explicitly referred to ensure anonymity. The hospitals were selected based on factors such as offering dental training, being referral centres and providing specialised dental treatment. For instance, these hospitals provide basic and specialist dental services such as maxillofacial surgery, orthodontics and rehabilitation of patients with CLP referred for dental treatment.¹⁴⁷ The

hospitals also provide other specialised medical health services that may be required by certain categories of CSHCN through the use of MDT.



Figure 3.2 Map of South Africa indicating the location of the ADHs

Source¹⁷⁷

3.2.2 Study population

The study participants included CSHCN and NSHCN aged between 1 and 16 years. All records of these children who received dental treatment under GA between 1 January 2017 and July 2023 at the ADHs were included for review. Furthermore, oral health professionals at ADHs who provide oral health services to these children were included in the study survey and interviews. An overview of the study components and methodology is summarised in Table 3.1.

Table 3.1 Overview of the study components, study design and methods

	Study 1	Study 2 (Objective 1)	Study 3 (Objective 2+3)	Study 3 (Objective 4)
Study sample	Review of literature on oral health status among CSHCN in SA between January 2002 and July 2023	Records of 1–16-year-old CSHCN and NSHCN treated under GA at ADHs between 1 January 2017 and 30 July 2023	Oral health professionals (OHPs) working at ADHs in SA	Heads of clinical unit in Paediatric Dentistry at ADHs and OHPs responding to the survey
Sampling method	Electronic databases searched for studies that met the eligibility criteria	Convenient sample of all available records	Purposive sample	Purposive sample
Study design	Literature Review	Retrospective record review	Cross-sectional study design	Explorative qualitative study
Sample size	6 studies	200 records per institution	150 OHPs	15 key informants
Data collection	Database search	Record review extraction form	Self-administered online questionnaire	Semi-structured online interviews and a focus group discussion
Data analyses	Thematic content analysis	Descriptive statistics Bivariate: Chi-square test, Fischer exact test	Descriptive statistics	Thematic framework analyses
Results	Chapter 4	Chapter 5	Chapter 6	

3.2.3 Quantitative data analyses

Data from the patient clinical records and self-administered questionnaires were captured in an Excel spreadsheet and stored in a password protected computer. Each ADH was assigned a unique identifier (nominal variable). Other demographic variables such as age, sex were recorded from patient clinical records and survey participants. Categorical variables from the Likert scale responses were ranked to measure perception of oral health professionals. Questions with ‘yes’ were coded as ‘1’ while ‘no’ was assigned code ‘0’.

Descriptive analyses using frequencies and measures of central tendencies were performed using STATA[®] Version 14 (Stata Corporation, Inc., College Station, TX, USA). Bivariate analyses were conducted at 5% statistical significance level.

3.2.4 Qualitative data analyses

Thematic content analysis using the framework method described by Ritchie et al was used to generate themes from the codes.¹⁷⁸ The steps consisted of initial familiarisation with the transcripts through repeated reading. This was done by the PI and MM. The second step involved generation of initial codes inductively, done independently by the PI and MM and, subsequently iteratively to build consensus. The third step was to build a thematic framework using the agreed codes. This process was done by the PI until data saturation. The fourth step was to align the selected codes to the Levesque framework of health access as supported by the interviewees' statements. The framework describes access in five dimensions including approachability, acceptability, availability and accommodation, affordability and appropriateness.¹⁵⁶ Finally, all the authors reviewed the final codes to check for potential biases.

Trustworthiness is an important element of qualitative data analysis. Trustworthiness or rigor is the extent to which measures to ensure quality of data, methods and interpretation are undertaken.¹⁷⁹ To ensure trustworthiness, the following criteria were used: credibility, dependability, conformability, and transferability.¹⁸⁰

Credibility relates to the accuracy of the data or reports by the OHPs represented by the researcher. In this study credibility was ensured by listening carefully during interviews, asking for clarification and keeping field notes, recording of the interviews and transcription of the responses.

Dependability relates to the stability of the data over time and over the conditions of the study.¹⁷⁹ The participants are employed full-time at the ADHs and engaged with the problem under investigation constantly; hence, their information was dependable and did not vary significantly over the study period.

Conformability relates to the objectivity or neutrality of the findings as reported and interpreted by the researcher. This was enabled by the recording of interviews and transcription of the responses. Additionally, objectivity was ensured using a systematic and structured framework

to analyse the findings and using rich text or quotes to support the findings in the reporting stage.

Transferability relates to whether the findings can relate to other settings or groups.¹⁷⁹ The researcher has outlined the research process and participants used in this mixed methods study. These included the participants (CSHCN, OHPs) and the study contexts to help other researchers involved in similar multi-disciplinary studies.

3.3 SPECIFIC METHODOLOGY BY STUDY COMPONENT

This Section has provided a summary of the specific approach for the different study objectives. The summary below shows the methods used for the three study components which were interlinked to address the research objectives.

3.3.1 Study 1

Study objective

To describe the characteristics and status of oral health among children and adolescents with special health care needs in SA.

Study design

An online literature review search was conducted to identify studies done in SA to determine the oral health status of CSHCN. The search was conducted on OVID MEDLINE databases. The review period was from 1 January 2002 to 31 July 2023.

Search strategy

A literature review was conducted based on the PRISMA 2020 statement for systematic reviews.¹⁸¹ The keywords used were: ‘oral health,’ ‘dental caries,’ ‘children’/ ‘adolescents,’ and ‘South Africa’.

Data extraction sheet

Every publication included was reviewed using a modified data extraction tool (DET).¹⁸² Two reviewers (NN and PH) piloted the DET to ensure a level of agreement of at least 0.8 Kappa

correlation. Data extracted from each article were populated and thematically organised in an Excel spreadsheet using DET. Data were analysed using a narrative synthesis.

3.3.2 Study 2

Study Objective

To compare the dental treatment provided to CSHCN and NSHCN at the ADHs in SA.

Study design and setting

This was a retrospective record review. All five ADHs in SA were approached for inclusion in the study.

Study population

The study population consisted of paediatric patients treated under general anaesthesia (GA) at five ADHs between 1 January 2017 and 30 July 2023. This period included the time before and after the Covid-19 pandemic which caused disruption of dental services.

Inclusion criteria: Records of CSHCN and NSHCN aged between 1-16 years who received dental treatment under GA/conscious sedation over the study period.

Exclusion criteria: children who received routine dental treatment.

Sampling method

The sample size was estimated based on an earlier study in SA.²⁹ Approximately 40 children received dental treatment under GA per year.²⁹ Thus, the sample size was estimated as 200 records per hospital over the study period. All available records that met the inclusion criteria were included in the sample.

Data collection

A standardised record review form,¹⁸³ was used to extract demographic and clinical data from the patient's treatment records (Appendix 2). Information retrieved included age, sex, referral

source, special health care need/medical status, dental complaint, treatment provided, and type of pharmacological management used.

Data management and analyses

Data were analysed using frequencies, percentages and measures of central tendencies utilising STATA® Version14 (Stata Corporation, Inc., College Station, TX, USA). Bivariate statistical tests were conducted at 5% significance level.

3.3.3 Study 3

Study objective

To explore the perceptions, and experiences of oral health professionals regarding the provision of dental services for CSHCN at the ADHs in SA.

Study design

This was a mixed-methods sequential study. The quantitative study comprised of a survey of oral health professionals working at ADHs to examine their perceptions and challenges whilst providing dental care for CSHCN. This was followed by the qualitative study to explore their experiences and the factors influencing the delivery of dental care to CSHCN at these hospitals. The qualitative study was utilised to provide context and greater depth for the quantitative arm of the study.

Study setting

All five ADHs in SA were approached for inclusion in the study. The hospitals provide comprehensive medical and dental treatment to CSHCN referred for specialised services from both private and other public health facilities.

Study participants

The quantitative survey comprised of clinical oral health professionals (general dentists, postgraduate student dentists, dental specialists, dental therapists and oral hygienists) at ADHs. The qualitative component of the study consisted of the clinical heads of paediatric dentistry

departments at ADHs. The FGD comprised of respondents from the survey who were directly involved in treating CSHCN.

Recruitment of participants

For the quantitative phase, participants were recruited from each dental hospital that provided approval for the study. An email was sent to an administrator at each ADH requesting circulation of the participant information (Appendix 3), and consent sheet (Appendix 4), and the questionnaire (Appendix 5) to the prospective participants. A reminder email was sent after two weeks to the contact administrator. A final email was sent after one month. The survey was open to participants for the duration of 6 weeks to give adequate time to complete the survey. Participants who consented to the study completed the questionnaire.

For the qualitative phase, the OHPs for the FGD were purposively selected from the survey respondents. For the interviews, the heads of paediatric dentistry at ADHs were invited by email following consent by their respective ADH. Participants who agreed to be interviewed received a meeting invite link on Microsoft Teams. The interviews were held online for the duration of approximately one hour.

Sampling

A convenient sample was used to invite OHPs for the quantitative phase. Based on the approximate number of full-time clinical staff at one dental hospital, the sample was estimated at 30 oral health professionals, per dental hospital.¹⁸⁴ Thus, the total sample from the five dental hospitals was estimated as 150 oral health professionals.

Purposive sampling¹⁸⁵ was employed to select OHPs for the qualitative phase. The plan was to invite 8-10 OHPs from the respondents of the survey for the FGD. In the final stage of the qualitative phase, five heads of paediatric dentistry, one representing each ADH were invited for the in-depth interviews which were to be conducted separately.

Sample size

The sample consisted of 150 OHPs for the quantitative phase. The sample for the qualitative phase comprised 8-10 OHPs for the FGD and five OHPs for the in-depth interviews.

Data collection

Quantitative data collection

Data were collected using a semi-structured self-administered online survey among OHPs working at ADHs. The questionnaire which was modified to include perceptions and challenges faced by OHPs at ADHs was based on a previous SA study among child care workers with CSHCN.¹⁴⁴ The research instrument was piloted among OHPs involved in the management of children with cleft lip and palate at one of the ADHs. The questionnaire was then emailed to OHPs through an administrator at each ADH.

Qualitative data collection

The focus group discussion was conducted among five OHPs purposively selected from the respondents of the survey and who were willing to participate in the discussion. One group comprised of OHPs directly involved in management of paediatric patients and the second group comprised of two OHPs involved in the management of patients in the craniofacial clinic at one of the ADHs. Finally, in-depth interviews were done separately with three key informants who were heads of department in paediatric dentistry from each ADH.

The interviews were conducted online by the PI using an interview guide (Appendix 6). Consent for participation and audio recording (Appendix 7) were emailed to the selected OHPs prior to the interviews. Information sought from each participant included their role in the organisation, the average number of CSHCN treated, the types of services provided, human and infrastructural resource availability, collaborations with other dental and medical professionals and any challenges faced. The interviews were conducted in English for 1 hour. The PI took additional notes during the interview process.

For the participants of the focus group discussion, consent for audio recording (Appendix 7) was obtained prior to the discussion. A question guide (Appendix 8) was used to allow participants to share their own perspectives and experiences while providing treatment for CSHCN. The discussion was conducted for about an hour. Field notes were done during the session. The discussion ended when no further information was forthcoming from the participants to ensure data saturation.

Data management and analyses

The data management plan involved first the collection and analysis of the quantitative data followed by the collection and analysis of the qualitative findings. Triangulation of both data sets was done at the reporting stage of the findings in chapter 6.

Quantitative data

The survey questionnaire data were entered into an Excel® spreadsheet and imported into STATA® Version14 (Stata Corporation, Inc., College Station, TX, USA) for analysis. Descriptive analysis of quantitative data such as demographic characteristics of the survey participants were analysed using frequencies and percentages.

Qualitative data

The audio recordings from the participants of the FGD and interviews were transcribed before analysis. However, no member checking was done prior to the analysis. Thematic framework method analysis¹⁷⁸ was used to analyse the qualitative findings. The detailed process is included in Chapter 6.

3.4 ETHICAL CONSIDERATIONS

The following ethical aspects were employed for the entire study:

Ethics approval: The study approval (M220266) was obtained from the Human Research Ethics Committee (HREC) (Medical) of the University of the Witwatersrand (Appendix 1). Written permissions to conduct the study were further obtained from the office of the CEO/Head of ADHs, and where necessary the clinical heads of paediatric dentistry from each ADH (Appendices 9).

Informed and voluntary participation: All participants of the survey and interviews received an information sheet explaining the research purpose, process, risks, and potential benefits. Participation was voluntary and informed consent was obtained. Participants of the interviews provided approval for audio recording.

Confidentiality and anonymity of participants: Confidentiality was maintained throughout the study. Each study institution and key informant was allocated a unique identifier. All patient records were coded, and no personal identifiable information was recorded. Participant views and quotes from the interviews were anonymised.

Security of data collected: all information was stored in a password protected computer accessible to the PI. Compliance with the protection of personal information guidelines of SA were followed.¹⁸⁶ Only data that were deemed necessary for the research were collected.

3.5 STUDY LIMITATIONS AND BIASES

This Section addresses some of the potential limitations, biases and ways of mitigating them. The methodological biases and limitations in the study included: selection bias, social desirability and researcher positionality bias.

The study was conducted only at ADHs in SA. Other health facilities whether private, public or non-profit organisations that provided dental care for CSHCN were not included. Thus, selection bias of the study settings may have occurred, and the study findings cannot be generalised to other public health facilities in SA. However, the study included all the five ADHs situated in three of the seven provinces in SA; therefore, the study captured the contexts of the ADHs in SA.

Social desirability arising from the tendency of participants to portray themselves favourably, may have resulted in over-or-under-reporting.¹⁸⁷ To mitigate against this tendency, the use of an online self-administered instrument ensured anonymity and may have encouraged the respondents to be more truthful in their responses. Participants in the interviews and FGD were not identified at the reporting stage which encouraged honesty. The survey instrument used a 4-point Likert scale for responses which could have been subjective. To minimise subjectivity, the questionnaire was semi-structured to reduce bias.

The selection of the participants of the FGD introduced a potential bias and is hereby acknowledged. These members although directly involved in the management of CSHCN at their institution were not representative of the five ADHs. To mitigate this potential bias, the data from the FGD was not reported separately but incorporated with interview data and OHPs survey at the reporting stage.

The primary investigator is a paediatric dentist registered with the Health Professions Council of SA, bound by the code of conduct on confidentiality and research integrity. Personal positionality bias may have occurred in the study. To minimise the researcher's influence on the data interpretation, reflexivity was employed throughout the study. Furthermore, a second independent coder was involved in analysing the qualitative data. Triangulation of the different data sets also helped to minimise personal bias.

CHAPTER 4

Oral Health in Children and Adolescents with Special Healthcare Needs in South Africa: A Narrative Review

In this chapter, the findings obtained from the literature review to describe the characteristics of individuals with special health care needs (SHCN) in South Africa are presented. The results of this review were published as a manuscript (Appendix 10)⁴⁴. Slight modifications have been made to the published manuscripts, such as the removal of acronyms that have previously been introduced, and the omission of journal-specific requirements, such as conflict-of-interest statements.

4.1 INTRODUCTION

Children and adolescents with special health care needs may experience disproportionately poorer general and oral health than healthy children.^{9, 10, 188} They are more at risk of common conditions such as dental caries and gingivitis resulting from poor oral health.⁶³ They comprise of children and youth ‘with or at risk of chronic physical, developmental, behavioural or emotional conditions..’¹ including, inter alia, intellectual disability (ID), cerebral palsy (CP), learning disability (LD), autism spectrum disorder (ASD), hearing impairment (HI), Down Syndrome (DS), physical disabilities (PD), visual impairments (VI) and epilepsy (EP). Globally, the prevalence of disabilities is increasing, even in developing countries such as South Africa (SA), resulting in a greater burden on health care systems.¹⁸⁹

The 2011 World Health Organisation report estimated that 15% of the global population had a disability. There was a slightly higher prevalence of individuals with disabilities in developing countries than in developed countries.³ Among children aged 0-14 years and those above 15 years, 5.1% or 93 million and 19.4% or 892 million had a moderate or severe disability, respectively. Due to the lack of current epidemiological data, there are no accurate figures of children with disabilities in SA. However, the 2011 census in SA found that about 609, 671 children aged between 5-14 years had a disability.⁴

Individuals with developmental disabilities such as ASD are more likely to develop oral diseases compared to typically developing children.¹⁹⁰ Poor dietary choices and between meal consumption of sugars increase the risk for dental caries,¹⁹¹ while inadequate oral hygiene additionally increases the susceptibility for gingivitis. Children with ID may lack the cognitive and /or manual dexterity to perform oral hygiene independently, whilst uncooperative

behaviour makes routine oral hygiene practices difficult for the parent/caregiver. Furthermore, medication such as phenytoin, an anticonvulsant drug used in children with epilepsy, may predispose to gingival hypertrophy,¹⁹² and impede proper plaque control. Caries risk also increases in the presence of developmental defects of enamel and enamel hypoplasia that may be present in young patients with CP.¹⁹³

Poor oral health can negatively impact general health, especially in children with disabilities.⁷ When left untreated, dental caries leads to chronic pain, infection, sleep disruption, premature tooth loss and poor weight gain as the child cannot feed properly, which may impact growth and development.⁸ Dental infections resulting from poor oral health also pose a risk for bacteraemia and potential life-threatening septicaemia, especially in immunocompromised children.¹⁹⁴ Mostly, the oral health management of CSHCN is performed under general anaesthetic. The time and cost associated with treatment under general anaesthesia puts additional strain on the health care system, especially in developing countries.¹²⁷ Furthermore, there is an associated economic burden on families related to the cost of treating oral diseases,⁸⁰ more so for CSHCN with additional healthcare needs.

Despite the adverse consequences of poor oral health, globally CSHCN are likely to encounter barriers to dental care.¹⁹⁵ In addition, factors related to the severity of the child's disability and the family's socio-economic level may limit access to non-preventative dental care.²¹ In SA, the lower socio-economic groups suffer from a greater burden of ill-health and disability and are less likely to use health services.¹⁹⁶ Understanding the characteristics and status of oral health among CSHCN helps to reveal their needs more specifically and address any barriers to dental care. In the area of oral health for individuals with disabilities, only a few studies have been conducted in SA which has significant health inequalities.¹⁹⁷ Thus, the aim of this review was to describe the characteristics and status of oral health among CSHCN in SA.

4.2 MATERIALS and METHODS

4.2.1 Search Strategy

A literature review was conducted based on the PRISMA 2020 statement for systematic reviews.¹⁸¹ An internet-based search was performed for the articles published between 1 January 2002 and 31 August 2023. This period was chosen as the last SA National Children's Oral Health survey (NCOHS) was conducted two decades ago (1999-2002).³⁹ Notably,

CSHCN were not included in the survey. The keywords used were: ‘oral health,’ ‘dental caries,’ ‘children’/ ‘adolescents,’ and ‘South Africa.’ The following electronic databases were searched for studies that met the eligibility criteria for this review: MEDLINE, PubMed, SCOPUS.

4.2.2 Eligibility criteria

The eligibility of potential studies was determined by reading the title and abstracts of each article identified by the search engine. All articles that appeared to meet the inclusion criteria based on their abstracts were selected and collected. Full-text articles were obtained for manuscripts with missing abstracts or those in which insufficient relevant information was found in the published abstract. Reference lists of the included studies were also screened for potentially relevant research. The final selection was independently carried out by the principal investigator (NN) and the co-authors after reading the complete articles and the results were compared for agreement. Studies were eligible for inclusion if they met the following criteria: (a) performed in SA, (b) children and/or adolescents with special health needs/disability, (c) assessed oral health by quantitative measurement or qualitatively as reported by a parent or caregiver, (d) the decayed, missing and filled teeth index (dmft for primary and DMFT for secondary teeth) was used to assess caries severity. Only articles published in English were included. Unpublished manuscripts and grey literature were excluded. The results of the search, selection process and the number of studies included and excluded at each stage are shown in Figure 4.1.

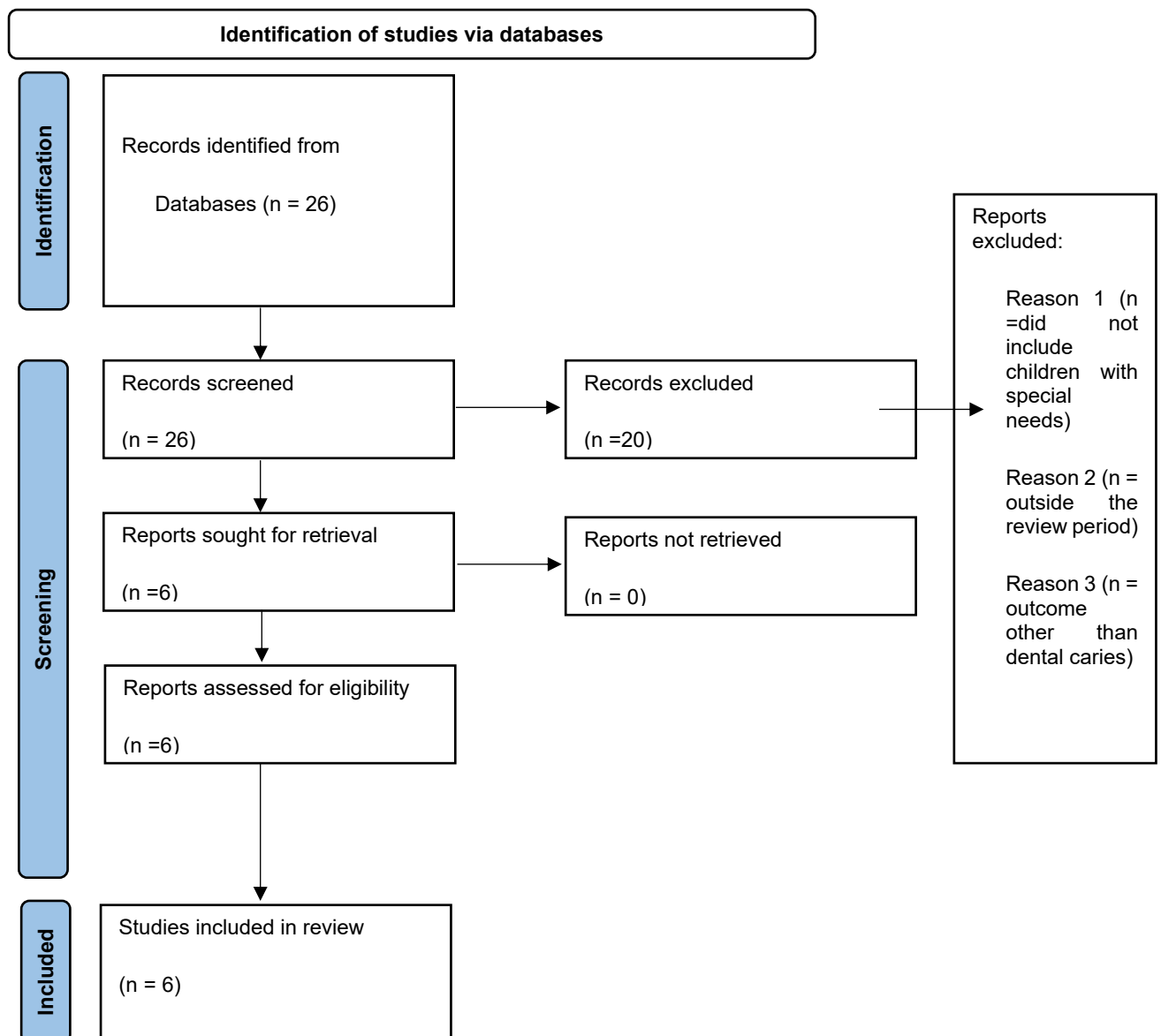


Figure 4. 1 PRISMA 2020 statement flow diagram for selection of studies

Source¹⁸¹

Every publication that was included was reviewed using a modified data extraction tool (DET)¹⁹⁸ (Table 4.1). The reviewers (NN and PH) piloted the DET to ensure a level of agreement of at least 0.8 Kappa correlation with each other. Data extracted from each article were populated and thematically organised in an Excel spreadsheet using DET.

Table 4.1 Data extraction tool

Author(s)	
Year of study	
Study objective	
Study setting	
Study design	
Study population and sample size	
Type of SHCN/disability	
Key findings	
Critique	

4.2.3 Ethical considerations

Approval to conduct the study was obtained from the University of Witwatersrand Human Research Ethics Committee (Clearance number M220266).

4.3 STUDY FINDINGS

4.3.1 Characteristics of the identified studies

A total of 26 articles were retrieved, of which 20 did not meet the eligibility criteria. The reasons for excluding these articles were (i) participants were not CSHCN, (ii) the study was conducted outside the review period or (iii) outcome other than dental caries. The six studies that were included in this review were cross-sectional in design and most participants were from public special needs schools. The studies were conducted in urban and peri-urban settings except for one in a rural setting, thereby representing different socio-economic backgrounds of the study participants in SA.¹⁵

4.3.2 Characteristics of the study participants

A total of 2,402 individuals with special health care needs were included in the review, 59.7% (n=1,433) of whom were male and 40.3% (n=969) were female. The age of the children ranged between 0 and 20 years. One study used caregivers of CSHCN as a proxy of their child's oral health status.²⁰

4.3.3 Types of disabilities

The types of disabilities varied across the studies. Among the disabilities included, inter alia, ID/MD n=787, CP n=205, LD n=182, ASD n=218, HI n=110, PD n=67, DS n=62, severe HI=47, EP n=20, 'complex/multiple disabilities' n=31, VI n=7, ED n=15 and other health disorders n=22 as shown in Figure 4.2

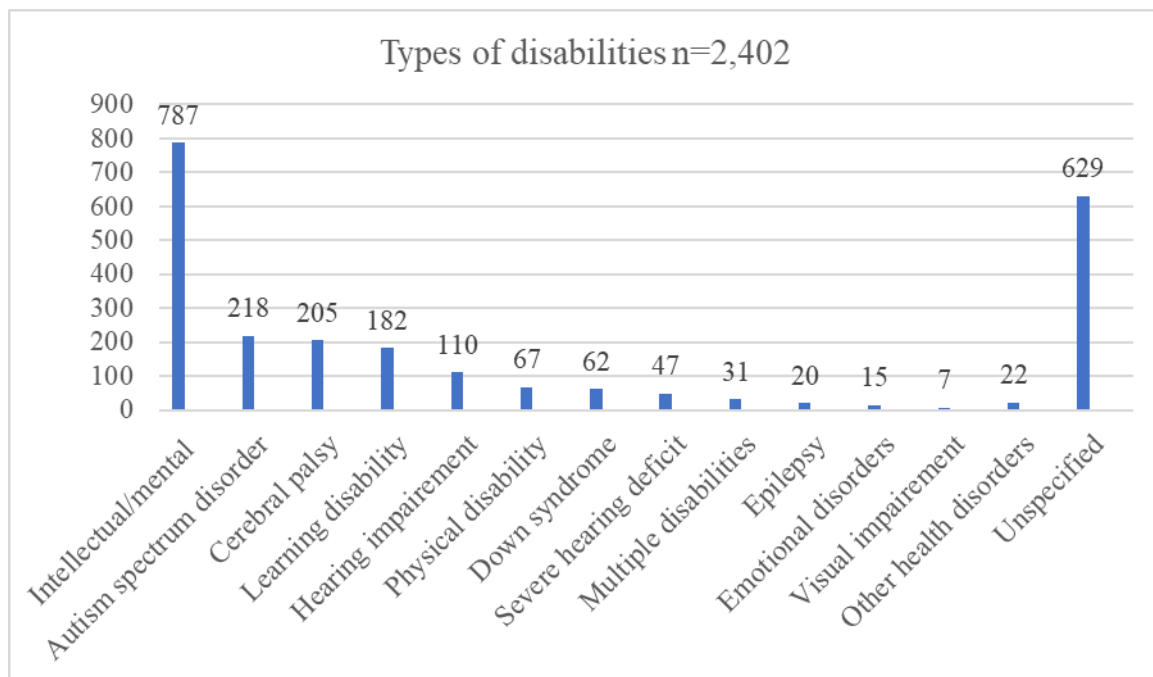


Figure 4.2 Types of disabilities among CSHCN

The type of disability among the 629 children with special needs in one rural setting was not recorded. A descriptive summary of the articles is presented in Table 4.2.

Table 4.2 Descriptive summary of the reviewed studies

Author	Year	Objective	Design	Sample (n)	Type of SHCN/disability	Study Setting	Results
Nqco et al ¹⁴	2012	To determine the caries prevalence and UTN of children with special needs and compare with data from NCOHS	Cross-sectional analytic study	882 children (3-18 years) (65% male) mean age 10.5 years	Cerebral palsy (CP) (18.5%) hearing impaired (HI) (11.2%), learning disabilities (LD) (19.4%) and mental disability (MD) (51%)	Five special needs schools in Johannesburg (urban)	•Prevalence of caries: primary dentition- 27.55%, permanent dentition-33.56% •Over 80% UTNs •dmft score 1.35 (LD) - 3.4 (CP) •DMFT score 0.67 (HI) - 1.27 (MD)
Nemutanda et al ¹⁵	2013	To determine the prevalence of dental caries among disabled individuals attending special schools in Vhembe districts.	Cross-sectional descriptive study	629 individuals with special needs (46% males) 0-6, 7-10, 11-18 and 19+ years	Disability not specified	Four special schools in Vhembe district, Limpopo (rural)	•Prevalence of caries - Over 80% in all age groups. •dmft score under 6 years- 5.51 (SD 2.1) •DMFTs of the 11-18 years- 7.38 (SD 3.22 and above 19 years -10.24 (SD 2.97). •High UTNs, < 1% restorative care.

Roberts et al ¹⁶	2016	To assess the dental needs of a group of children with intellectual disability (ID) attending six special educational facilities in Cape Town, South Africa	Cross-sectional study	157 children with intellectual disability (ID) (67% males) mean age 10.1 years	Intellectual Disability (ID)	Six special educational facilities in Cape Town (urban)	Prevalence of dental needs: •Gingival disease (69%), •Untreated dental caries (68%) •Malocclusion requiring orthodontic correction-29%
Naidoo and Singh ¹⁷	2018	To investigate the oral health status of children with ASD aged between 7-14 years in KwaZulu-Natal, South Africa.	Investigative cross-sectional quantitative study	149 children with autism spectrum disorder (ASD) (71.1% males), 7-8, 9-10, 10-11 and 12-14 years	Autism spectrum disorder (ASD)	Special needs schools in KwaZulu-Natal (78% peri-urban)	•Overall caries prevalence - 85.2%. •DMFT score- 3,42 •Molars- 50% of score •UTNs - 68.5% •Soft tissue trauma with lip biting - 25%. •Mild gingival inflammation - 46,3%
Nqco et al ²⁰	2019	To assess how caregivers of CSHCN perceived the contribution of OHRQoL to the quality of life of these children.	Survey of caregiver OHRQoL and child's oral health status	Convenient sample of 150 caregivers (mean age 39.5) and child pairs (mean age 8.7) years, (59.3% males)	Down syndrome (DS) (41%), CP (28%), ASD (10%), Epilepsy (EP) (10%), Complex disabilities (10%) and unknown (1%)	Down Syndrome Association (DSA) outreach sites in Johannesburg (urban)	•Overall caries prevalence -42% •56.7% of caregivers rated child's oral health as average. •Untreated caries (93-100%) regardless of disability type

Gumede et al ⁴¹	2023	To determine the prevalence of dental caries among learners with disabilities attending special schools' education in the eThekweni district	Cross-sectional descriptive study design	435 children with disabilities (62.3% male) mean age 13 years	ID (41.8%), physical disability (PD) (15%), ASD (12.4%), severe HI (10.8%), HI (2.5%), multiple disabilities (3.7%), LD 2.5%, Visual Impairments (VI) 1.6%, emotional disturbances (ED) 3.4%, other health impairments 6.2%	22 special schools in eThekweni (60% peri-urban and 27.1% urban)	Prevalence of caries: •Primary dentition-22.5%, permanent dentition-53.6%, •DMFT-1.97 (SD 2.36) •D-88%, F-4%, M-9% •dmft-0.95 (SD2.36) •decay component-99% •Highest caries prevalence in ID-46.4% •dmft/DMFT increase with age (p=0.01)
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CSHCN: children with special health care needs, OHRQoL: oral health related quality of life, UTN: unmet treatment needs, dmft: decayed, missing and filled teeth for deciduous dentition, DMFT: decayed, missing and filled teeth for permanent dentition, SHCN: special health care need

4.3.4 Oral health status of CSHCN

Poor oral health among CSHCN was observed in all studies presenting as caries and/or gingivitis. The prevalence of caries among CSHCN ranged from 22.5% to 85.2%.^{17, 41} The mean dmft/DMFT scores ranged between 0.95 (SD 2.36) to 5.51 (SD 2.1)^{15, 41} and 0.67 to 10.24 (SD 2.97)^{14, 15} for the primary and permanent dentition, respectively. The studies reported high UTNs and mostly constituted untreated caries among the study participants of between 68%¹⁶ and 100%,²⁰ attributed to low restorative care.

One study found that over half of the parents (56.7%) of CSHCN rated their child's oral health status as average,²⁰ despite the high UTNs among the study sample. Furthermore, most caregivers (61%) of CSHCN did not perceive the oral problems in their child as having an impact on overall health.

Two studies included a gingival health assessment and reported between 46% and 69% presence of gingival inflammation among children with ASD and ID, respectively.^{16, 17} One study reported plaque index as visible plaque in 43,6% of children with ASD.¹⁷

Other notable oral findings included mild loss of enamel (47%) and soft tissue trauma (lip biting) (25%) among children with ASD.¹⁷ Orthodontic need for the correction of malocclusion were reported in 29% of children with ID.¹⁶ However, the study did not elaborate on the types of occlusal disharmony in the study sample.

4.4 DISCUSSION

The characteristics and status of oral health among CSHCN in South Africa between 2002 and 2023 were reviewed. Only six studies among CSHCN were relevant, highlighting the paucity of data in SA. However, the review shows that the status of oral health for approximately 2,402 individuals with special health care needs (SHCN), aged between 0 and 20 years were evaluated in the last two decades. Of the total sample in the six studies reviewed, 59.7% were male and 40.3% were female. According to the 2011 census, the prevalence of disability in SA was 7,5%,⁵⁰ and more than 600,000 children aged between 5-14 years had a disability. Notably, due to the lack of current epidemiological data, the number of children with disabilities in SA is largely unknown. The NCOHS conducted between 1999-2002,³⁹ reported that 39.7% of the 6-year-old age group were caries-free; however, this survey did not include CSHCN.

Furthermore, the figure was below the 50% goal set by the SA Department of Health (DoH) for the year 2000.¹⁹⁹

The study findings showed that the types of disabilities included, inter alia, intellectual disabilities (ID), Down Syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP), epilepsy (EP) learning disabilities (LD), hearing impaired (HI), physical disabilities (PD), visual impairment (VI), emotional disorders (ED) and 'complex/multiple disabilities'. This list ;however, did not include all CSHCN defined as ‘..living with or at risk of chronic physical, developmental, and behavioural conditions...’¹. The study did; however, reflect the categories of disabilities provided in the 2011 SA census where the International Classification of Functioning Disability and Health,⁶ was used to categorise disability according to six functional domains: sight, hearing, communication, remembering/concentrating, walking and self-care. Using census data may have some limitations, for example parents are used as proxies to report on children with disabilities,⁵ leading to possible under-reporting. In addition, the use of functional domains may have resulted in the exclusion of children living with milder disabilities or chronic medical conditions who also form part of the diverse group of CSHCN.

The review found that caries prevalence among CSHCN ranged between 22.5% and 85.2%. In addition, the caries severity reported by the dmft/DMFT scores varied across the disability groups and age categories. Caries severity appeared to increase with the age of the child in keeping with the impact of increased exposure to fermentable carbohydrates on dental caries development over time, and inadequate oral hygiene. Maintenance of oral hygiene is challenging for CSHCN. For example, children with ASD display behavioural problems during routine tooth brushing whilst children with severe ID may lack the cognitive and manual dexterity to perform tooth brushing and rely on the parent/caregiver for assistance. Caregivers may be overburdened by the demands of caring for such children especially with poor support which is common in low resource settings.²⁰⁰ Although the severity of the disabilities was not recorded in the studies reviewed, it is likely that SA children with more severe cognitive or behavioural problems may have had higher dmft/DMFT scores in keeping with the results of a study in India where children with severe ID had higher DMFT scores.²⁰¹ Identifying CSHCNs who are at greater risk of dental caries and instituting early preventative measures may prevent the cumulative burden of dental caries over time.

Dental caries in children largely remains untreated. In 2010, untreated caries in the deciduous dentition was the 10th most prevalent condition affecting 9% of the global population.²⁰² Furthermore, the condition is even more prevalent in many low-and middle-income countries (LMICs)⁸⁰ including SA where more than 80% of caries in children in the last NCOHS was not treated.³⁹ More than two decades later, the few studies available for review indicated significant UTNs among CSHCN as reflected by the high ‘decay’ component of the dmft/DMFT scores. Similarly, high UTNs have been reported among CSHCN in other LMICs such as Brazil, India, Nigeria, and Rwanda.^{11, 88, 90, 143} Some of the reasons for high UTNs were low utilisation of oral health care services,¹⁴³ transportation difficulties,²⁰³ financial constraints of parents, reluctant dental providers, and behavioural challenges of CSHCN in the dental setting.²⁰⁴ In a systematic review of the determinants of dental caries among children residing in North Africa and the Middle East, the interplay of child characteristics, family background, diet, and oral hygiene habits influenced oral health in children.²⁰⁵ Thus, barriers related to the child’s special need/disability, family socio-economic status, and the environment may hinder access to preventative and restorative treatment for CSHCN, especially in LMICs. These barriers suggest that a multi-faceted approach is required to address the oral health inequalities and improve access to dental care. All stakeholders involved in children’s health need to prioritise oral health for CSHCN, especially for those from disadvantaged backgrounds. Policy guidelines need to address contextual issues related to poor oral health for this population group in both developing and developed countries. To this end, the SA government has shown a commitment to provide universal health coverage through the National Health Insurance (NHI) Bill, and improve access to quality health care to previously disadvantaged groups.²⁰⁶

Two studies in SA reported poor oral hygiene among children with ID and ASD.^{16, 17} Similar findings were reported in Nigeria among 5- to 19-year-old children where significantly poorer oral hygiene was found in children with special needs compared to healthy children.¹⁴³ Globally, poor oral hygiene has been reported among children with ID,⁹ resulting in gingivitis.²⁰⁷ Gingivitis can resolve with improved oral hygiene; however, when left untreated it may progress to periodontitis, a chronic inflammatory disease of the dental supporting structures. Periodontitis, in turn, increases the risk for the development of non-communicable diseases such as diabetes and cardiovascular diseases.²⁰⁸ Thus, it is vitally important to maintain good oral hygiene in CSHCN for both oral and general health.

In this review, other reported oral health problems among CSHCN in SA included malocclusion (29%),¹⁶ and soft tissue trauma (25%).¹⁷ A 1994 SA study found that 74.5% of the 381 children with disabilities, needed orthodontic treatment.²⁰⁹ Similarly, a high prevalence of malocclusion was found among children and adolescents with mental disabilities in India.²¹⁰ Occlusal disharmony may be more prevalent among certain groups of CSHCN such as spastic CP in whom an imbalance of the orofacial muscles may result in constriction of the dental arches, a posterior cross bite and an anterior open bite.¹⁹² Furthermore, patients with malocclusion characterised by protrusion of maxillary permanent incisors are more prone to traumatic dental and soft tissue injuries.¹⁰⁸ Among the risk factors associated with malocclusion in children with CP include mouth breathing and lip incompetence.²¹¹ Thus, there is a need to incorporate orthodontic treatment in children with milder forms of disabilities to improve their quality of life.

The oral health status of CSHCN may affect their overall quality of life.²¹² Untreated dental caries may affect the ability to eat, drink and sleep without discomfort or pain.²¹³ Developmental delay may affect speech and cognition making it difficult for the children to express discomfort or the feeling of pain.²¹⁴ However, despite evidence pointing to the negative impact of poor oral health such as severe dental caries on the quality of life among CSHCN,²¹⁵ one study in SA reported contradictory findings where 61% of caregivers of CSHCN did not consider the oral condition in their child to impact overall health.²⁰ The chronic medical condition of the child or disability may be more of a priority due to its impact on morbidity. Dental caries in the absence of pain, discomfort or sleep disruption may not be perceived as negatively affecting the child and needing attention. Caregivers' perceptions may be related to their socio-economic status (SES) as children from families with high SES and parental education had better oral health-related quality of life.²¹⁶ Hence, contextual factors, especially in resource constrained settings, may influence the extent to which untreated dental caries among CSHCN is perceived to impact overall quality of life.

Access to health care is a key global development agenda. The United Nations Millennium Development Goals (MDGs) in 2000 and later the Sustainable Development Goals (SDGs) and more specifically SDG3, committed to 'ensure healthy lives and promote well-being for all at all ages.'³⁷ Among the goals of the National Oral health Policy in SA (page 2) is the promotion of oral health and increased access to services. However, the policy is outdated and in need of

review based on current epidemiological data.¹³³ The inclusion of CSHCN, who may be more at risk for dental diseases, would be important to provide specific strategies for the prevention and treatment of oral diseases and increase access to services in line with the NHI Bill. In addition, an integrated maternal and child oral health policy aimed at increasing access to oral health services for mothers and children could reduce the oral disease burden among children and those with special needs.¹⁵⁴ South Africa has been successful in creating an enabling environment for policy development work in the field of disability.²¹⁷ However, policy implementation has faced challenges of capacity constraints, low resource allocation and lack of government commitment. In a review of the National Oral Health Policy in SA (page 3), Mukhari-Baloyi et al,¹³³ noted that the policy goals were clear but strategies for implementation were not well understood. Hence, more needs to be done to translate policies on people with disabilities to accessible and comprehensive healthcare that includes oral health, in developing countries such as SA, to promote equity and reduce inequalities.

Despite significant socio-economic reforms in SA in the last two decades,³¹ inequalities in health, including oral health, for people with disabilities persist.³¹ Factors related to poverty such as unemployment, low literacy, and inadequate access to healthcare have a greater negative impact on SA individuals living with disabilities.³² In SA, children with disabilities particularly from low resource settings may face challenges accessing basic services such as health and education. For example, in a group of 156 children with disabilities from a small town near Soweto in SA, few were able to access basic education, assistive devices and social grants.³³ The situation appears not to have improved significantly in post-apartheid SA. In one qualitative study, caregivers of children with ID from a small town in SA reported financial difficulties, poor care networks and community stigma as barriers to utilisation of specialised hospital services.²⁷ Apart from individual caregiver and community barriers, system level barriers have been cited. For instance, a scoping review found that among children with disabilities living in LMICs in sub-Saharan Africa, poor policy implementation, lack of physical access and inadequately trained health professionals were barriers to healthcare access.²¹⁸ These factors may affect the quality of life of not only the children with disabilities but also their families. Therefore, addressing the wider social and economic disparities affecting health and health care access may lead to better oral and general health for children with disabilities in SA.

Strengths and limitations of the study

The review focused on the status of oral health among CSHCN in SA over the past two decades. Among the limitations were, firstly, the availability of only a few studies. The exclusion of unpublished studies may have resulted in publication bias. Secondly, the exclusion of studies that did not report dental caries as an outcome may have led to selective outcome reporting bias. Thirdly, the main representative disability in the reported studies was intellectual/mental disabilities. The limited diversity created bias against other sub-categories of CSHCNs in SA, whose information was not available. In addition, CSHCN in the study were primarily from special needs schools which inadvertently omitted CSHCN not attending school. Among the strengths of the review was the use of a standard literature review method and DET, thereby decreasing the risk of bias. In addition, the review included participants with various special health care needs and not individual categories of disabilities, thereby increasing the sample. Lastly, the studies were conducted in different geographical and socio-economic settings of SA, possibly providing different contextual factors related to the oral health of CSHCN and enhancing generalisability of the results within SA.

Despite the limitations, the review offers useful insights into the lack of data related to the status of oral health among CSHCN in SA. In addition, the review has consolidated data on the characteristics and status of oral health among CSHCN in SA over the last two decades. The data are important in understanding the oral health needs of this vulnerable group and to plan strategies to improve oral health, oral health outcomes and reduce inequalities in line with the SDGs call to ‘leave no one behind.’³⁷

4.5 RECOMMENDATIONS

There is a need for a comprehensive nationwide survey to determine the oral health status of CSHCN in SA, to enable proper planning of preventative and comprehensive oral health care. Future research should focus on identifying the barriers to accessing early preventative and restorative care. Increasing awareness of the importance of good oral health for CSHCN among all stakeholders involved with children could facilitate early referrals for preventative and restorative care.

4.6 CONCLUSIONS

Poor oral health and high UTNs were prevalent among CSHCN in SA over the last two decades. There was a lack of preventative and restorative care among the CSHCN. There was insufficient data on the status of oral health among CSHCN in SA.

This chapter describes the characteristics of 2,402 individuals with special health care needs (SHCN) reviewed for dental treatment in South Africa between 2002 and 2023. The results of this review revealed that CSHCN presents with various types of disabilities to the dental facilities in SA. These children suffered poor oral health and high UTNs which supports the rationale for this study which aimed to assess the oral health care delivery for these individuals. The following chapter will examine the type of dental treatment that was provided to CSHCN at ADHs and factors that affect oral healthcare provision.

CHAPTER 5

Comparative Analysis of Dental Treatment for Children with and without Special Healthcare Needs at Academic Dental Hospitals in South Africa

This chapter describes the findings of the comparative analysis of the dental treatment received by CSHCN and NSHCN at the ADHs in SA. The results of the study have been published (Appendix 11)⁴⁴. Modifications have been done where necessary and specifications pertaining to the journal requirements have been removed.

5.1 INTRODUCTION

Children with special healthcare needs (CSHCN) may be more at risk of common oral diseases, yet encounter greater barriers and unequal access to dental care compared to healthy children.²¹,²¹⁹ Special health care needs are defined as ‘any physical, developmental, mental, sensory, behavioural, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialised services or programs’.²²⁰ Oral health is integral to overall wellbeing⁸² and, especially in CSHCN as some may experience greater barriers to dental care because of their chronic medical condition.²⁴

In the 2011 SA census, the prevalence of disability was 7,5% and more than 600,000 children aged between 5-14 years had a disability.⁴ National data in SA on the status of oral health for CSHCN are lacking. A few studies reported dental caries prevalence ranging between 22.5% and 85.2% among CSHCN in SA.¹⁴⁻¹⁸ Furthermore, in the 1999-2002 National Children’s Oral Health Survey (NCOHS),³⁹ only 39.7% of the 6-year-old age group were caries-free, a figure well below the 50% target that had been set by the Department of Health (DoH) for the year 2000.¹⁹⁹ This survey did not include CSHCN.

Dental caries, despite being preventable, mostly goes untreated in children globally.²⁰² In SA, according to last NCOHS, over 80% of the dental caries in children was untreated³⁹ leading to pain and/or sepsis. Tooth extraction is commonly done for pain relief, especially in CSHCN,¹⁹ while restorative treatment needs are not met.²¹

Children with SHCN may face different hurdles while receiving dental care compared to their healthy peers. Dental anxiety, uncooperative behaviour, or having a developmental disability

interferes with the safe delivery of routine dental treatment.²² Sedation or general anaesthesia (GA) are needed to provide quality and comprehensive dental treatment in a single sitting. These procedures are more risky in CSHCN, and are costly.²³ Thus, the provision of dental treatment for CSHCN particularly in resource constrained settings can increase oral health inequity.

There is a dearth of studies in SA focusing on the dental treatment provided for CSHCN at public hospitals except for one study which was conducted at a SA children's hospital almost a decade ago.¹⁹ Disparities in oral health persist among CSHCN in SA more than two decades post-independence.⁴⁰ To minimise these disparities and promote dental care provision for CSHCN, understanding the medical profile of patients receiving GA treatment is key. The aim of the retrospective study was to describe the characteristics of, and dental treatment received under GA for CSHCN and NSHCN at ADHs in SA. The results may facilitate better planning of comprehensive and integrated oral healthcare services for CSHCN.

5.2 MATERIALS and METHODS

5.2.1 Study design and setting

This was a retrospective descriptive study. All five ADHs in SA were approached for inclusion in the study. These ADHs are in three of the nine provinces of SA. Three of the ADHs are in Gauteng Province, one in the Western Cape Province and one in KwaZulu-Natal Province. The delivery of dental services in SA is decentralised to the provincial governments and provided through the primary health care (PHC) system. The services provided in PHC facilities consist primarily of pain relief extractions and management of infections. Thus, patients in need of more comprehensive services are referred to tertiary level or academic hospitals which have additional facilities and specialised health/dental professionals to manage CSHCN. However, access to these facilities is a challenge for caregivers of CSHCN living in remote areas of SA.

5.2.2 Study population

Participants were CSHCN and NSHCN aged between 1 and 16 years. All records of children receiving dental treatment under GA between 1 January 2017 and 30 June 2023 were included. Children receiving routine dental treatment during the study period were excluded from the study. Due to the challenges of establishing the accurate number of patients seen in each ADH

per year, the sample size was estimated based on an earlier study conducted at one of the study settings.²⁹ The number of children who received dental treatment under GA over a two-year period was reported as approximately 40 per annum.²⁹ This was estimated at approximately 240 records per hospital over the study period (January 2017-June 2023) to constitute the study sample.

5.2.3 Records review

A standardised record review form was used to retrieve demographic and clinical data.¹⁸³ Only one reviewer was involved in the data extraction to reduce inter-reviewer variability. Pilot testing of the review form was done with ten clinical records for patients attending the routine paediatric dental clinic at hospital A prior to the data collection exercise, to check if the review form had documented the required information. Minor adjustments were done on the review form and the records used for piloting were not included for the study analysis. The data extracted included: age at the time of first visit in years which was categorised according to dental developmental stage (i) <6 years (deciduous dentition), (ii) 6-11 years (transitional dentition) and (iii) 12-16 years (permanent dentition); sex (male and female); self-referred/referral information; previous dental history (yes or none); medical health status (CSHCN/NSHCN); the type of medical indication for GA treatment and, the dental diagnosis (dental caries and caries-related (caries, pulpitis, periapical infection)/non-caries related (dentofacial anomalies, trauma, cysts). The type of behavioural management was categorised as follows; (i) dental treatment under GA, (ii) sedation (iii) local anaesthetic, (iv) non-pharmacological or (v) not indicated. Sedation, LA and non-pharmacological methods were subsequently grouped together as non-GA. The treatment provided was categorised as (i) preventative (prophylaxis, fluoride, fissure sealants, preventative restorations); (ii) multiple extractions only; (iii) restorative and rehabilitation (pulp treatment, stainless steel crowns and extractions); (iv) Other (dentofacial/orthodontics, endodontics, biopsy) or (v) treatment not assigned.

5.2.4 Data analyses

Information from the records review form were captured in an Excel spreadsheet. All personal identifiers were removed from the records. Each study centre was assigned a unique identifier for anonymity. The data were stored in a password protected computer. Data were coded and

imported into STATA® Version 14 (Stata Corporation, Inc., College Station, TX, USA). The Shapiro-Wilk test was used to assess normality and confirmed that the age of the sample was not normally distributed. Participant age was reported as median and inter-quartile range (IQR). Descriptive analyses were used to summarise the data using frequencies and percentages. The Mann-Whitney test was used to determine differences in age between CSHCN and NSHCN. Chi-square/Fisher's exact test were used to examine differences between the categorical variables. All statistical tests were conducted at a 5% significance level.

5.3 RESULTS

Data were collected from three of the five ADHs that provided permission for the study. A convenient sample was used due to the inability to obtain the estimated sample size. The availability of patients' records varied across the hospitals. In hospital A, the highest number of records were accessed and reviewed because they were filed and stored in alphabetical order in a storage room. The files for children treated under GA were marked with a sticker and easily identifiable. Fewer records were retrieved from hospitals B and C as the paediatric records for GA over the study period were not kept in an orderly manner. All the available files retrieved were included for the analyses.

5.3.1 Demographic profile of participants

A total of 400 records were obtained and analysed from the three ADHs. Most of the patients (n=187; 46.8%) were from centre A, followed by centre C (n=114; 29%) whilst centre B had the lowest records retrieved (n=99; 25%) as shown in Table 5.1. There was a statistically significant difference between the CSHCN and NSHCN by centre, (p=0.02).

There were 116 patients (29%) in the CSHCN group and 284 (71%) in the NSHCN group. The median age of the patients was 5 years (IQR: 3-6.5), 56.3% of whom were male. The CSHCN were older than NSHCN (p<0.001). Two-thirds of the patients 267 (66.7%) were self-referred while 133 (33.3%) were referrals mostly from PHC facilities. A significantly greater percentage (52.6%) of CSHCN than NSHCN (25.4%) were referred, (p<0.001). The patients' demographic characteristics are presented in Table 5.1.

Table 5.1 Demographic characteristics of children with and without special healthcare needs

Characteristics	N=400	CSHCN (n=116)	NSHCN (n=284)	p-value
Median age years (IQR)	5 (3-6.5)	6 (4-10)	4 (4-6)	<0.001
Age category				<0.001
<6 years	237(59.3)	53(45.7)	184(64.8)	
6-11 years	135(33.7)	46(39.6)	89(31.3)	
12 and above	28(7)	17(14.7)	11(3.9)	
Gender, n (%)				0.54
Male	225 (56.3)	68 (58.6)	157 (55.3)	
Female	175 (43.7)	48 (41.4)	127 (44.7)	
Number of children at each Centre, n (%)				0.02
A	187 (46.8)	66 (56.9)	121 (42.6)	
B	99 (24.8)	26 (22.4)	73 (25.7)	
C	114 (28.5)	24 (20.7)	90 (31.7)	
Referral status, n (%)				<0.001
Referred	133 (33.3)	61 (52.6)	72 (25.4)	
Self-referral	267 (66.7)	55 (47.4)	212 (74.6)	

The majority were CSHCN and NSHCN aged below 6 years. The age distribution is depicted in Figure 5.1.

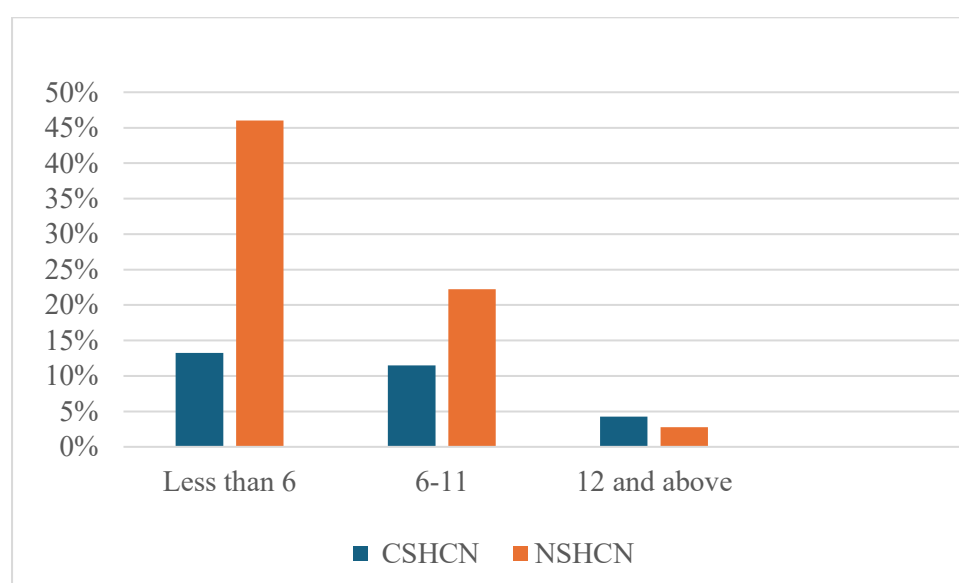


Figure 5.1 Age distribution of children with and without special healthcare needs

5.3.2 Clinical profile of the CSHCN

Figure 5.2 shows the medical conditions of the CSHCN who presented for dental treatment under GA. The majority of the CSHCN had cerebral palsy (CP) (n=26; 22.4%) followed by 19% who had various systemic conditions, inter alia cardiac, endocrine, respiratory, immune suppression or cancer.

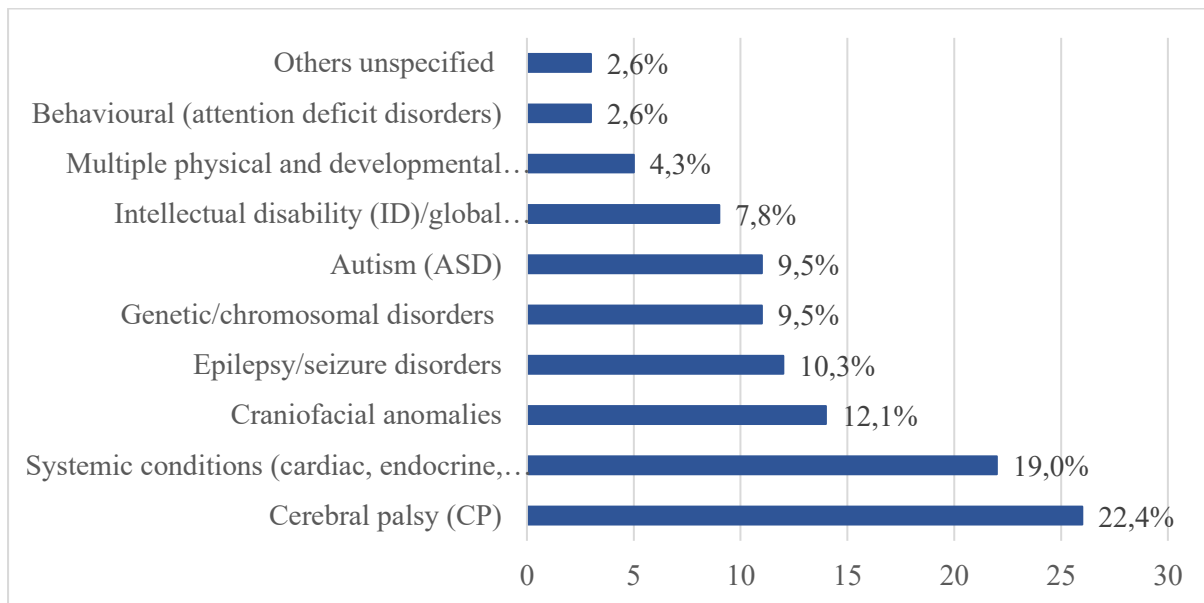


Figure 5.2 The medical conditions of the CSHCN who were treated under GA

The characteristics of the entire population categorised by age are shown in Table 5.2. There were significant associations between centre ($p<0.001$), sex ($p=0.033$), being CSHCN ($p<0.001$), dental diagnosis ($p<0.001$) and the age category of the child. There was not enough evidence to show a statistically significant association between referral status and age category of the child.

Table 5.2 Study sample variables by age category

Variable	<6 years n=237	6-11 years n=135	12-16 years n=28	p-value
Centre n (%)				<0.001
A	100 (42.2)	70 (51.9)	17 (60.7)	
B	48 (20.3)	48 (35.5)	3 (10.7)	
C	89 (37.5)	17 (12.6)	8 (28.6)	
Sex n (%)				0.033
Female	109 (46)	49 (36.3)	17 (60.7)	
Male	128 (54)	86 (63.7)	11 (39.3)	
SHCN n (%)				<0.001
NSHCN	184 (77.6)	89 (65.9)	11 (39.3)	
CSHCN	53 (22.4)	46 (34.1)	17 (60.7)	
Previous dental history n (%)				<0.001
Yes	19 (8.0)	37 (27.4)	6 (21.4)	
No	218 (92.0)	98 (72.6)	22 (78.6)	
Dental diagnosis n (%)				<0.001
Dental caries related	229 (96.6)	118 (87.4)	15 (53.6)	
Non-caries related	8 (3.4)	17 (12.6)	13 (46.4)	

Dental caries related=caries, pulpitis, periapical infection; non-caries related=dentofacial anomalies, trauma, cysts

The dental diagnosis and management of CSHCN and NSHCN categorised by age, are presented in Table 5.3. Dental caries, pulpitis and periapical infections occurred most commonly in both CSHCN and NSHCN across all age groups, except in NSHCN older than 12 years. Multiple extractions were commonly done among CSHCN across age categories (45-54%) and among the NSHCN aged 6-11 years (52.8%). In addition, about a quarter (26.1%) of CSHCN aged 6-11 and 27.2% of NSHCN younger than 6 years received restorative care. Overall, both groups received mainly extractions (43.5%), while 20 % had restorative care and <10% had preventative care.

More than two thirds (69.8%) of CSHCN and 60% of NSHCN younger than 6 years had treatment under GA. In contrast, in the 6–11-year-old age group, a higher percentage (69.6%) of CSHCN received treatment under GA than their NSHCN (38.2%). About one -third (34.8%) of NSHCN aged 6-11 years had treatment under local anaesthetic.

Table 5.3 Dental diagnosis and management of CSHCN and NSHCN

Characteristic	CSHCN n=116			NSHCN (n=284)			Total (n=400)
Age category	< 6	6-11	12-16	<6	6-11	12-16	
n	53	46	17	184	89	11	
(%)	(45.7)	(39.6)	(14.6)	(64.8)	(31.3)	(3.9)	
Sex n (%)							
Female	18 (34)	19 (41.3)	11 (64.7)	91 (49.6)	30 (33.7)	6 (54.5)	175(43.7)
Male	35 (66)	27 (58.7)	6 (35.3)	93 (50.5)	59 (66.3)	5 (45.5)	225(56.3)
Previous dental history n (%)							
No	46 (86.8)	36 (78.3)	15 (88.2)	172 (93.4)	62 (69.7)	7 (63.6)	338(84.5)
Yes	7 (13.2)	10 (21.7)	2 (11.8)	12 (6.5)	27 (30.3)	4 (36.4)	62 (15.5)
Clinical diagnosis n (%)							
Dental caries	48 (84.9)	41 (89.1)	13 (76.5)	181 (98.4)	77 (86.5)	2 (18.2)	362(90.5)
Non-caries related	5 (9.4)	5 (10.9)	4 (23.5)	3 (1.6)	12 (13.5)	9 (81.8)	38 (9.5)
Dental treatment provided n (%)							
Preventative	4 (7.5)	-	3(17.6)	20 (10.9)	9 (10.1)	2 (18.2)	38 (9.5)
Multiple extractions	29(54.7)	21 (45.7)	8 (47.1)	68 (37)	47 (52.8)	1 (9.1)	174(43.5)
Restorative	6 (11.3)	12 (26.1)	1 (5.9)	50 (27.2)	10 (11.2)	-	79 (19.8)
Others	2 (3.8)	3 (6.5)	1 (5.9)	-	8 (9)	2 (18.2)	16 (4)
Treatment not indicated	12 (22.6)	10 (21.7)	4 (23.5)	46 (25)	15 16.8	6 (54.5)	93 (23.2)
Pharmacological management n (%)							
GA	37(69.8)	32(69.6)	9(52.9)	111(60.3)	34 (38.2)	-	223(55.8)
LA	4 (7.5)	3 (6.5)	4(23.5)	22 (12)	31(34.8)	3(27.3)	67 (16.7)
IV Sedation	-	-	-	-	5 (5.6)	-	5 (1.2)
Non-pharmacological	-	1 (2.2)	-	5 (2.7)	4 (4.5)	2(18.2)	12 (3)
Treatment not indicated	12 (22.6)	10 (21.7)	4 (23.5)	46 (25)	15 (16.9)	6 (54.5)	93 (23.2)

The demographic and clinical characteristics of the patients by the type of behavioural management (GA/non-GA) are shown in Table 5.4. Of the total sample, only 307 patients received treatment while 93 patients did not have any treatment recorded and were omitted from further analyses. There were significant associations between age ($p<0.001$), being CSHCN ($p<0.001$), dental diagnosis ($p<0.001$), treatment provided ($p<0.001$) and the type of behavioural management. There was not enough evidence to show a statistically significant association between referral status and centre with type of behavioural management.

Table 5.4 Demographic characteristics by behavioural management (GA and non-GA)

Variables	GA=223 (72.6)	Non-GA=84 (27.4)	Total =307 (100)	p-value
Age groups				
<6 years	148 (66.4)	31 (36.9)	179 (58.3)	<0.001
6-11 years	66 (21.5)	44 (52.4)	110 (35.8)	
12 and above	9 (12.1)	9 (10.7)	18 (5.9)	
Medical status				
CSHCN	78 (35)	12 (14.3)	90 (29.3)	<0.001
NSHCN	145 (65)	72 (85.7)	217 (70.7)	
Centre				
A	80 (35.9)	35 (41.7)	115 (37.4)	0.22
B	67 (30)	29 (34.5)	96 (31.3)	
C	76 (34.1)	20 (23.8)	96 (31.3)	
Dental diagnosis				
Caries related	220 (98.7)	64 (76.2)	284 (92.5)	<0.001
Non-caries related	3 (1.3)	20 (23.8)	23 (7.5)	
Treatment provided				
Preventative	16 (7.2)	22 (26.2)	38 (12.4)	<0.001
Multiple extractions only	136 (61)	38 (45.2)	174 (56.7)	
Restorative and rehabilitation	71 (31.8)	8 (9.5)	79 (25.7)	
Others	0 (0)	16 (19.0)	16 (5.2)	
Referral status				
Referred	77 (34.5)	21 (25)	98 (31.9)	0.11
Self-referral	146 (65.5)	63 (75)	209 (68.1)	

GA=dental treatment under general anaesthesia; significant at p-value <0.05; 'others'=dentofacial/orthodontics, endodontics, biopsy; () =%

5.4 DISCUSSION

This study compared the dental care provided to CSHCN and NSHCN treated under GA at ADHs in SA. Among the CSHCN, the medical indications for treatment under GA included CP, various systemic conditions, craniofacial disorders, seizure disorders, autism and intellectual disabilities. Additionally, close to a quarter of the CSHCN had CP which could point to the higher risk of oral disease in this sub-category perhaps due to their cognitive and behavioural factors that make routine oral hygiene measures difficult. Additionally, PHC may not be adequately equipped with GA facilities to provide dental treatment for these children.

The findings emphasise the need to understand individual risk factors based on the underlying medical condition to reduce the need for treatment under GA for these children.

This study is among the first to assess the dental care provided under GA to CSHCN in ADHs. Data for the study was retrieved from three of the five ADHs with the majority from hospital A and thus, caution in generalising the findings across all ADHs in SA. However, the results of our study highlighted the types of paediatric patients both CSHCN and NSHCN that are perceived by dentists to be more challenging to treat in the PHC settings. The study findings revealed a lack of comprehensive data on CSHCN in the ADHs of SA, therefore, proper planning for dental services for these children is difficult.

The study indicated that there was a significant difference between CSHCN and NSHCN by centre of treatment. This could have been due to differences in the selection criteria used in different treatment centres. The protocol for GA selection was, however, not part of this study and could be part of a future study.

One third of our study sample were CSHCN, 50% of whom presented with developmental disabilities (DD) such as CP, ID, epilepsy, developmental delay or ASD. These children were typically under 6 years, male and half had been referred from PHC centres. Comparable findings were reported in a study conducted at an academic hospital in the United States (US) where 29.2% of the 1708 children treated under GA were CSHCN the majority with various DD.²¹⁹ Notably, despite the socio-economic differences in study settings (SA: middle income and US: high-income) the proportions of children with DD were similar, and perhaps point to common challenges of providing dental treatment for children with DD at PHC centres. This underscores the need to improve training in special care dentistry to facilitate access to dental care for CSHCN and reduce oral health disparities. Furthermore, the prevalence of children with DD has been shown to be greater in low-and middle-income countries⁵² which increases the demand for health services for these children.

In this study, the CSHCN were significantly older compared to NSHCN. The mean age in the study (CSHCN: 6 years; NSHCN: 4 years) was lower than in a study in Turkey (CSHCN: 7.9 years; NSHCN: 5.7 years).²²¹ In Taiwan, the findings were comparable to our study (CSHCN: 7.2 years; NSHCN 3.6 years).²²² Whilst in one SA study, the mean age of CSHCN treated under

GA was 6.7 years which was comparable to our study.¹⁹ In another SA study, the mean age was 3.7 years which was close to the average age of 4 years among NSHCN in this study.²⁹

The majority of the patients receiving treatment under GA in this study were CSHCN below the age of 11 years and NSHCN younger than 6 years. Pre-school children in need of extensive dental treatment are unable to withstand multiple dental appointments, possibly resulting in higher referrals for GA treatment. Sedation or GA is recommended to provide comprehensive, safe, and quality dental care for CSHCN when physical restraint for stabilisation is not feasible.²² Furthermore, there is a great need in SA for strategies to prevent caries that target pre-school children including CSHCN to reduce the need for GA treatment. Interventions that reduce caries and the cost of care are likely to be more effective from a public health and policy making perspective.²²³ An integrated maternal and oral health policy could perhaps address the burden of childhood caries in SA.¹⁵⁴

The study found that most of the patients were self-referrals (66.8%) and only one third of the patients had been referred to ADHs for treatment. This finding may imply the lack of a proper referral system of children seeking oral healthcare at PHCs to ADHs. A significantly greater number of CSHCN (52.6%) were referred to ADHs for treatment under GA than NSHCN (25.4%). Comparable findings were reported in Canada where primary GA treatment centres for CSHCN were hospitals.²²⁴ The relatively higher referral of CSHCN compared to NSHCN groups suggest challenges in providing dental care for CSHCN by oral healthcare professionals working in PHC settings. These challenges were not explored in this study but could be attributed to limited personnel trained in special care dentistry and may indicate the need for specialised paediatric clinics.

Most of the CSHCN (78-88%) across the age categories and NSHCN younger than 6 years (93%) had no previous dental care. There was an association between previous dental history and age category. However, there was no association between previous dental treatment and having a special health care need. Contrary to the findings of this study, in the US, significantly more children with DD compared to those without DD reported having used dental care services in the previous 12 months (86.1% vs 76.1%).⁸⁵ Some of the reasons for the lack of dental care reported among CSHCN from the parents' perspectives included a fear associated with dental treatment, uncooperative behaviour and a medical condition that could affect dental

treatment.²⁴ We did not examine the barriers to the use of dental services among the parents/caregivers. This is an area of future research.

Dental caries and its sequelae were the most common indications for GA treatment among the children in this study who were mainly under 6 years of age. There were significant associations between age, being CSHCN, dental diagnosis with type of behavioural management. This is a predictable finding as pre-school children and CSHCN with extensive dental caries often are unable to cooperate with routine dental treatment thus necessitating the use of GA. Dental caries was the most common reason for GA treatment among CSHCN in Alberta.²²⁴ Childhood caries is a common problem in SA children with prevalence rates of 47.74% reported in 2 to 5-year-old children in Johannesburg²²⁵ and, 71.6% among children under six years of age in the Western Cape.²²⁶ Studies have found that the caries prevalence ranges between 22.5% and 85.2% among CSHCN in SA.¹⁴⁻¹⁸ This high burden of childhood caries is a public health concern,¹⁹⁹ and is a strain on the health system due to the high cost of providing GA treatment. Other challenges facing the SA public health sector include a lack of budgetary allocation for oral health care services¹⁶⁵ and a lack of human resources.²²⁷

This study found that extractions were commonly done among CSHCN aged below 11 years and adolescents above 12 years (45-54%), and among the NSHCN aged 6-11 years (52.8%). In addition, about a quarter (26.1%) of CSHCN aged 6-11 and 27.2% of NSHCN younger than 6 years received restorative care. Comparable findings were reported in Alberta where treatment provided under GA for CSHCN was primarily extractions (76.5%) but with higher (57.5%) restorative care.²²⁴ In Taiwan, a greater mean number of teeth was extracted in patients with disabilities compared to healthy children.²²² Similarly, in Turkey, the mean number of extracted teeth was greater in the CSHCN group than NSHCN.²²¹ Pulp treatment at initial GA treatment in younger patients with multiple disabilities increased the risk of subsequent GA need whereas extractions, preventive and crowns reduced the risk of future GA treatment.²²⁴ Notably, only a very small proportion of children in our study received preventative treatment. There is a need to emphasise preventative care to reduce the risk of subsequent GA for CSHCN.²²⁴ Establishing dental homes that are accessible to the children may increase access to regular preventative care. Oral health promotion activities targeting parents/caregivers of CSHCN are important in creating awareness especially in PHC centres.

We found that almost a quarter of the children who had received an initial GA assessment had not received treatment, pointing to a lack of access to care. This may have been partly due to the long waiting time for GA in the ADHs. The average waiting time from the initial dental assessment to the date of GA treatment has been reported in SA as 4.98 months.²⁹ Perhaps the relatively higher number of children receiving GA treatment versus non-GA in the present study may have caused delays in accessing GA services in our hospitals. Failure of the patients to arrive for their appointment due to distance from the hospitals is another possible reason and is an area of future research.

Finally, this study indicated that the dental treatment provided was associated with the type of behavioural management. More preventative treatment was provided in non-GA cases while multiple extractions, restorative and crowns were done under GA. Although GA is indicated for some CSHCN, it has risks including airway obstruction, aspiration in CP patients or oversedation. Furthermore, GA increases the economic burden due to the need for theatre facilities, personnel, children's ward, and supplies.²³ Proper follow-up of children after GA treatment is essential as limited access to preventative care may increase the need for future GA for re-treatment of dental caries.²¹⁹ This has been highlighted by one study at an academic hospital in Pretoria, SA, where only 18% of children returned for follow-up within 15 months after GA, and half of them required further GA treatment for severe caries.²⁹ This underscores the importance of preventative care after GA to obviate the need for repeated GA especially for CSHCN. The AAPD guidelines recommend that patients with high caries risk should return for routine dental care every three to six months.

Understanding the barriers to preventative dental care for young children (NSHCN) and CSHCN, may enhance follow-up after GA treatment. Child anxiety, provider willingness and proximity to such providers are some of the challenges faced by parents of CSHCN in obtaining dental care.²¹⁹ Providing a dental home for CSHCN in PHC centres may improve access to early and continued preventative dental care,²²⁸ and perhaps reduce the burden of GA in our resource constrained settings. The proposed maternal and child oral health policy for SA,¹⁵⁴ suggests that integrating oral healthcare into PHCs specifically in maternal and child services and enhanced interdisciplinary networks could improve the oral health of SA children under six years.

This study had some limitations such as the retrospective design and the use of secondary data from the clinical records. Also, the estimated sample size was affected by a lack of organised filing of records in hospitals B and C, resulting in a smaller sample. Furthermore, 93 of the patients had no treatment assigned, which limited the ability to carry out regression analyses. These records were not designed and documented for research study purposes. Therefore, the results of this study cannot be generalised for all the CSHCN and NSHCN in SA but serves as a background for further studies. It is recommended that record keeping of all patients be done in a standardised and comprehensive manner to facilitate future clinical audits. Electronic or digital records could facilitate and improve data storage and access.

5.5 CONCLUSIONS

In conclusion, patients in need of GA treatment at ADHs in SA were CSHCN or NSHCN typically under the age of 6 years, presenting with extensive caries. The treatment provided consisted mainly of extractions with little restorative care. Limited preventative treatment was provided highlighting the need to identify children at risk of caries to institute timely preventative strategies to promote better oral health and reduce the burden of GA. In addition, we recommend a review of the curriculum for general dentists in SA which incorporates child management together with training of specialist paediatric dentists.

Why this study is important to paediatric dentists

- Paediatric dentists play an important role in providing both primary and comprehensive oral healthcare to infants, children, adolescents including CSHCN. There are only a few paediatric dentists in developing countries. Thus, there is a need to advocate for training of these specialists to build capacity to manage CSHCN in PHC centres and improve access to oral healthcare.
- Dentists should emphasise preventative care for children at risk of caries. Providing a dental home for regular prophylaxis, fluoride and fissure sealants may reduce the risk of dental caries requiring more extensive dental treatment under GA.
- A proper referral pathway from PHC settings to ADHs is important to facilitate access to dental care for both CSHCN and NSHCN. An integrated system is essential for providing comprehensive and holistic care.

This chapter compared the dental treatment provided to CSHCN and NSHCN at ADHs in SA. Twenty-nine percent of the total sample comprised of CSHCN, the majority of whom were referred from PHC facilities. The findings highlighted that dental treatment under GA provided to CSHCN and young NSHCN at ADHs was limited and comprised primarily of dental extractions. This service level is the same as what PHC facilities provide and could point to the lack of resource allocation to support provision of more restorative and rehabilitative care. In the next chapter, I have explored some of the factors that influenced oral health provision for these children at ADHs.

CHAPTER 6

Perspectives and Experiences of Oral Health Professionals in the Provision of Dental Care to Children with Special Healthcare Needs in South Africa

In this chapter, the perspectives of oral health professionals (OHPs) rendering services at ADHs are explored in order to draw out factors influencing the delivery of oral healthcare.

6.1 INTRODUCTION

Access to routine dental care at primary healthcare (PHC) facilities for children with special healthcare needs (CSHCN) is limited and referral to a hospital is often necessary.²²⁹ These children have diverse health conditions which require regular medical and dental care. Specialised dental care services may be required for some CSHCN. These services may require sedation or dental treatment under general anaesthesia (GA) to provide and use of various OHPs. The services include, inter alia, tooth extractions, restorations, endodontics, stainless steel crowns, management of CLP, orthodontic treatment and maxillofacial surgery. These services are provided by specialised oral health professionals working at academic dental hospitals (ADHs) or in the private sector.

Globally, the World Health Organisation estimates that 1.3 billion people (1 in 6 people) experience profound disability, about 93 million of whom are children below the age of 15 years.² In South Africa (SA), the 2011 census reported that about 609,671 (7.5%) of approximately 8.1 million children between 5-14 years of age had a disability.⁴ However, the report is not only outdated but did not include all CSHCN but rather only those with impairments as described by the WHO classification, which focus on activity limitations and participation restrictions.³ Therefore, the lack of information regarding the CSHCN in SA makes it difficult to plan adequate dental services for these children.

Over the last two decades (2000-2023), epidemiological data on the status of oral health among CSHCN in SA has been limited.⁴⁰ The few available studies mainly conducted in urban centres reported that the prevalence of caries ranged from 22.5% to over 80% in this population.¹⁴⁻¹⁸ In addition, the majority of dental caries (68-100%) among the CSHCN was untreated,⁴⁰ which point to barriers in accessing necessary dental care at PHC facilities and the challenges of prolonged waiting time for accessing GA services at tertiary hospitals.²⁹ These factors

consequently result in treatment of the children being largely reduced to the provision of dental extractions at SA's constrained public health facilities.^{19, 29}

A few other barriers affecting the provision of adequate dental care have been reported in the literature.^{26, 138, 167} In Kerala, India, over 80% of the clinics sampled had limited specialised facilities and equipment while, 71% of them lacked physical accessibility for patients with wheelchair.²⁶ In addition, other factors such as insufficient knowledge and training of dental professionals have been found in Australia,¹³⁸ India²⁰⁴ and Trinidad.¹³⁹ Furthermore, in Australia, OHPs cited insufficient funding, inadequate facilities and equipment within the public dental system¹³⁸ and, the lack of adequate support from specialists and other medical health professionals.¹⁶⁷

Despite efforts to provide school oral health preventative dental services for CSHCN in SA,⁴¹ poor oral health persists among these children,⁴⁰ and may point to difficulties in accessing dental care. Access to health care is influenced by several factors such as patient, provider and organisational factors.¹⁵⁶ A systematic review focusing on children with disabilities and access to oral health care concluded that barriers such as provider unwillingness, child's fear of dental treatment, cost of treatment and inadequate dental facilities hindered access to services.²³⁰ There are limited studies on barriers faced by OHPs while providing services for CSHCN at public health facilities in SA. Understanding how provider and organisational factors impact the provision of dental care to CSHCN could assist in improving access to dental care for these children. Thus, this study aimed to explore the perceptions, and experiences of OHPs regarding the provision of dental services for CSHCN at ADHs in SA.

6.2 METHODS

6.2.1 Study design

This was a mixed-methods study. A sequential explanatory design was chosen in which the quantitative data was collected first followed by qualitative data.²³¹ The initial quantitative arm consisted of a survey to examine the perceptions and challenges faced by OHPs in providing dental care to CSHCN at ADHs. This was followed by the qualitative arm to explore their experiences and the factors influencing the delivery of dental care to CSHCN at these hospitals.

6.2.2 Study setting

All five ADHs in SA were approached for inclusion in the study. Three dental hospitals are located in Gauteng Province, one in the Western Cape and one in KwaZulu-Natal Province. The hospitals are part of the tertiary health facilities where CSHCN requiring comprehensive treatment are referred to from primary healthcare facilities for basic and specialised dental treatment.

6.2.3 Study participants

The quantitative component of the study included clinical oral health professionals (general dentists, post graduate student dentists, dental specialists, dental therapists and oral hygienists) at participating ADHs. The qualitative component of the study consisted of the clinical heads of paediatric dentistry departments at ADHs and respondents from the survey who were directly involved in CSHCN management.

6.2.4 Recruitment of study participants

All five ADHs in SA were invited to participate in the study. For the quantitative phase, participants were recruited from each dental hospital that provided approval for the study. An email was sent to an administrator at each dental hospital. The administrator then sent the request to each department secretary who forwarded the questionnaire to the clinical oral health professionals by email. For the qualitative phase, the participants of the FGD were purposively selected from the survey respondents. In addition, the heads of paediatric dentistry at ADHs were invited by email following consent by their respective ADHs.

6.2.5 Sampling strategy

A convenient sample was employed for the quantitative phase to invite OHPs at ADHs to participate in the survey. A study conducted at a SA dental school reported that the number of general dentists working full-time was about 30.¹⁸⁴ Based on this approximate number of full-time non-specialist OHPs at one dental hospital, the sample was estimated at 30 OHPs per ADHs. Thus, the total sample from the five ADHs was estimated to be 150 OHPs.

For the qualitative component, purposive sampling was used. The plan was to invite 8-10 OHPs from the respondents of the survey for the FGD. In the final stage of the qualitative phase, five

heads of paediatric dentistry, one representing each ADH were invited for the in-depth interviews. The discussion and interviews were iterative. The PI ended the sessions when participants had no further insights to ensure data saturation.¹³⁹

Inclusion & exclusion criteria

Inclusion criteria: The study participants included OHPs working full-time at participating ADHs, clinical heads of paediatric dentistry departments at ADHs.

Oral health professionals not working full-time at the ADHs and other clinical heads of department at ADHs, visiting lecturers, honorary appointments and part-time and sessional workers were excluded from the study.

6.2.6 Data collection

The data collection process commenced with the quantitative arm comprising of a survey for OHPs at ADHs followed by the qualitative component consisting of interviews and focus groups. The data for the quantitative phase of the study were collected using a structured self-administered online questionnaire. The questionnaire which was modified to include perceptions and challenges faced by OHPs at ADHs was based on a previous study that assessed the knowledge and experiences of care for CSHCN among childcare workers in Gauteng, SA.¹⁴⁴ The link to the questionnaire was emailed to OHPs through an administrator at each ADH. Consenting OHPs followed the link provided, completed the questionnaire and submitted it online. A reminder email was sent after two weeks to the contact administrator. A final email was sent after one month.

For the qualitative arm, the process of data collection comprised two separate components. Firstly, a focus group discussion (FGD) was conducted among OHPs selected from those who had responded to the survey. Five OHPs consented to participate in the FGD. Consent for audio recording was obtained prior to the discussion. Participant anonymity was not possible during the discussion, but participant codes were used to anonymise the transcripts. The FGD was conducted online using a set of questions (Appendix 8), and each of the participants was given an opportunity to respond. The FGD took approximately 45 minutes after which the participants had no further insights to discuss implying data saturation was obtained. The data from the discussion were transcribed and checked for accuracy by the PI before analysis.

The second component of the qualitative phase involved in-depth interviews conducted among the clinical heads of paediatric dentistry at ADHs. Three of the five clinical heads consented to participate in the study. The interviews were conducted online using a semi-structured interview guide (Appendix 6). Information sought from individual participants included: the average number of CSHCN they see per week, types of services provided, human and infrastructural resources available, collaborations with other dental and medical colleagues in the hospitals, any challenges faced and ways of mitigating those challenges including future proposals. The interviews were conducted in English for one hour and were recorded and stored in a password protected computer. The researcher took additional notes during the interview process.

6.2.7 Data Analysis & Management

Quantitative data

The survey questionnaire data were entered into an Excel® spreadsheet and imported into STATA® Version14 (Stata Corporation, Inc., College Station, TX, USA) for analysis. Descriptive analyses were computed using frequencies and percentages to summarise participant demographic data, dental services provided to CSHCN, types of disabilities among CSHCN receiving treatment, whether the participants had received training in special care dentistry, adequacy of training, participants' perceptions of support from other healthcare professionals, perception of inter-professionals' collaboration and perceived barriers faced in the dental care of CSHCN.

Qualitative data

For the qualitative data (FGD and interviews), a thematic content analysis using the framework method²³² was utilised. In addition, the Levesque framework¹⁵⁶ was used to define access to dental care and guide the analyses.

The strategies used to ensure trustworthiness were credibility, dependability, conformability and transferability.¹⁸⁰ Credibility was ensured by describing the research methodology outlined in the methods section. The PI engaged with the data repeatedly through reading and re-reading of the transcripts. Dependability was assured as OHPs worked at the ADHs where they constantly treated patients including CSHCN. Counter-checking with participants during the

interviews was done for clarity to enhance dependability. However, the participants did not get an opportunity to review the transcripts, and this limitation is later mentioned. To improve transferability, this study was conducted at a tertiary level health setting so that the methodology can be applied to future mixed-methods studies. Conformability was enabled by ensuring that the interviews were recorded and later transcribed for accuracy, and that the use of direct quotes from participants were used to highlight the themes.

The analysis was conducted as follows: after the audio recordings were transcribed, the transcripts were read several times, and familiarisation of the transcripts was undertaken. With each reading, the PI noted similarities or differences in the texts. The codes from the transcripts were identified. Merging of similar codes and assigning appropriate names to the codes. The initial coding was done independently by the PI and one of the co-authors (MM). The two authors then compared the codes and categorised them into themes. The agreed prominent themes were then linked to the Levesque constructs.¹⁵⁶ All the authors reviewed the established codes and themes to check for potential biases before reporting the findings.

6.2.8 Ethical considerations

The study adhered to the Helsinki Ethical Principles for Medical Research involving Human subjects.²³³ Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Clearance number: M220266). Written permissions to conduct the study were obtained from each ADH to access the OHPs. Participants of the online survey consented before they completed and submitted the questionnaire. Consent for participation and audio recording was obtained from the key informants and participants of the FGD, this was done at the beginning of each session by the PI. All data were stored in a password protected computer accessible to the PI. Confidentiality was maintained throughout the reporting of the study findings. Guidelines for protection of personal data stipulated by the POPIA¹⁸⁶ were observed.

6.3 RESULTS

6.3.1 Findings of the OHPs survey

Fifty questionnaires were completed by OHPs from the four ADHs (three in Gauteng and one in the Western Cape Province). The majority of the OHPs were female (n=36; 72%), above 35 years (n=40; 80%). Two-thirds of the OHPs had more than 10 years of clinical experience (n=33;66%), while 10 (20%) had 5-10 years and 7 (14%) had less than 5 years of experience. Of the total respondents, 19 (38%) were postgraduate student dentists, 16 (32%) were general dentists and 7 (14%) were specialists (3 community dentistry specialists, orthodontist=1, maxillofacial surgeon=1, oral medicine=1, and anaesthetist=1), 5 (10%) were oral hygienists and 3 (6%) were dental therapists. Table 6.1 shows the study participants at ADHs.

Table 6.1 Study participants by institution and clinical experience

Characteristics	Postgraduate student dentists n=19 (38%)	General dentists n=16 (32%)	Dental specialists n=7 (14%)	Dental therapists n=3 (6%)	Oral hygienists n=5 (10%)	Total n=50 (100%)
Study centre:						
A	7	6	3	0	3	19 (38)
B	5	7	3	2	2	19 (38)
C	4	3	0	0	0	7 (14)
D	3	0	1	1	0	5 (10)
Clinical experience:						
< 5 years	4	3	0	0	0	7 (14)
5-10 years	5	3	1	0	1	10 (20)
>10 years	10	10	6	3	4	33 (66)

Dental care provided to CSHCN

Forty-three (86%) of the respondents reported that they had treated CSHCN while 14% mentioned that they referred them to OHPs in paediatric dentistry. The reported medical conditions of the CSHCN treated varied, with the most prevalent being chronic conditions (56%), (Figure 6.1). Over half (54%) comprised CSHCN with developmental disabilities such as autism spectrum disorders, cerebral palsy and behavioural problems like attention deficit disorders. The chronic medical conditions included cardiac conditions, immunosuppressive diseases, and cancer.

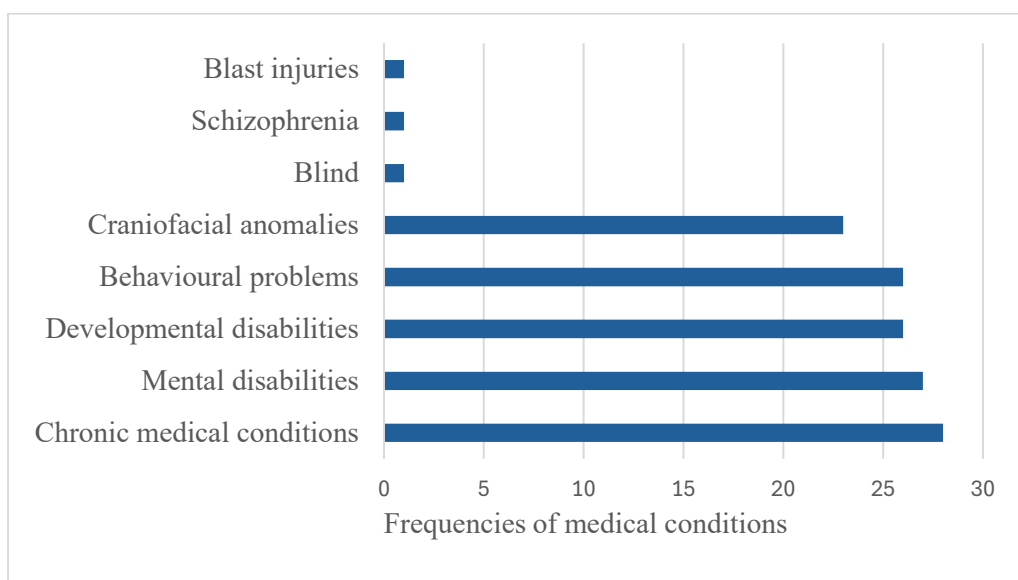


Figure 6.1 Types of medical conditions among CSHCN who received dental care at ADHs

The most common dental services provided to CSHCN comprised of extractions (n=27; 54%), preventative (prophylaxis, fissure sealants, fluoride treatment) (n=25; 50%) and restorative care (n=22; 44%) as shown in Figure 6.2. Other services provided were oral medicine/pathology and general anaesthetic for dental treatment.

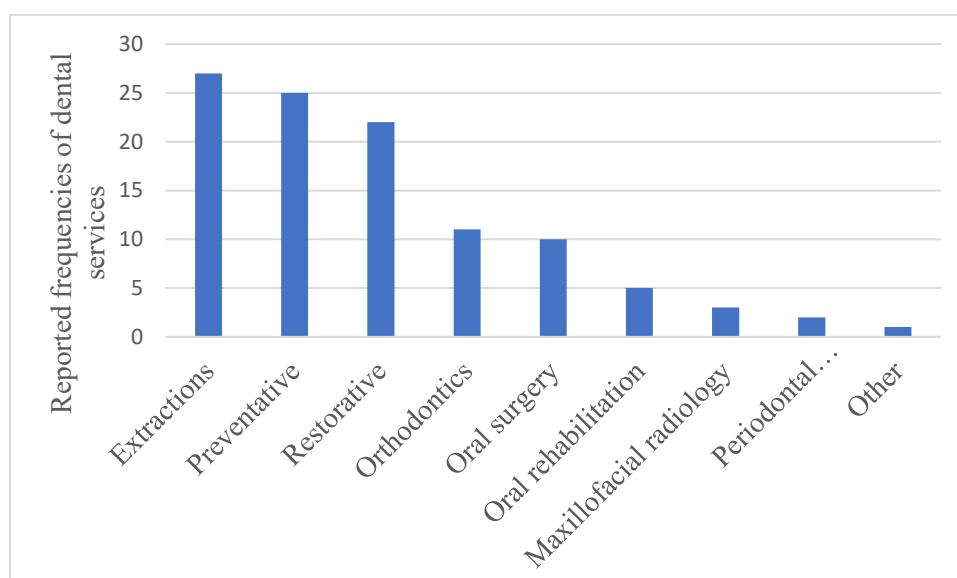
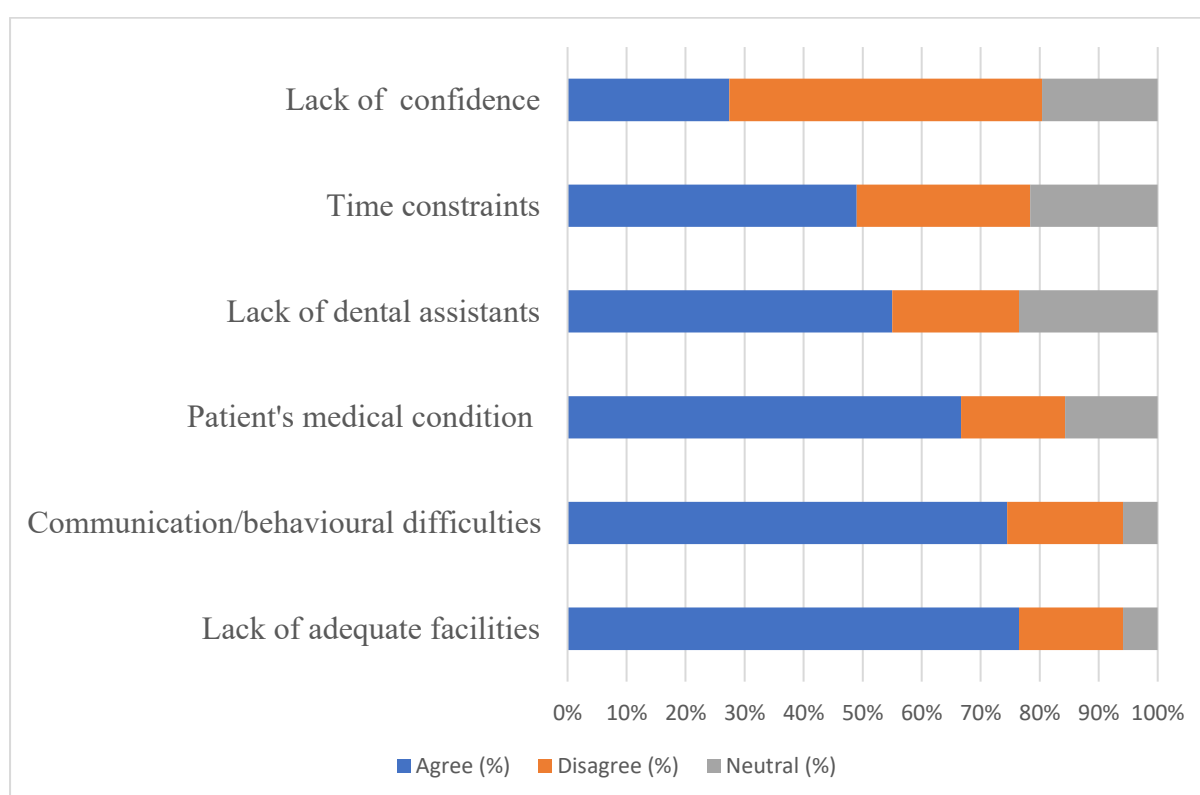


Figure 6.2 Reported frequencies of types of dental services provided to CSHCN

Perceived challenges reported by OHPs

The survey participants faced several challenges when providing dental care for CSHCN as highlighted in Figure 6.3. The greatest challenge reported by 76% of OHPs was the inadequate theatre facilities at the dental hospitals. Other concerns, such as the child's behaviour and/or communication difficulties, were reported by 74% OHPs while physical/medical condition of CSHCN was mentioned by 66% of the OHPs. More than half of the participants (54%) indicated that the lack of dental assistants trained to manage CSHCN was a challenge. Time constraints perhaps due to the high patient workload and extra time required to manage uncooperative children was cited by 48% as a problem.



Footnote** Agree=OHPs agreed or strongly agreed with statements; Disagree=OHPs disagreed or strongly disagreed with statements; Neutral=OHPs neither agreed nor disagreed with statements

Figure 6.3 Challenges experienced by OHPs

Overall, despite the challenges, most of the OHPs (78%) felt comfortable and fulfilled (88%) when providing dental care for CSHCN as shown in Figure 6.4.

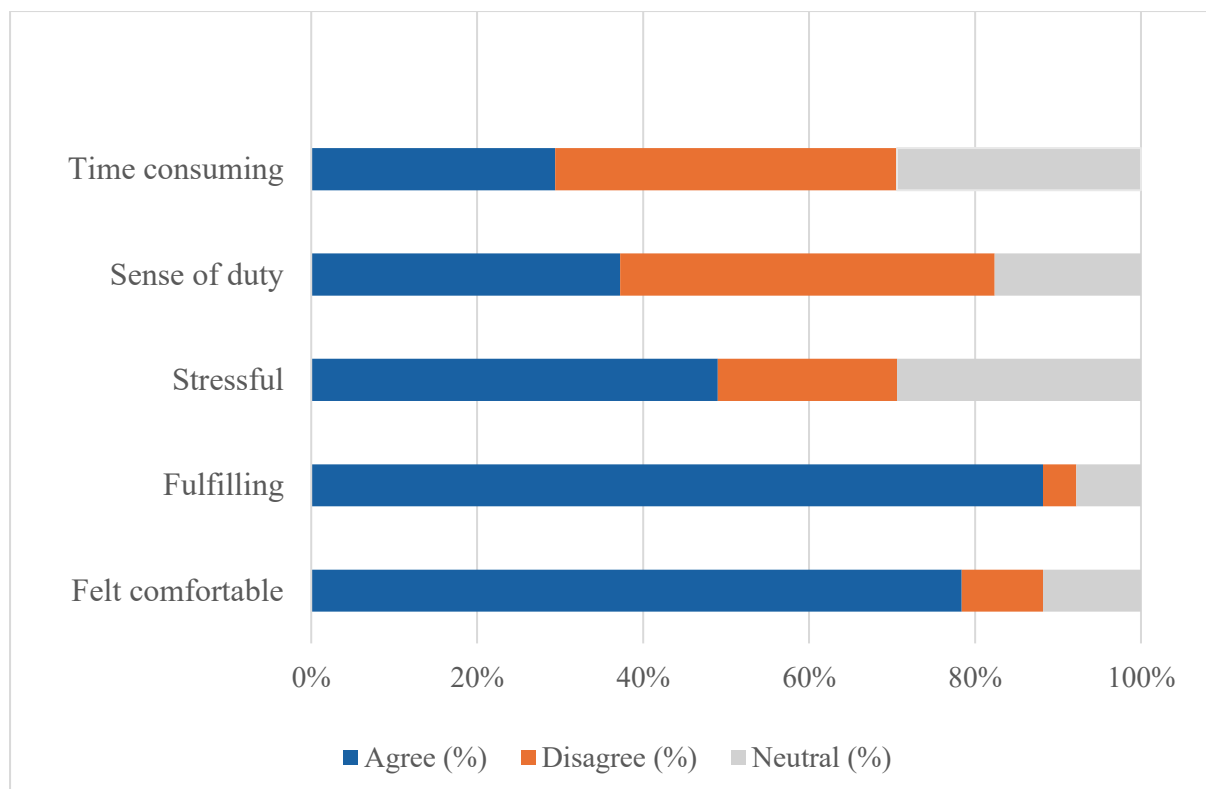


Figure 6.4 Perceptions of OHPs treating CSHCN

Twenty-six (52%) of the respondents had been trained during their graduate programs to provide dental care for CSHCN. However, of the fifty respondents in the survey, 13 (26%) felt that the training was not adequate while the same proportion (26%) of OHPs cited it was only satisfactory. Participants mentioned the various ways they improved their knowledge in the dental management of CSHCN, such as learning through experience, self-initiated online learning programs, continuous education, attending seminars and courses, reading journals and ‘learning from each other’ or ‘we learn as we go’.

Twenty-four (48%) respondents acknowledged that they received support from other dental specialists such as maxillofacial surgeons and orthodontists while providing treatment for CSHCN. In addition, most of the respondents (98%) felt that inter-disciplinary collaboration between the medical and dental professionals could improve the quality of dental services for CSHCN. Respondents suggested that additional support such as increased collaboration, multi-disciplinary clinics, a proper patient booking system for GA, increased theatre time allocation, more theatres and sedation facilities would improve dental care to CSHCN.

6.3.2 Findings from the interviews and FGD

Out of the estimated qualitative (QL) sample of 15, eight (53%) OHPs participated in this section of the study, five for the FGD and three for the interviews. Most of the participants were female (n=7) and dentists (n=6) while two of them were specialists.

Four themes emerged from the qualitative analyses. They were service provision, resource constraints, patient affordability and organisational factors. The themes were linked to the Lévesque framework as shown in Table 6.2. There was no link with the Lévesque constructs of acceptability and approachability themes because the study focused on the perspectives and experiences of the OHPs and not the patients.

Table 6.2 Emerging themes from OHP perceptions and experiences at ADHs

Themes	Summary Findings	Lévesque framework
Service provision	- Dental services were largely under GA. - There was variation across ADHs. - Patients travelled long distances to access treatment at ADHs. - Waiting list challenges were cited. - Recommendations included extended clinical partnerships.	Availability: the ability to reach health facilities and professionals timeously.
Resources constraints	- Resource constraints such as physical facilities, specialised facilities, finances, human resource and theatre time affected availability of services. - Lack of paediatric dental specialists - Services were offered by general dentists. - Proposed solutions included adequate resources, supplies and staff training.	Availability includes the availability of physical facilities and their capacity to generate services
Patient affordability	- Poverty amongst patients was high, - Cost of travel impacted the caregivers' access to services even though children below the age of 6 years were entitled to free services. - Equipping PHC facilities to provide services closer to the patients was proposed to reduce travel costs.	Affordability: includes the economic ability for people to use services and refers to both direct and indirect costs.
Organisational factors	- Poor inter-disciplinary collaborations. - Lack of specialty training in paediatric dentistry - Enhanced multi-disciplinary collaboration was proposed to improve quality of services.	Appropriateness: relates to the extent to which the services fit the needs of the patient. It includes type of services provided, quality of services, integration and follow-up care.

Service Provision

The OHPs highlighted that dental services for CSHCN were largely conducted under GA. However, the availability of GA services for dental treatment varied across the ADHs. Participants from three ADHs reported that one hospital had three GA morning sessions per week, another had one session while a third did not have any dedicated theatre time for dental treatment. The dental treatment provided also differed across the hospitals and included, inter alia, preventative (prophylaxis, fissure sealants, fluoride treatment), simple tooth extractions, restorations and surgical extractions. Specialty services such as orthodontics, maxillofacial and oral surgery for CSHCN with cleft lip and palate were also rendered from the three ADHs. The dental treatments were provided primarily by general dentists working in the paediatric dentistry department.

‘Our staff members should feel comfortable, we are general dentistry at the end of the day, and we should be able to manage a paediatric patient adequately.’ (KI 1)

Often patients were placed on waiting lists and pain relief tended to be given priority when patients sought care.

‘We will fast track the patients to do just the extractions so that we can do pain relief.’ (KI 2)

Resource Constraints

Resources constraints such as inadequate infrastructure, limited finances and time constraints were reported by the key informants.

‘No, ICU beds for us... There are just no beds for the little ones... and it will also not be good to now mix them together with adult patients that might have probably high infection rates.... No recovery wards.’ (KI 1)

‘We don’t have facilities to perform IV sedation, recovery areas that would be able to help reduce the theatre list and to help with the small emergencies such as extractions... and the clinical ward we don't have enough chairs.’ (KI 3)

Budgetary constraints reported at one hospital resulted in lack of theatre supplies and subsequent cancellation of theatre sessions. This constrained the ability to provide treatment to patients and thus to deliver services.

'We were told that we were at R28 million deficit before we even start. So, we need more than what they gave... So, we already starting on the back foot.' (KI 2)

Time constraints experienced by OHPs affected patient follow-up care. This was exacerbated by the high number of patients referred for treatment by the surrounding public and private hospitals.

'Not able to have those opportunities of scheduling appointments, scheduling recalls following a patient on time...' (FGD pp2)

Participants suggested some solutions to mitigate the limited availability of facilities, theatre supplies and resources constraints experienced at the ADHs. These included public-private partnerships, use of non-profit organisations, and upskilling OHPs in the administration of conscious sedation procedures in order to minimise their dependency on GA services.

'Umm, we busy now with the talks with uh... private Children's Hospital. That would be a nice private/ public partnership that, you know, we'll have.' (KI3)

'I've always wanted us to delve into this issue of conscious sedation... sending staff to go do the training on conscious sedation.' (KI1)

One participant suggested that adequate resource allocation from the government was a key solution to financial constraints.

'I think we could do better. Yeah, we could do better. But then government needs to come on board with funding...' (KI 2)

Patient affordability

The OHPs reported that some caregivers travelled from far and impacted on their ability to afford access to dental care. Thus, the cost of travel to the ADHs and low socio-economic status

of the families were barriers to accessing dental care. Hence, the OHP sometimes made concessions to attend to the patients especially if the child was in pain.

'Sometimes, I have had to request the anaesthetist to see a child who comes from far and is in pain as the parent doesn't have money to come another time.' (KI 2)

Despite the availability of general dentistry, and some specialty services at ADHs, patients had to travel from far to access services and this affected their ability to obtain dental treatment timeously.

'Yeah, that was one mother complaining about the distance ... And I realise that some of them come from far, very far. They travel 3 hours just to come for that clinic.' (FGD 5).

Furthermore, at one of the hospitals, poor families could not come for the prescribed preventative services (oral health education, diet counselling, prophylaxis, fluoride treatment) as part of the treatment protocols for GA and thus, services offered were solely pain relief.

In addressing patient affordability, OHPs suggested that CSHCN without behavioural issues should have access to basic services closer to their homes to reduce travel costs.

'So, if you find that it's special needs patient who can be cooperative and have that basic preventive care such as prophylaxis, fissure sealants, fluoride application at a local clinic, then it saves them travel.' (FGD pp1)

Organisational factors

The dental hospitals were largely able to provide dental care to the majority of CSHCN; however, other organisational factors affected the adequacy of services and follow-up care. These included a lack of specialty training in paediatric dentistry and poor interdisciplinary collaboration.

'We have a specific Cleft clinic that is run by the department of maxillofacial oral surgery, So, the issue of multi-disciplinary and collaborations may not be written down to say these are the structures, but there's a lot that's happening in that space.' (KI 1)

The nature of collaborations differed between OHPs. In some ADHs the relationships were lacking.

'We've got an anaesthesiologist, but we still struggle with collaboration, and they are in- house. So, you can't just call him for a consultation, you have to write the referral, but we are in the same building on the same floor down the passage... ' (KI 2)

'And what I find most challenging is the team, the multidisciplinary team as some of the specialists are frequently missing from the monthly cleft clinic... ' (FGD pp 4)

Another issue raised was the lack of specialty training in paediatric dentistry. In addition, OHPs expressed a lack of support for further training to enhance knowledge and skills in the management of CSHCN.

'And as you know, that paed (paediatric dentistry) not being a speciality in SA. You can only rely on the people who have special interest in paed.... ' (KI 1)

'The last training that we've had on special needs and paed, it was on our undergrad. ' (FGD pp2)

Only one participant indicated that she was trained to provide conscious sedation and was able to train other dental colleagues.

'So, I'm trained, and I train others to use nitrous oxide sedation...hence our staff are well trained to provide sedation but not everybody has a heart for paediatric dentistry. ' (KI 3)

To enhance appropriateness of care, some of the suggestions to the organisational issues raised by participants included enhanced multi-disciplinary teams, coordination of care, support for OHPs training, equipping other public health facilities and introducing specialty training in paediatric dentistry.

'To have more multidisciplinary activities and to also be integrated into the health system. ' (FGD pp1)

'I would very much like to see paediatric dentistry become a speciality in South Africa and that would give us more scope and would allow us to do more and to reach more children. ' (KI 3)

6.4 DISCUSSION

The mixed methods study explored the perceptions and experiences of OHPs in the provision of dental services for CSHCN at ADHs in SA. The findings from the quantitative (QT) arm revealed that dental services to CSHCN comprised mainly of basic treatment such as extractions, restorations, polishing, fluoride treatment and some specialty treatment including orthodontics, oral surgery for children with cleft lip/palate. The OHPs in the QT survey reported that they experienced key challenges that included, inadequate physical and specialised facilities (theatre and sedation) to provide dental care for these children. The following themes emerged from the perceptions of the OHPs: - service provision, resource constraints, patient affordability and organisational factors. However, the OHPs were positive and found their work fulfilling. They suggested proposals to alleviate the challenges they faced.

In this study, healthcare availability challenges were demonstrated by resource constraints related to physical and specialised facilities (dental chairs, private rooms, children ward, ICU beds, recovery areas, sedation), finances, lack of specialists, and inadequate theatre time and theatre supplies. Survey participants also highlighted the limited specialised facilities for GA and sedation at ADHs. As a result of this limited availability, patients were placed on a wait list for GA and pain relief was prioritised as evidenced by the QT results. Furthermore, caregivers travelled from far to access services. According to Lévesque et al,¹⁵⁶ availability issues include not only physical facilities such as wheel chair ramps, clinic space, and dental units but also the ability of patients to reach facilities timeously. Furthermore, a similar lack of specialised facilities has also been reported in other developing countries such as Trinidad, Tobago and India.^{26, 139}

Financial constraints due to inadequate budgetary allocation affected the availability of dental GA services for CSHCN at ADHs in SA. In addition, the survey participants reported on the infrastructure challenges due to financial constraints. Evidence from other studies has reported on under- resourcing and low priority for oral health services within the public sector.^{138, 151, 234} In SA, the lack of a dedicated budget for oral health affected the availability of consumables and money to repair equipment to provide dental services in Limpopo Province.¹⁵¹ Similarly, under-resourcing of the public health system and inadequate equipment and facilities were

experienced by oral health professionals providing treatment to individuals with special needs in Australia.¹³⁸ Similarly, in Rwanda it was noted that the lack of dental equipment and materials was partly due to the prioritisation of other health services such as maternal and child health.²³⁴ Thus, there is a great need for governments to provide adequate financial support for oral health services in the public health system to facilitate access to services especially for vulnerable children.

Oral health professionals in this study stated that some patients were faced with unaffordability issues. They noted that some of the caregivers were from low socio-economic backgrounds which affected their ability to afford transport costs to access services. This challenge was linked to the Lévesque's affordability construct¹⁵⁶ relating to the economic ability for people to use services. Other studies have reported similar concerns with regard to patient affordability.^{94, 139, 235, 236} In Saudi Arabia, caregivers, especially those from low-income families, experienced accessibility challenges such as distance to the dental clinic, transportation costs and financial cost.²³⁵ Similarly, in Uganda challenges with transportation and increased transport costs affected caregivers' ability to access dental services for children with cerebral palsy.⁹⁴ Furthermore, in Trinidad, unaffordability due to low income was cited by caregivers of persons with special needs.¹³⁹ This emphasises the need to provide services closer to the families of CSHCN.

In the study findings, organisational factors influenced the provision of dental services for CSHCN. These included the lack of specialty training in paediatric dentistry, lack of interdisciplinary collaborations, and inadequate OHPs training which impacted the quality of services. The survey respondents also experienced limited disciplinary collaborations in the management of CSHCN. In Trinidad, OHPs suggested that inter-disciplinary collaboration was required to provide holistic care and enhanced quality of life for individuals with special needs.¹³⁹ Studies in India, Australia and Malaysia have cited inadequate training of dentists as a barrier to dental care for CSHCN.^{26, 138, 204, 237} Supporting training of both dentists and specialists is key as part of increasing capacity and subsequently addressing improved access to dental care for CSHCN.

The OHPs in this study proposed solutions to the challenges encountered in the dental management of CSHCN. Their suggestions included advanced training of OHPs, private and non-profit sector engagement, enhanced public-private partnerships, increased budgetary

allocation and the development of paediatric dentistry as a specialty in SA. Equipping of PHC facilities to provide basic dental services closer to caregivers of CSHCN was also proposed. The success of these proposals to address the challenges experienced by OHPs requires intentional organisational efforts and government involvement. In a US study, partnerships among community organisations and the use of government oral health programs facilitated provision of oral health services for young CSHCN.³⁵ The importance of an appropriate policy and government engagement to address broader access issues encountered in the dental care for individuals with special needs was highlighted by OHPs in Trinidad, and emphasised the essential role of the government in providing financial support.¹³⁹ Other factors such as community dental outreach programs,²³⁶ enhanced collaborations of dental and medical health providers could additionally improve access to dental care for CSHCN. Patients accessing care in multi-disciplinary settings are also likely to receive regular dental care.²³⁸ Therefore, improved communication and collaborations between different stakeholders such as parents, dental and medical providers, and the establishment of clear referral systems are necessary for timely integrated and holistic care.²³⁹

Strengths and Limitations

The use of a sequential mixed-methods design combining firstly the quantitative followed by qualitative arms provided the breadth and the depth for the study findings. The QT survey enabled us to obtain the broad perceptions of OHPs regarding provision of dental services for CSHCN while the QL findings from the in-depth interviews revealed deeper insights into the challenges experienced. Triangulation of both QT and QL findings improved the validity of the research. Furthermore, the use of the framework analysis for the QL data helped to summarise the findings and derive more meaningful insights.²³² In addition, the Levesque framework of healthcare access strengthened this study as it enabled us to further report the QL findings in line with some of the access constructs.

The low response rate of OHPs in the online survey was a limitation; however, the few respondents provided insightful information with regards to the dental care of CSHCN. Another limitation was the absence of member checking/verification of transcripts with the participants. The experiences of the participants of the FGD were not representative of the ADHs. Despite the limitations, the QL findings provided deeper and richer information to augment the QL survey. The perspectives and experiences of OHPs rendering services at ADHs

may have been subjected to some recall bias; however, the multiple data collection approaches utilised including the focus group and in-depth interviews mitigated the impact of the bias. Although three of the four ADHs which participated in the study were from one province, the study findings capture the context of ADHs in SA. The study findings are not regionally representative.

6.5 CONCLUSIONS

The OHPs at ADHs experienced challenges related to service provision, resource constraints, low patient affordability and organisational factors that in turn affected the availability of quality dental care for CSHCN. These challenges can be addressed by advocating for enhanced multi-disciplinary collaborations, creation of more public-private partnerships, increasing training opportunities for OHPs in PHC settings and adequately equipping the PHC facilities to be able to provide basic dental services for CSHCN. This would subsequently alleviate the travelling costs of caregivers and referral load to ADHs. In addition, recognition of paediatric dentistry as a specialty in SA is long overdue in order that specialists can support the general dentists in the dental management of CSHCN and improve access to dental care.

This mixed methods study explored oral health care provision to CSHCN from the perspectives of OHPs rendering services at ADHs. The respondents of the survey noted that the dental services provided to CSHCN comprised of dental extractions and limited restorative care. The qualitative component highlighted that resource constraints negatively affected oral health service provision to CSHCN at ADHs, which could partly explain the limited services provided to CSHCN in chapter 5 and the high UTNs among CSHCN in chapter 4. This finding coupled with other organisational and patient-related factors revealed the importance of proper planning and adequate government resource allocation to improve dental care for CSHCN at ADHs. Some of these factors are discussed further in chapter 7.

CHAPTER 7

Discussion and Recommendations

This chapter presents a summary of the key findings arising from the study objectives. It discusses the study methodological approach and findings and how they contribute to the understanding of oral health and dental care for CSHCN in SA. The section concludes with some of the proposed recommendations and questions arising from this thesis for future research.

7.1 METHODOLOGICAL APPROACH

The overall aim of the study was to assess the oral health care delivery to CSHCN at ADHs in SA. The study consisted of an initial quantitative component followed by the qualitative arm. The use of the narrative literature review, quantitative (QT) and qualitative (QL) methods complemented each other, to provide context and depth to the findings resulting in a better analysis of the research problem. In their review, Ostlund and colleagues, have shown that triangulation is key to the integration of QT and QL findings. Additionally, they report on how the triangulation metaphor is helpful in reporting complementary findings such as those of this study.²⁴⁰

The characteristics and status of oral health among children and adolescents with special health care needs in SA was explored using the narrative literature review. This provided the study with background information on their demographic characteristics and their oral health status. The review of clinical records of paediatric patients treated under GA and completion of a survey questionnaire by OHPs at ADHs revealed the types of disabilities in CSHCN who were referred from PHC for dental treatment at ADHs.

The QL arm included in-depth interviews with clinical heads of paediatric dentistry at ADHs and a FGD from a sample of survey respondents directly involved with dental treatment to CSHCN. The QL data provided depth and context to the QT findings thereby enhancing triangulation and accuracy of the study findings.

In our study, the integration of different data source findings was achieved in various ways. For example, the findings from the QT survey were used to inform the questions in the focus group discussions and guide the in-depth interviews with clinical heads of paediatric dentistry.

Additionally, triangulation of convergent findings as described by Ostlund and colleagues was done. The QT survey of OHPs at ADHs revealed that dental care services for CSHCN comprised of tooth extractions and limited restorative treatment due to challenges of inadequate specialised facilities. The QL findings from the in-depth interviews highlighted themes related to service provision and resource constraints among other themes which influenced dental care for CSHCN at ADHs. Thus, the QT and QL findings complemented and reinforced each other as the QL arm validated the QT component thus improving the accuracy of the study findings.

All five ADHs of SA were approached for inclusion in this study; however, only three institutions responded. Regrettably, bureaucratic issues hindered access to the remaining two ADHs, pointing to the challenges of multi-centre studies. However, this study fulfilled the WHO goal of data collection among individuals with disabilities by including CSHCN, their dental treatment at ADHs and the challenges faced by OHPs who provide dental care at ADHs in SA.

To my knowledge, this is one of the first mixed methods studies to explore the challenges faced by OHPs at ADHs in SA. It also highlights the dental care provided to CSHCN at ADHs and the perspectives of OHPs rendering services which could be used to inform strategies to strengthen oral health service delivery among vulnerable groups in SA. Reflecting on the methodological choice, interviews with caregivers would have provided additional insight on their experiences while seeking dental care at PHC. This is therefore an area for future research. The main findings emanating from this study are summarised in Table 7.1.

7.2 SUMMARY OF MAIN STUDY FINDINGS

The main findings arising from the study components of this thesis as outlined in chapter 3 are highlighted in Table 7.1.

Table 7.1 Summary of the main findings of the study components

Study Components	Key Findings
To describe the characteristics and status of oral health among children and adolescents with special health care needs in SA.	• CSHCN diverse group, the majority (>70%) with developmental and cognitive disabilities • Poor oral health among CSHCN in SA • Prevalence of dental caries among CSHCN ranged between 22.5% to 85.2% • 68%-100% of dental caries untreated • CSHCN lacked preventative and restorative treatment
To compare the dental treatment provided to CSHCN and NSHCN at ADHs in SA	• Median age of the children was 5 years (IQR: 3-6.5) • CSHCN were older than NSHCN, ($p < 0.001$). • More CSHCN (52.6%) compared to NSHCN (25.4%) were referred from PHC ($p < 0.001$) • Caries and related complaints prevalent in both groups (>80%) • CSHCN and NSHCN younger than 6 years needed treatment under GA • Overall, most children received extractions (43.5%), • Limited restorative (20%), and preventative treatment (<10%) • There were significant associations between age ($p < 0.001$), being CSHCN ($p < 0.001$), dental diagnosis ($p < 0.001$), treatment provided ($p < 0.001$) and the type of behavioural management.
To describe the dental care services provided for CSHCN at ADHs in SA	• The majority of the OHPs were dentists • Basic dental services such as extractions, restorations, fissure sealants, polishing. Limited specialty services including orthodontics and oral surgery for cleft patients
To explore the perceptions of oral health professionals towards provision of dental care to CSHCN at ADHs in SA	• There is lack of specialist paediatric dentists in SA • OHPs reported challenges; inadequate facilities, infrastructure, theatre, and patient health concerns, insufficient training
To identify factors influencing the delivery of oral healthcare for CSHCN at ADHs in SA	• The emerging themes were as follows: - service provision, resource constraints, patient affordability and organisational factors.

7.2.1 Status of oral health among children with special healthcare needs in SA

This study aimed to assess the oral health care delivery for CSHCN at ADHs in SA; therefore, a narrative review was conducted to provide insight into their oral health status. Among the key findings of the review was the poor oral health of CSHCN, attributed mainly to dental caries.⁴⁰ Prevalence of dental caries ranged from 22.5% to 85.2% and most of the caries was untreated (68%-100%). Thus, caries and related complaints were prevalent (>80%) among

CSHCN and young NSHCN seeking treatment at ADHs. Treatment consisted primarily of dental extractions perhaps due to the extent of the caries and poor prognosis for restorative procedures. The burden of oral disease continues to persist in LMIC such as SA. Despite the high prevalence of untreated caries in children, they experience minimal treatment perhaps due to poverty and limited resources at PHC and tertiary health facilities of resource limited settings. Furthermore, children from low socioeconomic backgrounds and other vulnerable groups such as CSHCN are more affected by oral diseases and encounter greater barriers to dental care.⁸⁰

The study conceptual framework for oral healthcare of CSHCN (Figure 3.1) emphasises the child's oral health status and the importance of integrating oral health into PHC services. Basic dental services such as oral health screenings, fluoride applications, dental sealants, atraumatic restorative technique that are essential for the prevention and early management of dental caries should be available at PHC centres. However, the study findings point to a lack of these basic services, increased extractions and treatment backlog for CSHCN requiring GA. These findings suggest that integrating oral healthcare at PHC level could potentially result in timely preventative strategies, less invasive dental procedures and reduce the GA waiting list at ADHs.

Another major finding from the narrative review indicated that CSHCN were a diverse and heterogeneous group with individual, biological and health-related risk factors for poor oral health. The clinical record review study indicated that children with developmental disabilities, a sub-set of CSHCN commonly presented for treatment under GA. In addition, OHPs reported that they encountered these children more frequently at ADHs where they were referred from PHC facilities. Children with developmental disabilities constitute a higher proportion of under-five year-olds in sub-Saharan Africa and Asia and require health systems to respond to their diverse medical and dental needs.⁵² An integrated system of healthcare was suggested by Gallagher (2007) utilising diverse health professionals to be optimal in providing healthcare services for CSHCN.²⁴¹ Therefore, the study findings in line with the conceptual framework, suggests the need for inter-disciplinary care for these children both at PHC and tertiary level for optimal and holistic care. However, this may not always be feasible in resource constrained settings due to staff shortages.

An individualised patient-centred approach to dental care is essential in CSHCN for the delivery of quality dental treatment. This entails knowledge of the underlying medical

condition, assessment of cognitive ability, behaviour and oral hygiene status and focus on early preventative care at PHC facilities. Ideally, a dental home should be situated at the PHC where CSHCN and their families are able to access services regularly. A similar proposal to integrate oral health at PHC facilities in SA to enhance access to dental care and reduce oral health inequalities has previously been suggested by Thema and Singh.²⁴² However, nurses at maternal and child health (MCH) facilities in SA have been shown to lack the time and training to provide oral health education services to mothers,²⁴³ pointing to capacity constraints at PHC to address the oral health of young children. Lessons can also be derived from the conceptual framework proposed for the comprehensive management of children with cleft lip and palate in SA. The Ekhasya Lethu model²⁴⁴ proposed that this 'house of care' is an ideal place for comprehensive management of vulnerable children. Therefore, the PHC in this model could be situated in the care environment of the CSHCN. This is especially important for children under the age of six years who frequent PHC facilities for routine medical care and vaccinations.

A key aid for SA parents to track the growth and development of their children from birth until five years is the Road to Health Booklet.²⁴⁵ It contains information on immunisations, feeding and developmental milestones including the deciduous dentition.²⁴⁵ The booklet emphasises comprehensive childcare and early preventative measures to promote overall health.²⁴⁵ However, the oral health portion in this booklet is minimal, pointing to the relegation of oral health compared to other healthcare needs. This lack of emphasis on the importance of the child's oral health may contribute to the burden of childhood caries in SA. Use of this booklet provides an ideal opportunity for an integrative approach to oral health promotion by general health workers at PHC facilities.

Dental caries and its sequelae were the most common clinical diagnosis among CSHCN.⁴⁴ The results of the review showed that more than two-thirds of the dental caries among CSHCN was not treated, which suggested limited access to dental care for these children. However, untreated caries was also evident among young pre-school children with no special needs who required treatment under GA.⁴⁴ The burden of untreated caries among CSHCN and preschool children remains a concern in SA. Efforts to reduce the burden of caries require not only improved access to early preventative care but also addressing the dietary habits of under-five year-old children. South Africa has over the last three decades undergone a nutritional transition, attributed to urbanisation, socio-demographic and changes in lifestyle.²⁴⁶ There has

been a change in diet from healthy non-processed foods such as fruits and vegetables to highly refined sugary foods which are more cariogenic. Therefore, nutrition education targeting caregivers of children under-five years old should be emphasised as one of the measures to reduce childhood caries.

Biological, social and environmental determinants influence the child's nutrition and therefore caries risk. Factors such as food insecurity, child illness,²⁴⁷ poor dietary intake, unemployment,²⁴⁸ child age, caregiver level of education, inadequate household income, poor weaning habits²⁴⁹ have been shown to negatively impact the nutritional status of pre-school children in SA. Additionally, one systematic review in SA reported various risk indicators of childhood caries.¹²⁰ These factors included parental income, education level, oral health knowledge, dietary factors and oral hygiene habits of the child. Children from higher-income families had a lower prevalence of caries compared to those from low-income ones. In addition, children whose parents had a low education had a higher caries prevalence. Children who were exclusively breast-fed had the same odds for caries as those who were exclusively bottle-fed. Oral hygiene habits in the children such as toothbrushing frequency and parental supervision were also identified as risk indicators of childhood caries.¹²⁰ This therefore emphasises the need to address the social and environmental determinants of childhood caries in order to reduce the burden of childhood caries in SA.

7.2.2 Dental treatment provided to CSHCN and NSHCN at ADHs

The findings of the narrative review indicated a high prevalence of caries among CSHCN. Notably, the burden of untreated caries in CSHCN was a concern, and this had implications on the dental treatment provided. As a result, dental care consisted mainly of extractions due to extensive caries and late presentation for treatment. Similar findings have been reported among SA children as indicated by the last National Children Oral Health Survey (NCOHS) where 80% of the caries in 6-year-olds children was untreated.²⁵⁰ This could have been partly due to low oral health awareness among parents,²⁰ the lack of capacity among dentists to treat children with behavioural problems at PHCs, and the cost of transport to access care at ADHs. The findings imply low and episodic dental care utilisation among children, which underscores the need to address the barriers encountered by caregivers. This would facilitate access to timely care and reduce the burden of untreated caries.

Dental care is important in promoting good oral health in children. The types of dental services provided point to the oral health needs and resource availability to meet the needs in these children.¹⁹⁵ Another key finding of the second study component was that CSHCN and NSHCN younger than 6 years needed treatment under GA, partly due to the cooperation difficulties and extensive dental disease. Treatment under GA may be necessary to manage extensive dental caries for CSHCN,²² and childhood caries in healthy NSHCN.^{29, 152} Notably, in SA this type of service may be limited at PHC facilities. Thus, CSHCN in need of GA treatment are referred to private or tertiary hospitals as indicated in this study, perhaps due to challenges of providing dental care, the limited resources and facilities such as sedation at PHC.

In my study, the position of PHC within the conceptual framework shows its importance in providing some basic dental care for CSHCN with mild medical or behavioural problems. These facilities would require sedation equipment and dentists who are trained or have an interest in special needs dentistry to provide primary dental care to reduce the need to refer patients to tertiary health facilities, a resource that is lacking in SA due to budgetary constraints. In the UK, dental care for persons with mild to moderate special needs is provided through general dentists working in the public health sector, and where necessary supported by appropriate specialists.¹⁵³ Although the UK context is different to the PHC system of SA, this is also an option that could be explored and contextualised in SA where there are limited specialists in paediatric dentistry and where special needs dentistry is not well established.

Another significant finding from the record review study indicated that about a quarter of both CSHCN and NSHCN who had received an initial assessment indicating a need for treatment under GA failed to receive treatment. Although the reasons for not accessing treatment remain speculative, the findings of the qualitative study suggested inadequate resources in the provision of GA services at these hospitals. The findings when related to the study conceptual framework may also point to the ill equipped primary and tertiary health systems in meeting the needs of children and possibly the lack of oral health prioritisation.

7.2.3 Perceptions of OHPs towards provision of dental care to CSHCN

The perspectives of OHPs are key as they directly interact with patients. Among the OHPs involved in the treatment of CSHCN at ADHs included dentists (general, postgraduate students), dental specialists, dental therapists and oral hygienists. The OHPs together with other

medical and allied health professionals provide care for the diverse medical and dental needs of these children. The study conceptual framework emphasises the important role of multidisciplinary teams in the provision of dental care to CSHCN at tertiary level hospitals.

In this PhD study, OHPs had a positive attitude towards their work with CSHCN which they found fulfilling and meaningful. However, they felt inadequately trained to effectively treat CSHCN. In addition, the OHPs felt the need for greater support in their work particularly around multi-disciplinary collaboration. Furthermore, the lack of capacity was compounded by the lack of opportunities for upskilling their knowledge in the management of CSHCN as indicated by lack of training in conscious sedation. Other studies have reported a similar lack of knowledge in the management of CSHCN among OHPs.^{138, 141, 237, 251} This could in turn affect the willingness of OHPs to treat CSHCN with behavioural challenges. However, this was not evident in the study findings as the OHPs in the survey noted that they resorted to self-initiated methods and experiential learning to enhance their knowledge and skills in the management of CSHCN. Thus, the above sentiments expressed by OHPs in this study call for greater support in training opportunities and enhanced multi-disciplinary collaboration to improve access to dental care for CSHCN in SA.

Despite their positive outlook towards their work with CSHCN, OHPs in this study experienced several challenges such as concerns about the medical conditions and behaviour of some CSHCN. These concerns were valid considering their sentiments of lack of capacity and support as they perhaps increased the risk of providing treatment safely to these children. This may be why a higher proportion of CSHCN compared to NSHCN were treated under GA, as noted from the findings of the record review study component. Similar concerns relating to the medical condition or behaviour of CSHCN receiving dental treatment were reported among dentists in India.¹³⁷ Thus, OHPs who provide dental care for CSHCN often require additional support from medical professionals to alleviate some of the concerns of providing treatment safely.¹⁶⁷

Another challenge experienced by OHPs in this study was the lack of adequate GA and sedation facilities, ICU beds and recovery areas at some ADHs. Similar constraints of facilities and equipment for dental care for individuals with special needs have been reported by OHPs in Australia and Trinidad.^{138, 139} Therefore, this highlights the challenge in providing appropriate

services for vulnerable groups, which may be related to the high costs of managing extensive dental disease under GA in resource limited settings as demonstrated in this study.

The OHPs in this study suggested solutions to most of the issues faced. Some of the proposals included enhanced public-private clinical partnerships and more training opportunities for OHPs to enhance their capacity to manage CSHCN.

7.2.4 Factors influencing the delivery of oral healthcare to CSHCN at ADHs

From the mixed-methods study four themes emerged including service provision, resource constraints, patient affordability and organisational factors. The themes of service provision and resource constraints were aligned to constructs of availability. The patient affordability theme was aligned to affordability construct while the appropriate construct was linked to the theme of organisational factors. In addition, the Lévesque themes when linked to the study conceptual framework highlight the service delivery and health system deficiencies affecting the provision of services for CSHCN.

In this study, service provision was a major theme. The lack of basic services at PHC, limited facilities and budgetary deficits at ADHs had a negative impact on service delivery. As a result, CSHCN and young NSHCN treated under GA received limited services. Waiting lists for GA were common at the ADHs further pointing to constraints to meet demands for services. Similar findings of limited-service provision for pre-school children treated under GA in the public health sector were reported by Peerbhay and Barrie in the Western Cape Province, SA more than a decade ago.¹⁵² Another key finding from the OHPs perspective was resource constraints emanating from the budgetary deficits which adversely impacted service delivery. These findings are similar to those reported by Gumede and colleagues (2024) in KwaZulu-Natal Province where inadequate resources affected delivery of oral health care programmes at special needs schools, pointing to a lack of oral health priority and lack of integration at PHC.⁴¹

Another issue raised by OHPs was patient affordability. Dental treatment is rendered at no cost to children under the age of six years at SA public health facilities. However, the majority of those who utilise PHC are from low socio-economic communities and may experience lack of finances to travel to healthcare facilities. Other studies in Saudi Arabia,²³⁵ Uganda,⁹⁴ and Trinidad¹³⁹ have cited affordability problems (travel and treatment costs) among caregivers of CSHCN. In Limpopo Province, SA, OHPs cited similar challenges regarding long distances

travelled by patients from PHC settings to access services.¹⁵¹ Proper equipping of PHC facilities to provide services closer to the patients would reduce the travel costs incurred by caregivers. Furthermore, this highlights the importance of integrating oral health into PHC in line with the conceptual framework. This could alleviate the cost of seeking treatment for CSHCN experienced by caregivers from low socio-economic communities.

The OHPs experienced other organisational factors which influenced service delivery at ADHs. These included the lack of inter-disciplinary collaborations, inadequate OHPs training, the lack of paediatric dental specialists which affected the multi-disciplinary care of patients. The lack of adequate collaborations between the various health professionals was also cited by the survey participants who were primarily dentists. These factors when linked to the Lévesque framework¹⁵⁶ of healthcare access pointed to the limited availability of appropriate dental care for CSHCN at ADHs. Furthermore, considering my study proposed conceptual framework for integrated care, the findings reveal the need to strengthen interdisciplinary collaboration across service providers and sectors to enhance integrated care for CSHCN. Not only are greater collaborations between various health providers required, but the inclusion of other sectors such as basic education and social services is essential for optimal service delivery and integrated care for these vulnerable children.

Strengths and Limitations of the study

One of the key strengths of this study was the use of the QT and QL arms which provided more breadth and the depth for the study findings. The narrative review, record review and OHPs survey provided the QT data. The interviews and the FGD enabled us to obtain the QL findings which provided more depth and context to the QT findings. Triangulation of both QT and QL findings improved the validity of the research and the implications of the study to inform service delivery, policy and OHPs training.

One of the main limitations of this study was the study scope which was limited to ADHs. The study did not include PHC facilities and CSHCN seeking oral health services in these facilities. Although this may have led to selection bias of CSHCN at ADHs been limited to only children with severe disabilities, the finding that the majority of CSHCN presenting at ADHs for dental treatment were referred from PHC may point to the lack of capacity to manage these children including those with milder forms of disabilities or those with low levels of dental disease. In

hindsight, it would have been useful to include PHC in our study and therefore recommended as an area of future research.

Another limitation of this study was the lack of adequate data. This was evident in the few numbers of studies available for the narrative review. It would have been useful to carry out a survey of the oral health status of CSHCN in SA to obtain current data. However, this was not the focus of this study.

The record review study component had low numbers of clinical records due to the poor record keeping at ADHs. However, all the available records were included in the data analysis to mitigate the small sample. It is recommended that ADHs should consider electronic record keeping alleviating the issue of misplaced patient information.

Although descriptive and inferential statistics were appropriate for the record review study, more advanced modelling (e.g., multivariable regression) could further strengthen future research.

The use of a convenient sample of OHPs was another limitation; however, the sampling strategy provided suitable participants who were able to provide appropriate information related to the dental care of CSHCN. The perspectives and experiences of OHPs rendering services at ADHs may have been subjected to some recall bias; however, the qualitative data interviews mitigated the impact of the bias. Finally, this study did not include the perceptions of the caregivers of CSHCN, which should be explored in future research. Caregivers' inclusion in FGD could have provided perspectives on their health seeking behaviour. Caregivers have been reported to experience shame and grief when caring for children born with cleft lip and palate. They reported feelings of shock, anxiety, and sadness, aggravated by the burden of care, poverty, health system deficiencies, lack of public awareness and social support services for them.²⁵²

South Africa has a duty to ensure the health of all children, including CSHCN. South Africa is also a signatory to the UN Convention on the rights of people with disabilities. Yet, the study findings revealed a lack of oral health priority and under resourcing by the government which inadvertently compromised service delivery. Nonetheless, with the recent passing of the NHI Bill, this could be an opportunity to prioritise dental care for vulnerable groups such as CSHCN, persons with disabilities in SA. In addition, considering the diverse issues influencing

the delivery of dental care to CSHCN uncovered in this study, wider inter-disciplinary and multi-sectoral collaborative efforts are recommended to address the issues faced. This will hopefully reduce the burden of untreated caries among CSHCN and young NSHCN, reduce oral health inequities and ensure that no SA child is left behind.

7.3 RECOMMENDATIONS

The recommendations arising from the study findings are presented below.

7.3.1 Recommendations for service delivery

- *Explore barriers to utilisation of oral health services by CSHCN*

To address the high proportion of CSHCN and young NSHCN receiving multiple dental extractions under GA at ADHs, identifying and addressing some of the barriers to early preventative and restorative care at PHC facilities is important. Strengthening oral healthcare services for CSHCN within ADHs and PHC facilities is key to improving oral health outcomes. An example is incorporating oral health services into paediatric well-baby clinics. In the US, the Bright Smiles from Birth Program II is one such initiative aimed at educating primary medical providers on prevention of early childhood caries.²⁵³ Such an initiative can be contextualised at PHC settings in SA such as well-baby clinics to improve paediatric oral health and reduce the need for dental GA at ADHs. In addition, the proposed CF for this study can be used to strengthen oral health services for children under six years and CSHCN in SA. However, on personal reflection, the PI acknowledges that as a paediatric dentist working at one of the ADHs, her training may influence her perceptions on oral health services provided to CSHCN.

- *Improved collaborations*

This study revealed a lack of adequate collaboration between providers. Therefore, we recommend improved multi-disciplinary collaboration to enhance more integrated and holistic care for these children in line with the conceptual framework for this study. Equally important is the need to enhance family-centred care through empowering caregivers on the importance of good oral health for their children.

- ***Facilitate OHPs training***

This study uncovered some of the challenges experienced by OHPs rendering services for CSHCN at ADHs. These challenges imply the need to facilitate OHPs training, enhance collaboration and provide greater support in patient management. This could be done through online case discussions with different providers or seminars. Other studies have advocated increased collaborations in the dental management of individuals with special needs.^{139, 167}

Incorporating special care dentistry into the undergraduate dental curriculum so that dentists are better equipped to treat and manage children with cognitive and developmental disabilities should be explored.

For those OHPs at the PHC facilities, continuous professional development should be provided so that they are better able to treat children with mild disabilities. This could reduce unnecessary referral of these patients for dental care to tertiary level facilities. Although it is possible that PHC facilities could be able to provide dental extractions for CSHCN without subjecting the children to GA, the finding perhaps point to the perceptions of dental providers towards children with disabilities. This study has recommended that special care dentistry be incorporated into the dental curriculum so that dentists are better equipped to treat and manage children with disabilities who consist of a sub-group of CSHCN.

Lastly, this study indicated the lack of paediatric dental specialists in SA. This implies the need to train these specialists and recognition of the specialty by the Health Professional Council of SA. Furthermore, to support and justify the need for training more paediatric dentists, it is important to establish the number of these professionals at ADHs in SA. The specialists form part of the multi-disciplinary team of health professionals at tertiary level health facilities that are involved in the comprehensive care of CSHCN. In addition, they could enhance training of general dentists, conduct research, provide advocacy and leadership and promote children's overall wellbeing.

7.3.2 Recommendations for policy

- ***National Children's Oral Health Survey***

One of the key gaps identified was the lack of adequate and recent data on the oral health status of CSHCN in SA. There is a dire need for the SA government to conduct a National Children's Health Survey which includes oral health for all children including CSHCN. Additionally, this survey should incorporate sociodemographic factors that may impact both oral health and access to dental care which would be instrumental in planning for services considering the burden of disease and treatment needs.

- ***Improve resource allocation to ADHs***

This study identified some of the public health challenges impacting the provision of dental care for CSHCN at ADHs. Resource constraints, budgetary deficits, human resource inadequacies and dental theatre time were highlighted by OHPs in this study. The situation was made worse by the high patient referrals to ADHs amidst resource constraints. Therefore, there is need to improve resource allocation to ADHs. Additionally, the quality statements made by OHPs highlight the importance of further public health research that will assist in mitigation strategies to strengthen delivery of oral health services in SA.

- ***UHC and oral health***

South Africa has made significant efforts towards UHC through the recently passed NHI Bill.¹⁵⁵ The SDG 2030 call to leave 'no one behind' reiterates the need for inclusivity of previously marginalised and vulnerable groups.³⁷ This global call for inclusivity is aligned to other key organisations such as the FDI, and policy documents for individuals with disabilities.²⁵⁴ Therefore, it is important for oral healthcare to be part of UHC in SA. Policies related to individuals with disabilities should include oral health.

7.3.3 Recommendations for future research

Some of the questions on the provision of dental care for CSHCN in SA and ways to improve access to services that have emanated from this thesis are outlined below:

- How can digital health applications be used to promote oral health for CSHCN in SA?

- What are the perceptions of PHC workers towards oral health integration into Road to Health?
- What is the knowledge, perceptions and attitudes (KPA) of general dentists at PHC facilities towards dental care for CSHCN?
- How is the readiness of ADHs to train specialist paediatric dentists in SA?
- How can the integration of medical and dental undergraduate education at ADHs in SA be used to enhance multi-disciplinary collaboration in management of CSHCN?
- How can the integration of oral health into nursing education in SA be used to promote oral health of children at PHC?

7.4 SCHOLARLY CONTRIBUTION

This study has contributed to new knowledge regarding the dental care for CSHCN and NSHCN treated at ADHs within the public health system of SA. In addition, the findings of this work have theoretical framework implications on integrated healthcare which could be used to improve services at both PHC and tertiary level. Furthermore, this is one of the first studies in SA to compare the dental treatment provided to CSHCN and NSHCN, highlighting the differences in both groups, thus contributing to clinical practice.

Moreover, the study proposed a conceptual framework for integrated care. This study has advocated for integration of oral healthcare for CSHCN at various levels. At the family level, the caregiver requires to be educated on the importance of good oral health for the child. Community support initiatives are key at this level. In addition, oral healthcare needs to be incorporated at PHC level. This can be done through incorporating risk assessments and providing anticipatory guidance by professional nurses and establishing referral networks for dental care of children requiring further treatment. At the organisational level, enhanced interdisciplinary partnerships, incorporating oral health into nursing training and paediatric residency programs are examples of supporting medical-dental integration. At the macro level, policy development and adequate budgetary allocation are key to ensure sustainable integration of oral health care at all levels. These initiatives could help improve oral health and overall health for CSHCN in SA.

This thesis has given further insight into the SA public health system and the delivery of oral health care for CSHCN. These include strengthening PHC facilities, supporting OHP training, improving facilities at ADHs and enhancing inter-disciplinary collaborations.

7.4.1 Methodological contribution

The narrative literature review on the status of oral health among CSHCN over the past two decades in SA was conducted at the onset of this study. The findings consolidated the information available, providing baseline data on the characteristics, oral health status and unmet dental needs of CSHCN which could inform service provision.

The records review study was among the first to compare the dental treatment provided to CSHCN and NSHCN at ADHs in SA. This study included three of the five ADHs, hence contextually representative. The findings indicated the types of paediatric patients referred from PHC facilities to ADHs for treatment under GA, which could inform resource allocation for enhanced services.

The mixed methods study exploring the perceptions of OHPs towards provision of dental care to CSHCN was also among the first in SA. The findings highlighted the challenges faced by OHPs in providing dental care to CSHCN. The information could be used to inform policy and to develop areas where additional support is necessary for the OHPs.

The use of the Levesque framework for healthcare access enhanced the interpretation of the qualitative study findings and their potential implications. The FDI vision 2030 is to ensure optimal delivery of oral health for all and that none is left behind.²⁵⁵ In addition, the vision will entail delivery of more evidence-based, comprehensive and integrated oral healthcare. Realisation of this vision will require OHPs to participate in improving the health of their patients and advocating for greater integration of oral health and general health.

7.5 CONCLUSIONS

The study findings revealed that CSHCN in SA were a diverse and heterogenous group. From the limited data available over the last two decades, poor oral health and high unmet treatment needs were prevalent among these children. Patients who received dental treatment under GA at ADHs in SA were CSHCN or NSHCN typically under the age of 6 years, presenting with extensive caries. The treatment provided consisted mainly of extractions with little restorative and preventative treatment. The OHPs at ADHs experienced challenges related to service provision, resource constraints, low patient affordability and organisational factors that in turn affected the availability of quality dental services for CSHCN. These challenges can be addressed by advocating for enhanced multi-disciplinary collaborations, creation of more public-private partnerships, increasing training opportunities for OHPs especially in PHC settings, properly equipping the PHC facilities to be able to provide basic dental services for CSHCN; thus, the travelling costs of patients and referral load to ADHs would be alleviated. Recognition of paediatric dentistry as a specialty in SA is long overdue so that the specialists can support the general dentists in the dental management of CSHCN and hence improve access to dental care. The various strategies underscore the importance of government support and other relevant stakeholders to ensure oral health for SA children is prioritised.

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APPENDICES

Appendix 1: Ethics Certificate



R49 Dr N Njoroge

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M220266

NAME: Dr N Njoroge **DEGREE:** PhD
(Principal Investigator)

SCHOOL: Department of Othodontics
School of Oral Health Sciences
Faculty of Health Sciences
University

PROJECT TITLE: *An assessment of oral health care delivery to children with special needs at Dental Schools in South Africa*

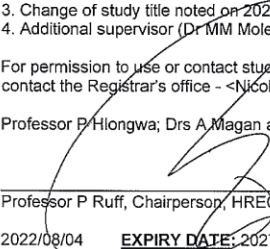
DATE CONSIDERED: 2022/02/25

DECISION: Approved unconditionally

CONDITIONS:
1. All phases of the study approved as of 2022/11/23
2. Annex 1 added on 2022/11/17
3. Change of study title noted on 2024/12/12
4. Additional supervisor (Dr MM Molete) noted on 2025/01/29

NOTE: For permission to use or contact student study participants, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Professor P Hlongwa; Drs A Magan and MM Molete

APPROVED BY: 
Professor P Ruff, Chairperson, HREC (Medical)

DATE OF APPROVAL: 2022/08/04 **EXPIRY DATE:** 2027/08/03

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

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 submit details to the Committee. I agree to submit a yearly progress report in the format available at <https://wits.ac.za/research/researcher-support/research-ethics/ethics-committees/>. This report is due annually, for the duration of the Clearance Certificate, beginning on the first anniversary of Date of Approval above. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).


Signature of Principal Investigator

29/01/2025
Date

Appendix 2: Records Review Form

An assessment of oral healthcare delivery to children with special health needs at Dental Schools in South Africa.

1	Dental Hospital	Centre number
2	Patient number	Case number
3	Date of 1 st visit	Year of visit
4	Age at time of 1 st visit	Age in years
5	Gender	Male
		Female
		Not specified
6	Source of referral	Self -referred
		Referred
7	Chief complaint	Dental Pain/Sepsis
		Dental Caries
		Dental Trauma
		Orthodontic problems
		Gum disease
		Other, please specify
8	Special needs Y/N	Developmental
		Learning disabilities
		Behavioural/Emotional
		Sensory Impaired
		Medical co-morbidity
		Other, please specify
9	Previous dental care	Yes
		None
10	Dental diagnosis	Dental caries related
		Non-caries related
11	Treatment provided at 1 st visit	Kindly specify
12	Was there need for further treatment?	Yes/No
13	If yes, how was treatment provided?	GA
		LA
		Other (indicate)
14	Treatment provided	Extractions
		Preventative
		Restorative

		Other	
		Not indicated	
15	Was the treatment completed?	Yes/No	
16	Follow-up care	Yes/No	

END OF FORM

Appendix 3: OHPs Participant Information Sheet



Study title: An assessment of oral health care delivery to children with special health needs at Dental Schools in South Africa.

Introduction

Greetings. My name is Dr Nancy Njoroge. I am conducting a study aimed at assessing the oral health care delivery to children with special needs at dental schools in South Africa. The study forms the basis of a PhD program.

Invitation to participate

I would like to request your participation in this study as an oral health care provider.

Background

Children with special healthcare needs (CSHCN) comprise a broad population group whose management may be complex, often requiring the services of different healthcare providers for holistic care. Oral health care delivery is affected by a variety of factors including child's medical status, dental treatment needs, and the human and infrastructural resources available at the dental schools. The study has the potential to improve integrated and holistic care for these children.

What the study involves

The study is a mixed methods iterative design and will begin with the quantitative phase then proceed to the qualitative arm. A retrospective record review of children between 3-18 years with special healthcare needs (CSHCN) and without (NSHCN) treated under GA between 1st January 2017 to June 2023. In addition, an online survey of all oral healthcare workers (OHCWs) at each academic dental hospital including dental specialists, dentists, registrars, dental therapists and oral hygienists will be conducted to explore their experiences and perceptions towards dental care for CSHCN.

In the second qualitative phase, online interviews will be conducted with each key informant (HOD/HCU) from the department of paediatric dentistry at each academic dental hospital. In addition, an online focus group discussion (FGD) with OHCWs involved in the management of CSHCN will be conducted to explore their experiences and challenges faced while providing treatment for CSHCN.

Confidentiality and anonymity

Personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and her supervisor. However, confidentiality and anonymity cannot be guaranteed in the focus groups discussions. Kindly see separate PIS and consent form provided for the FGD. All guidelines that relate to the POPI Act will be observed throughout the study.

Participation is voluntary and submission of the online questionnaire is taken to mean consent to participate.

Benefits of being involved in the study

There are no direct benefits to the participants and no re-imbursements will be provided for the time used to participate in the surveys.

Risks to the participants

There are no foreseeable risks to the participants.

Outputs

The study will be reported in the form of a thesis and manuscripts for publication.

Contact details:

The study has been reviewed by the University of Witwatersrand Human Research Ethics Committee(medical) and granted provisional approval. For any questions or concerns about the study, kindly contact the Chairperson of the Ethics Committee at the following email: HREC-Medical.ResearchOffice@wits.ac.za. In addition, one may also contact the principal researcher Dr Nancy Njoroge on 078-247-0860 or the supervisor Prof. Phumzile Hlongwa on 072-664-4664.

April 2022

Thank you for your time.

Appendix 4: Participant Consent Sheet



Project Title: An assessment of oral health care delivery to children and adolescents with special health needs (SHCN) at Dental Schools in South Africa.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Dr Nancy Njoroge, Principal Investigator, telephone no. 078-247-0860, or by e-mail at, Nancy.Njoroge@wits.ac.za

Prof. Phumzile Hlongwa, Supervisor, on telephone no. 072-664-4664, or by e-mail at Phumzile.hlongwa@up.ac.za

Dr CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.

Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix 5: Oral Health Care Providers Questionnaire

Perceptions of oral health care providers towards dental care for CSHCN.

Perceptions of dentists regarding oral health care for children with special health care needs (SHCN) attending dental teaching hospitals.

A. Socio-demographic characteristics:

1	Age bracket (tick one)	☐	☐	☐	☐
		25-34	35-44	45-54	>55
2	Gender M/F	☐	☐		
		M	F		
3	Do you have a Post-graduate qualification?	☐	☐	☐	☐
		Y	N		
4	How long have you been in clinical practice?	☐	☐	☐	
		< 5 years	5-10 years	>10 years	

B. Experiences in the care of

☐	☐
--------------------------	--------------------------

children with
special health
care needs
(SHCN) :

1

Do you currently treat
children with SHCN?

Y

N

2

On average, how many
SHCN do you treat per
month?

1-3

3-5

>5

3

What category of special
needs do you often
encounter: ,

physical
disability

developmental
disorders

behavioural/
emotional
disorders

medically
compromised

craniofacial
anomalies

others

4

What category of special
needs do you find most
challenging to manage?
Kindly tick one.

physical
disability

developmental
disorders

behavioural/
emotional
disorders

medically
compromised

craniofacial
anomalies

others

5

At what point do you
provide care for children
with special needs?

A/E initial
appointment

Subsequent
routine dental
appointments

Multidisciplinary
clinics eg cleft
clinic

Dental
General
Anaesthesia
(DGA)

Undergraduate
dental clinics

Outreach
platforms

Other

6

What is the most common
treatment rendered to
patient?

Pain relief
meds

Extraction

Oral hygiene
instructions and
preventive
treatment

Periodontal
treatment

Restorative
care

Other

7	What guides your approach to care? Kindly rank in order of your approach.						
		Patient dental needs	Patient's behaviour	Patient's medical status	Parent's desires/motivation	Infrastructure available	Dental team support
		My own experience	Time available	Other, kindly indicate			
8	Do you have a protocol in your institution that guides your care approach?						
		Y	N				
9	Do you collaborate/consult with other dental teams in your care approach?						
		Y	N				
10	If yes, which professionals?						
		Maxillofacial surgeons	Oral pathologist	Orthodontist	Restorative	Others name	
11	Do you collaborate with other medical professionals in the hospital in your care approach? Y/N						
		Y	N				
12	If yes, which professionals?						
		Paediatrician	Anaesthetist	Speech therapist	Others name		

C. Perceptions
on education
and Training
Needs:

1	How well did your undergraduate education prepare you to treat children with SHCN? Very well, well, fairly well, poor, not at all	Very well	Well	Fairly well	Poorly	Not at all
2	Did you have any hands-on experience in treating children with SHCN in your undergraduate training?	Y	N			
3	Have you had any additional training in special care dentistry since graduation? Y/N	Y	N			
4	If yes, kindly indicate update how you update your current knowledge and expertise regarding care of children with special needs?	CDE programs	Conferences	Online resources	Seminars or Journal clubs	other

5

In the last 2 years how many times have you attended the above programs?

CDE programs	Conferences	Online resources	Seminars or Journal clubs	other

6

Do you think special care dentistry should be part of undergraduate curriculum?
Y/N

Y

N

D. Challenges encountered in the care of children with SHCN:

Kindly indicate if you agree, disagree or not sure for each statement.

The following challenges affect the way I care for child with SHCN:

1

Patient's inability to cooperate

2

Patient's problems with communication

Agree	Disagree	No Sure

3	My level of training and/or experience			
4	Inadequately motivated parent,			
5	Time constraints,			
6	Lack of supportive dental team,			
7	Lack of suitable equipment,			

	Other challenges, please indicate			
	Which of the following statements describes how you feel towards caring for a child with SHCN? (tick the ones that apply)			
		Agree	Disagree	No Sure
1	I like treating a child with special needs.			
2	I find treating a child with special needs stressful.			
3	I find caring for child with special needs fulfilling.			
4	I do not enjoy treating a child with special needs.			
5	I do not mind treating a child with special needs with appropriate support/facilities.			

Thank you for
your time.

Appendix 6: Key informants Online Interview Guide

1) Socio-demographic information:

a) Age bracket in years

25-34	
35-44	
45-54	
>55	

b) Gender

M	
F	

c) Post-graduate education

Y	
N	

d) Area of specialty

e) Current position: HOD, HCU, other

HoD	
HCU	
Other	

f) Length of time in position above: < 5, 5-10 years, >10

<5 years	
5-10 years	
>10 years	

2) How is Paediatric Dentistry teaching and training done at your institution?

.....

.....

.....

.....

.....

.....

3) The following questions relate to the dental care for children with special needs (CSHCN) at your institution:

a) Do you provide oral health services for CSHCN?

Y	
N	

b) Approximately how many CSHCN do you see per week?

c) What types of oral health care services to CSHCN do you provide?

d) Do you provide GA services for CSHCN?

Y	
N	

e) If no, how do you manage patients in need of dental treatment under GA?.....

.....

.....

- f) How would you describe the current infrastructure for providing GA services for these children?

4) The following questions relate to staff training

- a) Do your staff members have any additional training in management for CSHCN?
 b) Does the department provide any support for training?
 c) Do you think further training would be helpful in equipping staff with knowledge and skills to better care for CSHCN?

5) The following questions relate to inter-disciplinary collaboration in management of CSHCN

- a) Do you involve other departments in the dental care of CSHCN?

Y	
N	

- b) If yes, what departments do you collaborate with?

- c) Are there any external collaborations with other departments in the hospital?

Y	
N	

- d) If yes, what departments do you collaborate with?

- e) How would you describe the current level of collaborations in the care of CSHCN?

Adequate	
Satisfactory	
Not adequate	

- f) Do you have a dedicated staff member to coordinate the dental care between health professionals?

Y	
N	

6) How would you improve your current services for CSHCN?

Thank you for your time.

Appendix 7: Consent Form for Audio Recording of Study Participation



Project Title: An assessment of oral health care delivery to children with special health needs (SHCN) at Dental Schools in South Africa.

I hereby consent to audio recording of the online focus group discussion (FGD)

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of witness: _____

Signature: _____

Date: _____

Appendix 8: Focus Group Schedule

Identify factors influencing delivery of oral health care to children with SHCN at dental schools

The principal investigator (PI) will start the session by welcoming participants and introducing the purpose of the discussion. The PI will proceed to read aloud the oral consent for audio recording before starting the discussion.

The following series of questions will be used to guide the discussion with the PI acting as a facilitator:

1. What is your experience in managing children with SHCN?
2. How do you go about providing oral health care to SHCN?
3. What challenges (personal, patient, professional and infrastructural) do you encounter while providing services?
4. In your opinion, how would the above challenges be overcome?

Each question will take approximately 10 minutes, and the entire session completed in 45 minutes. At the end of the session, the recording will be stopped, and participants informed. The PI will thank the participants for their time and contribution.

Appendix 9: Approvals from Academic Dental Hospitals



12 August 2022

Dr Nancy Njoroge
Student Number (2498995)
Doctor of Philosophy
School of Oral Health Sciences

TO WHOM IT MAY CONCERN

"Evaluation of oral health care delivery to children with special needs at Dental Schools in South Africa."

This letter serves to confirm that the above project has received permission to be conducted on University premises, and/or involving staff and/or students of the University as research participants. In undertaking this research, you agree to abide by all University regulations for conducting research on campus and to respect participants' rights to withdraw from participation at any time.

If you are conducting research on certain student cohorts, year groups or courses within specific Schools and within the teaching term, permission must be sought from Heads of School or individual academics.

Ethical clearance has been obtained. (Protocol number: M220266)

Research Expiration: (04 August 2027)

A handwritten signature in black ink, which appears to read "N Potgieter".

Nicoleen Potgieter
University Deputy Registrar

20 April 2022

Dr Nancy Njoroge
School of Oral Health Sciences
Faculty of Health Sciences
University of Witwatersrand
Email: Nancy.Njoroge@wits.ac.za

Dear Thandolwenkosi

RE: PERMISSION TO CONDUCT RESEARCH

Gatekeeper's permission is hereby granted for you to conduct research at the University of KwaZulu-Natal (UKZN), towards your postgraduate degree, provided Ethical clearance has been obtained. We note the title of your research project is:

"An assessment of oral health care delivery to children with special needs at dental schools in South Africa."

It is noted that you will be constituting your sample as follows:

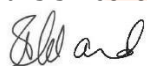
- With a request for responses on the website. The questionnaire must be placed on the notice system <http://notices.ukzn.ac.za>. A copy of this letter (Gatekeeper's approval) must be simultaneously sent to (govenderlog@ukzn.ac.za) or (ramkissonb@ukzn.ac.za).

Please ensure that the following appears on your notice/questionnaire:

- Ethical clearance number;
- Research title and details of the research, the researcher and the supervisor;
- Consent form is attached to the notice/questionnaire and to be signed by user before he/she fills in questionnaire;
- gatekeepers approval by the Registrar.

You are not authorized to contact staff and students using the 'Microsoft Outlook' address book. Identity numbers and email addresses of individuals are not a matter of public record and are protected according to Section 14 of the South African Constitution, as well as the Protection of Public Information Act. For the release of such information over to yourself for research purposes, the University of KwaZulu-Natal will need express consent from the relevant data subjects. Data collected must be treated with due confidentiality and anonymity.

Yours sincerely



Dr KE CLELAND. REGISTRAR

Office of the Registrar

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 7971 Email: registrar@ukzn.ac.za Website: www.ukzn.ac.za

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville



Western Cape
Government

TYGERBERG HOSPITAL

Reference:

Research Projects

Enquiries:

Dr E van der Merwe

Manager: Medical services

Erike.vandermerwe@westerncape.gov.za | Tel: 021 938 4430

Ethics Reference: WITS 220266

NHRD Reference: WC_202204_017

Title: AN ASSESSMENT OF ORAL HEALTH CARE DELIVERY TO CHILDREN WITH SPECIAL NEEDS AT DENTAL SCHOOLS IN SOUTH AFRICA

Dear Dr Nancy Njoroge

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

1. In accordance with the Tygerberg Hospital Health Research Policy and Protocol of April 2018, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital for a year based on your HREC approval.
2. Researchers, in accessing the Provincial Health facilities, are expressing consent to provide the department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial research Co-Ordinator (Health.Research@westerncape.gov.za).

DR E VAN DER MERWE

MANAGER: MEDICAL SERVICES

Date: 22/04/2022

Administration Building, Francie van Zijl Avenue, Parow, 7500
Tel: +27 938 4430

Private Bag X3, Tygerberg, 7505
www.cape.gateway.gov.za



Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002507, Approved dd 18 March 2022 and Expires 18 March 2027.
- ICRG #: ICRG0001762 OMD No. 0890-0278 Approved for use through August 31, 2023

Faculty of Health Sciences Research Ethics Committee

10 August 2022

Approval Certificate New Application

Dear N Gichuhi

Ethics Reference No.: 385/2022

Title: An assessment of oral health care delivery to children with special needs at dental schools in South Africa

The **New Application** as supported by documents received between 2022-08-24 and 2022-08-10 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2022-08-10 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2023-08-10.
- Please remember to use your protocol number (385/2022) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

On behalf of the FHS REC, Dr R Sommers

MBChB, MMed (Int), MPharmMed, PhD

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 46 and 45. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2016 (Department of Health)

Research Ethics Committee
Room 1 08, Level 1, Tloasele Building
University of Pretoria, Private Bag x823
Gedisa 0031, South Africa
Tel: (+27) 012 329 3051
Email: deap@ethics.up.ac.za
www.up.ac.za

Fakeliset: Gesondheidswetenskap
Lefapha la Lipenseiso Naphele

PERMISSION TO DO RESEARCH

TO: PROF SL SHANGASE
Chair of the School of Dentistry, University of Pretoria
CEO Oral and Dental Hospital

FROM: THE INVESTIGATOR: Dr Njoroge NW

PERMISSION TO DO THE FOLLOWING RESEARCH AT ORAL AND DENTAL HOSPITAL

Part-time, Department of Orthodontics, Wits SOHS

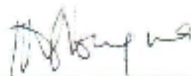
I am requesting permission to conduct a study on the Oral and Dental Hospital grounds that involves the access of dental records and radiographs for this retrospective study.

The title of the study is: AN ASSESSMENT OF ORAL HEALTH CARE DELIVERY TO CHILDREN WITH SPECIAL NEEDS AT DENTAL SCHOOLS IN SOUTH AFRICA

I intend to submit the findings of the study for publication in a professional journal and/or at professional meeting like symposia, congresses, or other meetings of such a nature.

I undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Ethics Committee, University of Pretoria.

Yours sincerely,



SIGNATURE OF THE INVESTIGATOR

PERMISSION TO DO RESEARCH STUDY AT THIS HOSPITAL AND TO ACCESS THE INFORMATION AS REQUESTED IS HEREBY APPROVED



PROF SL SHANGASE
CHAIR – SCHOOL OF DENTISTRY
CEO OF ORAL AND DENTAL HOSPITAL

7/9/2022
DATE

Oral health in children and adolescents with special healthcare needs in South Africa: A narrative review

SAGJ March 2024, Vol. 79 No.2 p102-108

N Njoroge¹, A Magan², P Hongwa³

INTRODUCTION

Children and adolescents with special healthcare needs (CWSHCN) may experience disproportionately poorer general and oral health than healthy children.^{1,2} They are more at risk of common conditions such as dental caries and gingivitis resulting from poor oral health.⁴ They comprise of children and youth "with or at risk of chronic physical, developmental, behavioural or emotional conditions",⁵ including, inter alia, intellectual disability (ID), cerebral palsy (CP), learning disability (LD), autism spectrum disorder (ASD), hearing impairment (HI), Down Syndrome (DS), physical disabilities (PD), visual impairments (VI) and epilepsy (EP). Globally, the prevalence of disabilities is increasing, even in developing countries such as South Africa (SA), resulting in a greater burden on healthcare systems.⁶

The 2011 World Health Organisation (WHO) report estimated that 15% of the global population had a disability. There was a slightly higher prevalence of individuals with disabilities in developing countries than in developed countries.⁷ Among children aged 0-14 years and those above 15 years, 5.1% or 63 million and 19.4% or 892 million had a moderate or severe disability, respectively. Due to the lack of current epidemiological data, there are no accurate figures of children with disabilities in SA. However, the 2011 census in SA found that about 609,671 children aged between 5-14 years had a disability.⁸

Individuals with developmental disabilities such as ASD are more likely to develop oral diseases compared to typically developing children.⁹ Poor dietary choices and between meal consumption of sugars increase the risk for dental caries,¹⁰ while inadequate oral hygiene additionally increases the susceptibility for gingivitis. Children with ID may lack the cognitive and/or manual dexterity to perform oral hygiene independently, while uncooperative behaviour

makes routine oral hygiene practices difficult for the parent/caregiver. Furthermore, medication such as phenytoin, an anticonvulsant drug used in children with epilepsy, may predispose to gingival hypertrophy¹¹ and impede proper plaque control. Caries risk also increases in the presence of developmental defects of enamel and enamel hypoplasia that may be present in young patients with CP.¹²

Poor oral health can negatively impact general health, especially in children with disabilities.¹³ When left untreated, dental caries leads to chronic pain, infection, sleep disruption, premature tooth loss and poor weight gain as the child cannot feed properly, which may impact growth and development.¹⁴ Dental infections resulting from poor oral health also pose a risk for bacteraemia and potential life-threatening septicemia, especially in immunocompromised children.¹⁵ Mostly, the oral health management of CWSHCN is performed under general anaesthetic. The time and cost associated with treatment under general anaesthesia puts additional strain on the healthcare system, especially in developing countries.¹⁶ Furthermore, there is an associated economic burden on families related to the cost of treating oral diseases,¹⁷ more so for CWSHCN with additional healthcare needs.

Despite the adverse consequences of poor oral health, globally CWSHCN are likely to encounter barriers to dental care services.¹⁸ In addition, factors related to the severity of the child's disability and the family's socioeconomic level may limit access to non-preventative dental care.¹⁹ In SA, the lower socioeconomic groups suffer from a greater burden of ill-health and disability and are less likely to use health services.²⁰

Understanding the characteristics and status of oral health among CWSHCN helps to reveal their needs more specifically and address any barriers to dental care. In the area of oral health for individuals with disabilities, only a few studies have been conducted in SA, a country which has significant health inequalities.²¹ Thus, the aim of this review was to describe the characteristics and status of oral health among CWSHCN in SA. The study forms part of a PhD programme for the principal investigator (NN).

MATERIALS AND METHODS

Search strategy

A literature review was conducted based on the PRISMA 2020 statement for systematic reviews.²² An internet-based search was performed for the articles published between January 1 2002 and August 31 2023. This period was chosen as the last SA National Children's Oral Health survey (NCOHS) was conducted two decades ago (1999-2002).²³ Notably, CWSHCN were not included in the survey. The keywords used were: oral health, dental caries, children/adolescents and South Africa. The following electronic

Authors' information

1. Dr Nancy Njoroge, BDS, MSc (Paed Dent), Department of Orthodontics, School of Oral Health Sciences, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa
ORCID: 0009-0000-3693-9406
2. Dr Anusiyeh Magan, BSc (Hons), BDS, MSc (Dent), PhD (Paed), SAMRC/Wits Developmental Pathways for Health Research Unit, Department of Paediatrics, School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa
ORCID: 0000-0001-9183-6476
3. Prof Phumle Hongwa, BCh, BSc, MSc (Dent), PhD (Orthod), FCD (Orthod), PhD, Department of Orthodontics, School of Dentistry, Faculty of Health Sciences, University of Pretoria, South Africa
ORCID: 0000-0002-8052-9275

Corresponding author

Name: Dr N Njoroge
 Email: Nancy.Njoroge@wits.ac.za

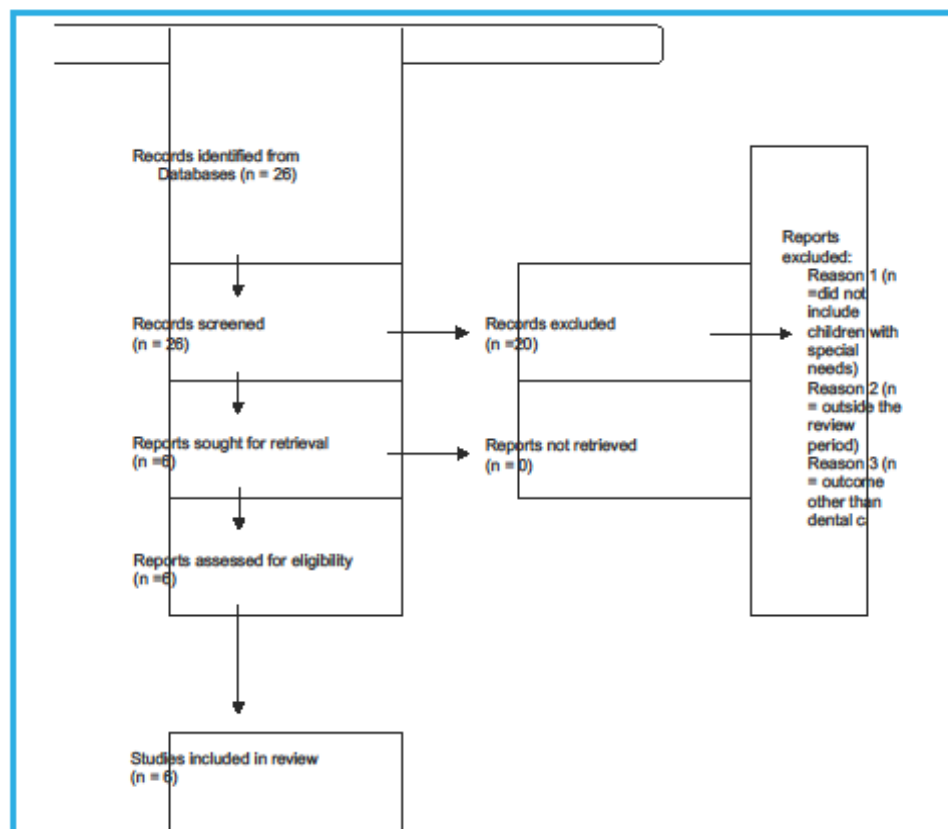


Figure 1. PRISMA 2020 statement flow diagram for selection of studies.

databases were searched for studies that met the eligibility criteria for this review: MEDLINE, PubMed, SCOPUS.

Eligibility criteria

The eligibility of potential studies was determined by reading the title and abstracts of each article identified by the search engine. All articles that appeared to meet the inclusion criteria based on their abstracts were selected and collected. Full-text articles were obtained for manuscripts with missing abstracts or those in which insufficient relevant information was found in the published abstract. Reference lists of the included studies were also screened for potentially relevant research. The final selection was independently carried out by the principal investigator (NN) and the co-authors after reading the complete articles and the results were compared for agreement. Studies were eligible for inclusion if they met the following criteria: (a) performed in SA, (b) children and/or adolescents with special health needs/disability, (c) assessed oral health by quantitative measurement or qualitatively as reported by a parent or caregiver, (d) the decayed, missing and filled teeth index (dmft for primary and DMFT for secondary teeth) was used to assess caries severity. Only articles published in English were included. Unpublished manuscripts and grey literature were excluded. The results of the search, selection process and the number of studies included and excluded at each stage are shown in Figure 1.

Table 1: Data extraction tool

Author(s)	
Year of study	
Study objective	
Study setting	
Study design	
Study population and sample size	
Type of SHCN/disability	
Key findings	
Critique	

Ethical considerations

Approval to conduct the study was obtained from the University of Witwatersrand Human Research Ethics Committee (Clearance number M220266).

STUDY FINDINGS

Characteristics of the identified studies

A total of 26 articles were retrieved, 20 of which did not meet the eligibility criteria. The reasons for excluding these articles were (i) participants were not CWSHCN, (ii) the study was conducted outside the review period or (iii) outcome other than dental caries. The six studies that were included in this review were cross-sectional in design and most participants

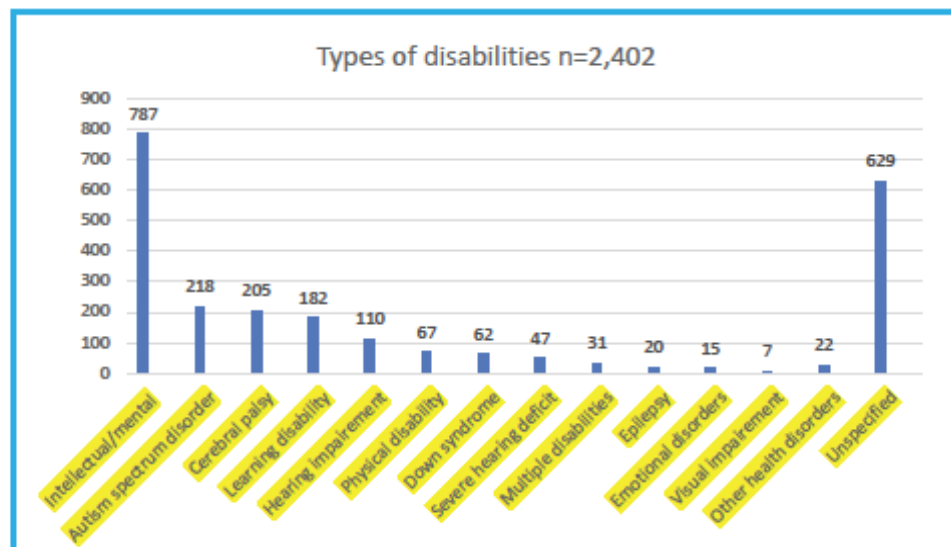


Figure 2. Types of disabilities among CWSHCN.

were from public special needs schools. The studies were conducted in urban and peri-urban settings except for one in a rural setting, thereby representing different socioeconomic backgrounds of the study participants in SA.²⁵

Characteristics of the study participants

A total of 2,402 individuals with special healthcare needs were included in the review, 59.7% (n=1,433) of whom were male and 40.3% (n=969) were female. The age of the children ranged between 0 and 20 years. One study used caregivers of CWSHCN as a proxy of their child's oral health status.²⁶

Types of disabilities

The types of disabilities varied across the studies. Among the disabilities included, *inter alia*, ID/MD n=787, CP n=205, LD n=182, ASD n=218, HI n=110, PD n=67, DS n=62, severe HI=47, EP n=20, "complex/multiple disabilities" n=31, VI n=7, ED n=15 and other health disorders n=22 as shown in Figure 2. The type of disability among the 629 children with special needs in one rural setting was not recorded. A descriptive summary of the articles is presented in Table 2.

Oral health status of CWSHCN

Poor oral health among CWSHCN was observed in all studies presenting as caries and/or gingivitis. The prevalence of caries among CWSHCN ranged from 22.5% to 85.2%.²⁷ The mean dmft/DMFT scores ranged from 0.95 (SD 2.36) to 5.51 (SD 2.1)^{28,29} and 0.67 to 10.24 (SD 2.97)^{28,29} for the primary and permanent dentition, respectively. The studies reported high UTNs and mostly constituted untreated caries among the study participants of between 68%³⁰ and 100%,²⁶ attributed to low restorative care.

One study found that over half of the parents (56.7%) of CWSHCN rated their child's oral health status as average,²⁶ despite the high UTNs among the study sample. Furthermore, most caregivers (61%) of CWSHCN did not perceive the oral problems in their child as having an impact on overall health.

Two studies included a gingival health assessment and reported between 46% and 89% presence of gingival inflammation among children with ASD and ID, respectively.^{28,30} One study reported plaque index as visible plaque in 43.6% of children with ASD.²⁸

Other notable oral findings included mild loss of enamel (47%) and soft tissue trauma (lip biting) (25%) among children with ASD.²⁸ Orthodontic need for the correction of malocclusion were reported in 29% of children with ID.²⁹ However, the study did not elaborate on the types of occlusal disharmony in the study sample.

DISCUSSION

The characteristics and status of oral health among CWSHCN in SA between 2002 and 2023 were reviewed. Only six studies among CWSHCN were relevant, highlighting the paucity of data in SA. However, our review shows that the status of oral health for approximately 2,402 CWSHCN, aged between 0 and 20 years, were evaluated in the past two decades. Of the total sample in the six studies reviewed, 59.7% were male and 40.3% were female. According to the 2011 census, the prevalence of disability in SA was 7.5%³¹ and more than 600,000 children aged between 5–14 years had a disability. Notably, due to the lack of current epidemiological data, the number of children with disabilities in SA is largely unknown. The NCOHS conducted between 1999–2002³² reported that 39.7% of the 6-year-old age group were caries-free; however, this survey did not include CWSHCN. Furthermore, the figure was below the 50% goal set by the SA Department of Health (DoH) for the year 2000.³²

Our study findings showed that the types of disabilities included, *inter alia*, intellectual disabilities (ID), Down Syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP), epilepsy (EP), learning disabilities (LD), hearing impaired (HI), physical disabilities (PD), visual impairment (VI), emotional disorders (ED) and "complex/multiple disabilities". This list, however, did not include all CWSHCN defined as "...living with or at risk of chronic physical, developmental

Table 1: Descriptive summary of the studies reviewed

Author	Year	Objective	Design	Sample (n)	Type of SHCN/ disability	Study setting	Results
Yengopal <i>et al</i>	2012	To determine the caries prevalence and UTN of children with special needs and compare with data from NCOHS	Cross-sectional analytic study	882 children (3-18 years) (65% male) mean age 10.5 years	Cerebral palsy (CP) (18.5%), hearing impaired (HI) (11.2%), learning disabilities (LD) (19.4%) and mental disability (MD) (51%)	Five special needs schools in Johannesburg (urban)	- Prevalence of caries: primary dentition – 27.55%, permanent dentition – 33.56% - More than 80% UTNs - dmft score 1.35 (LD) – 3.4 (CP) - DMFT score 0.67 (HI) – 1.27 (MD)
Nemutandani <i>et al</i>	2013	To determine the prevalence of dental caries among disabled individuals attending special schools in Vhembe districts.	Cross-sectional descriptive study	629 Individuals with special needs (46% males) 0-6, 7-10, 11-18 and 19+ years	Disability not specified	Four special schools in Vhembe district, Limpopo (rural)	- Prevalence of caries – more than 80% in all age groups. - dmft score under 6 years – 5.51 (SD 2.1) - DMFTs of the 11-18 years – 7.38 (SD 3.22) and above 19 years – 10.24 (SD 2.97). - High UTNs, < 1% restorative care
Roberts <i>et al</i>	2016	To assess the dental needs of a group of children with Intellectual disability (ID) attending six special educational facilities in Cape Town, SA	Cross-sectional study	157 children with ID (67% males) mean age 10.1 years	Intellectual disability (ID)	Six special educational facilities in Cape Town (urban)	- Prevalence of dental needs: - Gingival disease (69%) - Untreated dental caries (68%) - Malocclusion requiring orthodontic correction (29%)
Naldoo and Singh	2018	To investigate the oral health status of children with ASD aged between 7-14 years in KwaZulu-Natal, SA	Investigative cross-sectional quantitative study	149 children with ASD (71.1% males), 7-8, 9-10, 10-11 and 12-14 years	Autism spectrum disorder (ASD)	Special needs schools in KwaZulu-Natal (78% peri-urban)	- Overall caries prevalence – 85.2%. - DMFT score – 3.42 - Molars – 50% of score - UTNs – 68.5% - Soft tissue trauma with lip biting – 25%. - Mild gingival inflammation – 46.3%
Nqobo <i>et al</i>	2019	To assess how caregivers of CWSHCNs perceived the contribution of OHRQoL to the quality of life of these children	Survey of caregiver OHRQoL and child's oral health status	Convenient sample of 150 caregivers (mean age 39.5) and child pairs (mean age 8.7 years) (59.3% males)	Down syndrome (DS) (41%), CP (28%), ASD (10%), epilepsy (EP) (10%), complex disabilities (10%) and unknown (1%)	Down Syndrome Association (DSA) outreach sites in Johannesburg (urban)	- Overall caries prevalence – 42% 56.7% of caregivers rated child's oral health as average - Untreated caries (93-100%) regardless of disability type
Gumede <i>et al</i>	2023	To determine the prevalence of dental caries among learners with disabilities attending special schools education in the eThekweni district	Cross-sectional descriptive study design	435 children with disabilities (62.3% male) mean age 13 years	ID (41.8%), physical disability (PD) (15%), ASD (12.4%), severe HI (10.8%), HI (2.5%), multiple disabilities (3.7%), LD 2.5%, visual impairments (VI) 1.6%, emotional disturbances (ED) 3.4%, other health impairments 6.2%	22 special schools in eThekweni (80% peri-urban and 27.1% urban)	- Prevalence of caries: Primary dentition – 22.5%, permanent dentition – 53.6%, DMFT – 1.97 (SD 2.36) - D-88%, F-4%, M-9% - dmft-0.95 (SD 2.36) - Decay component – 99% - Highest caries prevalence in ID – 46.4% - dmft/DMFT increase with age (p=0.01)

CWSHCN: children with special health care needs OHRQoL: oral health related quality of life UTN: unmet treatment needs dmft/DMFT: decayed, missing, filled tooth for deciduous and permanent tooth respectively

and behavioural conditions...".² Our study did, however, reflect the categories of disabilities provided in the 2011 SA census where the International Classification of Functioning Disability and Health²⁰ was used to categorise disability according to six functional domains: sight, hearing, communication, remembering/concentrating, walking and self-care. Using census data may have some limitations, for example parents are used as proxies to report on children with disabilities,²⁴ leading to possible underreporting. In addition, the use of functional domains may have resulted in the exclusion of children living with milder disabilities or chronic medical conditions who also form part of the diverse group of CWSHCN.

Our review found that caries prevalence among CWSHCN ranged between 22.5% and 85.2%. In addition, the caries severity reported by the dmft/DMFT scores varied across the disability groups and age categories. Caries severity appeared to increase with the age of the child in keeping with the impact of increased exposure to fermentable carbohydrates on dental caries development over time, and inadequate oral hygiene. Maintenance of oral hygiene is challenging for CWSHCN. For example, children with ASD display behavioural problems during routine tooth brushing while children with severe ID may lack the cognitive and manual dexterity to perform tooth brushing and rely on the parent/caregiver for assistance. Caregivers may be overburdened by the demands of caring for such children especially with poor support which is common in low resource settings.²⁵ Although the severity of the disabilities was not recorded in the studies reviewed, it is likely that SA children with more severe cognitive or behavioural problems may have had higher dmft/DMFT scores in keeping with the results of a study in India where children with severe ID had higher DMFT scores.²⁶ Identifying CWSHCNs who are at greater risk of dental caries and instituting early preventative measures may prevent the cumulative burden of dental caries over time.

Dental caries in children largely remains untreated. In 2010, untreated caries in the deciduous dentition was the 10th most prevalent condition affecting 9% of the global population.²⁷ Furthermore, the condition is even more prevalent in many low- and middle-income countries (LMICs).¹⁷ In SA, more than 80% of caries in children in the last NCOHS was not treated.²³ More than two decades later, our review has shown significant UTNs among CWSHCN as reflected by the high "decay" component of the dmft/DMFT scores. Similarly, high UTNs have been reported among CWSHCN in other LMICs such as Brazil, India, Nigeria and Rwanda.²⁸⁻⁴¹ Some of the reasons for high UTNs were low utilisation of oral healthcare services,⁴² transportation difficulties,⁴² financial constraints of parents, reluctant dental providers and behavioural challenges of CWSHCN in the dental setting.⁴³ In a systematic review of the determinants of dental caries among children residing in North Africa and the Middle East, the interplay of child characteristics, family background, diet and oral hygiene habits influenced oral health in children.⁴⁴ Thus, barriers related to the child's special need/disability, family socioeconomic status and the environment may hinder access to preventative and restorative treatment for CWSHCN, especially in LMICs. These barriers suggest that a multifaceted approach is required to address the oral health inequalities and improve access to dental care. All stakeholders involved in children's health need

to prioritise oral health for CWSHCN, especially for those from disadvantaged backgrounds. Policy guidelines need to address contextual issues related to poor oral health for this population group in both developing and developed countries. To this end, the South African government has shown a commitment to provide universal health coverage through the National Health Insurance (NHI) Bill, and improve access to quality healthcare to previously disadvantaged groups.⁴⁵

Two studies in SA reported poor oral hygiene among children with ID and ASD.^{28,30} Similar findings were reported in Nigeria among 5- to 19-year-old children where significantly poorer oral hygiene was found in children with special needs compared to healthy children.⁴⁰ Globally, poor oral hygiene has been reported among children with ID,² resulting in gingivitis.⁴⁶ Gingivitis can resolve with improved oral hygiene; however, when left untreated it may progress to periodontitis, a chronic inflammatory disease of the dental supporting structures. Periodontitis, in turn, increases the risk for the development of noncommunicable diseases such as diabetes and cardiovascular diseases.⁴⁷ Thus, it is vitally important to maintain good oral health in CWSHCN for both oral and general health.

In this review, other reported oral health problems among CWSHCN in SA included malocclusion (29%)³⁸ and soft tissue trauma (25%)²⁸. A 1994 SA study found that 74.5% of the 381 children with disabilities needed orthodontic treatment.⁴⁸ Similarly, a high prevalence of malocclusion was found among children and adolescents with mental disabilities in India.⁴⁹ Occlusal disharmony may be more prevalent among certain groups of CWSHCN such as spastic CP, in whom an imbalance of the orofacial muscles may result in constriction of the dental arches, a posterior cross bite and an anterior open bite.¹¹ Furthermore, patients with malocclusion characterised by protrusion of maxillary permanent incisors are more prone to traumatic dental and soft tissue injuries.⁵⁰ Among the risk factors associated with malocclusion in children with CP include mouth breathing and lip incompetence.⁵¹ Thus, there is a need to incorporate orthodontic treatment in children with milder forms of disabilities to improve their quality of life.

The oral health status of CWSHCN may affect their overall quality of life.⁵² Untreated dental caries may affect the ability to eat, drink and sleep without discomfort or pain.⁵³ Developmental delay may affect speech and cognition making it difficult for the children to express discomfort or the feeling of pain.⁵⁴ However, despite evidence pointing to the negative impact of poor oral health such as severe dental caries on the quality of life among CWSHCN,⁵⁵ one study in SA reported contradictory findings where 61% of caregivers of CWSHCN did not consider the oral condition in their child to impact overall health.²⁶ The chronic medical condition of the child or disability may be more of a priority due to its impact on morbidity. Dental caries in the absence of pain, discomfort or sleep disruption may not be perceived as negatively affecting the child and needing attention. Caregivers' perceptions may be related to their socioeconomic status (SES) as children from families with high SES and parental education had better oral health-related quality of life.⁵⁶ Hence, contextual factors, especially in resource constrained settings, may influence the extent to which untreated dental caries among CWSHCN is perceived to impact overall quality of life.

Access to healthcare is a key global goal on the development agenda. The United Nations Millennium Development Goals (MDGs) in 2000 and later the Sustainable Development Goals (SDGs) and, more specifically, SDG3, committed to "ensure healthy lives and promote wellbeing for all at all ages".⁵⁷ Among the goals of the National Oral Health Policy in SA is the promotion of oral health and increased access to services. However, the policy is outdated and in need of review based on current epidemiological data.⁵⁸ The inclusion of CWSHCN, who may be more at risk for dental diseases, would be important to provide specific strategies for the prevention and treatment of oral diseases and increase access to services in line with the NHI Bill. In addition, an integrated maternal and child oral health policy aimed at increasing access to oral health services for mothers and children could reduce the oral disease burden among children and those with special needs.⁵⁹ SA has been successful in creating an enabling environment for policy development work in the field of disability.⁶⁰ However, policy implementation has faced challenges of capacity constraints, low resource allocation and lack of government commitment. In a review of the National Oral Health Policy in SA, Mukhari-Baloyi et al⁶¹ noted that the policy goals were clear but strategies for implementation were not well understood. Hence, more needs to be done to translate policies on people with disabilities to accessible and comprehensive healthcare that includes oral health, in developing countries such as SA, to promote equity and reduce inequalities.

Despite significant socioeconomic reforms in SA in the past two decades,⁶¹ inequalities in health, including oral health, for people with disabilities persist.⁶¹ Factors related to poverty such as unemployment, low literacy and inadequate access to healthcare have a greater negative impact on South African individuals living with disabilities.⁶² In SA, children with disabilities, particularly from low-resource settings, may face challenges accessing basic services such as health and education. For example, in a group of 156 children with disabilities from a small town near Soweto in SA, few were able to access basic education, assistive devices and social grants.⁶³ The situation appears not to have improved significantly in post-apartheid SA. In one qualitative study, caregivers of children with ID from a small town in SA reported financial difficulties, poor care networks and community stigma as barriers to utilisation of specialised hospital services.⁶⁴ Apart from individual caregiver and community barriers, system level barriers have been cited. For instance, a scoping review found that among children with disabilities living in LMICs in sub-Saharan Africa, poor policy implementation, lack of physical access and inadequately trained health professionals were barriers to healthcare access.⁶⁵ These factors may affect the quality of life of not only the children with disabilities but also their families. Therefore, addressing the wider social and economic disparities affecting health and healthcare access may lead to better oral and general health for children with disabilities in SA.

STRENGTHS AND LIMITATIONS OF THE STUDY

Our review focused on the status of oral health among CWSHCN in SA over the past two decades. Among the limitations were, first, the availability of only a few studies. The exclusion of unpublished studies may have resulted in publication bias. Second, the exclusion of studies that did

not report dental caries as an outcome may have led to selective outcome reporting bias. Among the strengths of the review was the use of a standard literature review method and DET, thereby decreasing the risk of bias. In addition, the review included participants with various special healthcare needs and not individual categories of disabilities, thereby increasing the sample. Finally, the studies were conducted in different geographical and socioeconomic settings in SA, possibly providing different contextual factors related to the oral health of CWSHCN and enhancing generalisability of the results within SA.

Despite the limitations, the review offers useful insights into the lack of data related to the status of oral health among CWSHCN in SA. In addition, the review has consolidated data on the characteristics and status of oral health among CWSHCN in SA over the past two decades. The data are important in understanding the oral health needs of this vulnerable group and to plan strategies to improve oral health, oral health outcomes and reduce inequalities in line with the SDGs call to "leave no one behind".⁵⁷

CONCLUSION

Poor oral health and high UTNs were prevalent among CWSHCN in SA, with little evidence of preventative and restorative care. There was insufficient published data on the status of oral health among CWSHCN in SA.

RECOMMENDATIONS

There is a need for a nationwide survey to determine the oral health status of CWSHCN in SA, to enable proper planning of preventative and comprehensive oral healthcare. Future research should focus on identifying the barriers to accessing early preventative and restorative care. Increasing awareness of the importance of good oral health for CWSHCN among all stakeholders involved with children could facilitate early referrals for preventative and restorative care.

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CPD questionnaire on page 120

The Continuing Professional Development (CPD) section provides for twenty general questions and five ethics questions. The section provides members with a valuable source of CPD points whilst also achieving the objective of CPD, to assure continuing education. The importance of continuing professional development should not be underestimated, it is a career-long obligation for practicing professionals.





ORIGINAL ARTICLE

Comparative Analysis of Dental Treatment for Children With and Without Special Healthcare Needs at Academic Dental Hospitals in South Africa

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ABSTRACT

Background: Children with special healthcare needs (CSHCN) experience higher unmet dental treatment needs than their healthy peers (NSHCN).

Aim: We compared dental treatment received by CSHCN and NSHCN at academic dental hospitals in South Africa (SA).

Design: Clinical records of 1–16-year-old children who had dental treatment under general anaesthetic (GA) between 2017 and 2023 were reviewed. Descriptive analyses were performed, and the Chi-square/Fisher's exact test used to analyse the categorical variables.

Results: Four hundred records (CSHCN: 116 [29%] and NSHCN: 284 [71%]) were analysed. The median age at assessment was 5 years (IQR: 3–6.5). CSHCN were older than NSHCN, ($p < 0.001$). More CSHCN (52.6%) than NSHCN (25.4%) were referred from primary health centres, ($p < 0.001$). Caries was the main dental diagnosis. Multiple extractions were done in 54.7% of CSHCN < 6 years and 52.8% of 6–11-year-old NSHCN. Restorative treatment was performed in 26.1% of 6–11-year-old CSHCN and 27.2% of NSHCN < 6 years.

Conclusions: Most of the CSHCN and NSHCN who needed GA were young with extensive caries. Treatment provided to both groups was primarily extractions, perhaps due to late presentation and limited resources. Timely preventative strategies for children at risk of caries could enhance oral health and reduce the burden of GA in SA.

1 | Introduction

Children with special healthcare needs (CSHCN) may be more at risk of common oral diseases, yet encounter greater barriers and unequal access to dental care compared to healthy children [1, 2]. Special health care needs are defined as 'any physical, developmental, mental, sensory, behavioural, cognitive, or emotional impairment or limiting condition that requires medical

management, health care intervention, and/or use of specialised services or programs.' [3] Oral health is integral to overall well-being [4] and especially in CSHCN as some may experience greater barriers to dental care because of their chronic medical condition [5].

In the 2011 SA census, the prevalence of disability was 7.5% and more than 600 000 children aged between 5 and 14 years had a

Summary

- Why this study is important to paediatric dentists?
 - Paediatric dentists play an important role in providing both primary and comprehensive oral healthcare to infants, children, adolescents including CSHCN. There are only a few paediatric dentists in developing countries. Thus, there is a need to advocate for training of these specialists to build capacity to manage CSHCN in PHC centres and improve access to oral healthcare.
 - Dentists should emphasise on preventative care for children at risk of caries. Providing a dental home for regular prophylaxis, fluoride and sealants may reduce the risk of dental caries requiring more extensive dental treatment under GA.
 - A proper referral pathway from PHC settings to ADHs is important to facilitate access to dental care for both CSHCN and NSHCN. An integrated system is essential for providing comprehensive and holistic care.

disability [6]. National data in SA on the status of oral health for CSHCN are lacking. A few studies reported dental caries prevalence ranging between 22.5% and 85.2% among CSHCN in SA [7–11]. Furthermore, in the 1999–2002 National Children's Oral Health Survey (NCOHS) [12], only 39.7% of the 6-year-old age group were caries-free, a figure well below the 50% target that had been set by the Department of Health (DoH) for the year 2000 [13]. This survey did not include CSHCN.

Dental caries, despite being preventable, mostly goes untreated in children globally [14]. In SA, according to last NCOHS, over 80% of the dental caries in children was untreated [12] leading to pain and/or sepsis. Tooth extraction is commonly done for pain relief, especially in CSHCN [15], while restorative treatment needs are not met [1].

Children with SHCN may face different hurdles while receiving dental care compared to their healthy peers. Dental anxiety, uncooperative behaviour, or having a developmental disability interferes with the safe delivery of routine dental treatment [16]. Sedation or general anaesthesia (GA) are needed to provide quality and comprehensive dental treatment in a single sitting. These procedures are more risky in CSHCN, and are costly [17]. Thus, the provision of dental treatment for CSHCN particularly in resource constrained settings can increase oral health inequity.

There is a dearth of studies in SA focusing on the dental treatment provided for CSHCN at public hospitals except for one study which was conducted at a SA children's hospital almost a decade ago [15]. Disparities in oral health persist among CSHCN in SA more than two decades post-independence [18]. To minimise these disparities and promote dental care provision for CSHCN, understanding the medical profile of patients receiving GA treatment is key. The aim of our retrospective study was to describe the characteristics of, and dental treatment received under GA for CSHCN and NSHCN at academic dental hospitals in SA. The results may facilitate better planning of comprehensive and integrated oral healthcare services for CSHCN.

2 | Materials and Methods

2.1 | Study Design and Setting

This was a retrospective descriptive study. All five academic dental hospitals (ADHs) in SA were approached for inclusion in the study. These ADHs are in three of the nine provinces of SA, as shown in Figure 1. Three of the ADHs are in Gauteng Province, one in the Western Cape Province and one in KwaZulu-Natal Province. The delivery of dental services in SA is decentralised to the provincial governments and provided through the primary health care (PHC) system. The services provided in PHC facilities consist primarily of pain relief extractions and management of infections. Thus, patients in need of more comprehensive services are referred to tertiary level or academic hospitals which have additional facilities and specialised health/dental professionals to manage CSHCN. However, access to these facilities is a challenge for caregivers of CSHCN living in remote areas of SA.

2.2 | Study Population

Participants were CSHCN and NSHCN aged between 1 and 16 years. All records of children receiving dental treatment under GA between 1 January 2017 and 30 June 2023 were included. Children receiving routine dental treatment under local anaesthetic (LA) were excluded from the study. Due to the challenges of establishing the accurate number of patients seen in each ADH per year, the sample size was estimated based on an earlier study conducted at one of the study settings [20]. The number of children who received dental treatment under GA over a two-year period was reported as approximately 40 per annum [20]. This was estimated to approximately 240 records per hospital over the study period (January 2017–June 2023) to constitute our study sample.

2.3 | Records Review

A standardised record review form was used to retrieve demographic and clinical data [21]. Only one reviewer was involved in the data extraction to reduce inter-reviewer variability. Pilot testing of the review form was done with ten clinical records for patients attending the routine paediatric dental clinic at hospital A prior to the data collection exercise, to check if the review form had documented the required information. Minor adjustments were done on the review form and the records used for piloting were not included for the study analysis. The data extracted included: age at the time of first visit in years which was categorised according to dental developmental stage (i) younger than 6 years (deciduous dentition), (ii) 6–11 years (transitional dentition) and (iii) 12–16 years (permanent dentition); sex (male and female); self-referred/referral information; previous dental history (yes or none); medical health status (CSHCN/NSHCN); the type of medical indication for GA treatment and, the dental diagnosis (dental caries and caries-related [caries, pulpitis, periapical infection]/non-caries related (dentofacial anomalies, trauma, cysts). The type of behavioural management was categorised as follows: (i) dental treatment under GA, (ii) sedation (iii) local anaesthetic, (iv) non-pharmacological or (v) not indicated. Sedation, LA and non-pharmacological methods were subsequently grouped



FIGURE 1 | Map of SA showing the location of the dental academic hospitals (red dots) [19].

together as non-GA. The treatment provided was categorised as (i) preventative (prophylaxis, fluoride, fissure sealants, preventative restorations); (ii) multiple extractions only; (iii) restorative and rehabilitation (pulp treatment, stainless steel crowns and extractions); (iv) Other (dentofacial/orthodontics, endodontics, biopsy) or (v) treatment not assigned.

2.4 | Data Analyses

Information from the records review form were captured in an Excel spreadsheet. All personal identifiers were removed from the records. Each study centre was assigned a unique identifier for anonymity. The data were stored in a password protected computer. Data were coded and imported into STATA Version 14 (Stata Corporation Inc., College Station, TX, USA). The Shapiro-Wilk test was used to assess normality and confirmed that the age of the sample was not normally distributed. Participant age was reported as median and inter-quartile range (IQR). Descriptive analyses were used to summarise the data using frequencies and percentages. The Mann-Whitney test was used to determine differences in age between CSHCN and NSHCN. Chi-square/Fisher's exact test were used to examine differences between the categorical variables. All statistical tests were conducted at a 5% significance level.

2.5 | Ethics Approval

The study was approved by the Human Research Ethics Committee (Clearance number: M220266). Further permissions

to access and review patient records were sought from each ADH, and written approval was provided from each of the hospitals that gave consent for the study. Guidelines regarding the protection of personal data stipulated in the POPIA were observed [22].

3 | Results

Data were collected from three of the five ADHs that provided permission for the study. A convenient sample was used due to the inability to obtain the estimated sample size. The availability of patients' records varied across the hospitals. In hospital A, the highest number of records were accessed and reviewed because they were filed and stored in alphabetical order in a storage room. The files for children treated under GA were marked with a sticker and easily identifiable. Fewer records were retrieved from hospitals B and C as the paediatric records for GA over the study period were not kept in an orderly manner. All the available files retrieved were included for the analyses.

3.1 | Demographic Profile of Participants

A total of 400 records were obtained and analysed from the three ADHs. Most of the patients ($n=187$; 46.8%) were from centre A, followed by centre C ($n=114$; 29%) whilst centre B had the lowest records retrieved ($n=99$; 25%) as shown in Table 1. There was a statistically significant difference between the CSHCN and NSHCN by centre, ($p=0.02$).

TABLE 1 | Demographic characteristics of children with and without special healthcare needs.

Characteristics	N = 400	CSHCN (n = 116)	NSHCN (n = 284)	p
Median age years (IQR)	5 (3–6.5)	6 (4–10)	4 (4–6)	<0.001
Age category				
Younger than 6 years	237 (59.3)	53 (45.7)	184 (64.8)	<0.001
6–11 years	135 (33.7)	46 (39.6)	89 (31.3)	
12 years and above	28 (7)	17 (14.7)	11 (3.9)	
Gender, n (%)				
Male	225 (56.3)	68 (58.6)	157 (55.3)	0.54
Female	175 (43.7)	48 (41.4)	127 (44.7)	
Number of children at each Centre, n (%)				
A	187 (46.8)	66 (56.9)	121 (42.6)	0.02
B	99 (24.8)	26 (22.4)	73 (25.7)	
C	114 (28.5)	24 (20.7)	90 (31.7)	
Referral status, n (%)				
Referred	133 (33.3)	61 (52.6)	72 (25.4)	<0.001
Self-referral	267 (66.7)	55 (47.4)	212 (74.6)	

Abbreviation: IQR, Inter-quartile range.

There were 116 patients (29%) in the CSHCN group and 284 (71%) in the NSHCN group. The median age of the patients was 5 years (IQR: 3–6.5), 56.3% of whom were male. The CSHCN were older than NSHCN ($p < 0.001$). Two-thirds of the patients 267 (66.7%) were self-referred while 133 (33.3%) were referrals mostly from PHC facilities. A significantly greater percentage (52.6%) of CSHCN than NSHCN (25.4%) were referred, ($p < 0.001$). The patients' demographic characteristics are presented in Table 1, and the age distribution is depicted in Figure 2.

3.2 | Clinical Profile of the CSHCN

Figure 3 shows the medical conditions of the CSHCN who presented for dental treatment under GA. The majority of the CSHCN had cerebral palsy (CP) ($n = 26$; 22.4%) followed by 19% who had various systemic conditions, Inter alia cardiac, endocrine, respiratory, immune suppression or cancer.

The characteristics of the entire population categorised by age are shown in Table 2. There were significant associations between centre ($p < 0.001$), sex ($p = 0.033$), being CSHCN ($p < 0.001$), dental diagnosis ($p < 0.001$) and the age category of the child. There was not enough evidence to show a statistically significant association between referral status and age category of the child.

The dental diagnosis and management of CSHCN and NSHCN categorised by age, are presented in Table 3. Dental caries, pulpitis and periapical infections occurred most commonly in both CSHCN and NSHCN across all age groups, except in NSHCN older than 12 years. Multiple extractions were commonly done

among CSHCN across age categories (45%–54%) and among the NSHCN aged 6–11 years (52.8%). In addition, about a quarter (26.1%) of CSHCN aged 6–11 and 27.2% of NSHCN younger than 6 years received restorative care. Overall, both groups received mainly extractions (43.5%), while 20% had restorative care and <10% had preventative care.

More than two thirds (69.8%) of CSHCN and 60% of NSHCN younger than 6 years had treatment under GA. In contrast, in the 6–11-year-old age group, a higher percentage (69.6%) of CSHCN received treatment under GA than their NSHCN (38.2%). About one-third (34.8%) of NSHCN aged 6–11 years had treatment under local anaesthetic.

The demographic and clinical characteristics of the patients by the type of behavioural management (GA/non-GA) are shown in Table 4. Of the total sample, only 307 patients received treatment while 93 patients did not have any treatment recorded and were omitted from further analyses. There were significant associations between age ($p < 0.001$), being CSHCN ($p < 0.001$), dental diagnosis ($p < 0.001$), treatment provided ($p < 0.001$) and the type of behavioural management. There was not enough evidence to show a statistically significant association between referral status and centre with type of behavioural management.

4 | Discussion

This study compared the dental care provided to CSHCN and NSHCN treated under GA at ADHs in SA. Among the CSHCN, the medical indications for treatment under GA included CP, various systemic conditions, craniofacial disorders, seizure

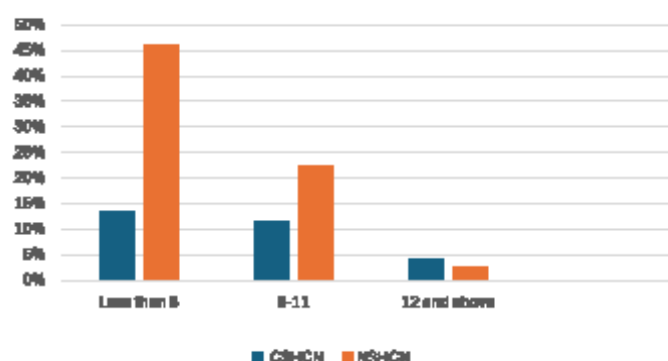


FIGURE 2 | Age distribution of children with and without special healthcare needs.

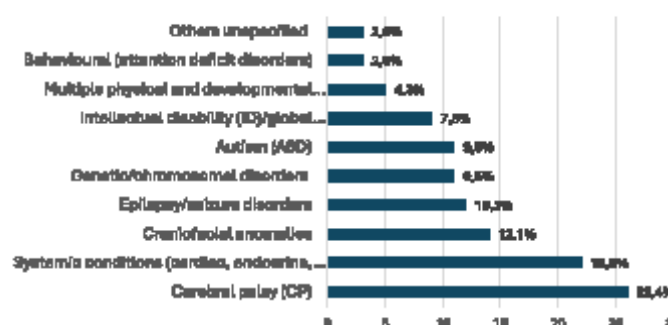


FIGURE 3 | The medical conditions of the CSHCN who were treated under GA.

disorders, autism, and intellectual disabilities. This finding emphasizes the need to understand individual risk factors based on the underlying medical condition to reduce the need for treatment under GA for these children.

Our study is among the first to assess the dental care provided under GA to CSHCN in ADHs. The results of our study highlighted the types of paediatric patients both CSHCN and NSHCN that are perceived by dentists to be more challenging to treat in the PHC settings. Our study findings revealed a lack of comprehensive data on CSHCN in the ADHs of SA, therefore, proper planning for dental care services for these children is difficult.

One third of our study sample were CSHCN, 50% of whom presented with developmental disabilities (DD) such as CP, ID, epilepsy, developmental delay or ASD. These children were typically under 6 years, male and half had been referred from PHC centres. Comparable findings were reported in a study conducted at an academic hospital in the United States (US) where 29.2% of the 1708 children treated under GA were CSHCN the majority with various DD [2]. Notably, despite the socio-economic differences in study settings (SA: middle income and US: high-income) the proportions of children with DD were similar, and perhaps point to common challenges of providing dental treatment for children with DD at

PHC centres. This underscores the need to improve training in special care dentistry to facilitate access to dental care for CSHCN and reduce oral health disparities. Furthermore, the prevalence of children with DD has been shown to be greater in low-and middle-income countries [23] which increases the demand for health services for these children.

In our study, the CSHCN were significantly older compared to NSHCN. The mean age in our study (CSHCN: 6 years; NSHCN: 4 years) was lower than in a study in Turkey (CSHCN: 7.9 years; NSHCN: 5.7 years) [24]. In Taiwan, the findings were comparable to our study (CSHCN: 7.2 years; NSHCN 3.6 years) [25]. Whilst in one SA study the mean age of CSHCN treated under GA was 6.7 years which was comparable to our study [15]. In another SA study, the mean age was 3.7 years which was close to the average age of 4 years among NSHCN in our study [20].

The majority of the patients receiving treatment under GA in our study were CSHCN below the age of 11 years and NSHCN younger than 6 years. Pre-school children in need of extensive dental treatment are unable to withstand multiple dental appointments, possibly resulting in higher referrals for GA treatment. Sedation or GA is recommended to provide comprehensive, safe, and quality dental care for CSHCN when physical restraint for stabilisation is not feasible [16]. Furthermore, there

TABLE 2 | Study sample variables by age category.

Variable	<6 years n = 237	6–11 years n = 135	12– 16 years n = 28	p
Centre n (%)				
A	100 (42.2)	70 (51.9)	17 (60.7)	<0.001
B	48 (20.3)	48 (35.5)	3 (10.7)	
C	89 (37.5)	17 (12.6)	8 (28.6)	
Sex n (%)				
Female	109 (46)	49 (36.3)	17 (60.7)	0.033
Male	128 (54)	86 (63.7)	11 (39.3)	
SHCN n (%)				
NSHCN	184 (77.6)	89 (65.9)	11 (39.3)	<0.001
CSHCN	53 (22.4)	46 (34.1)	17 (60.7)	
Previous dental history n (%)				
Yes	19 (8.0)	37 (27.4)	6 (21.4)	<0.001
No	218 (92.0)	98 (72.6)	22 (78.6)	
Dental diagnoses n (%)				
Dental caries related	229 (96.6)	118 (87.4)	15 (53.6)	<0.001
Non-carries related	8 (3.4)	17 (12.6)	13 (46.4)	

Note: Dental caries related = caries, pulpitis, periapical infection; non-carries related = dentofacial anomalies, trauma, cysts.

is a great need in SA for strategies to prevent caries that target pre-school children including CSHCN to reduce the need for GA treatment. Interventions that reduce caries and the cost of care are likely to be more effective from a public health and policy making perspective [26]. An integrated maternal and oral health policy could perhaps address the burden of childhood caries in SA [27].

Our study found that most of the patients were self-referrals (66.8%) and only one third of the patients had been referred to ADHs for treatment. A significantly greater number of CSHCN (52.6%) were referred for treatment under GA than NSHCN (25.4%). Comparable findings were reported in Canada where primary GA treatment centres for CSHCN were hospitals [28]. The relatively higher referral of CSHCN compared to NSHCN groups suggest challenges in providing dental care for CSHCN by oral healthcare professionals working in PHC settings. These challenges were not explored in our study but could be attributed to limited personnel trained in special care dentistry and may indicate the need for specialised paediatric clinics.

Most of the CSHCN (78%–88%) across the age categories and NSHCN younger than 6 years (93%) had no previous dental care. There was an association between previous dental history and

age category. However, there was no association between previous dental treatment and having a special health care need. In contrast to our findings, in the US, significantly more children with DD compared to those without DD reported having used dental care services in the previous 12 months (86.1% vs. 76.1%) [29]. Some of the reasons for the lack of dental care reported among CSHCN from the parents' perspectives included a fear associated with dental treatment, uncooperative behaviour and a medical condition that could affect dental treatment [5]. We did not examine the barriers to the use of dental care services among the parents/caregivers. This is an area of future research.

Dental caries and its sequelae were the most common indications for GA treatment among the children in our study who were mainly under 6 years of age. There were significant associations between age, being CSHCN, dental diagnosis with type of behavioural management. Dental caries was the most common reason for GA treatment among CSHCN in Alberta [28]. Childhood caries is a common problem in SA children with prevalence rates of 47.74% reported in 2 to 5-year-old children in Johannesburg [30] and 71.6% among children under 6 years of age in the Western Cape [31]. Studies have found that the caries prevalence ranges between 22.5% and 85.2% among CSHCN in SA [7–11]. This high burden of childhood caries is a public health concern [13], and is a strain on the health system due to the high cost of providing GA treatment. Other challenges facing the SA public health sector include a lack of budgetary allocation for oral health care services [32] and a lack of human resources [33].

Our study found that extractions were commonly done among CSHCN aged below 11 years and adolescents above 12 years (45%–54%), and among the NSHCN aged 6–11 years (52.8%). In addition, about a quarter (26.1%) of CSHCN aged 6–11 and 27.2% of NSHCN younger than 6 years received restorative care. Comparable findings were reported in Alberta where treatment provided under GA for CSHCN was primarily extractions (76.5%) but with higher (57.5%) restorative care [28]. In Taiwan, a greater mean number of teeth was extracted in patients with disabilities compared to healthy children [25]. Similarly, in Turkey, the mean number of extracted teeth was greater in the CSHCN group than NSHCN [24]. Pulp treatment at initial GA treatment in younger patients with multiple disabilities increased the risk of subsequent GA need whereas extractions, preventive and crowns reduced the risk of future GA treatment [28]. Notably, only a very small proportion of children in our study received preventative treatment. There is a need to emphasise preventative care post GA treatment to reduce the risk of subsequent GA for these children. Establishing dental homes that are accessible to the children may increase access to regular preventative care. Oral health promotion activities targeting parents/caregivers of CSHCN are important in creating awareness especially in PHC centres.

We found that almost a quarter of the children who had received an initial GA assessment had not received treatment, pointing to a lack of access to care. This may have been partly due to the long waiting time for GA in the ADHs. The average waiting time from the initial dental assessment to the date of GA treatment has been reported in SA as 4.98 months [20]. Perhaps the relatively higher number of children receiving GA treatment versus

TABLE 3 | Dental diagnosis and management of CSHCN and NSHCN.

Characteristic	CSHCN <i>n</i> = 116			NSHCN (<i>n</i> = 284)			Total (<i>n</i> = 400)
	<6	6–11	12–16	<6	6–11	12–16	
Age category <i>n</i> (%)	53(45.7)	46(39.6)	17(14.6)	184(64.8)	89(31.3)	11(3.9)	
Sex <i>n</i> (%)							
Female	18 (34)	19 (41.3)	11 (64.7)	91 (49.6)	30 (33.7)	6 (54.5)	175 (43.7)
Male	35 (66)	27 (58.7)	6 (35.3)	93 (50.5)	59 (66.3)	5 (45.5)	225 (56.3)
Previous dental history <i>n</i> (%)							
No	46 (86.8)	36 (78.3)	15 (88.2)	172 (93.4)	62 (69.7)	7 (63.6)	338 (84.5)
Yes	7 (13.2)	10 (21.7)	2 (11.8)	12 (6.5)	27 (30.3)	4 (36.4)	62 (15.5)
Clinical diagnosis <i>n</i> (%)							
Dental caries	48 (84.9)	41 (89.1)	13 (76.5)	181 (98.4)	77 (86.5)	2 (18.2)	362 (90.5)
Non-caries related	5 (9.4)	5 (10.9)	4 (23.5)	3 (1.6)	12 (13.5)	9 (81.8)	38 (9.5)
Dental treatment provided <i>n</i> (%)							
Preventative	4 (7.5)	—	3 (17.6)	20 (10.9)	9 (10.1)	2 (18.2)	38 (9.5)
Multiple extractions	29 (54.7)	21 (45.7)	8 (47.1)	68 (37)	47 (52.8)	1 (9.1)	174 (43.5)
Restorative	6 (11.3)	12 (26.1)	1 (5.9)	50 (27.2)	10 (11.2)	—	79 (19.8)
Others	2 (3.8)	3 (6.5)	1 (5.9)	—	8 (9)	2 (18.2)	16 (4)
Treatment not indicated	12 (22.6)	10 (21.7)	4 (23.5)	46 (25)	15 (16.8)	6 (54.5)	93 (23.2)
Pharmacological management <i>n</i> (%)							
GA	37 (69.8)	32 (69.6)	9 (52.9)	111 (60.3)	34 (38.2)	—	223 (55.8)
LA	4 (7.5)	3 (6.5)	4 (23.5)	22 (12)	31 (34.8)	3 (27.3)	67 (16.7)
IV Sedation	—	—	—	—	5 (5.6)	—	5 (1.2)
Non-pharmacological	—	1 (2.2)	—	5 (2.7)	4 (4.5)	2 (18.2)	12 (3)
Treatment not indicated	12 (22.6)	10 (21.7)	4 (23.5)	46 (25)	15 (16.9)	6 (54.5)	93 (23.2)

Abbreviations: GA, general anaesthesia; IV, intravenous; LA, local anaesthetic; Others, dental/oral orthodontics, endodontics, biopsy.

non-GA in our study may have caused delays in accessing GA services in our hospitals. Failure of the patients to arrive for their appointment due to distance from the hospitals is another possible reason and is an area of future research.

Finally, our study indicated that the dental treatment provided was associated with the type of behavioural management. More preventative treatment was provided in non-GA cases while multiple extractions, restorative and crowns were done under GA. Although GA is indicated for some CSHCN, it has risks including airway obstruction, aspiration in CP patients or over-sedation. Furthermore, GA increases the economic burden due to the need for theatre facilities, personnel, children's ward, and supplies [17]. Proper follow-up of children after GA treatment is essential as limited access to preventative care may increase the need for future GA for re-treatment of dental caries [2]. This has been highlighted by one study at an academic hospital in Pretoria, SA, where only 18% of children returned for follow-up

within 15 months after GA, and half of them required further GA treatment for severe caries [20].

Understanding the barriers to preventative dental care for young children (NSHCN) and CSHCN, may enhance follow-up after GA treatment. Child anxiety, provider willingness and proximity to such providers are some of the challenges faced by parents of CSHCN in obtaining dental care [2]. Providing a dental home for CSHCN in PHC centres may improve access to early and continued preventative dental care [34], and perhaps reduce the burden of GA in our resource constrained settings. The proposed maternal and child oral health policy for SA [27] suggests that integrating oral healthcare into PHCs specifically in maternal and child services and enhanced interdisciplinary networks could improve the oral health of SA children under 6 years.

Our study had some limitations such as the retrospective design and the use of secondary data from the clinical records. Also,

TABLE 4 | Sample characteristics according to GA and non-GA management.

	GA = 223 (72.6)	Non-GA = 84 (27.4)	Total = 307 (100)	p
Age groups				
Younger than 6 years	148 (66.4)	31 (36.9)	179 (58.3)	< 0.001
6–11 years	66 (21.5)	44 (52.4)	110 (35.8)	
12 years and above	9 (12.1)	9 (10.7)	18 (5.9)	
Medical status				
CSHCN	78 (35)	12 (14.3)	90 (29.3)	< 0.001
NSHCN	145 (65)	72 (85.7)	217 (70.7)	
Centre				
A	80 (35.9)	35 (41.7)	115 (37.4)	0.22
B	67 (30)	29 (34.5)	96 (31.3)	
C	76 (34.1)	20 (23.8)	96 (31.3)	
Dental diagnosis				
Caries related	220 (98.7)	64 (76.2)	284 (92.5)	< 0.001
Non-caries related	3 (1.3)	20 (23.8)	23 (7.5)	
Treatment provided				
Preventative	16 (7.2)	22 (26.2)	38 (12.4)	< 0.001
Multiple extractions only	136 (61)	38 (45.2)	174 (56.7)	
Restorative and rehabilitation	71 (31.8)	8 (9.5)	79 (25.7)	
Others	0 (0)	16 (19.0)	16 (5.2)	
Referral status				
Referred	77 (34.5)	21 (25)	98 (31.9)	0.11
Self-referral	146 (65.5)	63 (75)	209 (68.1)	

Note: GA = dental treatment under general anaesthesia; significant at p-value < 0.05; 'others' = dentofacial/orthodontics, endodontics, biopsy; () = %.

the estimated sample size was affected by a lack of organised filing of records in hospitals B and C, resulting in a smaller sample. Furthermore, 93 of the patients had no treatment assigned, which limited the ability to carry out regression analyses. These records were not designed and documented for research study purposes. Therefore, the results of this study cannot be generalised for all the CSHCN and NSHCN in SA but serves as a background for further studies. It is recommended that record keeping of all patients be done in a standardised and comprehensive manner to facilitate future clinical audits. Electronic or digital records could facilitate and improve data storage and access.

In conclusion, patients in need of GA treatment at ADHs in SA were CSHCN or NSHCN typically under the age of 6 years, presenting with extensive caries. The treatment provided consisted mainly of extractions with little restorative care. Limited preventative treatment was provided highlighting the need to identify children at risk of caries to institute timely preventative strategies to promote better oral health and reduce the burden of treatment under GA. In addition, we recommend a review of the curriculum for general dentists in SA which incorporates

child management together with training of specialist paediatric dentists.

Author Contributions

N.N. designed the study, collected, and analysed the data, led the writing as part of her PhD thesis. A.M. and P.H. edited, revised, and critically reviewed the work. All authors approved the final paper.

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Ethics Statement

The study was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Clearance number: M220266).

Conflicts of Interest

The authors declare no conflicts of interest.

Appendix 12: Plagiarism Declaration



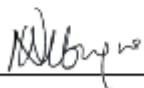
PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Nancy Njoroge (Student number: 2498995) am a student registered for the degree of Doctor of Philosophy in the academic year 2025.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: 

Date: 11/03/2025

Appendix 13: Turnitin Report

Nancy Njoroge An assessment of oral health care delivery to children with special needs at dental schools in South Africa			
ORIGINALITY REPORT			
14%	13%	14%	0%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS
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1	www.sada.co.za Internet Source	13%	
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3	pure.manchester.ac.uk Internet Source	1%	
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