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Perspectives of health care professionals, caregivers, and patients

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ABSTRACT

People with disabilities (PWDs) often have poor oral health and inadequate health services. This disproportionate burden underscores the need for research into barriers to effective and accessible care. This thesis aimed to examine the perspectives of PWDs by investigating their challenges in accessing dental care, Oral Health-Related Quality of Life (OHRQoL), and levels of dental fear and anxiety (DFA). In addition, the thesis investigated the role of education in preparing providers for special care dentistry (SCD). Five original studies investigated clinical, institutional and educational factors that influence oral care utilising various study designs.

The challenges of dental care and education for PWDs were investigated in Trinidad and Tobago (T&T) by interviewing healthcare professionals (HCPs) and caregivers. Surveys assessed OHRQoL and DFA of patients aged 6–18 years at the Special Needs Dental Clinic (SNDC) and the Child Dental Health Unit (CDHU). The impact of a workshop on SCD for dentists, dental students and allied HCPs was evaluated using questionnaires. An international survey assessed the effect of dental student training delivered at European and American universities.

Barriers to care included cost, limited access to dental care for PWDs, and HCPs' readiness. OHRQoL among children at these clinics was generally poor, especially for those with disabilities, who were significantly more likely to experience DFA at a moderate level than those without. Lack of knowledge and professional development motivated participants' attendance at the SCD workshop. The participants perceived communication and non-compliance as the main challenges in dental treatment at the SCD workshop. The dental students showed a positive intention to treat PWDs after SCD training. Variations in clinical exposure, health care systems, and cultural expectations were observed between the international universities.

This thesis indicates that addressing barriers in oral care access, clinical preparedness, and training can improve dental experiences for PWDs. Educational initiatives may foster positive attitudes and readiness among HCPs, leading to better dental care, improved OHRQoL, and reduced DFA among PWDs.

KEYWORDS: Attitudes, barriers, dental fear and anxiety, dental students, education, people with disabilities, quality of life, special care dentistry.

TURUN YLIOPISTO
Lääketieteellinen tiedekunta
Hammaslääketieteen laitos
Sosiaalihammaslääketiede
RAMAA BALKARAN: Suun terveydenhoito vammaisille potilaille:
Terveydenhuollon ammattilaisten, huoltajien ja potilaiden näkemykset.
Väitöskirja, 208 sivua
Kansallinen suun terveystieteiden tohtoriohjelma – FINDOS-Turku
Toukokuuta 2006

TIIVISTELMÄ

Vammaisten suun terveys on usein heikko ja terveyspalvelut riittämättömät. Tämän opinnäytetyön tavoitteena oli tutkia vammaisten henkilöiden näkemyksiä hammashoidon saannista, suuterveyteen liittyvää elämänlaatua (OHRQoL), hammashoitopelkoa ja ahdistusta. Lisäksi selvitettiin koulutuksen roolia palveluntuottajien valmennuksessa erityistarpeisten hammashoitoon. Viidessä alkuperäistutkimuksessa analysoitiin kliinisten, palvelujärjestelmään ja koulutukseen liittyvien tekijöiden vaikutusta suun hoitoon monipuolisin tutkimusasetelmin.

Vammaisten henkilöiden hammashoidon ja koulutuksen haasteita tutkittiin Trinidad & Tobagossa haastattelemalla terveydenhuollon ammattilaisia ja huoltajia. Kyselytutkimuksilla selvitettiin 6–18-vuotiaiden potilaiden elämänlaatua ja hammashoitopelkoa. Lisäksi analysoitiin suun terveydenhuollon ammattilaisille ja hammaslääketieteen opiskelijoille suunnatun kurssin vaikutusta vammaisten hoitoon. Kansainvälisessä tutkimuksessa analysoitiin hammaslääketieteen opiskelijoiden koulutuksen vaikusta vammaisten henkilöiden hoitoon Euroopassa ja Yhdysvalloissa.

Hoidon esteitä olivat hoidon kustannukset, vammaisten rajallinen pääsy hammashoitoon ja terveydenhuollon ammattilaisten valmius. Vammaisten lasten suunterveyteen liittyvä elämänlaatu oli yleisesti ottaen heikko ja he kokivat hammashoitopelkoa ja kohtalaista ahdistusta useammin kuin vammattomat. Tiedon puute ja ammatillinen kehittyminen motivoivat osallistujia erityiskurssille. Kurssin osallistujat kokivat kommunikaation ja hoitomyöntyvyyden puutteen suurimmiksi hoitohaasteiksi. Koulutuksen jälkeen hammaslääketieteen opiskelijoilla oli myönteinen asenne hoitaa vammaisia potilaita. Erilaiset kliiniset kokemukset, terveydenhuoltojärjestelmät ja kulttuuriset odotukset selittivät yliopistojen välisiä eroja eri maissa.

Tämä opinnäytetyö osoittaa, että poistamalla suun terveydenhuollon esteitä, kehittämällä kliinistä valmiutta ja koulutusta voidaan parantaa vammaisten hammashoitoa. Koulutuksella voidaan edistää suun terveydenhuollon ammattilaisten myönteisiä asenteita ja valmiutta parempaan hammashoitoon, kohentaa vammaisten elämänlaatua ja vähentää hammashoitopelkoa.

AVAINSANAT: Asenteet, esteet, hammashoitopelko ja ahdistus, hammaslääketieteen opiskelijat, koulutus, vammaiset ihmiset, elämänlaatu, erikoishammashoito

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Abbreviations

AAPD	American Academy of Pediatric Dentistry
AC	Afro-Caribbean
ADEE	Association for Dental Education in Europe
ADHD	Attention-Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
ATSU	Arizona School of Dentistry & Oral Health, A.T. Still University
CDA	Canadian Dental Association
CDHU	Child Dental Health Unit
CG	Caregiver
CI	Confidence Interval
CODA	Commission of Dental Accreditation
CP	Cerebral Palsy
DFA	Dental Fear and Anxiety
DHCPs	Dental Healthcare Providers
DHDT	Dental Hygienist/Dental Therapist
DS	Down Syndrome
DSA	Dental Surgery Assistant
FASD	Foetal Alcohol Spectrum Disorder
FDI	World Dental Federation (formerly Fédération Dentaire Internationale)
HbA1C	Glycosylated Haemoglobin
HCPs	Healthcare providers
iADH	International Association for Disability and Oral Health
IC	Indo-Caribbean
M	Mixed
MDAS	Modified Dental Anxiety Scale
NCDs	Noncommunicable Diseases
NGO	Non-Governmental Organisation
NHS	National Health Service
O	Other
OHIP	Oral Health Impact Profile
OHIP-14	Oral Health Impact Profile, short version (14 questions)

OHRQoL	Oral Health-Related Quality of Life
OR	Odds ratio
P	Physician
PAHO	Pan American Health Organisation
PHE	Public Health England
PI	Principal investigator
PWDs	People with disabilities
QOL-Q	Quality-of-Life Questionnaire
SAID	Special Care Advocates in Dentistry
SCD	Special Care Dentistry
SHCN	Special Health Care Needs
SNDC	Special Needs Dental Clinic
TDI	Traumatic Dental Injuries
TPB	Theory of Planned Behaviour
UN	United Nations
USA	United States of America
UWI	The University of the West Indies
WHO	World Health Organisation

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Balkaran R, Esnard T, Perry M, Virtanen, J.I. Challenges experienced in the dental care of persons with special needs: a qualitative study among health professionals and caregivers. *BMC Oral Health*, 2022; 22: 116.

II Balkaran R, Lahti S, Ramroop V, Virtanen J. I. Oral Health-Related Quality of Life in Children attending University Special Needs and Pediatric Dental Clinics in Trinidad and Tobago: A parental perspective. *Acta Odontol Scand* 2025; 84: 1–8.

III Balkaran R, Lahti S, Ramroop V, Virtanen J.I. Dental Anxiety in Children Attending University Special Needs and Paediatric Dental Clinics in Trinidad and Tobago. *BMC Oral Health*, 2025; 25: 1262.

IV Balkaran R, Perry M, Maharaj A, Rajhbeharrysingh A, Virtanen J.I. Evaluation of a special needs dental workshop for health professionals and students in Trinidad and Tobago. *Front Oral Health*, 2022; 3: 951165.

V Balkaran R, Perry M; Faulks D, Eschevins C, Virtanen, J. I. Dental students' behavioural intent after comprehensive exposure to Special Care Dentistry: A survey in two dental Universities. *JBSSCD*, 2025; 2: 55-64.

1 Introduction

In the literature, 'persons with special needs,' 'impairments,' 'people with disabilities' (PWDs), and 'people with special health care needs' (SHCN) are often used interchangeably. This thesis adopts the term PWDs to include, but not be limited to, those experiencing impairments, activity limitations, and restrictions on participation (WHO, 2019). PWDs often have health inequalities which result from unjust challenges such as stigma and impediments within the health care system (WHO, 2023). This is also true for the oral health of PWDs, as dental diseases are challenging and can significantly affect their quality of life. Special care dentistry (SCD) involves adapting specialised techniques to treat patients with unique needs, promoting preventive dentistry, and tailoring routine dental care to meet the specific requirements of each individual.

Research has shown that oral health care is the most common unmet health care need for children with special needs (Faulks et al., 2012; Gazzaz et al., 2022). Many people with special needs frequently experience barriers to oral health care. These barriers include cost, dental fear and anxiety (DFA), no perceived need for care, transportation/distance, and waiting time (Davis & Reisine, 2015; Williams et al., 2015; Alfaraj et al., 2021). This population may have more dental disease due to delayed treatment and their disabilities, along with dental anxiety, which prevents them from accepting invasive dental treatment (da Silva et al., 2017). DFA, which includes anticipatory anxiety, may prevent them from accessing dental care, which in turn may prolong their dental treatment and worsen their existing dental disease. This underscores the need to provide preventive measures that reduce some barriers to accessing dental care.

In addition to these barriers, there may be a lack of education and clinical training at the dental undergraduate level, which may result in hesitations to treat this group of patients by dentists upon graduation (Derbi & Borromeo, 2016; Lang et al., 2021), which may further serve as a barrier to dental care in this vulnerable population. Health care providers (HCPs) may have several challenges in providing dental care for this population. Additionally, an investigation indicated that in training, dentists who had very little involvement with treating PWDs would rarely opt to treat those

patients in their practice as opposed to dentists who had experience with such patients during training (Shah et al., 2011).

A study has suggested that most people requiring SCD should be able to access treatment in a local, primary care setting (Faulks et al., 2012). This underscores the need for training in the dental management of PWDs at both the undergraduate and postgraduate levels for the dental team. The didactic component of dental students' education in preparing treatment for PWDs is equally as important as clinical practice, which ensures confidence in treating this patient population upon graduation (Vainio et al., 2011; Hector et al., 2023).

Research has shown that the comfort and preparedness of dental graduates can help address the considerable unmet dental needs faced by PWDs when care is delivered by both general dental health care providers (DHCPs) and specialists (Fuad et al., 2015; Rosales García et al., 2025). Assessing dental students' attitudes and intended behaviours towards PWDs can be challenging to determine. However, there are methods, such as the validated toolbox of questionnaires, created by the International Association for Disability and Oral Health (iADH), to evaluate dental students' intentions and future behaviours, focusing on integrity, altruism, and attitudes (Faulks et al., 2017).

Given the paucity of literature on this subject, this thesis aims to further explore the barriers and facilitators to dental treatment faced by PWDs, to determine their Oral Health-Related Quality of Life (OHRQoL) and levels of DFA. It further evaluates the longitudinal effect of a workshop on SCD in Trinidad and Tobago (T&T), along with dental students' intentions to treat PWDs after receiving training in SCD at two dental schools: one in Europe and the other in the United States of America (USA).

2 Review of the Literature

Over one billion individuals live with a significant disability, accounting for 16% of the global population (WHO, 2023). This number is increasing due to the rise of Noncommunicable diseases (NCDs) and the growing longevity of the population (WHO, 2023). This cohort is diverse, and although specific diseases are more prevalent in a certain sex, there is no predilection for either one in the prevalence of general disabilities. However, females with disabilities often experience a greater impact from social determinants of health, such as poverty and exclusion from education and employment, than their male counterparts (WHO, 2023; World Bank, 2025).

Individuals with disabilities who are also part of other marginalised communities, such as those defined by race or sexual orientation, experience additional obstacles when seeking care, education, and health services (WHO, 2023). Additionally, the World Bank (2025) indicates that having a disability can increase the risk of poverty. This arises from inadequate education, which leads to restricted job prospects, lower salaries, and elevated living expenses associated with disabilities.

PWDs are often excluded from research on social determinants due to the ongoing undervaluation of their health impact (Faulks, 2023). This exclusion may arise from challenges in adapting protocols and obtaining ethical approval, as well as from a lack of awareness of the size of the disabled community or a form of ableism (Faulks, 2023).

Furthermore, PWDs typically encounter earlier mortality, poorer health outcomes, and greater limitations in daily functioning compared to those without disabilities (WHO, 2023). Additionally, these individuals have poorer oral health than the general population (WHO, 2023). PWDs are often seen on the ‘cliff-edge’ of the oral health social gradient, facing a higher risk of poor oral health alongside worse access to necessary care (Watt et al., 2019).

2.1 People with Disabilities (PWDs)

2.1.1 Definition of Disability

The Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations has defined disability as "an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (UN, 2006). Furthermore, SHCN as defined by the American Academy of Paediatric Dentistry (AAPD) are "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" (AAPD, 2024a).

Moreover, the iADH defines disability not as an illness but as a way to describe an individual's human experience about their unique context and circumstances (iADH, 2015). Further, given the multiplicity of disability, which includes "people with physical, sensory, intellectual, medical, emotional or social impairment or disabilities; or more often a combination of these factors," the iADH highlights this "range of impairments with or without additional needs, although not everyone who is disabled will have complex needs" (iADH, 2015).

2.1.2 Models of Disability

Different historical and social models of disability have evolved over time, each reflecting the dominant beliefs, values, and assumptions held by societies about what disability is and how it should be understood. Early perspectives often framed disability through a narrow, biomedical lens, viewing it primarily as an individual deficit or abnormality requiring treatment or correction (WHO, 1980; Barnes, 2005; 2012).

As social awareness and human rights movements gained traction, alternative models emerged that emphasised the role of environmental, structural, and attitudinal barriers in shaping the lives of PWDs (Anspach, 1979). These evolving models illustrate a gradual shift from seeing disability as a personal problem to recognising it as a complex interaction between individuals and the societies in which they live (Barnes, 2012). They also highlight how cultural, political, and economic contexts influence the ways disability is defined, addressed, and experienced by individuals and communities.

2.1.2.1 Traditional Model of Disability

The traditional model, also known as the moral model, is one of the earliest recorded ways in which societies attempted to explain human difference. Within this framework, PWDs are often blamed, shamed, or even concealed from the public. The model is rooted in the belief that disability results from moral failure or wrongdoing, either by the individual or by their family. As a result, disability is viewed not as a natural part of human diversity, but as a form of punishment or divine retribution. Such beliefs historically led to significant stigma, exclusion, and discrimination. Families might hide children with disabilities out of fear of social judgment, while communities may treat PWDs with suspicion, pity, or rejection. PWDs' historical absence from communities may explain why they are now more visible in society.

This perspective frames disability entirely as a personal problem, placing the responsibility and the burden on the individual rather than acknowledging broader social or environmental factors. By attributing disability to moral fault, the moral model diverts attention away from societal obligations, such as creating inclusive environments, providing support services, or challenging harmful cultural attitudes (Barnes, 2005; 2012).

The moral model reinforces the notion that disability is a source of shame rather than a social justice issue, contributing to long-standing barriers that still influence perceptions in many parts of the world today.

2.1.2.2 Medical Model of Disability

Within the framework of the medical model of disability (Figure 1a), is predominantly regarded as a defect, disorder, or illness inherent in the individual, which should ideally be addressed, rectified, or remedied through medical intervention or professional rehabilitation (WHO, 1980). Impairments are identified as the primary causes of any restrictions in activity or participation, and these restrictions are presumed to result in disadvantage, inevitably, diminished quality of life, and personal suffering (de Kleijn-de Vrankrijker, 2003).

Medical professionals are positioned as the primary authorities responsible for diagnosing, managing, and mitigating disability. Consequently, interventions emphasise clinical assessments, treatments, and rehabilitative strategies aimed at correcting or compensating for the impairment (WHO, 1980; de Kleijn-de Vrankrijker, 2003; Barnes & Mercer, 2005).

Although the medical model has significantly contributed to advancements in treatment and the enhancement of health outcomes, it has been subject to critique for neglecting the social, cultural, and environmental barriers that influence the lived

experiences of individuals with disabilities. By conceptualising disability as an individual pathology, it tends to diminish the significance of societal structures, accessibility challenges, and discriminatory attitudes, which often exert a greater impact on disadvantage than the impairment itself.

Medical Model of Disability

Figure 1a. Medical Model of Disability (Modified from https://www.inclusionlondon.org.uk/about-us/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/).

2.1.2.3 Social Model of Disability

The social model of disability (Figure 1b) reflects a paradigm shift regarding society's role in shaping the experiences of PWDs. Instead of viewing disability as an individual deficit or personal tragedy, this perspective argues that the real source of disadvantage lies in physical, social, and institutional environments that fail to accommodate human diversity. Barriers such as inaccessible buildings, inadequate transportation, discriminatory attitudes, and exclusionary policies are seen as the main factors that create disability, not the impairment itself (Barnes, 2005).

Since society, rather than individuals, is seen as responsible for disabling conditions, disability is viewed as an issue of social justice and civil rights. This new perspective casts people with disabilities as a marginalised group whose rights need to be recognised and protected, just like those of other minority groups. Consequently, this model highlights the importance of political action, legal reforms, and collective advocacy to tackle structural inequalities and ensure full participation in all areas of life (Anspach, 1979; Barnes, 2005).

Figure 1b. Social Model of Disability (Modified from https://www.inclusionlondon.org.uk/about-us/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/)

2.1.2.4 International Classification of Functioning, Disability & Health (ICF)

The WHO approved a framework on disability that highlights the reduced participation of PWDs due to society's inability to accommodate their individual needs (WHO, 2001). It emphasises that impairments and activity limitations must be considered within the context of the environment, personal factors (such as health issues), and the necessity for personalised support systems. It assesses the impact on

the functional domains of PWDs. These domains of functioning include learning and applying knowledge, as well as accomplishing general tasks and demands. The WHO has developed a figure (Figure 2) that effectively illustrates the 'bio-psycho-social model' of health (WHO, 2013).

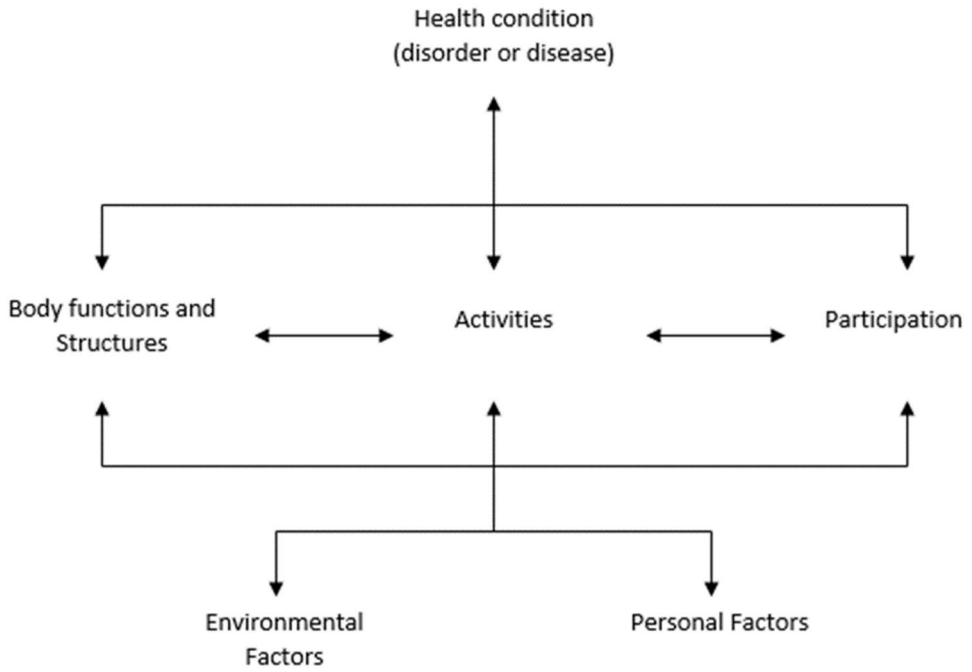


Figure 2. ICF definition of disability (Modified from: https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf) (WHO, 2001).

2.1.3 Disabilities Commonly Encountered by Dentists

The condition causing the disability may be congenital, developmental, or acquired through disease, trauma, or environmental factors, which can impose limitations in performing daily self-maintenance activities or significant limitations in a major life activity (AAPD, 2024a). Many PWDs can be treated routinely in a typical dental setting with minimal accommodations. In contrast, others may require moderate to higher levels of adaptation, including restraints and sedation techniques (Queen, 2016).

PWDs seen in the dental setting may have exclusively one category of disability or may have combinations of disabilities, such as a person with Down syndrome (DS) who also has autism. Furthermore, developmental disabilities may be linked with intellectual disabilities, like those seen in individuals with DS. Each patient will require specific approaches and modifications in dental care suited to their condition

and individual needs (Hennequin et al., 2000; Faulks & Hennequin, 2006). The clinical management of each disability is beyond the scope of this thesis; however, the causes of the various types will be briefly discussed.

2.1.3.1 Developmental and medical disabilities

Developmental disabilities encompass those that affect daily functioning in three or more of the following areas (Sackett, 2007, p. 3; CDC, 2024a):

- Capacity for independent living
- Economic self-sufficiency
- Learning
- Mobility
- Receptive and expressive language
- Self-care
- Self-direction

Conditions related to developmental disabilities encompass a broad spectrum of cognitive, behavioural, and physical impairments. These may include neurodevelopmental disorders such as Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD); intellectual and genetic conditions like DS; physical and motor impairments such as Cerebral Palsy (CP); teratogenic disorders like Foetal Alcohol Spectrum Disorder (FASD); and conditions with multifactorial origins, including cleft lip and palate.

2.1.3.1.1 Neurodevelopmental disorders

ADHD is associated with alterations in neurotransmitter regulation and structural and functional changes within the brain, which may interfere with essential neural pathways involved in attention, motivation, and impulse control and may be correlated with learning disabilities (Cortese et al., 2012; Yu et al., 2022; Parlatini et al., 2023). ASD is more frequently diagnosed in males than in females (Werling & Geschwind, 2013) and is characterised by difficulties in social interaction and communication, along with repetitive and restricted behaviours (Elsabbagh et al., 2012). Individuals with ASD may experience heightened sensitivity, which can make routine dental care challenging (AAPD, 2024b).

2.1.3.1.2 Intellectual and genetic conditions

DS results from the nondisjunction of chromosome 21 during oogenesis or spermatogenesis (Down, 1866; SAID, 2023). It represents the most common genetic cause of intellectual disabilities (Ilyas et al., 2020). Those with DS are described by intellectual disability, distinct facial features, short stature, and congenital heart defects and are at a higher risk of malocclusions and periodontal diseases (Rondón-Avalo et al., 2024).

2.1.3.1.3 Physical and motor impairments

CP is a form of static encephalopathy (Tezol, & Sıddıka, 2022). Individuals with this condition may face an increased risk of occlusal issues, such as anterior open bite and Class II malocclusion, and have an increased risk of dental caries, especially in those with intellectual disabilities (Bensi et al., 2020).

2.1.3.1.4 Teratogenic disorders

Foetal Alcohol Spectrum Disorder (FASD) is the most common human teratogenic disorder caused by maternal alcohol consumption during pregnancy and is associated with intellectual disabilities (CDC, 2025).

2.1.3.1.5 Multifactorial inheritance conditions

These include cleft lip and palate, which can occur independently or as part of a syndrome (Phalke & Goldman, 2024). When the clefts remain unrepaired, dental management can be challenging and complicated. An unrepaired cleft palate can negatively impact speech, swallowing, and psychosocial development (Kortelainen et al., 2016; Phalke & Goldman, 2024).

2.1.3.1.6 Medically Compromised Conditions

These conditions involve medical disabilities encompassing health issues that are not immediately visible, such as cancer or diabetes (WHO, 2001). Oral cancer is among the most common cancers worldwide and requires a multidisciplinary team approach to its management (WHO, 2025). Managing medically compromised patients involves adjusting medications due to drug interactions, modifying the timing of dental treatment based on their condition and medications, and addressing the associated side effects of polypharmacy (Little et al., 2013).

2.1.3.2 Intellectual disabilities

These conditions begin at birth and often emerge before age 22, frequently accompanied by related issues such as mental health disorders (e.g., depression, anxiety), neurodevelopmental disorders (e.g., autism, ADHD), and medical complications (e.g., meningitis) (Lee et al., 2023). Individuals with intellectual disabilities face neurodevelopmental challenges that impact their abilities and adaptive behaviours (WHO, 2019). Genetic issues in patients with DS, Fragile X Syndrome, and environmental exposures like FASD, severe malnutrition, toxic substances (e.g., lead), and neglect or abuse can cause intellectual disabilities through violent damage to the developing brain or malnutrition, which can affect neural cell development (WHO, 2019; Lee et al., 2023).

2.1.3.3 Sensory impairments

These include individuals who are blind, visually impaired, deaf, or hard of hearing. While those with sensory impairments do not necessarily have intellectual deficits, communicating oral hygiene practices with the dentist can be challenging and may influence dental outcomes (Fabiana et al., 2018; Ahmed et al., 2022).

2.1.3.3.1 Visual Impairments

Those with visual impairments may also find difficulties in recognising the onset of dental issues (Ahmed et al., 2022). Additionally, children with visual impairments frequently experience dental caries, gingivitis, traumatic dental injuries (TDI), and malocclusion (Mehta et al., 2025). There may also be congenital conditions related to vision loss, such as Ehlers-Danlos syndrome. Systemic diseases like diabetes may also be associated with visual impairments and systemic diseases like cardiovascular issues (Mahoney et al., 2008).

2.1.3.3.2 Hearing Impairments

For individuals who are deaf or hard of hearing, communication barriers may impact the delivery of preventive advice and treatment planning. Furthermore, there are syndromes associated with deafness and periodontal diseases, including Chediak-Higashi syndrome, DS, and Papillon-Lefèvre syndrome (Fabiana et al., 2018).

Both patients with visual and hearing impairments may have increased bruxism and occlusal wear (Ahmed et al., 2022). Therefore, dental prevention and treatment for individuals with sensory impairments can be challenging for both patients and dentists, underscoring the importance of tailored communication strategies and preventive care (PHE, 2017).

2.2 PWDs and Oral Health

2.2.1 Burden of Oral Diseases in PWDs

PWDs may encounter a higher incidence of dental issues due to deferred treatments, compounded by both their disabilities and dental anxiety, which leads to reluctance towards invasive procedures (da Silva et al., 2017; Wilson et al., 2018). Oral health is linked to general health and has even assisted in diagnosing systemic diseases based on accompanying oral signs. Like systemic health, oral health can be affected by social determinants of health. Social determinants, such as transportation (CDC, 2024b), can directly and disproportionately affect PWDs.

The most common unmet health care need for children with special needs is oral health care (Faulks et al., 2012). Children with intellectual disabilities typically attend primary dental care less frequently. Compared to their peers, those who visit are also less likely to receive preventive services, including fluoride varnish, oral hygiene guidance, or dietary recommendations (Sherriff et al., 2023). Older PWDs have been reported to have a higher prevalence of untreated dental caries and an increased incidence of periodontal lesions (Biasotto et al., 2024). An unmet need for restorative and periodontal treatment existed in a dental clinic catering to PWDs, where primarily preventive and urgent treatments were administered (Marchan et al., 2022).

2.2.2 Prevalence of Oral Diseases in PWDs

Evidence suggests that PWDs have an increased likelihood of oral diseases (da Silva et al., 2017; Davies et al., 2000). Those with intellectual disabilities often have poorer oral health, such as untreated dental caries and more missing teeth, than those without disabilities (Oliveira et al., 2013).

In China, 53.5% of adolescents aged 12–17 with intellectual disabilities had dental caries, compared to 28.9% of 12-year-olds without disabilities in the same country (Liu et al., 2014). In Canada, between 2023 and 2024, nearly 46% of PWDs of all ages reported ongoing mouth pain or avoided certain foods due to oral health issues, versus 24% of those without disabilities. Persistent oral pain affected 37% of PWDs compared to 20% of those without, and 31% avoided specific foods due to oral problems, more than twice the rate of those without disabilities (14%) (Statistics Canada, 2024).

Among Special Olympics athletes with intellectual disabilities from 181 countries, gingival disease prevalence exceeded 40% from age 13 onwards, with Europe/Eurasia and Latin America most affected. In Latin America, untreated dental caries was highest (67%) among athletes aged 12–18 and those over 40 (Marks et

al., 2018). Additionally, medications prescribed for developmental disabilities can contribute to oral health problems. These findings underscore persistent global oral health inequities for PWDs.

2.2.3 Risk Factors for Oral Diseases in PWDs

The adult and child populations of PWDs have shown high cavity indices and inadequate oral hygiene (Pini et al., 2016). Many syndromes are associated with malocclusions, tooth abnormalities in tooth number or size, and varying degrees of cognitive impairments. This combination of conditions can increase the risk of oral diseases by impairing the ability to remove plaque effectively (Rondón-Avalo et al., 2024). Reduced manual dexterity, which is common in several developmental and congenital disorders, may also further affect oral hygiene practices, making routine tasks such as brushing and flossing more challenging and less effective in this population.

Importantly, even syndromes that do not involve cognitive impairment, such as Marfan syndrome or Treacher–Collins syndrome, are still frequently linked with dental anomalies like hypodontia and microdontia (Mahoney et al., 2008). These structural differences can create spaces or irregular surfaces that trap food debris and plaque, again elevating the risk of dental disease. Additionally, nutritional factors play a critical role in oral health. Some people with disabilities may experience difficulties with mastication, leading to altered dietary patterns. In contrast, others may have prolonged bottle-feeding habits—both of which can compromise the health of the oral tissues (Lee & Chang, 2021).

PWDs frequently present with multiple medical conditions that require ongoing management, often resulting in polypharmacy. The adverse effects of many commonly prescribed medications, such as those causing xerostomia, can accelerate the development of dental caries by reducing salivary flow (Queen, 2016). Additionally, PWDs may be on prolonged liquid medications that may have sugar and can increase their risk for dental caries (PHE, 2017). Furthermore, certain systemic diseases, such as diabetes, have well-established bidirectional relationships with oral conditions like periodontal disease. Poor glycaemic control can exacerbate periodontal breakdown, and periodontal inflammation can, in turn, worsen diabetic status, creating a self-perpetuating and destructive cycle (Borgnakke, 2019).

Table 1 below summarises these conditions and their risk factors (Mahoney et al., 2008; Asten et al., 2013; Queen, 2016; Borgnakke, 2019; Cervino et al., 2020; Lee & Chang, 2021; Rondón-Avalo et al., 2024; Aggarwal et al., 2025).

Table 1. Summary of Risk Factors for Oral Diseases in PWDs

Condition	Notable Oral Features	Risk Factors
DS	Open bite, missing teeth, delayed eruption, and periodontal susceptibility	Cognitive impairment and diminished dexterity affect oral hygiene
CP	Malocclusion, bruxism, drooling	Severe motor impairment and reduced oral-motor control, prolonged bottle use and a nutritional deficit
ASD	Bruxism, self-injury, variable occlusion	Sensory sensitivities, behavioural challenges affecting hygiene and dental visits
Marfan syndrome	High-arched palate, crowding, and enamel anomalies	Craniofacial growth differences increase caries risk
Treacher–Collins syndrome	Hypodontia, microdontia, craniofacial hypoplasia	Airway issues affecting dental treatment, feeding difficulties, dry oral mucosa, increased caries risk, and complex treatment needs
Diabetes	Periodontal disease, poor wound healing	Uncontrolled diabetes (HbA1C > 7%), Polypharmacy leading to xerostomia

ASD- Autism Spectrum Disorder, CP- Cerebral Palsy, DS- Down syndrome, HbA1C- Glycosylated haemoglobin.

2.2.4 Concept of Intersectionality on PWDs

The concept of intersectionality was initially articulated by Crenshaw (1989) in her landmark publication titled “When They Enter, We All Enter." This rhetoric has recently been employed to illustrate the impact of race and disability, highlighting that PWDs desire to be viewed as someone whose experience is "more than the sum of their parts” (Abrokwa, 2018). This understanding fosters an appreciation for how the experiences of individuals with disabilities, who also belong to racial minorities and specific genders, differ from those of others from different races or genders (Abrokwa, 2018).

Intersectionality has been applied in public health and health promotion to reduce health inequalities through the multidimensional framework of the social determinants of health (Heard et al., 2020). The physical limitations arising from a disability would be experienced differently by a female accessing transportation compared to a male of a different race, albeit with the same disability. The choice of dental treatment may also be influenced by the patient’s disability, level of cooperation, and the prioritisation of dental treatment in the operating room. For instance, the allocation of the operating room to other specialities, such as cardiac surgery, would be prioritised over tooth restorative procedures. The complexity of the ‘social systems, power, and inequalities in shaping health’ cannot be overstated

(Heard et al., 2020). This is evident in the unequal access to routine dental care faced by PWDs due to various barriers.

2.3 Barriers and Facilitators to Dental Treatment in PWDs

The inequalities faced by PWDs are exacerbated by limited and inconsistent access to preventive dental services, which could alleviate these challenges (Wilson et al., 2018; Sherriff et al., 2023). PWDs frequently encounter multiple barriers to accessing dental health care, including cost, the preparedness of HCPs, resources for patient treatment, and limited access to dental care for this population (da Rosa et al., 2020). Both direct and indirect costs, such as opportunity costs and travel expenses, associated with dental attendance should be considered when accessing dental care, as they impose large economic burdens on families and health-care systems. Self-reported barriers to dental care also included transportation and psychosocial issues (Marchan et al., 2022).

DFA have also been identified as a significant barrier to accessing dental care (Davis & Reisine, 2015; Stein Duker et al., 2022). Delayed access to care may exacerbate existing dental issues. PWDs may face additional challenges, including a lack of perceived need for care and longer waiting times compared to the general population (Davis & Reisine, 2015; Williams et al., 2015). The facilitators often provide solutions to these barriers by addressing these challenges.

2.3.1 Access to Dental Care Globally for PWDs

Although PWDs should ideally receive care in primary dental settings (Gallagher & Fiske, 2007; Faulks et al., 2012), many general dentists report limited training or confidence in managing this population. Consequently, they are frequently referred to paediatric dentists or special care dentists for routine dental needs (Suhasini et al., 2021). Dental care for PWDs should be tailored towards their specific needs and preferences. For instance, preventive measures aimed at improving oral health should be patient-centred, with tailored advice for each patient to address their circumstances based on their risk factors and disability (PHE, 2017). Treatment provided to PWDs, especially when sedation or general anaesthesia is required, has historically prioritised completing care efficiently and minimising the need for future interventions. Consequently, extractions are often chosen over more time-intensive preventive or restorative procedures such as endodontic therapy (Biasotto et al., 2024).

For PWDs, oral health needs evolve throughout life, emphasising a life course approach. Health and well-being are influenced by experiences from childhood to

old age. Early conditions and behaviours can affect later oral health, while adult experiences also shape future outcomes. A life course approach highlights the need for continuous, appropriate, and preventive care across all ages (Northridge et al., 2020). It encourages early intervention, regular monitoring, and supportive environments to maintain long-term oral health, noting that timely adult care can reduce risks and improve outcomes.

Moreover, health care systems worldwide vary in the funding and coverage provided to PWDs at the point of access. A clear example of this can be seen in the comparison between the USA and France. In the USA, dental care is chiefly accessed privately through dental insurance, although public programmes are available (Fellows et al., 2022). Despite initiatives such as Medicaid, the Children's Health Insurance Program (CHIP), and the Affordable Care Act (ACA) for PWDs, access remains limited (Fellows et al., 2022). In contrast, France operates a publicly funded health care system (Pegon-Machat et al., 2016) that financially and legally incentivises dentists to treat PWDs according to evidence-based public health policies that reduce specific barriers to accessing oral care (Camiat et al., 2023).

The availability of dental care for PWDs is heavily influenced by a country's economic status and healthcare policies. High-income nations like Australia and Japan have established SCD programs within their universal healthcare systems, yet still experience shortages of these specialists, particularly in underserved regions. Conversely, middle-income countries such as Brazil and Taiwan, despite offering universal healthcare, encounter disparities in access to specialised services and face limited training resources due to financial constraints (Vahdati et al., 2024).

T&T provides dental care privately through insurance, and publicly at no cost, funded by hypothecation of general salary taxation. The government of T&T determines the locations and staffing for dental care. Government clinics also offer a 'walk-in' option, available weekly. Once there is sufficient equipment and staffing to accommodate these patients, they are seen on the same day of attendance or given an appointment within a week once they present with an emergency. However, access is limited because the number of dentists working in the public sector is relatively small compared to the private sector (Naidu et al., 2006).

These limitations, along with a lack of accommodations, negatively impact PWDs. Access to oral health services for PWDs can be understood by examining the experiences and perceptions of three key groups: the individuals, their caregivers, and HCPs providing oral care. Each group faces distinct challenges and has specific roles in determining when, how, and whether PWDs receive suitable dental treatment. The following sections will explore these perspectives, highlighting the barriers, facilitators, and contextual factors affecting access to care. Figure 3 illustrates these groups that influence oral health care for PWDs.

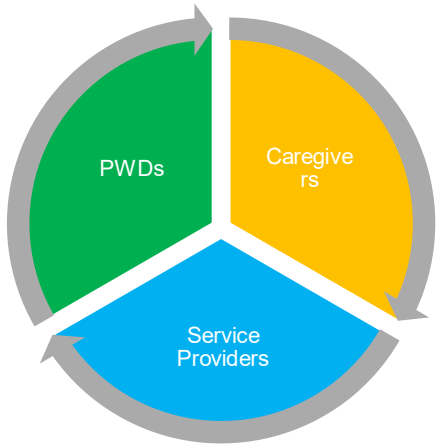


Figure 3. Oral Health Access for PWDs.

2.3.2 Cooperation level of PWDs

Due to cognitive, developmental or behavioural challenges, PWDs may be uncooperative with DHCPs. Such challenges can present as communication barriers, difficulty following instructions, or sensory sensitivities that make routine dental procedures overwhelming. This can lead to dentists being reluctant to treat PWDs. A recent study indicated that more than half of the dentists surveyed were unwilling to treat patients with cognitive impairments, highlighting a persistent gap in provider confidence and preparedness (D'Addazio et al., 2021).

Lack of cooperation can also influence the type and quality of care that dentists are willing or able to offer. When practitioners worry about the risk of unintentional injury to patients or staff, they may resort to nonideal or less comprehensive procedures (Salah et al., 2022). These adaptations, while intended to maintain safety, can compromise the standard of care and may contribute to poorer oral health outcomes over time.

In more severe cases of care-resistant behaviour, standard procedures usually done in a clinical chair may become unfeasible. As a result, some PWDs need dental treatment under general anaesthesia, especially for urgent or complex procedures (Schnabl et al., 2019; Jockusch et al., 2021). Although general anaesthesia enables safe and effective treatment, it also carries higher medical risks, greater costs, and limited availability, which add to the challenges PWDs face in accessing timely dental care (Jockusch et al., 2021).

2.3.3 Caregivers' Inadequate Health Education on PWDs

Caregivers are essential for accessing dental care for PWDs who cannot communicate or function independently. For many PWDs, especially those with severe cognitive or developmental disabilities, caregivers act as the primary interpreters of symptoms, decision-makers, and coordinators of dental appointments. However, identifying orofacial pain can be exceptionally challenging. Non-verbal PWDs may express discomfort through subtle or atypical behavioural changes, such as irritability, withdrawal, agitation, altered eating patterns, or changes in sleep routines. These signs can be ambiguous and are not always immediately recognised as pain-related, making timely detection and intervention difficult (Mac Giolla et al., 2025).

Regarding dental care, a parent's or caregiver's decision may be influenced by their awareness of their child's oral health condition. In that, caregivers with limited knowledge of oral health conditions may underestimate the severity of dental disease or fail to recognise early signs of deterioration. Therefore, parents' or caregivers' decisions may be influenced by their awareness of their child's oral health status (Sohn et al., 2008).

Furthermore, they may be responsible for implementing preventive measures, such as daily oral health practices and oral hygiene, for PWDs with functional limitations that prevent them from independently performing these practices (Anders & Davis, 2010). When caregivers lack sufficient knowledge of dental health, they may struggle to communicate effectively with HCPs or follow their advice. This communication gap can reduce the PWD's cooperation during treatment and complicate clinical decision-making, ultimately contributing to broader difficulties in dental care for this population (Jockusch et al., 2021).

It should be emphasised that effective dental care goes beyond educating parents and caregivers about the oral health of PWDs. It involves a comprehensive approach that considers individual circumstances, addresses structural and behavioural risk factors, and supports long-term, evidence-based prevention measures (PHE, 2017). This way, education becomes one component of a broader, patient-focused strategy aimed at achieving lasting improvements in oral health.

2.3.4 Service Providers' Training to treat PWDs

PWDs occasionally require specialised dental care; however, many can receive routine and comprehensive treatment in general dental practices, provided the dentist is willing, confident, and competent to manage their needs (Faulks & Hennequin, 2006). Even when specialised care is necessary, it may be required only for specific procedures or developmental stages rather than throughout the patient's lifespan. Moreover, a substantial proportion of PWDs have no functional limitations or

behavioural challenges that would restrict their access to standard oral health services; therefore, they can be managed effectively in primary care settings without modification to usual treatment protocols (Faulks et al., 2012).

However, one of the most frequently cited issues is the lack of undergraduate didactic and clinical training related to disability care. Dental graduates who have not received structured education or hands-on experience in treating PWDs often feel unprepared and apprehensive, which can translate into reluctance or refusal to treat this population (Derbi & Borromeo, 2016). Research has demonstrated that dentists without formal training are far less likely to provide care for PWDs than their peers who were exposed to disability-related teaching and clinical encounters during their undergraduate years (Shah et al., 2011). This reinforces the crucial role of early educational experiences in shaping practitioners' confidence, attitudes, and willingness to treat vulnerable populations.

When dental practitioners perceive a lack of adequate training or familiarity with the comprehensive management of PWDs, they may choose to refer these patients to specialists. While referrals are justified in certain clinical scenarios, unnecessary or premature referrals may pose an additional obstacle to care. Specialist services are frequently limited and associated with longer waiting times, which can delay treatment and exacerbate existing oral health conditions (Suhasini et al., 2021). This practice contributes to structural disparities in access to oral health care, underscoring how deficiencies in workforce preparation and service delivery can disproportionately impact PWDs (Faulks et al., 2012; Scambler & Curtis, 2019). To promote equitable access, it is imperative to enhance general practitioners' confidence and competence in managing PWDs within primary dental care settings.

2.4 Parent and Patient Perspectives

2.4.1 Oral Health-Related Quality of Life (OHRQoL) in PWDs

2.4.1.1 Definition of OHRQoL

Oral health transcends the absence of oral diseases. Recently, the World Dental Federation (FDI) defined it as the "ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence, without pain or discomfort" (FDI, 2016a). Quality of Life and self-esteem can also be negatively affected by oral health-related diseases (Sheiham, 2005; Omara et al., 2021).

The measurement of the patient's perspective on the impact of dental disease on their daily life is important and is defined by the concept of OHRQoL (Reissmann, 2021). This model has been researched for the past few decades. The most commonly used definition is by Locker (1988), who described OHRQoL as the degree to which oral disorders affect performance and psychosocial well-being. The impact of the patient's oral health on their quality of life has been defined across several dimensions of routine life, including pain, functional limitation, impairment, disability, discomfort, and handicap (Locker, 1988).

2.4.1.2 Types of Measures of OHRQoL for PWDs

The impacts of these oral health dimensions, including pain, functional limitation, impairment, disability, discomfort, and handicap, on patients' quality of life have been measured in PWDs using various tools (Reissmann, 2021). Most measures have been extensively adapted to various cultural settings and different ages. In PWDs, limited communication and comprehension may be problematic. The Quality-of-Life Questionnaire (QOL-Q) (Schalock & Keith, 1993) and the Comprehensive Quality of Life Scale Intellectual Disability (Cummins, 1997) have been used to determine the OHRQoL in PWDs.

It is preferable to obtain responses directly from patients, such as using the Child Perceptions Questionnaire, the most commonly used tool (Gilchrist et al., 2014). However, this may not be feasible, and proxies provided by parents are used instead, which still offer helpful information (Jokovic et al., 2004). These include the Parent-Caregiver Perception Questionnaire (P-CPQ) and the Quality-of-Life Inventory-Disability (QI Disability), which involve significant reliance on parent or proxy reports in the paediatric literature and practice, especially in the area of intellectual disability (Downs et al., 2019; Leonard et al., 2022).

Proxies who spend time with their ward can provide reliable information on how oral health impacts their overall well-being. These include using the shortened form of the Oral Health Impact Profile (OHIP-14), which has been used for adult, child and adolescent populations (Giannetti et al. 2007; Montero et al., 2018; Riva et al., 2021). Other measures have been developed for PWDs.

2.4.1.3 OHRQoL for PWDs

Poor oral health negatively affects overall health and well-being, impacting critical functions such as nutrition, communication, and social interactions (Asiri et al., 2024). These functional limitations can lead to pain, embarrassment, avoidance of social situations, and reduced participation in educational or work settings, thereby diminishing overall quality of life.

Globally, oral diseases pose a significant public health challenge, affecting approximately 3.5 billion people. Conditions like dental caries, periodontal disease, and tooth loss share common modifiable risk factors, including high sugar consumption and alcohol intake, alongside major NCDs such as diabetes and cardiovascular disease (The Lancet, 2019). The negative impact of the relationship between NCDs and oral health on overall quality of life has been reported (Masood et al., 2017; Peres et al., 2019).

Similar patterns are observed in PWDs, whose OHRQoL is often compromised by a combination of biological, behavioural, and environmental factors (Canico et al., 2018). Challenges such as difficulty maintaining oral hygiene, reliance on caregivers, limited access to dental services, and higher prevalence of oral pathology all contribute to reduced OHRQoL in this population. For example, children with autism have been shown to experience significantly poorer OHRQoL compared to their neurotypical peers, affected by sensory sensitivities, communication difficulties, and behavioural challenges that complicate both daily oral care and dental treatment (Du et al., 2020). These findings highlight the need for targeted interventions to address the unique oral health needs of PWDs and to improve their overall health and social well-being.

2.4.1.4 Caregivers' Perception of OHRQoL for PWDs

Reports from parents and caregivers regarding children's OHRQoL play an essential role in understanding children's well-being, particularly those who are unable to communicate their needs effectively. Parents and caregivers are typically the primary observers of a child's daily functioning, behaviour, and discomfort, and they often make critical decisions about when and how to seek health care services. Their evaluations, therefore, provide valuable insights into the child's perceived oral health status, the impact of oral conditions on daily activities, and the need for treatment (Jokovic et al., 2003).

Although direct reports from children are preferred, given that OHRQoL is inherently subjective and influenced by personal emotional, social, and functional experiences, self-reporting is not always feasible. This is especially true for very young children or children with disabilities that limit communication or cognitive processing. In such cases, parent or caregiver assessments serve as a crucial proxy. Research has shown that parents and caregivers generally offer reliable evaluations that align closely with children's self-reported OHRQoL when self-report is possible (Jokovic et al., 2004).

Evidence from a study conducted in Brazil further highlights the importance of caregiver perspectives. Caregivers of children with disabilities reported a significantly negative impact on their children's OHRQoL, reflecting challenges

such as pain, difficulty eating, aesthetic concerns, and reduced social participation (Canico et al., 2018). These findings underscore the complex interplay between oral health, disability, and daily functioning, and they reinforce the critical role that caregivers play in identifying problems, supporting oral care, and advocating for appropriate dental services.

2.4.2 Dental Fear and Anxiety (DFA) in PWDs

2.4.2.1 Definition of DFA

Dental fear (DF) is an emotional response presumed to be a normal reaction to a threatening stimulus in a dental situation. This differs from dental anxiety (DA), which is understood as an apprehensive state that is linked to loss of control and a feeling of dread during dental treatment (Shim et al., 2015; Grisolia et al., 2021). The terms 'anticipatory anxiety' and 'anxiety' are frequently employed to refer to concern experienced in the absence of the feared stimulus (Olumide et al., 2009). These terms have also been distinguished from a dental phobia (DP), which prevents a person's regular functioning and is matched with an intense fear (Grisolia et al., 2021). The terms dental anxiety and dental fear have often been used synonymously or even as combined terms, Dental Fear and Anxiety (DFA) (Stein Duker et al., 2022). The term DFA will be used in this thesis.

DFA is multidimensional and may arise from endogenous factors like anxiety disorders or exogenous ones based on direct or anecdotal experiences (Beaton et al., 2014). Patients with anxiety and painful dental problems, requiring invasive procedures, especially when anaesthesia is involved, often feel heightened fear during treatment. Their memories are typically associated with negative experiences during dental visits and dentistry in general. Taheri et al. (2024) conducted a study indicating a link between pain-related anxiety and perceptions of dental pain.

More than two-thirds of children diagnosed with autism are estimated to experience clinically significant DFA (Park et al., 2022). Additionally, approximately one-fifth of individuals with intellectual disabilities exhibit DFA (Fallea et al., 2016). Furthermore, adolescents with special needs, as seen in those with cleft lip and palate, have been shown to have a higher incidence of DA (Corcoran et al., 2021).

2.4.2.2 Measures of DFA for PWDs

The Modified Dental Anxiety Scale (MDAS) is a reliable and valid tool that provides insight into specific dental situations or treatments (Humphris et al., 1995; Humphris

et al., 2000). Various instruments and study designs have been utilised worldwide to evaluate DFA in children and adolescents (Grisolia et al., 2021).

2.4.2.3 Factors associated with DFA for PWDs

Given the multifactorial complexity involved in the aetiology of DFA, research has assessed different dynamics associated with its development (Beaton et al., 2014). One such factor is age, where, when studied in an adult population, half of the respondents reported that DFA began during childhood (Locker et al., 1999). The DFA prevalence is approximately one-fifth of the population, with younger children being more affected than adolescents. They have a comparatively higher pooled DFA of approximately one-third of the population versus one-tenth (Grisola et al., 2021).

This may be due to the ability of adolescent children to develop cognitive skills and various coping styles, in contrast to younger children. Children with low verbal intelligence have been shown to suffer from an increased DFA (Blomqvist et al., 2013), and children with attention or learning problems have dental behaviour management problems and dental anxiety (Blomqvist et al., 2004). Additionally, gender differences seem to emerge during the teenage years, with 15-year-old girls reporting DFA more frequently than boys (Rantavuori et al., 2009). However, the findings of DFA have not been consistent regarding gender (Klingberg & Broberg, 2007; Grisolia et al., 2021).

Studies have also associated DFA with reduced OHRQoL (McGrath & Bedi, 2004; Wide & Hakeberg, 2018). Moreover, individuals with DFA had poorer oral health and OHRQoL compared to those without (Slabšinskienė et al., 2021). Therefore, they may face a double burden of poor OHRQoL and high levels of DFA.

2.4.2.4 Effects of DFA on dental attendance and treatment

Children who are anxious about dental procedures may be less likely to seek and receive dental care (Grisolia et al., 2021). This delayed attendance can exacerbate oral health issues and overall well-being, leading to a ‘vicious cycle’ of dental fear associated with dental visits (Pohjola et al., 2009). Furthermore, dental fear may negatively impact a child's OHRQoL, particularly regarding their social and emotional well-being (Luoto et al., 2010). Children who experience anxiety regarding dental procedures may be less likely to seek and obtain dental care. This delay can result in untreated dental problems, pain, and infection, adversely affecting oral health and overall well-being.

2.4.2.5 Effects of Caregivers' DFA on PWDs

Research indicates that caregivers of children, irrespective of whether they have disabilities, often experience comparable levels of anxiety. Notably, caregivers reporting higher levels of dental anxiety frequently exhibit elevated general trait anxiety, suggesting a more extensive pattern of heightened emotional responsiveness (Pinho et al., 2017). Such underlying traits can influence caregivers' perceptions and reactions to dental situations.

Consequently, their own concerns or fears may be inadvertently communicated to their children through verbal cues, body language, or anticipatory behaviours. Over time, this can lead to children developing increased fear and anxiety regarding dental treatment, thereby perpetuating a cycle in which caregiver distress affects child distress and vice versa. This dynamic underscores the importance of understanding and addressing caregiver anxiety as an integral part of efforts to enhance children's dental experiences and outcomes.

2.5 Educational Challenges

2.5.1 Dental education challenges in managing PWDs

Dental students and practitioners should have access to training at both undergraduate and postgraduate levels, enabling all dentists to provide the treatment required by PWDs (FDI, 2016b; Queen, 2016). However, despite advocacy for its inclusion in undergraduate curricula for almost two decades (Gallagher & Fiske, 2007), this has been challenging to incorporate into dental school curricula. Dentistry is an experiential field that necessitates both knowledge and practical experience. Both the didactic and clinical components in dental education play crucial roles in building the confidence of future practitioners to treat PWDs (Vainio et al., 2011). Although students encounter PWDs, increased clinical exposure in the programme's early years is suggested to enhance confidence in the comprehensive management of this population (Hector et al., 2023).

Comprehensive dental education in the management of PWDs is not a standard component in the curricula of many international dental schools. Historically, the dental management of PWDs has been seen as the responsibility of paediatric dentists, who collaborate with anaesthetists and often employ pharmacological methods to provide urgent dental treatment. While paediatric dentists continue to treat PWDs as they age, a transition to adult management is often necessary (AAPD, 2024b). However, in certain countries, a dedicated field of dentistry, Special Care Dentistry (SCD), educates professionals in the comprehensive management of PWDs. SCD is often used interchangeably with Special Needs Dentistry (SND) and

prepares professionals for the modifications necessary in routine dental care to ensure comprehensive dental treatment for PWDs.

Dental schools have faced challenges in providing adequate exposure to PWDs (Vainio et al., 2011). When such exposure is offered, it primarily consists of didactic teaching with minimal clinical interaction for students. SCD is implemented in developed countries such as the USA, Canada, Australia, and some European nations; however, the extent of its delivery remains unclear (Scepanovic et al., 2024). In T&T, students participate in didactic sessions and clinical exposure to SCD in an environment that exclusively treats PWDs throughout their clinical years (Hector et al., 2023). When SCD is taught with both practical and theoretical components, students report increased confidence in providing dental treatment to PWDs (McQuistan et al., 2010; Mohebbi et al., 2014; O'Rourke et al., 2023).

2.5.2 International Educational Guidelines for Special Care Dentistry (SCD)

Dental curricula in SCD vary considerably across the globe, reflecting differences in national policies, institutional priorities, workforce capacity, and the availability of clinical training opportunities (Vahdati et al., 2024). To address this variation and promote a more consistent approach to educating dental students, the International Association for Disability and Oral Health (iADH) developed the first international consensus guidelines for an Undergraduate Curriculum in Special Care Dentistry in 2014 (Dougall et al., 2014). These guidelines outline core competencies, essential knowledge, and recommended clinical experiences intended to prepare future dentists to provide safe, equitable, and patient-centred care for PWDs.

At the European level, further progress was made in 2017 when the Association for Dental Education in Europe (ADEE) introduced “The Graduating European Dentist” framework, which set out recommended learning outcomes for all European dental graduates (Field et al., 2017). This framework emphasises a holistic and collaborative approach to care, encouraging the entire dental team to be involved in managing patients with additional needs. Although these guidelines provide a valuable pedagogical foundation, they have not yet been formalised as mandatory or standardised requirements across European dental schools, resulting in continued variability in the depth and breadth of SCD training (O’Rourke et al., 2023).

In the United States, significant policy advancement occurred in 2020, when the Commission on Dental Accreditation (CODA) implemented a revised accreditation standard requiring that “graduates of dental programs must be competent in assessing and managing the treatment of patients with special needs” (CODA, 2023). This requirement established a clear expectation for all accredited U.S. dental

programmes and represents an important step toward ensuring that new dentists possess baseline competence in caring for PWDs.

Together, these international and national guidelines represent essential efforts to establish minimum educational expectations for preparing dental students to care for PWDs. Although the implementation and delivery of SCD curricula still vary across institutions and regions, the existence of these benchmarks provides a shared framework that supports curricular development, encourages continuous improvement, and promotes a more equitable standard of care worldwide (Holzinger et al., 2020). There is no framework for T&T; however, the lectures delivered between 2018 and 2025 followed the iADH guidelines.

2.5.3 Dental students' perceptions of PWDs

Dental students who gain clinical exposure to PWDs often develop more positive attitudes toward providing care, as demonstrated by Holzinger et al. (2020). These attitudinal improvements may emerge from enhanced dental knowledge, greater understanding of disability-related needs, and increased technical proficiency acquired through structured curriculum experiences (Brown et al., 2002). Evidence suggests that increasing opportunities for students to engage directly with PWDs in supervised clinical settings can build their confidence, reduce apprehension, and ultimately improve their readiness to treat this population in future practice (Hector et al., 2023).

Dental students' attitudes are particularly important because they influence their professional behaviour upon graduation; thus, changes developed during training can contribute to lasting transformations in the dental clinician's approach to care (Brown et al., 2002). This was further supported by Dao et al. (2005), who found that dentists who received education and training related to treating PWDs were significantly more likely to provide such care in their professional practice than those whose curricula lacked this component. These findings highlight the crucial role of targeted education and clinical exposure in fostering a competent and committed workforce capable of delivering equitable care to PWDs.

2.5.4 Behavioural intent of dental students after training in SCD

The theory of planned behaviour aims to explain behaviours where individuals can exercise self-control, for instance, in professional conduct. It postulates that these behavioural intentions are shaped by one's attitude toward the likelihood of achieving the expected outcome, which is shaped by the subjective evaluation of the associated risks and benefits (Faulks et al., 2017).

Despite the idea that the more positively an individual evaluates a behaviour, the more determined they are to engage in it (Ajzen, 1991), the intention of dental students to treat PWDs after exposure to SCD courses was challenging to assess. Feedback provided to the iADH reported ease in assessing knowledge and skills, but difficulty in evaluating the impact of teaching SCD on attitudes and intended behaviour of dental students toward PWDs. In response, the iADH developed a validated toolbox of questionnaires to assess attitudes and behavioural intentions (Faulks et al., 2017).

2.5.5 Complexity assessment requiring SCD

Although PWDs may receive routine dental care from a general dentist, there are instances when referral to a specialist becomes necessary (NHS England, 2022). This is usually a clinically based decision since all PWDs have unique complexities, some of which may require hospital-based services (Vahdati et al., 2024). When treating PWDs, it is essential to consider multiple patient-specific factors, identify potential barriers to dental care, and make the case selection process more efficient and consistent for practitioners.

The recently developed 'Dental Treatment Case Complexity Assessment Form and Recommendations for Persons with Special Health Care Needs' (CDA, 2021) assists the dental team in deciding when such referrals are appropriate. This tool allows a dental practitioner to determine the complexity of a patient's case, helping both the practitioner and the caregiver better understand the factors influencing the patient's dental treatment needs. There are three levels of case complexity: routine, moderate and complex. This tool, which has been disseminated in Canada, can be used to assess the level of complexity of PWDs. It encourages the practitioner to assess the patient and refer them, including details of attempts made to facilitate care thus far (CDA, 2021).

Additionally, NHS England (2022) also recommends referring patients at level 2 to a dentist with advanced skills or experience, or to a level 3 registered specialist or consultant when appropriate. This shared care might be temporary or for a specific episode. Once that period or episode concludes, patients are typically discharged back to their regular dentist for routine care and monitoring.

2.5.6 Summary of Key Arguments

Research indicates that PWDs encounter persistent inequalities in accessing oral health care, despite the global acknowledgement of their entitlement to equitable and person-centred services (WHO, 2023). Barriers are present at multiple levels, including the organisation of care systems, the preparedness and confidence of dental

professionals, and societal attitudes that influence perceptions and treatment of PWDs within clinical environments (Anspach, 1979; Barnes, 2005; da Rosa et al., 2020). From a life-course perspective, unmet oral health needs during childhood often persist into adulthood or worsen further, underscoring the importance of age-inclusive strategies that emphasise prevention, early intervention, and ongoing care (Northridge et al., 2020). Nevertheless, the provision of SCD remains inconsistent across nations, resulting in disparities in the quality of care and access for PWDs (Wilson et al., 2018; Sherriff et al., 2023).

A primary reason for this inconsistency is the lack of standardised, universally accepted educational frameworks for SCD. Although organisations such as iADH, ADEE, and CODA have established guidelines and competencies for dental training, their implementation varies widely (Dougall et al., 2014; Field et al., 2017). Many dental curricula provide limited opportunities to interact with PWDs, and clinical training experiences vary considerably. Research shows that dental students who have regular clinical contact with PWDs tend to develop more positive attitudes, increased confidence, and a higher willingness to treat PWDs after graduation (Brown et al., 2002). In contrast, inadequate or inconsistent training can lead to anxiety, uncertainty, and avoidance behaviours among new clinicians, which further restricts access to dental care for PWDs (Holzinger et al., 2020).

Research on PWDs' care experiences remains limited, especially within specific cultural, social, and health-system contexts. The views of caregivers and HCPs, who are crucial in enabling or restricting access, are also understudied (Anders & Davis, 2010). When caregivers lack sufficient knowledge of dental health, they may have difficulty effectively communicating with HCPs or adhering to their advice (Jockusch et al., 2021). Existing research often depends on small samples, diverse methodologies, or single locations, making broad generalisations difficult and hindering clear conclusions on best practices for equitable, high-quality care (Santos et al., 2025). Additionally, the relationship between dental anxiety and oral health-related outcomes needs further investigation, particularly in PWDs.

These gaps highlight the need for research that:

- investigates the experiences and barriers faced by PWDs and their caregivers in accessing oral health care;
- evaluates the readiness, attitudes, and educational requirements of dental professionals across various countries and educational systems;
- explores the factors affecting dental pain and behaviour to inform more compassionate and effective clinical practices.

Addressing these areas will enhance understanding of the factors influencing oral health care for PWDs and support the development of improved educational programs, service models, and patient-centred interventions.

3 Aims

The general aim of this thesis was to investigate ways to enhance oral health care for patients with special needs by exploring barriers to dental treatment for individuals with disabilities. This thesis aims to identify facilitators of dental care and examine the relationship between the oral health of PWDs and their overall well-being, including their dental fear levels. Additionally, this thesis aims to evaluate the long-term impact of an educational initiative in SCD on the provision of dental care for PWDs. It subsequently aims to assess dental students' attitudes and intended behaviours regarding SCD following their training in this area.

The research was conducted across five studies to address the following questions: What barriers prevent PWDs from accessing appropriate oral healthcare? How does the oral health of PWDs relate to their overall well-being? What are the long-term effects of educational initiatives focused on SCD on dental practitioners' confidence and their willingness to treat PWDs? How does SCD training affect dental students' attitudes and their intended clinical behaviour when managing PWDs?

The specific aims of the studies were:

I. To examine the challenges faced in dental health care by professionals and caregivers of PWDs in Trinidad and Tobago (T&T).

II. To analyse the OHRQoL for children aged 6 to 18 who visit the special needs and paediatric dental clinics at the UWI.

III. To investigate dental fear in children aged 6 to 18 attending the SNDC and the CDHU at the UWI School of Dentistry.

IV. To evaluate a workshop on SCD for dentists, allied DHCPs, and dental students in T&T.

V. To evaluate the intentions of dental students to treat PWDs after they have completed both didactic and clinical training on providing treatment for PWDs at two different institutions, one in Europe and another in the USA.

4 Materials and Methods

The challenges that professionals and caregivers in T&T face in providing and accessing dental health care for PWDs are largely unknown. For this reason, a qualitative research methodology was employed to explore these barriers and facilitators, to understand the participants' lives within different community contexts over a specific period through storytelling. The narrative analysis framework served as a tool for analysing the participants' stories during the interview, enhancing the context of their experiences.

Subsequently, quantitative methodologies were employed to analyse the perspectives of patients and caregivers regarding OHRQoL and DFA of children aged 6-18 visiting the SNDC and CDHU at UWI. Following this, a mixed methods approach provided an analysis and evaluation of a workshop on SCD for dentists, allied DHCPs, and dental students in T&T, offering a broader perspective than either a solely quantitative or qualitative study methodology. This methodology also allows each method's strengths to offset the weaknesses of the other. Finally, a quantitative methodology was used in Study V to understand the effect of education in SCD on dental students' intentions to treat PWDs after they had been trained in the treatment of this population.

4.1 Studies I-V

4.1.1 Study Design

This thesis utilised several datasets and various methods. Study I incorporated elements from a qualitative study by Balkaran et al. (2022a). This was followed by two quantitative studies, II and III (Balkaran et al., 2025a; 2025b). Subsequently, Study IV (Balkaran et al., 2022b) employed a mixed methods approach, combining quantitative and qualitative elements in the initial and follow-up surveys. Finally, Study V (Balkaran et al., 2025c) was quantitative in design. All questionnaires, interviews and consents were conducted in English (Appendices 1a, 1b, 2a, 2b, 2c, 3a, 3b, 4a), except for Study V (Balkaran et al., 2025c), which was carried out in

French by native speakers (Appendix 4b). Table 2 summarises these studies, including the participants and focus of each study.

Table 2. Participant Group and number (n), methodology and the study's focus.

Study	Participant Group and Number (n)	Methodology	Study's Focus
I	Health care Professionals, dentists, dental therapists/assistants, caregivers of PWDs and self-advocates (16)	Qualitative through interviews	Examination of facilitators and barriers in dental health care for PWDs
II	Parents/ caregivers (201) and their children aged 6 to 18 (150), with and without disabilities	Quantitative through a questionnaire	Analysis of OHRQoL
III	Parents/ caregivers (201) and their children aged 6 to 18 (150), with and without disabilities	Quantitative through a questionnaire	Investigation of levels of DFA
IV	Dentists, allied dental health care professionals, and dental students at a workshop on SCD (131) and one year after (95)	Mixed methodology through surveys at a workshop on SCD and one year after	Evaluation of the workshop and its effect one year later
V	Dental students from Arizona (77) and France (62)	Quantitative through a questionnaire	Evaluation of the intentions of dental students to treat PWDs after SCD training

OHRQoL- Oral Health-Related Quality of Life, DFA- Dental Fear and Anxiety, PWDs- People with disabilities, SCD- Special Care Dentistry.

4.1.2 Study Participants

Participants were from T&T in Studies I-IV (Balkaran et al., 2022a; Balkaran et al., 2025a; Balkaran et al., 2025b; Balkaran et al., 2022b). T&T is an English-speaking Caribbean country consisting of two islands with an estimated total population of 1.4 million (CIA, 2017). In 2024, approximately 70% of the population was aged 15-64, while children under 15 comprised one-fifth of the population (PAHO, 2024). Study I's (Balkaran et al., 2022a) participants included DHCPs, parents and caregivers of PWDs, and HCPs who treat PWDs aged 30-70. They were recruited through purposive sampling. Participants for Studies II and III (Balkaran et al., 2025a; 2025b) were selected from a convenience sample of children aged 6 to 18 years and their

accompanying adults. The disabilities of participants in Study I included sensory impairments: one was blind, and the other was deaf and mute. In Studies II and III (Balkaran et al., 2025a; 2025b), the participants had various disabilities such as Autism, ADHD, Global Developmental Delay, Intellectual Disability, DS, Speech Delay, and CP.

Study IV involved a convenience sample of dentists, dental therapists, dental assistants, and dental students from years 1–5 of the UWI dental school. The target population of Study IV was adults aged 20 to 70 years. Finally, Study V involved final-year dental students from the 2023 class from both the Arizona School of Dentistry & Oral Health at A.T. Still University (ATSU) in the USA and the Université Clermont Auvergne in France, at the end of their SCD training. The target population was adults aged 20 to 45. Both universities utilised the advised competencies outlined in the iADH curriculum.

Written consent was obtained from all participants for Studies I-III (Appendices 1b, 2c), and implied consent was obtained for Studies IV and V, which were stated at the beginning of the respective questionnaires (Appendices 3a, 3b, 4a and 4b). Respondents who did not reply to the questionnaires in Studies IV and V (Balkaran et al., 2022b; Balkaran et al., 2025c), who had missing data in Study II (Balkaran et al., 2025a), or who did not meet the inclusion criteria in Studies II and III (Balkaran et al., 2025a; 2025b) were excluded from the study.

4.2 Facilitators & Barriers

4.2.1 Study I

4.2.1.1 Development of Questions

Data were collected through semi-structured interviews (see Appendix 1a), specifically focusing on PWDs and their experiences within the dental care system. The interview schedules were developed by the principal investigator (PI), and face validity was verified by a co-author of Study I (Balkaran et al., 2022a). The questions were constructed to effectively capture the complexities associated with PWDs while remaining acutely aware of the influences of intersectionality. Consistency in questions was maintained within and across each group. The content of the questions varied slightly for DHCPs, caregivers, and HCPs.

4.2.1.2 Measures of Observation

Sixteen (16) participants were recruited from DHCPs, caregivers, and HCPs. Purposive sampling identified respondents experienced in caring for PWDs, while snowball sampling helped recruit additional participants. Table 3 presents the participants' profiles. After obtaining consent, I arranged interviews as the PI. Figure 4 outlines the study sequence. An intersectionality approach based on my positionality guided data collection and influenced caregivers' and HCPs' views on PWDs' dental care access. Participants signed an informed consent form prior to the interview, which was sent to them via email. They were verbally informed of their voluntary participation and assured confidentiality at the beginning of the interviews (see Appendix 1b). The questions focused on PWDs, their dental treatment, the adequacy of care, and related challenges. Narrative inquiry illustrated the stories of HCPs and caregivers of PWDs (Figure 5). The open-ended questions encouraged in-depth exploration of their experiences. Interviews lasted about one hour and were conducted via Zoom from March to June 2021.

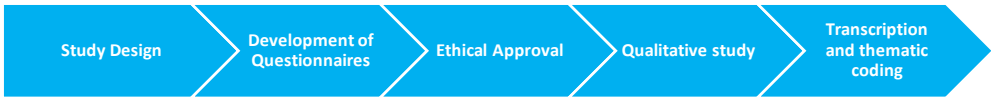


Figure 4. Sequence of the process of the Qualitative Study.

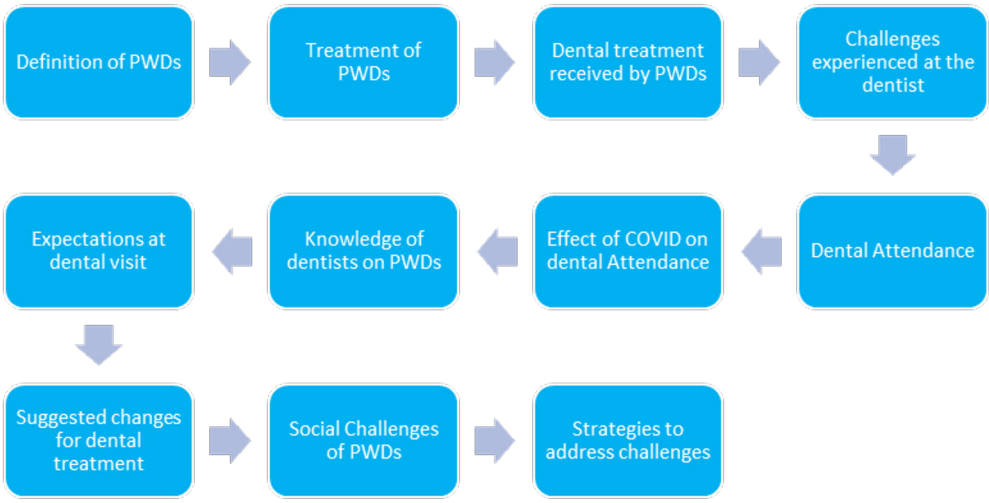


Figure 5. Order of Interview Questions of Study I.

4.3 Parent and Patient Perspectives

Understanding patients' and caregivers' perceptions is essential, highlighting the need to incorporate their narratives into data collection tools based on their lived experiences. Given that both OHRQoL and DFA require an understanding of the effect of oral health on overall well-being and how DFA impacts access to dental care, these perspectives are necessary to improve stakeholders' experiences in dental care and treatment.

4.3.1 Studies II & III

4.3.1.1 Development of Questions

Studies II (Balkaran et al., 2025a) and III (Balkaran et al., 2025b) employed the same questionnaire for the accompanying adults (parents/ caregivers) (see Appendix 2a) and the children (see Appendix 2b), which were administered on their arrival at the two UWI dental clinics with a paediatric population: the SNDC and the CDHU. In both Studies II and III (Balkaran et al., 2025a; 2025b), variables measured included demographics (such as gender, age, and ethnicity), the presence of an accompanying adult, the reason for the visit, recent dental attendance (last dental appointment), and the child's oral health rating. Table 4 highlights the participants' demographics and the types of disabilities seen.

Both studies used validated and standardised international survey instruments (Balkaran et al., 2025a; 2025b). Study II (Balkaran et al., 2025a) evaluated the OHRQoL using the shortened form of the English version of the Oral Health Impact Profile (OHIP-14). It utilised a 5-point Likert scale in the OHIP-14 questions, ranging from 'very often' (1) to 'never' (5), along with an 'I don't know' option (Slade et al., 2005). It included 14 questions assessing the frequency of oral adverse impacts across seven dimensions: functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap (Slade et al., 2005; Riva et al., 2021). A one-month reference period was employed to evaluate the OHRQoL (Slade, 1997; Sutinen et al., 2007).

In Study III (Balkaran et al., 2025b), the children's DFA was evaluated using the reliable and valid Modified Dental Anxiety Scale (MDAS) (Humphris et al., 1995; Humphris et al., 2000). The MDAS employed a 5-point Likert scale, with responses ranging from 'not anxious' (1) to 'extremely anxious' (5). The overall scores fell within the range of 5 to 25. The accompanying adults were asked five questions regarding their children's feelings about attending the dentist for different components of the visit and procedures.

4.3.1.2 Data Collection

Data collection took place from July 2022 to February 2023. The PI administered these questionnaires at the SNDC, while a calibrated researcher also administered them at the CDHU. The responses were obtained from the parents or caregivers of patients and children who were capable of verbal expression, whose accompanying adult consented to their participation in the study, and are discussed in this thesis. Eligible respondents, who remained anonymous throughout the study, provided written informed consent before each study (Appendix 2c).

4.4 Educational Perspectives

Education serves as a tool for reducing the stigmatisation of PWDs by adequately training HCPs. This improves their ability to manage PWDs and reduces barriers to accessing oral health care. Furthermore, the trained HCPs can educate the caregivers of PWDs on techniques to maintain a healthy oral health status and services intended to assist them.

4.4.1 Study IV

The seminar-based workshop in which Study IV (Balkaran et al., 2022b) recruited participants was advertised on national television and social media. It focused on treating and managing PWDs, featuring a medical and dental specialist experienced in treating PWDs. The significance of collaboration between physicians and dentists for effectively treating PWDs was emphasised. The dental seminar underscored the necessity of improving oral health for PWDs to ultimately enhance their quality of life, utilising video clips to demonstrate various techniques to the attendees.

Two surveys were conducted at the workshop, and another a year later. The original survey sample consisted of 176 attendees, including dentists, dental therapists, dental assistants, and dental students from years 1–5 of the UWI dental school. In the initial survey, 133 respondents participated, while 95 individuals responded to the subsequent survey.

4.4.1.1 Questionnaires

Two distinct questionnaires were administered to assess interest in SCD (see Appendices 3a & 3b). Both surveys included closed and open-ended questions. The latter were designed as open inquiries based on face validity to foster an environment that encourages an in-depth examination of participants' beliefs.

The first survey comprised an anonymous questionnaire, which participants were directed to submit to the designated box at the registration table upon completion.

It featured questions on the attendees' demographics (such as gender, age, ethnicity, enrolled degree for students, and year of graduation for dentists) and the weekly number of PWDs that are typically treated. It also assessed the obstacles faced in treating PWDs and the motivations behind their attendance at the workshop.

The second survey employed an anonymous online tool based on the COVID-19 restrictions existing in 2020 in T&T. It assessed the attendees' demographics as in the first survey. A 5-point Likert scale was used to evaluate participants' views on the workshop, the knowledge and confidence they gained, and how they applied that education one year after the workshop. It also gathered participant feedback on the most rewarding aspects of their experience and suggestions for enhancing the workshop.

4.4.2 Study V

The cross-sectional survey in Study V (Balkaran et al., 2025c) was conducted at the ATSU in the USA and at the Université Clermont Auvergne in France. All students in the class of 2023 from both institutions were invited to complete a self-administered questionnaire at the end of their respective curricula during their final year.

4.4.2.1 Questionnaire

The questionnaire was used in both schools (Arizona and France), and the students were advised that their responses were anonymous and that no item had a right or wrong answer (see Appendices 4a and 4b). The questionnaire was designed to measure the attitudes and intended behaviours of student groups while evaluating how teaching SCD influences these attitudes and behaviours (Faulks et al., 2017). Scenario #2 was chosen out of the twelve scenarios in the iADH Toolbox for Measuring Attitudes and Intended Behaviours in SCD (Faulks et al., 2017). The scenario was described in the questionnaire concerning the provision of treatment for an adult patient with DS, which was within the student's clinical competence (see Appendix 4a in English and 4b in French).

One of the questionnaires within the iADH toolkit (Faulks et al., 2017), utilised the Theory of Planned Behaviour (TPB) to assess the intended actions of dental students in treating PWDs (Ajzen, 1991; Francis et al., 2004). The TPB is a theoretical model that predicts certain intentional behaviours based on individuals' attitudes, subjective norms, and perceived control over their actions (Francis et al., 2004). This model evaluates individuals' intentions and prospective behaviours, including integrity, altruism, and attitude (Faulks et al., 2017).

This internationally validated tool, using closed questions, ascertained participants' demographics (gender, age) and personal experiences working with or caring for PWDs and other marginalised groups. Five questions on a 7-point Likert scale assessed students' beliefs about behaviour outcomes, subjective norms, motivation to comply, and control beliefs (see Appendices 4a and 4b). Additionally, the influence of different control beliefs on the likelihood of treating this patient was evaluated (Faulks et al., 2017).

4.5 Analysis of Data for Studies I-V

In Study I (Balkaran et al., 2022a), after transcribing the interviews with Otter.ai 2.0, the PI ensured the accuracy of all transcripts. The responses were coded individually, and a peer debriefing session was conducted to cross-reference them and verify the reliability of the interpretation. This session addressed differing views among the co-authors and established justifiable interpretations of the data. The researchers identified narrative codes to emphasise the relational aspects of dental care experiences. They discussed comparative coding to identify potential themes, thereby enhancing data interpretation and the validity of the findings.

Data from Studies II and III were analysed using SPSS version 26.0 (IBM SPSS Statistics for Windows, Armonk, NY: IBM Corp.) for both studies (Balkaran et al., 2025a; 2025b). Bivariate associations between outcome and explanatory variables were analysed using cross-tabulations. The statistical significance of these associations was evaluated using Chi-square tests, and for skewed data, the Kruskal-Wallis and Mann-Whitney U tests were employed.

In Study II (Balkaran et al., 2025a), responses were coded from 0 (never) to 4 (very often). Three OHRQoL outcomes were assessed: severity, prevalence, and the seven OHIP-14 dimensions (Rantavuori et al., 2023). Severity scores ranged from 0 (good quality of life) to 56 (poor quality of life) and were obtained by summing all 14 items. Prevalence was determined as the percentage of individuals reporting at least one impact from the OHIP-14 at two threshold levels: ‘occasionally’, ‘fairly often’, or ‘very often’ (OFoVo) and ‘fairly often’ or ‘very often’ (FoVo) (Raittio et al., 2015; Rantavuori et al., 2023). Participants were coded 1 if any impact was reported within the threshold and 0 otherwise. The seven domains were calculated by summing the values of two items for each dimension (Slade et al., 2005).

Participants were potentially excluded if they missed over two OHIP items or had more than two ‘don’t know’ responses. However, there were no missing values that exceeded two ‘don’t know’ responses, so no exclusions occurred. Four participants were excluded due to missing data on both items within any domain. For one missing item, the response of the other was treated as 0. Missing severity scores were imputed using group means (n=201). Re-coded missing items ranged from 6 to

16 per domain. Prevalence at thresholds OFoVo and FoVo, and related variables, are reported as frequencies and percentages, by accompanying adults (Table 5a) and verbal children (Table 5b). Severity and scores were summarised with means, standard deviations, and ranges. Two logistic regression models analysed prevalence outcomes (dependent variable) at both thresholds, with Disability (yes=1) as the independent variable (n=197) for adults (Table 6). Covariables were dichotomised and included gender, age, ethnicity, caregiver, reason for visit, last dental visit, and child's oral health rating. Odds ratios (ORs) with 95% confidence intervals (CIs) were reported.

In Study III (Balkaran et al., 2025b), the MDAS was used with the accompanying adult as a proxy, a method previously employed by AlAzmah et al. (2024). Additionally, the MDAS was used on verbal child participants. A score under 10 indicates low anxiety, a score between 11 and 18 reflects moderate anxiety, while a score of 19 or higher signifies high anxiety (King & Humphris, 2010). These cut-off points were previously used in studies by Kankaanpää et al. (2019) and Lahti et al. (2020). Two factors of the MDAS were determined by summing the item responses: anticipatory dental anxiety (items 1 and 2; score range 2-10) and treatment dental anxiety (items 3-5; score range 3-15) (Yuan et al., 2008; Kankaanpää et al., 2019; Lahti et al., 2020).

The distribution of adult participants according to outcomes and covariables for Study III (Balkaran et al., 2025b) is presented using frequencies and percentages (see Table 7a), as well as for the child participants (Table 7b). The means, standard deviations, medians, and first and third quartiles of the MDAS total sum and treatment-related and anticipatory sum scores were calculated for both the children and their accompanying adults. Subsequently, a multinomial logistic regression model was fitted to data from the accompanying adults on the MDAS across the three groups: 5–9 (low), 10–18 (moderate), and 19+ (high anxiety), with the low anxiety group serving as the reference category (see Table 8). Disability (yes = 1) was the factor considered. Covariables were dichotomised as in Study II (Balkaran et al., 2025a), where possible confounding factors such as age, gender and accompanying adult were considered in the regression model.

In Study IV (Balkaran et al., 2022b), the data on age were reorganised into three categories: under 25, 25–40, and over 40 years for both surveys. Ethnicity was also categorised into Indo-Caribbean, Afro-Caribbean, and Other.

All responses to open-ended inquiries in both surveys were categorised according to similar themes, and the frequency of these themes was documented. For instance, under the category of knowledge, these analogous themes were combined "to prepare for clinical years", "to learn how to improve treatment for patients' comfort", and "to know how to be able to care and improve skills in this field." Under the theme of communication, the "patient may have limited knowledge and

understanding", "difficulty with informed consent", and "the patient is non-communicative". However, a more in-depth analysis of this qualitative data was not undertaken. The demographics and knowledge as the reason for the participants' attendance were presented using frequencies and percentages (see Table 9). The Chi-square test was utilised for statistical analysis.

In Study V (Balkaran et al., 2025c), following data collection, each item was scored according to the toolkit by Faulks et al. (2017). Question 1 was presented as the percentage of respondents answering 'Yes' (Figure 10), while questions 2 to 9 were reported as means with standard deviations (Figures 11, 12, 13 and Table 10). The Mann-Whitney U Test was employed for statistical analysis. All data were analysed using SPSS version 26.

4.6 Ethical Considerations

Respondents' participation was voluntary and anonymous in all studies I-V (Balkaran et al., 2022a; Balkaran et al., 2025a; Balkaran et al., 2025b; Balkaran et al., 2022b; Balkaran et al., 2025c). Studies I-IV (Balkaran et al., 2022a; Balkaran et al., 2025a; Balkaran et al., 2025b; Balkaran et al., 2022b) were approved by the UWI Ethics Committee (Appendix 5). All participants gave written informed consent for Studies I-III (Balkaran et al., 2022a; Balkaran et al., 2025a; 2025b), and implied consent was obtained for Studies IV and V (Balkaran et al., 2022b; Balkaran et al., 2025c). No identifiable data were stated at the introduction of each survey in Studies II-V (Balkaran et al., 2025a; 2025b; Balkaran et al., 2022b; Balkaran et al., 2025c). In the qualitative study (Balkaran et al., 2022a), the participants' identities were known only to the PI. However, upon transcription, all identifiers were removed from these interviews, and therefore, they were unknown to the co-authors during the data analysis. In Study V (Balkaran et al., 2025c), the courses' post-assessments were conducted for internal review to assess the impact of teaching on students' attitudes, and ethical approval was not required from either institution for this research.

5 Results

5.1 Study I

All participants agreed to contribute to the research and provided written consent before the interviews. The interview timing varied depending on the respondents' availability. This qualitative analysis (Balkaran et al., 2022a) identified several facilitators and barriers that HCPs, caregivers, and self-advocates face. The results of this study addressed the following research questions:

- What barriers prevent PWDs from accessing appropriate oral healthcare?
- What facilitators contribute to successful oral healthcare for PWDs?

5.1.1 Characteristics of Participants in Study I

In addition to Table 3 below, the results section includes the designations and genders of all participants in parentheses to help identify the individual who provided the quote.

Table 3. Profile of Participants.

ID	Gender	Ethnicity	Age	Children's Ages	Disability
D1*	F	M	39	N/A	N/A
D2	M	IC	53	N/A	N/A
D3	F	AC	31	N/A	N/A
D4	F	AC	32	N/A	N/A
D5	F	AC	48	N/A	N/A
CG1 (self-advocate)	M	IC	52	None	N/A
CG2	F	M	49	23, 21	Autism, none
CG3	M	AC/M	58	22	DS
CG4a	M	M	65	27,37	CP, none
CG4b	M	M	42	8, 17	CP, none
CG5 (self-advocate and interpreter)	Both F	AC	49	None	N/A
P1	F	IC	35	N/A	N/A
P2	M	IC	44	N/A	N/A
P3	F	AC	54	N/A	N/A
P4	F	O	46	N/A	N/A
P5	F	IC	70	N/A	N/A

*D- Dental Therapist/ Assistant, D- Dental professional, CG- Caregiver, P- Physician.
Gender of participants: F-Female, M-Male
Ethnicity of participants: M-Mixed, IC-Indo-Caribbean, AC-Afro-Caribbean, O-Other
Disability of participants: DS- Down syndrome, CP- Cerebral Palsy

5.1.2 Barriers

The barriers included issues with health care systems, caregivers', and educational challenges, expenses, lack of access, and absence of social support. The results focused on the challenges associated with providing dental care. This evolved into a multifaceted issue, centering on HCPs' preparedness, the extent of specialised care offered, and the necessary resources for treating PWDs in the health care setting.

5.1.2.1 Issues with health care systems

5.1.2.1.1 Preparedness of HCPs

P2(M) highlighted the anxiety experienced by parents of children with disabilities when seeking dental care, fearing the dentists' inexperience and understanding. This concern was emphasised during the interview when he stated:

> "…the fear of how the kids may react to the dentist...the dentist may not be able to handle the kid who has autism, or Down syndrome, cerebral palsy as the case may be so many parents attend to the dental care themselves, but many of them do not regularly see dentists".

Furthermore, the multidisciplinary approach emphasised that teamwork and collaboration are essential for achieving improved results in the overall care of PWDs. P5 (F) underscored this by stating that there is a necessity to:

> "...include dental and physiotherapy and occupational therapy and speech therapy and medical teams and social workers and psychiatrists...psychologists. There is [a] work division at different levels. Special needs centres where these patients may get holistic (comprehensive) care would be beneficial. There's also a need to get the organisations together for planning."

5.1.2.1.2 Specialised Care Offered

The issue of having a designated service for PWDs and sufficient time afforded to PWDs was raised by a few participants, where P4 (F) stated:

> "I think there should be specialized dental clinics for children with special needs… [with sufficient] time…so that the dentist, themselves, can feel quietly confident and take their time and do what they need to do with the thoroughness that is required."

CG4b (M) also discussed concerns about having specific clinics that meet the needs of PWDs, and said:

> "[we need] a special area for people with disabilities"

This sentiment was also echoed by CG 2 (F), who discussed the accommodations provided by health care personnel for PWDs:

> "… It will mean maybe infrastructure change. … how they set up waiting area if there's a space to have a quiet room with somebody who can't tolerate, all that noise out into the regular clinic, there's a place where this person could go in this quiet space. … And really, I feel like the waiting time is just too long. .... And again, it's a rush clinic. You know, as one come out, one goes back in, and it's just like it's just too much, it's overwhelming."

5.1.2.1.3 Resources

The concern about the infrastructural issues raised in the previous section extended to staffing and equipment at various facilities. CG2 (F) spoke of the frustrations experienced as a result of these challenges:

> "And then you hear the dentist don't have all the tools to do the kind of work you need to go somewhere else. Because … [the dentist] don't have the equipment…. So, you open a free service, you paying the staff, and then you'd want equipment to do the job, then you're frustrated. Because the client keeps going back again and again and not get any service. Everybody, even the person taking the person, get frustrated."

Additionally, the discussion highlighted the necessity for improved communication, as CG 5 (F) advocated for increased support levels for PWDs:

> "Support, when it comes to people with wheelchairs, we should have maybe special transport …. The other challenge may be for the blind, they will be dependent on someone to guide them. …also pick them up and carry them. So, when it comes to the deaf, we can see. So, we can travel. But the other problem is just communication, writing, reading…. I would like all dentists to know about the deaf community, the blind and other differently abled and learn sign language."

5.1.2.2 Caregivers' Challenges

Caregivers offered distinct insights into the challenges of obtaining quality dental care and the perception of PWDs in society. Key issues highlighted included the stigmatisation of PWDs, the cost of dental care, limited access to dental services, and the lack of social support for PWDs.

5.1.2.3 Educational Challenges

5.1.2.3.1 Concerns for PWDs

Three participants highlighted the negative reactions towards PWDs and the tendency to isolate these children, both at home and in institutional settings. CG 3 (M) stated:

> "We still have this kind of stigma where parents still keep their children at home … we are not an inclusive society. So, they are segregated. By putting them in the special schools and institutions. And they probably… go there until they become adults and they don't want to go anymore. And then they are back to home. So, it really affects how society perceives them and view them."

P4 (F) highlighted the impact of this:

> "…. there really is a lack of social support and a lack of institutional support for patients like this……They really are marginalised and disrespected as a result of poor educational opportunities…"

5.1.2.3.2 Concerns for HCPs

The lack of knowledge and education in dealing with PWDs also extended to CG2 (F), who shared the following on the inadequate training and medical accommodations within dental care for PWDs:

> "… the biggest challenge that parents … face, my child will not sit, …. So, parents just end up not taking them…...hence the reason why I'm saying that personnel need to be trained and how to reassure or how to understand how this person has been affected by their disability or by their impairment, to be able to support them..."

5.1.2.4 Expenses

P4 (F) emphasised the challenges of costs related to delivering proper care for PWDs, illustrating this with an example of a patient struggling to obtain financial assistance, she stated:

> "… I had an adult, a woman who is … 47-48 who … [had] never been diagnosed. … lived with her brother her whole life. Two weeks ago...[he] died. ..[and he] was taking care of her his whole life. So, in comes two nieces, who have to start from scratch …. And they've come to me because [of] something as simple as getting her disability grant, which is something like $1800 a month because she has seizure disorders as well… And of course … they have to purchase it…alongside, you know, adult Pampers. So, to get access to her $1800 … they need a letter from me, …stating … the circumstances that they find themselves in [since] the doctor who usually sees her … office is closed because of COVID. So, I have access to no medical records; I just have to go on what I can see....

> And I mean, the diagnosis was not in question. She couldn't complete a mini-mental status exam. … I mean, for her to just get $1800 from the bank, I had to give a letter stating she has diminished capacity, she's not able to make decisions, not just financial, but her legal, and that she lacks the competence."

5.1.2.5 Lack of Access

Six interviewees spoke about the lack of access as a significant challenge. For most participants, the issues of long wait times, insufficient accommodations, and increased frustration were emphasised. P4 (F) discussed problems related to system failures and delays in waiting times:

> "They spent 9-10 hours in casualty [emergency] waiting to be seen. And it's not fair because that's a vulnerable population, and they should be triaged, seen quickly, and sent home."

Furthermore, CG 4a (M) advised that:

> "We don't have infrastructure for people with disabilities" facilities in; for instance, governmental buildings etc. (parking, waiting rooms, toilets) "So, what we need to do is for the government to get together with the NGOs or the organisations and sit down and.…[the] United Nations Convention on the Rights of People with Disabilities has been ratified in Trinidad, practically nothing is done - it is on paper only."

This was supported by P3 (F), who considered transportation to be a barrier to accessing care:

> "Sometimes the lack of access of care within the public health sector, for children health care is free. But some persons they may be living in such levels of integer that they still can't afford, especially if they are positioned in remote areas where they may have to hire some form of transport exclusively to come to wherever the point of service is, so that's sometimes a barrier."

5.1.2.6 Absence of Social Support

Caregivers of PWDs are at a disadvantage in terms of social support systems, and this was raised by P4 (F), who stated:

> "…I think social support is lacking, financial support is lacking, and policy that protects these people and caregivers who look up to them has to be put in place. Because nobody really is doing that…."

5.1.3 Facilitators

The facilitators of these challenges included advocating for the education of key stakeholders, promoting policy changes, enhancing advocacy efforts, improving resources, and implementing preventive measures to address these challenges.

5.1.3.1 Education

Participants highlighted the importance of increasing societal awareness and understanding of PWDs. They believe that having more inclusive schools could assist with destigmatising PWDs. They also emphasised the value of strengthening HCPs' knowledge and training in supporting PWDs, as well as enhancing caregivers' capacity for effective prevention and care.

5.1.3.1.1 Addressing the Issue of Stigma

CG1 (M) indicated that this stigma presents an opportunity for the educational system to adopt more inclusive practices and better accommodate diverse learning styles and student needs, stating:

> "Yes, and why can't we when we train teachers to know that don't tell the student they can't do something? Find out how to get it done…. and every student is different every student perform differently we are not equal. Some are visual learners. Some are audio learners. Some are tactile learner. So even if a child is blind with tactile learning, that would benefit other students in the class."

5.1.3.1.2 Training for HCPs on PWDs

This was a key strategy for enhancing care for PWDs. This updated training emerged as a way to raise awareness among HCPs, cultivate essential skills to support PWDs and commit to diversifying care delivery approaches. Consequently, P4 (F) stated:

> "I do think the curriculum needs to reflect that, special needs, is a vulnerable population and should be treated as such. I think if our junior dentists are taught from now, then we stand the chance for the future generation."

P4 (F) also suggested:

> "So, from a dental point of view, I think special needs clinics should be mandated. I think if there's certain homes that you know, you know, if you're going to do home visits …where there are persons with special needs, I think that would be invaluable to them, rather than having the orders being put on the caregivers who already overwhelmed. Even if it's once a year. I think that would be good."

5.1.3.1.3 Education of Caregivers

P1 (F) recommended that parents and caregivers should have access to information to enhance their capacity to support the lives of their loved ones with special needs, stating:

> "They're poorly fed, and they're just drinking bottles for their whole life, right… the parents, just ...don't know what they do with their mouth, for lack of not knowing it's not their fault at all, they probably just, you know, use some glycerine or use a washcloth or whatever. And then they get to six, seven years of age, and then they have this massive build-up in their mouth. And that's when you need…. anaesthesia, and that's a need to be put to sleep and all of that. …, when it could have been introduced at a much younger age and wouldn't be, you know, that difficult."

Additionally, D2 (M) highlighted the importance of health promotion:

> "In dental school, ..., they need to ….do more outreach programs and get outside and let people know that, hey we have a dental school, …. we need to educate the public about dental health."

5.1.3.2 Policy Implications

In light of the challenges discussed, many participants indicated that a national policy with a focus on dental care for PWDs is essential. CG4a (M) underscored this requirement, stressing the significance of consultations before adopting a national policy and remarked:

> "I think the first thing we need to do is meet … and then we can discuss a way forward in terms of what is needed and the fastest and best way to get to where they need to be……. trying to program a policy without knowledge of the

> situation [in the field] so it will never work ……. We need proper health care, social, educational spaces for people with disabilities in this country……the system has to be more trained, more understanding to deal with people."

In addition, CG1 (M) highlighted the need for changes to current policies, stating:

> "Just to start from the top, you have to have policy change. You have to have, you know, we talk about millennial goals, we talk about health in all places, we talk about a community is needed to help the individual but to be able to do that, you have to give that individual access to healthy spaces, health places, dental care, free medical care, transport, accessible transport. We have to provide caregivers in case that loved one wants to go out and work."

Additionally, P3 (F) discussed the need for a strategy and the implementation of existing policies that are not being enforced due to a lack of consultation and stated:

> "On a national level, we're talking about governmental policy and plans that would allow for greater access of children with special needs to have equitable access to health care."

5.1.3.3 Advocacy

This was emphasised as a crucial element in addressing the gaps identified in the treatment of PWDs, with both HCPs and caregivers advocating for more effective support and protection for PWDs. Therefore, P5 (F) noted that:

> "I suppose lots of advocacy, and at the level of our influence to kind of keep pushing for the support services that are needed with the aim of eventually being able to..... be based on region or if it might be nationally but, [have] some sort of service or centre that's able to kind of house all the service that they need ……. and there's a whole team that really should go into it and baby steps for now, obviously, but,.... the aim should always still be the bigger picture, what would be ideal for these patients so we can we can get there."

The concerns surrounding access to existing grants, their shortage, and the ambiguous process for PWDs to obtain them were not clear. Therefore, P5 (F) stated:

> "So, the parents get problems paying, we try to send them all to get a grant, to go to the public assistance to get a form to fill out for special child grants. We've

been doing that; some parents are lucky enough to get it, and some are not. I don't know why. Right. But some parents are lucky enough to get it"

5.1.3.4 Improved Resources

Most participants emphasised the importance of dental community outreach. P1 (F) mentioned the possibility of outreach services:

"In an ideal setting, they should be able to have some services brought to them at home."

P5 (F) noted that for these recommendations to work effectively, their implementation required a "much better collaboration and information flow between primary and secondary [and tertiary] care."

5.1.3.5 Prevention

Several interviewees highlighted the importance of prevention, especially at the primary care level. D3 (F) stated:

"So, one thing I will like, uh, to get across the board is preventative treatment is key. So, if they come in for regular check-ups, and to avoid getting to that last day scenario where you're in pain or for emergency treatment,"

CG2 (F) also proposed:

"Telemedicine could be one possibility in the prevention of oral diseases."

5.2 Parent and Patient Perspectives

5.2.1 Studies II & III

5.2.1.1 Participants

In Studies II and III (Balkaran et al., 2025a, 2025b), 101 responses were collected from accompanying adults (parents/guardians) of children with disabilities and 100 from those without disabilities, as well as 150 verbal children (50 with disabilities and 100 without); all parents and caregivers agreed to participate (Table 4).

A total of 150 children responded, compared to 201 accompanying adults. For this reason, studies II and III (Balkaran et al., 2025a; 2025b) focused on data from the accompanying adults. However, this thesis will also include the findings of the children's data.

The results of these studies addressed the following research questions:

- Study II- How does the oral health of PWDs relate to their overall well-being?
- Study III- Is there a connection between access to oral health services for PWDs and their levels of dental fear?

Table 4. Participants of Studies II and III.

Children	Age Mean (SD)	Gender (%)	First-Time Dental Attendees(%)	Accompanied By Mother (%)	Condition (%)
With disabilities	10.6 (3.4)	M (68.3) F (31.7)	20.8	62.4	Non-Verbal (22.9) Autism (21.9) ADHD (8) Global Developmental Delay (7.5) Intellectual Disability (6.5) DS (6.5) Speech Delay (4) CP (2.5) Others (18)
Without disabilities	11.3 (2.8)	M (48.0) F (52.0)	44.0	74.0	None

Gender of participants: F-Female, M-Male

Condition: D.S- Down syndrome, CP- Cerebral palsy and 'Others' which includes: epilepsy, hydrocephalus, speech impediment, Prader-Willi syndrome, Cornelia de Lange syndrome, sickle cell anaemia, behavioural problems, spina bifida, problems walking, encephalitis, Amelia, Tetralogy of Fallot, deaf and mute, hearing impairment, meningitis, Oculodentaldigital dysplasia, brain tumours, cleft palate, Foetal Alcohol Syndrome, Fragile X syndrome, microcephaly, visual impairment

5.2.1.2 OHIP-14 Impacts

5.2.1.2.1 At the FoVo Threshold

Accompanying adults reported that children with disabilities generally showed better OHRQoL than their peers without disabilities. The prevalence of impacts occurring at the FoVo threshold was 29.7% vs. 42.0%, respectively (when p=0.07) (Table 5a).

5.2.1.2.2 At the OFoVo Threshold

The responses from the accompanying adults revealed statistically significant differences, indicating that children with disabilities generally experienced better OHRQoL compared to those without disabilities. This difference was particularly evident in the prevalence of impacts occurring at the OFoVo threshold. The OHIP-14 impacts showed a prevalence of 52.5% for children with disabilities vs. 74.0% for those without disabilities (when p=0.001) (Table 5a).

5.2.1.2.3 Children's data at the FoVo and OFoVo Thresholds

At the FoVo threshold, the OHRQoL did not differ considerably between responses from children with and without disabilities, with prevalence rates of 42.9% and 47.0%, respectively (when p = 0.73). Furthermore, these results were comparable at the OFoVo threshold for children's responses with a prevalence of 70.0 % in those without disabilities and 67.3 % in children with disabilities (when p=0.21) (Table 5b).

Table 5a. Prevalence (%) * of OHIP-14 impacts occurring Fairly Often or Very Often (FoVo) and Occasionally or Fairly Often or Very Often (OFoVo) reported by parents/ caregivers of children ≤18 years of age visiting the Special Needs Clinic (SNDC) and Child Dental Health Unit (CDHU) in Trinidad and Tobago (n=201).

		FOVO						OFOVO					
Variables		**Children in SNDC n =101 (Valid %) FoVo**		**p-value n= 201**	**Children in CDHU n =100 (Valid %) FoVo**		**p-value n= 201**	**Children in SNDC n =101 (Valid %) OFoVo**		**p-value n= 201**	**Children in CDHU n =100 (Valid %) OFoVo**		**p-value n= 201**
		Yes	**No**		**Yes**	**No**		**Yes**	**No**		**Yes**	**No**	
		30 (30)	71 (70)		42 (42)	58 (58)	0.07	53 (53)	48 (48)		74 (74)	26 (26)	**0.001***
Gender													
Male	**117**	17 (25)	52 (75)		15 (31)	33 (69)	**0.04***	35 (51)	34 (49)	0.61	15 (31)	33 (69)	0.25
Female	**84**	13 (41)	19 (59)	0.10	27 (52)	25 (48)		18 (56)	14 (44)		11 (21)	41 (79)	
Age													
6–12-Year-Old	**132**	23 (32)	49 (68)	0.44	20 (33)	40 (67)	**0.03***	39 (54)	33 (46)	0.59	39 (65)	21 (35)	**0.01***
13-18-Year-Old	**69**	7 (24)	22 (76)		22 (55)	18 (45)		14 (48)	15 (52)		35 (88)	5 (13)	
Ethnicity													
Afro-Caribbean	**69**	10 (25)	30 (75)	0.60	13 (45)	16 (55)	0.46	19 (48)	21 (53)	0.06	21 (72)	8 (28)	0.56
Indo-Caribbean	**46**	5 (28)	13 (72)		9 (32)	19 (68)		14 (78)	4 (22)		19 (68)	9 (32)	
Mixed	**86**	15 (35)	28 (65)		20 (47)	23 (54)		20 (47)	23 (54)		34 (79)	9 (21)	
Parent/ Guardian													
Mother	**137**	24 (38)	39 (62)	**0.05***	33(45)	41 (55)	**0.04***	37 (59)	26 (41)	0.26	55 (74)	19 (26)	**0.04***
Father	**34**	2 (11)	16 (89)		5 (31)	11 (69)		8 (44)	10 (56)		13 (81)	3(19)	

Variables		FOVO						OFOVO					
		Children in SNDC n =101 (Valid %) FoVo		p-value n= 201	Children in CDHU n =100 (Valid %) FoVo		p-value n= 201	Children in SNDC n =101 (Valid %) OFoVo		p-value n= 201	Children in CDHU n =100 (Valid %) OFoVo		p-value n= 201
		Yes	No		Yes	No		Yes	No		Yes	No	
Caregiver	**30**	4 (20)	16 (80)		6 (60)	4 (40)		8 (40)	12 (60)		6 (60)	4 (40)	
Reason for Visit													
Pain	**18**	7 (58)	5 (42)	**0.01***	5 (83)	1 (17)	**0.01***	12(100)	0 (0)	**0.00***	6 (100)	0 (0)	0.06
Filling	**28**	4 (50)	4 (50)		9 (45)	11 (55)		5 (63)	3 (38)		16 (80)	4 (20)	
Cleaning	**21**	0 (0)	11(100)		6 (60)	4 (40)		3 (27)	8 (73)		9 (90)	1 (10)	
Check-Up	**114**	16 (25)	49 (75)		13 (27)	36 (74)		29 (45)	36 (55)		30 (61)	19 (39)	
Other	**20**	3 (60)	2 (40)		9(60)	6 (40)		4 (80)	1 (20)		13 (87)	2 (13)	
Last Visit to the Dentist													
Less Than One Year	**101**	19 (33)	39 (67)	0.69	18 (42)	25 (58)	0.66	30 (52)	28 (48)	0.7	35 (81)	8 (19)	0.23
One Year	**7**	2 (50)	2 (50)		2 (67)	1 (33)		3 (75)	1 (25)		3 (100)	0 (0)	
Two Years	**20**	4 (27)	11 (73)		1 (20)	4 (80)		9 (60)	6 (40)		4 (80)	1 (20)	
Pain/Emergency	**8**	1 (33)	2 (67)		3 (60)	2 (40)		2 (67)	1 (33)		4 (80)	1 (20)	
Never	**65**	4 (19)	17 (81)		18 (41)	26 (59)		9 (43)	12 (57)		28 (64)	16 (36)	
Rating of Child's Oral Health													
Excellent	**9**	0 (0.0)	5 (100)	**0.05***	1 (25)	3 (75)	0.31	0 (0.0)	5(100)	**0.05***	3 (75)	1 (25)	0.51
Very Good	**29**	2 (17)	10 (83)		4 (24)	13 (77)		4 (33.3)	8 (67)		11 (65)	6 (35)	

		FOVO						OFOVO					
Variables		**Children in SNDC n =101 (Valid %) FoVo**		**p-value n= 201**	**Children in CDHU n =100 (Valid %) FoVo**		**p-value n= 201**	**Children in SNDC n =101 (Valid %) OFoVo**		**p-value n= 201**	**Children in CDHU n =100 (Valid %) OFoVo**		**p-value n= 201**
		Yes	**No**		**Yes**	**No**		**Yes**	**No**		**Yes**	**No**	
Good	**63**	10 (32)	21 (68)		13 (41)	19 (59)		17 (55)	14 (45)		22 (69)	10 (31)	
Fair	**75**	11 (26)	31 (74)		16 (49)	17 (52)		24 (57)	18 (43)		28 (85)	5 (15)	
Poor	**25**	7 (64)	4 (36)		8 (57)	6 (43)		8 (73)	3 (27)		10 (71)	4 (29)	

*Percentage of subjects reporting at least one OHIP impact at the FoVo and OFoVo thresholds

***p-value < 0.05** (Chi-square test)

All percentages have been rounded to the nearest whole digit because the numbers in the groups are relatively small.

Table 5b. Prevalence (%) * of OHIP-14 impacts occurring Fairly Often or Very Often (FoVo) and Occasionally or Fairly Often or Very Often (OFoVo) reported by verbal children ≤18 years of age visiting the Special Needs Clinic (SNDC) and Child Dental Health Unit (CDHU) in Trinidad and Tobago (n=150).

		FoVo						OFoVo					
Variables		**Children in SNDC n =50 (Valid %) FoVo**		**p-value n= 150**	**Children in CDHU n =100 (Valid %) FoVo**		**p-value n= 150**	**Children in SNDC n =50 (Valid %) OFoVo**		**p-value n= 150**	**Children in CDHU n =100 (Valid %) OFoVo**		**p-value n= 150**
		Yes	**No**		**Yes**	**No**		**Yes**	**No**		**Yes**	**No**	
		22 (44)	28 (56)		47 (47)	53 (53)	0.73	34 (68)	16 (32)		77 (77)	23 (23)	0.21
Gender													
Male	**82**	13 (37)	22 (63)	0.14	17 (36)	30 (64)	**0.04***	22 (63)	13 (37)	0.23	32 (68)	15 (32)	**0.05***
Female	**68**	9 (60)	6 (40)		30 (57)	23 (43)		3 (20)	12 (80)		8 (15)	45 (85)	
Age													
6–12-Year-Old	**93**	13 (39)	20 (61)	0.30	25 (42)	35 (58)	0.19	22 (67)	11 (33)	0.78	44 (73)	16 (27)	0.29
13-18-Yr-Old	**57**	9 (53)	8 (47)		22 (55)	18 (45)		12 (71)	5 (29)		33 (83)	7 (18)	
Ethnicity													
Afro-Caribbean	**51**	7 (33)	14 (67)	**0.05***	13 (43)	17 (57)	**0.04***	12 (57)	9 (43)	0.26	21 (70)	9 (30)	0.36
Indo-Caribbean	**31**	4 (100)	0 (0.0)		8 (30)	19 (70)		4 (100)	0 (0)		20 (74)	7 (26)	
Mixed	**68**	11 (44)	14 (56)		26 (61)	17 (40)		18 (72)	7 (28)		36 (84)	7 (16)	

*Percentage of subjects reporting at least one OHIP impact at the FoVo and OFoVo thresholds

***p-value < 0.05** (Chi-square test)

All percentages have been rounded to the nearest whole digit because the numbers in the groups are relatively small.

5.2.1.3 Severity scores

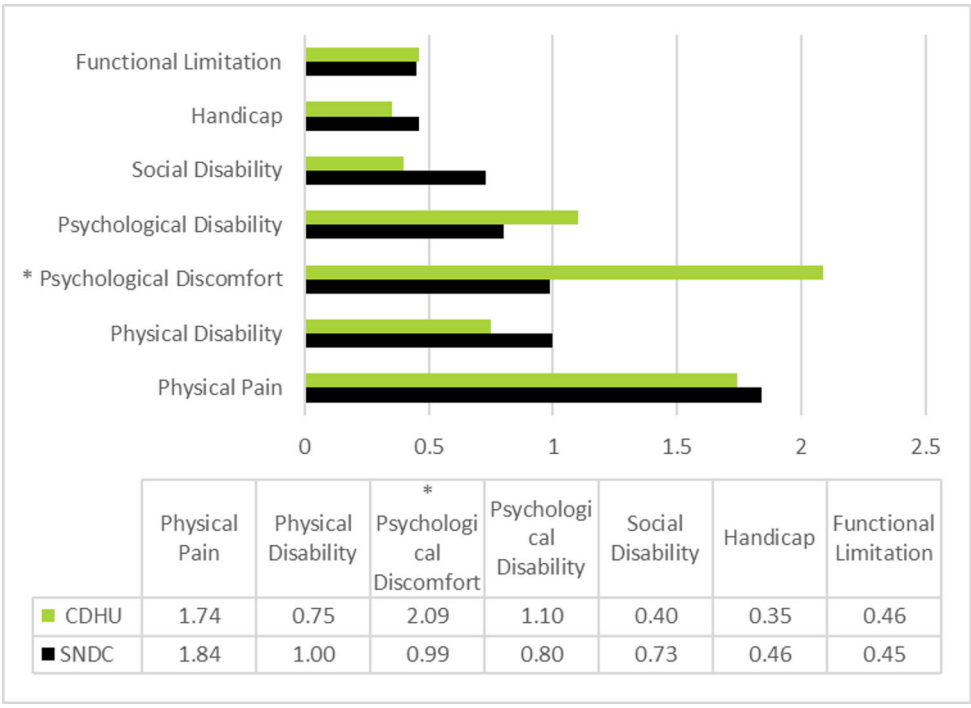
These scores reported by their accompanying adult also included the impacts experienced hardly ever. They suggest that the OHRQoL showed minimal differences yet remained statistically significant between children with disabilities (6.41 ± 9.09) and those without (7.01 ± 6.87) ($p = 0.020$). However, the highest severity score was 41 (median: 2.0; range: 0-41) for participants with children with disabilities, compared to 33 (median: 5.8; range: 0-33) for those without disabilities.

These scores, as reported by the children, were similar for those with disabilities (10.02 ± 11.52) and those without (10.25 ± 8.44) ($p = 0.134$). However, the highest severity score was 48 (median: 6.0; range: 0-48) for participants with disabilities, compared to 34 (median: 9.0; range: 0-34) for those without disabilities.

5.2.1.4 OHIP-14 domains

The accompanying adults reported that children with disabilities generally experience worse OHRQoL impacts than those without disabilities. These were noticeable in the mean OHIP-14 values of the domains of 'Physical Pain' (1.84 ±2.67), 'Physical disability' (1.00 ±1.99), 'Social disability' (0.73 ±1.50), and 'Handicap' (0.46 ±1.29). Notably, the difference in the 'Psychological discomfort' domain between the SNDC and CDHU was the only statistically significant domain ($p = 0.000$) (Figure 6a).

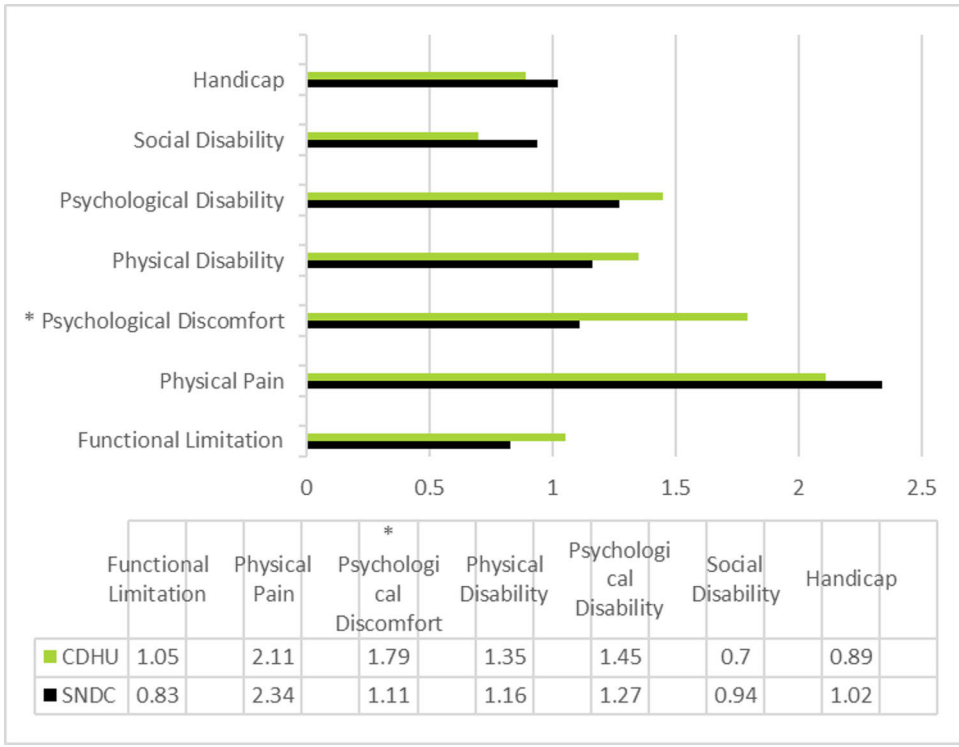
Children with disabilities reported that they experienced more severe impacts on OHRQoL than their peers without disabilities, as shown by the mean OHIP-14 values in the 'Physical Pain' (2.34 ±2.64), 'Social disability' (0.94 ±1.62), and 'Handicap' (1.02 ±1.74) domains. Notably, the difference in the 'Psychological discomfort' domain between the SNDC and CDHU was the only one to reach statistical significance ($p = 0.027$) (Figure 6b).



	Physical Pain	Physical Disability	* Psychological Discomfort	Psychological Disability	Social Disability	Handicap	Functional Limitation
CDHU	1.74	0.75	2.09	1.10	0.40	0.35	0.46
SNDC	1.84	1.00	0.99	0.80	0.73	0.46	0.45

*Statistically significant differences

Figure 6a. Mean OHIP-14 values of dimensions comparing parents' and caregivers' responses of children visiting the Special Needs Dental Clinic (SNDC) and Child Dental Health Unit (CDHU) in Trinidad and Tobago (n=197).



	Functional Limitation	Physical Pain	* Psychological Discomfort	Physical Disability	Psychological Disability	Social Disability	Handicap
CDHU	1.05	2.11	1.79	1.35	1.45	0.7	0.89
SNDC	0.83	2.34	1.11	1.16	1.27	0.94	1.02

*Statistically significant differences

Figure 6b. Mean OHIP-14 values of dimensions comparing children's responses when visiting the Special Needs Dental Clinic (SNDC) and Child Dental Health Unit (CDHU) in Trinidad and Tobago (n=143).

5.2.1.5 Regression Analyses

5.2.1.5.1 At the FoVo Threshold

After adjusting for gender, age, ethnicity, presence of an accompanying adult, 'reason for visit', 'last visit to the dentist', and 'rating of child's oral health', there was no significant difference in OHRQoL between children with and without disabilities at the FoVo threshold. Among these factors, gender, parent/caregiver status, 'reason for visit', and 'rating of child's oral health' had a more pronounced effect on OHRQoL than disability. Specifically, males showed half the odds of experiencing OHIP-14 impacts compared to females, suggesting better OHRQoL. Mothers were more likely to report OHIP-14 impacts on their children than fathers or caregivers. Additionally, those visiting for 'pain and filling' had higher odds of reporting OHIP-14 impacts than those coming for 'cleaning, check-up, and other' services. Furthermore, children with oral health rated as 'excellent or very good' had

lower odds of experiencing OHIP-14 impacts compared to those rated as ‘good, fair, or poor ' (Table 6).

5.2.1.5.2 At the OFoVo Threshold

Conversely, when adjusted for gender, age, ethnicity, presence of an accompanying adult, ‘reason for visit’, ‘last visit to the dentist’, and ‘rating of the child’s oral health’ at the OFoVo threshold, children with disabilities exhibited poorer OHRQoL. Children with disabilities had 2.9 times higher odds of experiencing an OHIP-14 impact, indicating poorer OHRQoL compared to children without disabilities. Additionally, the ‘reason for visit’ had an even greater effect on OHRQoL, with those attending for ‘pain’ and ‘filling’ showing 3.9 times the odds of having an OHIP-14 impact compared to those attending for ‘cleaning, check-up, and other’ (Table 6).

Table 6. Logistic regression analysis of accompanying adults of children ≤18 years visiting the Special Needs Clinic (SNDC) and Child Dental Health Unit (CDHU) in Trinidad and Tobago at the FoVo/OFoVo thresholds (n=197).

Variables	B		S.E.		Wald		df	OR		95% CI		P-Value *	
	FoVo	OFoVo	FoVo	OFoVo	FoVo	OFoVo	FoVo/OFoVo	FoVo	OFoVo	FoVo	OFoVo	FoVo	OFoVo
Gender	-0.69	-0.18	0.33	0.34	4.36	0.28	1	0.50	0.84	0.26-0.96	0.43-1.63	**0.037***	0.600
Age	-0.40	-0.54	0.34	0.35	1.41	2.36	1	0.67	0.58	0.35-1.30	0.29-1.16	0.236	0.125
Disability	0.30	1.07	0.34	0.36	0.78	8.91	1	1.35	2.91	0.69-2.65	1.43-5.87	0.377	**0.003***
Ethnicity	0.01	-0.07	0.34	0.34	0.001	0.05	1	1.01	0.93	0.50-1.97	0.48-1.82	0.971	0.930
Parent/ Guardian	0.86	0.43	0.37	0.35	5.28	1.54	1	2.36	1.54	1.13- 4.91	0.78- 3.05	**0.022***	0.215
Reason for Visit	0.82	1.35	0.37	0.47	4.86	8.38	1	2.27	3.87	1.10-4.71	1.55-9.68	**0.027***	**0.004***
Last Visit to the Dentist	-0.01	0.56	0.35	0.35	0.00	2.50	1	0.99	1.75	0.50-1.97	0.88-3.49	0.985	0.114
Rating of Child's Oral Health	-1.02	-0.70	0.48	0.40	4.60	3.10	1	0.36	0.50	0.14-0.92	0.23-1.08	**0.032***	0.078
Constant	-0.75	-0.22	0.59	0.57	1.59	0.14	1	0.47	0.81			0.207	0.706

At the FoVo threshold: "Prevalence" of Oral Health Impact Profile (OHIP-14) impacts was the dependent variable (answering fairly often or very often to one or more items = 1). The Independent variable is disability (yes = 1). Covariables dichotomised as 0 and 1 were: gender (male = 1), Age (6-12 = 1), Ethnicity (Afro-Caribbean = 1), Parent/ guardian (Mother = 1), Reason for visit (Pain +Filling = 1), Last visit to the dentist (Two years/ less=Less than one year + One year + Two years = 1), Rating of child's oral health (Excellent+ Very Good =1)

At the OFoVo threshold: "Prevalence" of Oral Health Impact Profile (OHIP-14) impacts was the dependent variable (answering occasionally, fairly often or very often to one or more items = 1). The Independent variable is disability (yes = 1). Covariables are the same as at the FoVo threshold stated above.

SE: standard error; df: degree of freedom; OR: odds ratio; CI: confidence interval.

***p < 0.05**

5.2.1.6 MDAS Scores

The mean MDAS score for the total population, as reported by the accompanying adults, was 11.1 (4.8 SD), and most (54.7%) reported low anxiety. The mean MDAS score was higher in children with disabilities (12.2 ± 4.6) who attended "check-up" appointments than in those without disabilities (9.9 ± 4.7) (when p=0.815). Accompanying adults reported that children with disabilities experienced a higher proportion of moderate levels of anxiety compared to those without disabilities (Table 7a).

The mean MDAS score for the total population reported by children was 9.6 (4.3 SD), and most (58.0%) reported low anxiety. The mean MDAS score was higher in females (10.4 ± 4.7) than in males (8.9 ± 3.8) (when p=0.144). Verbal children without disabilities reported that they experienced a higher proportion of moderate levels of anxiety (40%) compared to those with disabilities (30%) (Table 7b).

Table 7a. Frequency (N), mean (SD) of the MDAS total score, and percentage of moderate anxiety reported by accompanying adults (n=201).

Variables	N	Mean MDAS score (SD)	Moderate Anxiety %
Disability			
Yes	101	12.2 (4.6)	27.4
No	100	9.9 (4.7)	15.9
Gender			
Male	117	11.3 (5.0)	24.4
Female	84	10.8 (4.5)	18.9
Age			
6–12-Year-Olds	132	11.9 (4.9)	31.8
13-18-Year-Olds	69	9.5 (4.1)	11.4
Ethnicity			
Afro-Caribbean	69	10.8 (4.4)	15.4
Indo-Caribbean	46	10.8 (5.3)	9.5
Mixed	86	11.4 (4.8)	18.4
Parent/Caregiver			
Mother	137	11.6 (5.0)	30.3
Father	34	9.8 (3.9)	7.5
Caregiver	30	9.8 (3.9)	5.5
Reason for Visit			
Pain, Filling, Cleaning, Other	87	10.8 (4.9)	17.9
Check-Up	114	11.3 (4.7)	25.4
Last Visit to the Dentist			
Less Than One Year, One Year Two Years, Pain/ Emergency	136	10.9 (4.8)	28.9
Never	65	11.3 (4.7)	14.4
Rating of Child's Oral Health			
Excellent, Very Good, Good	101	10.5 (4.4)	22.4
Fair, Poor	100	11.6 (5.1)	20.9

Reason for visit: Pain + Filling + Cleaning + Other have been combined (Check-up has not been changed). Last visit to the dentist: Less than one year + One year + Two years + Pain/Emergency have been combined (Never has not been changed). Rating of child's oral health: Excellent +Very Good + Good have been combined, and then Fair + Poor have been combined.

Table 7b. Frequency (N), mean (SD) of the MDAS total score, and percentage of low, moderate, and high DFA reported by verbal children (n=150).

Variables	N	%	Mean	SD	Low anxiety %	Moderate anxiety %	High anxiety %
Disability							
Yes	50	33.3	1.42	0.61	64.0	30.0	6.0
No	100	66.7	1.50	0.59	55.0	40.0	5.0
Gender							
Male	82	54.7	8.96	3.80	35.3	18.0	1.3
Female	68	45.3	10.37	4.70	22.7	18.7	4.0
Age							
6–12-year-olds	93	62.0	9.49	4.22	38.0	20.7	3.3
13-18-year-olds	57	38.0	9.77	4.38	20.0	16.0	2.0
Ethnicity							
Afro-Caribbean	51	34.0	9.52	4.14	18.7	13.3	2.0
Indo-Caribbean	30	20.7	9.52	4.27	11.3	8.7	0.7
Mixed	68	45.3	9.69	4.43	28.0	14.7	2.7

5.2.1.7 Anticipatory and Treatment-related Anxiety

Accompanying adults reported that children with disabilities exhibited significantly higher mean and median levels of dental anxiety compared to their peers without, both overall and specifically regarding anticipatory and treatment-related anxiety. The mean MDAS scores for children with disabilities exceeded those of their counterparts without disabilities by more than two points (Figure 7a).

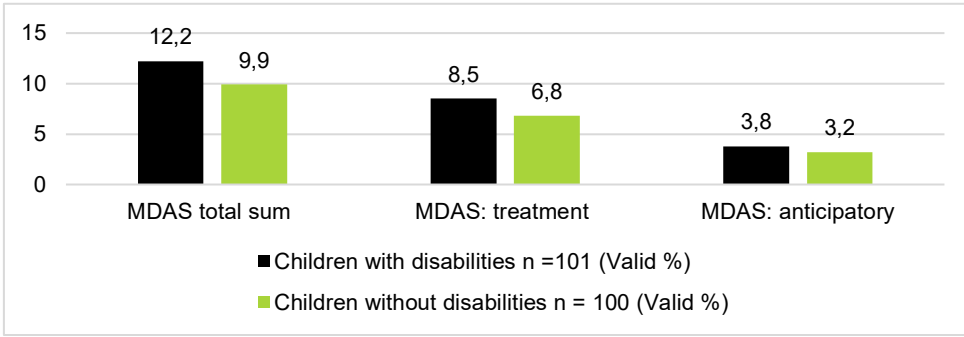


Figure 7a. MDAS total (5-25), treatment-related (3-15), and anticipatory (2-10) factor scores, means reported by the accompanying adults (n =201).

Conversely, when the children's data was assessed, those without disabilities reported similar but slightly higher mean and median levels of dental anxiety compared to their peers with disabilities, both overall and specifically regarding anticipatory and treatment-related anxiety (Figure 7b).

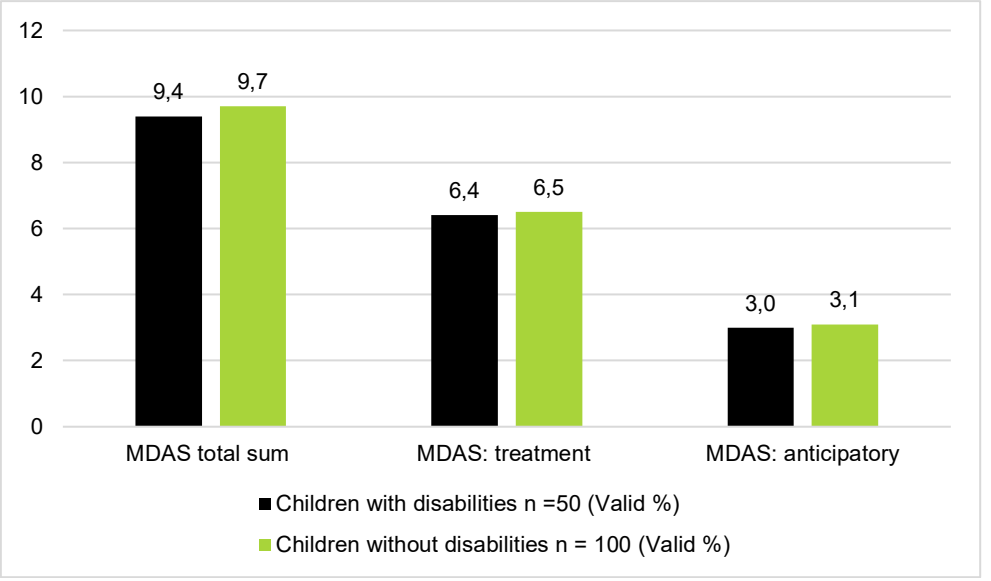


Figure 7b. MDAS total (5-25), treatment-related (3-15), and anticipatory (2-10) factor scores and means reported by verbal children (n=150).

5.2.1.8 Regression Analyses

In the data from the accompanying adults, children with disabilities were nearly four times more likely (OR: 3.7; CI: 1.9–7.5) to experience moderate DFA than those without disabilities (Table 8). Younger children had almost six times the likelihood of experiencing high DFA levels (OR: 5.6; CI: 1.1–27.1) compared with those aged 13 to 18, and were twice as likely to show moderate DFA levels as the older group (Table 8).

Table 8. Multinomial analysis of accompanying adults of children in both clinics, using low anxiety (MDAS score 5-9) as the reference category (n=201).

Variables	B		OR		95% CI		p-value*	
Anxiety Level	**Moderate**	**High**	**Moderate**	**High**	**Moderate**	**High**	**Moderate**	**High**
Intercept	-1.1	-4.4					**0.045***	**0.001***
Gender	-0.3	0.7	0.7	2.0	0.4-1.4	0.6-7.3	0.328	0.284
Age	0.7	1.7	2.1	5.6	1.1-4.0	1.1-27.1	**0.029***	**0.033***
Disability	1.3	1.1	3.7	3.0	1.9-7.5	0.8-11.8	**0.000***	0.106
Ethnicity	-0.1	-0.7	0.9	0.5	0.5-1.7	0.1-1.8	0.676	0.272
Parent/ Guardian	0.5	1.5	1.6	4.6	0.8-3.2	0.9-23.0	0.163	0.062
Reason For Visit	0.2	0.4	1.2	1.5	0.6-2.4	0.5-4.8	0.520	0.481
Last Visit to The Dentist	-0.5	-0.8	0.6	0.4	0.3-1.2	0.1-1.6	0.152	0.225
Rating Of Child's Oral Health	0.1	-0.7	1.1	0.5	0.6-2.1	0.1-1.6	0.759	0.232

Anxiety range: 5-9 (low), 10-18 (moderate), and 19+ (high anxiety) was the dependent variable (the reference category is low anxiety). Disability (yes=1 was the factor). The covariables were dichotomised as 0 and 1 were: gender (male=1), Age (6-12=1), Ethnicity (Afro-Caribbean= 1), Parent/caregiver (Mother=1), Reason for visit (Pain +Filling+ Cleaning+ Other = 1), Last visit to the dentist (Two years/ less=Less than one year + One year + Two years+ Pain/ Emergency = 1), Rating of child's oral health (Excellent+ Very Good +Good =1).
Abbreviations: SE, standard error; df, degree of freedom; OR, odds ratio; CI, confidence interval
*p < 0.05

5.2.2 Educational Perspectives

5.2.2.1 Study IV

The results of this study addressed the following research question:

- What are the long-term effects of educational initiatives focused on SCD on dental practitioners' confidence and their willingness to treat PWDs?

5.2.2.1.1 Participants

In Study IV (Balkaran et al., 2022b), of the 176 workshop attendees, 131 completed the initial survey, achieving a 74.4% response rate. Most respondents were female (81.5%), with an average age of 27.6 years (SD 7.41) (Table 9). Nearly half (47.7%) identified as Indo-Caribbean, primarily consisting of dental students (50.3%) and dentists (38.9%). Educational backgrounds varied, with dental graduates having

experience from less than 1 to 24 years, the majority (39.2%) being recent graduates. Most students were in their fourth (16.5%) or fifth year (26.4%). There were 3.8% practising Dental Hygienists/Dental Therapists (DHDTs) and 6.9 % Dental Surgery Assistants (DSAs).

In the second survey, 95 of 131 respondents participated, resulting in a 72.5% response rate. The reduction in participants from the workshop was not determined. The primary reasons for attending the workshop included knowledge (73.1%), professional development (14.2%), and improving clinical skills for patients with disabilities (9.7%).

Table 9. Demographics of participants in Survey I (n=131) and Survey II (n=95). Knowledge as the reason for attendance in Survey I (n=131).

Variables	Survey I n=131 (Valid %)	Survey II n=95 (Valid %)	Knowledge as the reason for attendance: Yes n=131 (Valid %)	Knowledge as the reason for attendance: No n=131 (Valid %)
Gender				
Male	24 (18.3)	15 (15.8)	16 (66.7)	8 (33.3)
Female	106 (80.9)	80 (84.2)	82 (77.4)	24 (22.6)
Age				
Under 25	59 (45.7)	49 (51.6)	49 (83.1)	10 (16.9)
25-40	58 (44.3)	38 (40.0)	41 (70.7)	17 (29.3)
Over 40	12 (9.3)	8 (8.4)	6 (50.0)	6 (50.0)
Ethnicity				
Afro-Caribbean	34 (26.2)	19 (20.0)	27 (79.4)	7 (20.6)
Indo-Caribbean	62 (47.7)	48 (50.5)	47 (75.8)	15 (24.2)
Caucasian	1 (0.8)	0 (0)	1 (100.0)	0 (0.0)
Chinese	3 (2.3)	1 (1.1)	3 (100.0)	0 (0.0)
Mixed	27 (20.8)	23 (24.2)	16 (59.3)	11 (40.7)
Other	3 (2.3)	4 (4.2)	3 (100.0)	0 (0.0)
Educational Program				
Dentist	51 (38.9)	40 (42.1)	32 (62.7)	19 (37.3)
DSA/DHDT*	14 (10.7)	7 (7.4)	12 (85.7)	2 (14.3)
Dental Student	80 (50.3)	48 (50.5)	57 (71.3)	23 (28.8)

*DSA- Dental Surgery Assistant, DHDT- Dental Hygienist/ Dental Therapist

5.2.2.1.2 Challenges Reported

Participants encountered several challenges when caring for patients with disabilities. These challenges included non-compliance (34.5%) among patients they were treating, communication issues (31.8%), and limited experience in this area (17.3%), which were the most commonly reported (Figure 8).

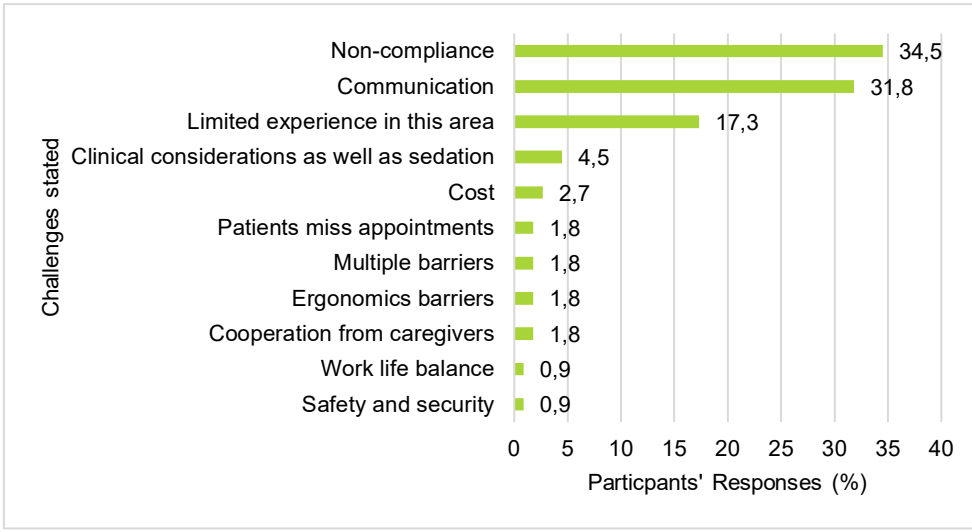


Figure 8. The most common themes emerged regarding the challenges in treating patients with special needs.

5.2.2.1.3 Participants' perspectives on the workshop one year later

Most participants (90.5%) viewed the workshop's overall assessment positively. Additionally, 80% reported increased knowledge, and 64.2% expressed the need for more education (Figure 9).

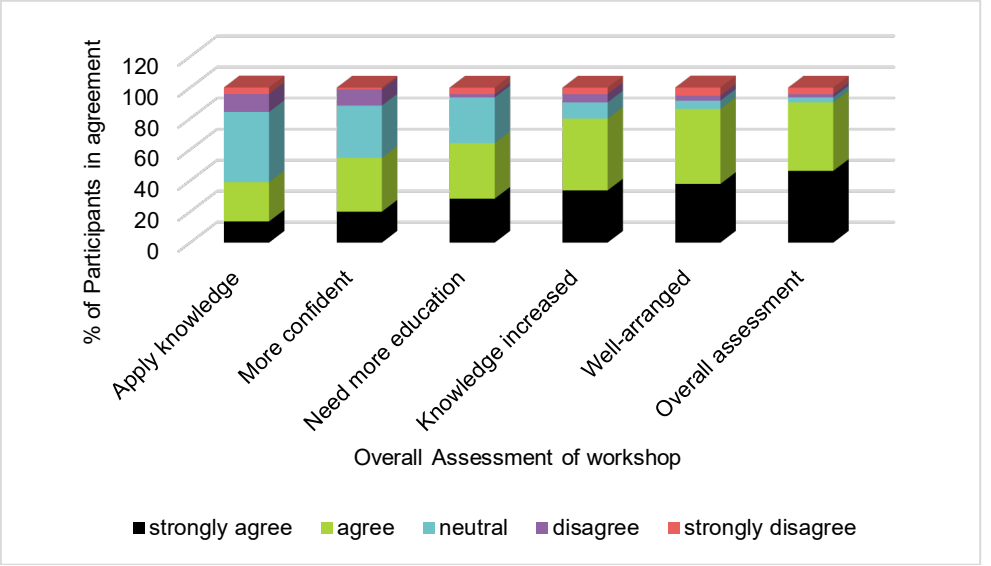


Figure 9. Participant assessment of the workshop one year later.

5.2.2.2 Study V

The results of this study addressed the following research question:

- How does SCD training affect dental students' attitudes and their intended clinical behaviours when managing PWDs?

5.2.2.2.1 Participants

The convenience samples comprised a cohort of dental students from the USA (n = 77) and a cohort of students from France (n = 62). The response rate at the French university was 61/62 (98.4%), while in ATSU, Arizona, it was 77/77 (100%) for items related to TPB and the Influence of Control Beliefs. The mean age of respondents was 26.8 years, with a majority being female (56.5%). There were instances of missing data for the initial three questions, with Arizona reporting 47 missing responses (61.0%) in their dataset.

5.2.2.2.2 Treatment Intentions and Decision Difficulty

The students from both schools were asked about their willingness to treat the patient within their clinical competence in this scenario, as well as the difficulty of that decision. Figures 10 and 11 below show the percentage of valid responses to questions 1 and 2, respectively. The most common response from students in France (24.2%) was that the decision was 'A bit difficult'. In contrast to the students in ATSU, 56.7% of participants described it as 'somewhat difficult'.

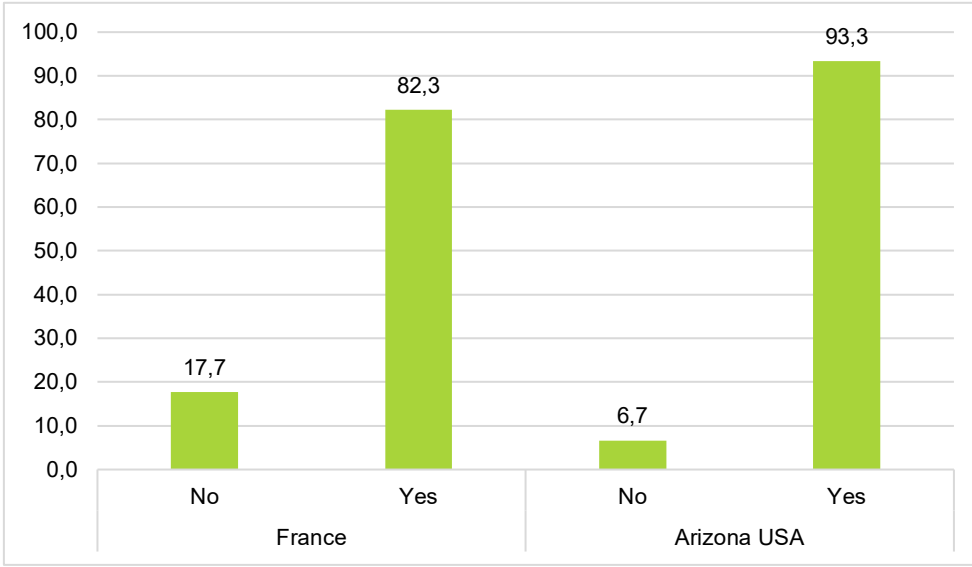


Figure 10. Participants' responses (Valid %) to Question 1: Assuming that the treatment required was within your clinical competence, would you provide care for this patient?

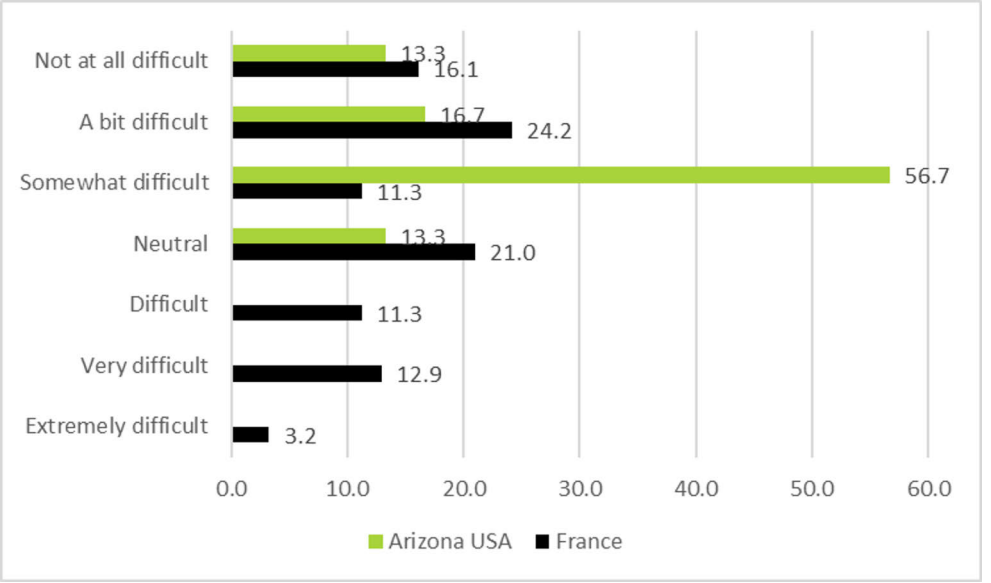


Figure 11. Participants' responses (Valid %) to Question 2: How difficult was it for you to make this decision?

5.2.2.2.3 Behavioural beliefs

The behaviour outcome evaluation in Question 3, conducted through a mean comparison of responses from participants at both dental universities, revealed that those from the Arizona dental school exhibited a higher mean than those from the French school (see Figure 12). The response to the question 'If I were to provide care for this patient, it would' demonstrated statistically significant differences in two outcomes between the universities: "Take too long", students from Arizona (1.84) and those from France (0.95) ($p<0.001$), and "Make the patient anxious", Arizona (2.45) and France (2.03) ($p=0.025$).

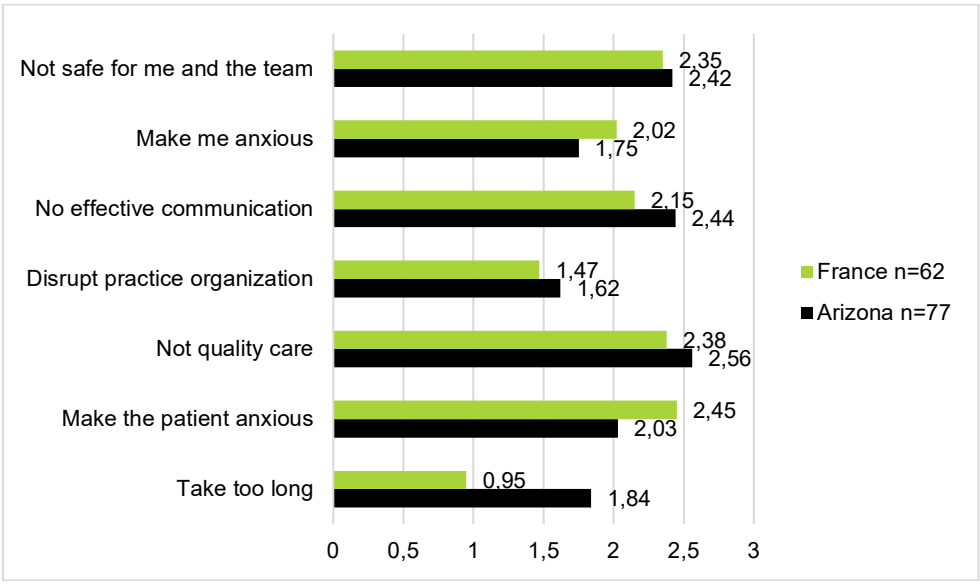


Figure 12. Participants' mean responses to Question 3: If I were to provide care for this patient it would:

5.2.2.2.4 Subjective norms

When comparing the two universities, the participants' responses to subjective norms demonstrated a statistically significant difference in the mean responses to the statement 'Legally, I am expected to treat this patient,' with students from Arizona reporting a mean of 0.86 and those from France reporting a mean of 1.53 ($p = 0.040$). Additionally, for the statement 'I would feel under social pressure to treat this patient,' students from Arizona showed a mean of -0.84. In contrast, those from France reported a mean of 0.34 ($p = 0.000$) (see Figure 13).

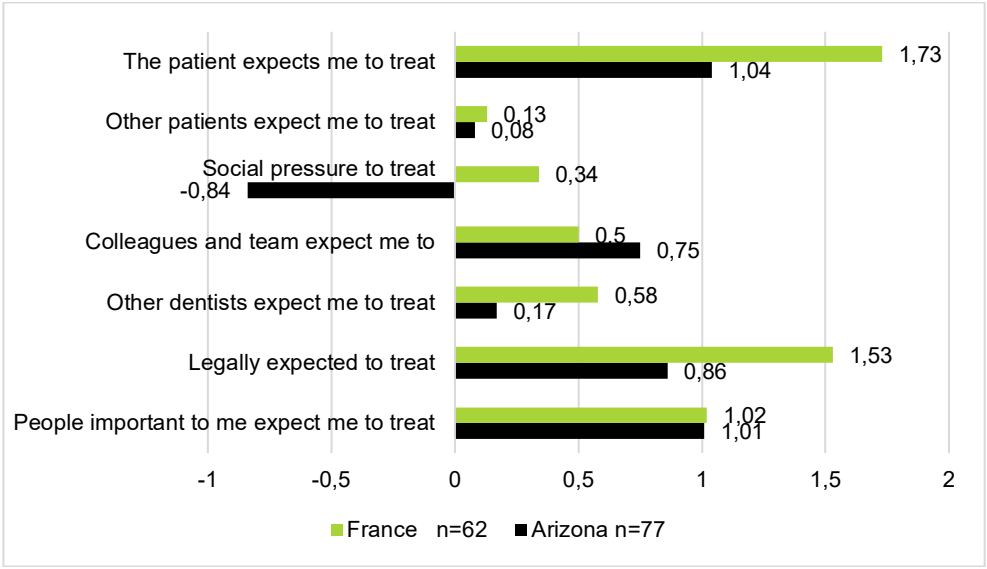


Figure 13. Participants' mean comparison of responses to subjective norms in Question 5.

5.2.2.2.5 Perceived behaviour control

Five questions using a 7-point Likert scale assessed students' control beliefs about confidence, experience, and responsibility for patient decision-making. French participants had higher mean control belief scores than those from Arizona. The mean differences were statistically significant for the statement 'It would be easy for me to treat this patient', students from Arizona (0.13) and those from France (0.48) ($p = 0.004$). Additionally, the statement 'I am confident that I could treat this patient' was statistically significant, with students from Arizona having a mean of 0.30 and those from France a mean of -0.65 ($p < 0.001$) (Table 10).

Table 10. Responses to Question 8 on control beliefs with a mean comparison (Mann-Whitney U Test) of both dental universities in Arizona (n= 77) and France (n= 62).

Control Beliefs	Arizona n=77 Mean (SD)	France n=62 Mean (SD)	Mean (SD) [p-value]
Be easy to treat	0.13 (1.25)	-0.48 (1.46)	-0.14 (1.38) **[0.004]** *
Not confident to treat	0.30 (1.33)	-0.65 (1.51)	-0.12 (1.48) **[0.000]** *
Decision not mine	0.17 (1.76)	0.58 (1.82)	0.35 (1.79) [0.145]
Factors beyond my control	0.75 (1.86)	0.50 (1.58)	0.64 (1.74) [0.335]
Insufficient experience	-0.84 (1.69)	0.34 (1.80)	-0.32 (1.83) **[0.000]** *

* $p < 0.05$

6 Discussion

6.1 Summary of Studies I-V

These studies identified key soft skills, resources, and policies to improve oral health care for PWDs. They examined barriers and facilitators, analysed children's perceptions of OHRQoL and DFA, and explored the link between oral health and well-being, including dental anxiety. The educational views of DHCPs and dental students were assessed, along with their treatment intentions after training. The long-term effects of an educational programme on SCD were also studied, and training outcomes from European and American schools were compared.

Findings indicated that institutional issues, such as service availability, quality of care, and provider interactions, can affect access. In T&T, children both with and without disabilities generally had poor OHRQoL, with those with disabilities being more affected. However, children without disabilities occasionally reported greater psychological impacts, possibly due to delays in attendance or costs. Children with disabilities also experienced higher levels of moderate dental anxiety, emphasising the need for regular visits combined with anxiety-reducing techniques and provider monitoring of DFA to enhance care. These studies highlight the importance of improved SCD training for practitioners in T&T. Although dental students felt positive about caring for PWDs, their behaviours and motivations varied between these European and American institutions, likely due to differences in laws and clinical training.

6.2 Facilitators & Barriers

The barriers to accessing oral care for PWDs included cost, the readiness of the dental practitioner to offer specialised care, adequately furnished facilities, resources for the HCPs and PWDs and the parent/ caregiver's perception of the oral health need, HCPs' preparedness, the extent of services offered, and the necessary resources for treating PWDs in the health care setting (Balkaran et al., 2022a). The findings presented herein are comparable to other studies concerning children's utilisation of dental services (Isong et al., 2010; Badri et al., 2014; Nagdev et al., 2023). These studies encompass a range of factors, including the utilisation of dental

care by the parents, the educational attainment of the parents, socioeconomic status, income level, employment status, access to dental care services, transportation to the dental clinic, and the preventive practices employed by parents (Menon et al., 2025).

The proposed facilitators involved in this thesis encompass educating key stakeholders, promoting policy adjustments, enhancing advocacy initiatives, improving resources, such as outreach services for PWDs, and implementing preventive measures to address these challenges effectively. Enhancing access to SCD for undergraduate dental students fulfils their responsibility of caring for everyone (Gallagher & Fiske, 2007; Britton & Bradley, 2021). Increasing public awareness through outreach can also help tackle barriers related to awareness and acceptance. This is noteworthy because parental/caregiver awareness is a barrier to improving oral health care for PWDs (Khan et al., 2022). Access to dental treatment remains costly, and costs related to transportation and caregiver time off work must also be considered in the overall dental expenses for PWDs.

Menon et al. (2025) advocated for mobile dental clinics and improved public transportation to ensure consistent access to dental care in underserved rural areas. This alleviates barriers, allowing all families to obtain preventive and routine services more efficiently. The issues of affordability and accessibility in oral health care impede equitable access and underscore the need for strategies that extend beyond merely reducing costs to ensure inclusive access to dental services. These insights from Study I (Balkaran et al., 2022a) are crucial for policymakers globally who seek to create inclusive dental care programs that emphasise the affordability and accessibility of well-resourced oral health professionals who possess the expertise and experience to treat PWDs effectively.

The findings of this thesis are consistent with the dental literature, indicating that access to oral healthcare for PWDs is impeded by systemic barriers such as inadequate service delivery, limited professional training, and organisational challenges (da Rosa et al., 2020; Asiri et al., 2024). Nevertheless, as literature addressing the lived experiences of access remains comparatively limited, it is beneficial to situate these findings within the broader healthcare context for PWDs. Research from Australia demonstrates similar patterns across health services, in which patients and caregivers report difficulties navigating fragmented systems, a shortage of appropriately trained professionals, and inconsistent policies aimed at reducing barriers (Lim et al., 2021; Yang et al., 2023). Linking patient and parent perspectives from this thesis with broader healthcare evidence reinforces the understanding that dental access issues are not isolated phenomena but stem from more comprehensive structural and policy-level challenges that affect care for PWDs (Pucchio et al., 2025). This alignment highlights the necessity for integrated policy and practice strategies that acknowledge oral health as an integral component of

overall health and advocate for coordinated, patient-centred approaches to improve access and reduce inequalities (Yang et al., 2023).

6.3 Parents/Caregivers' and Patients' Perspectives

Along with the previously identified barriers, anxiety or fear is also a contributing factor. When DFA was assessed in Study III (Balkaran et al., 2025b), the accompanying adults reported moderate levels of DFA in their children attending the SNDC, and delayed dental attendance was a factor influencing their children's attendance at the CDHU. Existing literature highlights the crucial importance of early dental care in achieving favourable long-term oral health outcomes in PWDs (AAPD, 2024b).

Most children in Studies II and III (Balkaran et al., 2025a; 2025b) who had not previously visited a dentist were from the CDHU. Delayed dental attendance has been attributed to cost in another recent study by Menon et al. (2025), who similarly observed parents' concerns regarding the affordability of dental care, their capacity to access services from dental health care professionals, and the scheduling of dental appointments for their children solely when deemed necessary.

While these studies did not evaluate the socioeconomic status of the children, it is noted that those visiting the SNDC received dental care free of charge, thanks to funding from Community Chest Limited, a non-governmental organisation (NGO) in T&T. In contrast, children attending the CDHU were required to pay fees at the time of care services. National surveys in T&T show that children of primary school age are the most vulnerable to dental caries and often require emergency dental care. Children from lower-income families tend to rely more on publicly funded paediatric emergency services, indicating a social disparity in the use of dental health resources. (Naidu et al., 2006). Furthermore, poverty is recognised as a social determinant of health and may account for the differences in reported ORHQoL between the CDHU and the SNDC (CDC, 2024b).

In Study II (Balkaran et al., 2025a), the OHRQoL was observed to be significantly poorer in children with disabilities compared to their counterparts without disabilities, particularly regarding the frequency of oral impacts, which were perceived occasionally, daily, or very often. Interestingly, when adjusted for other variables in the bivariate analyses, the children without disabilities had poorer OHRQoL. Irregular attendees frequently reported a poor rating of the OHIP-14 (Kaprio et al., 2012). Additionally, the findings demonstrated statistical significance at the FoVo threshold, indicating that males had half the likelihood of experiencing the impact of OHIP-14 compared to females.

Also, the analysis of the children's data revealed findings that aligned with those of their accompanying adults. This observed consistency in OHRQoL between

children and parents at a group level, as reflected in the total scores, has been noted previously (Jokovic et al., 2004).

In Study III (Balkaran et al., 2025b), this population of children with disabilities showed notably higher levels of moderate anxiety compared to their peers without, as reported by their accompanying adults. In analysing the children's data, those with disabilities exhibited elevated levels of both low and high anxiety compared to their peers without disabilities, who displayed higher levels of moderate anxiety. This was similar to the DFA reported by just over one-third of children aged 10-16 years, who had high levels of DFA (Kowlessar et al., 2013). In this thesis, the younger children were almost six times more likely (OR: 5.6; CI: 1.1–27.1) to experience a high level of DFA than the older group, a finding consistent with those of Cianetti et al. (2017).

Additionally, females showed increased levels of high anxiety compared to their male counterparts. This observation, which reveals that females demonstrate a higher DFA response, aligns with the findings of Cianetti et al. (2017). However, it is worth noting that gender differences have historically been inconsistent in previous research (Klingberg & Broberg, 2007; Grisolia et al., 2021). Furthermore, there were generally comparable levels of DFA, both in total and specifically regarding anticipatory and treatment-related anxiety, among children with and without disabilities in the children's data.

The mean MDAS score for children without disabilities, as reported by their accompanying adults (9.9), was comparable to the mean MDAS scores reported by the children (9.7). However, for children with disabilities, the mean MDAS score was nearly three points higher in the data provided by accompanying adults (12.2) compared to the scores reported by the children themselves (9.4). This difference between parents and children without disabilities has been noted previously (Luoto et al., 2010). It may have occurred if the parents were fearful, as research has shown that they tend to judge the child as fearful more frequently, regardless of the child's actual level of fear, compared to their non-fearful counterparts (Luoto et al., 2010).

Regular dental visits at clinics that implement DFA-minimising strategies are recommended to prevent the onset and continuation of DFA in these children. These include behaviour management strategies and Cognitive Behavioural Therapy (Wide & Hakeberg, 2021). Regular dental visits can help mitigate the expenses linked to inadequate oral health.

DFA and OHRQoL are correlated; children experiencing dental fear report a diminished degree of OHRQoL (Merdad & El-Housseiny, 2017). Therefore, health care professionals should assess and manage patients' DFA. Evaluating DFA enhances patient care and helps to overcome obstacles caused by misconceptions of dental fear.

6.4 Educational and Clinical Implications for SCD

Study IV (Balkaran et al., 2022b) discussed a dental school in T&T that has had a designated clinic for PWDs for over sixteen years and highlighted that it lacked a lecturer in SCD for nine years, which created a gap in the training of dentists since the school's inception. Many dental schools worldwide do not offer a specific subject on SCD at their clinics, nor do they provide clinical exposure to PWDs, although it should be recognised as an academic discipline in its own right (iADH, 2015). Furthermore, postgraduate training options for SCD are scarce in T&T and worldwide (Hector et al., 2023). The didactic one-day workshop on SCD was evaluated in Study IV (Balkaran et al., 2022b) and revealed a significant demand for ongoing education in this area.

Most participants attended primarily to enhance their knowledge, develop professionally, and improve their clinical skills. The findings reflect international trends showing limited didactic and clinical exposure to the treatment of PWDs in dental schools (Vainio et al., 2011). Although the overall evaluation of the workshop was favourable, attendees expressed caution regarding their confidence and clinical practice one year later, which was understandable, given that the workshop was didactic in nature.

Nevertheless, a large majority felt that their knowledge had increased after the workshop, and research indicates that new learning can significantly influence dental practice, depending on participants' ability to apply what they have learned (Spangler, 2016). The confidence gained through clinical experience enhances the intention to provide patient treatment, subsequently influencing the type of practice that graduates select and modifying future access to care for these populations. On average, most participants treated fewer than five PWDs weekly, which could be attributed to challenges in providing dental care to this population (Biasotto et al., 2024). This thesis highlighted the importance of further educating dental providers and allied HCPs in the field of SCD, as this will increase capacity through enhanced education and subsequently improve access to dental treatment for PWDs.

The number of PWDs is rising (WHO, 2011), leading to heightened demands on general dental practitioners to possess the necessary knowledge and skills for effective treatment. Even those who manage to seek dental care independently may face hurdles due to a dentist's inexperience with PWDs. Dentistry is undergoing significant changes as a growing demographic of PWDs requires dental services, highlighting the urgent need for dental professionals to provide safe and effective treatment for this population. Countries such as New Zealand, Australia, and the UK have established postgraduate SCD programmes, which complement undergraduate dental courses. The implementation of SCD should be readily accessible to undergraduate students and practising dentists. This initiative must be executed consistently and should encompass both clinical and theoretical training to

effectively meet the needs of vulnerable communities (Koh et al., 2025). This improvement will better prepare future dentists to handle the complexities involved in treating PWDs.

This was further evident in Study V (Balkaran et al., 2025c), which compared two dental schools that exposed their students to both didactic and clinical instruction, highlighting the disparity in confidence levels among students. This statistically significant difference was notably observed in students from the school in the USA, who exhibited greater confidence, possibly due to increased clinical exposure with PWDs, compared to those from the school in France.

Furthermore, notable disparities were observed in subjective norms, motivation to comply, control beliefs, and the influence of control. For example, a greater number of students in the school from the USA believed that their dental treatment could induce anxiety in this patient and that modifications to their usual treatment techniques would be unnecessary, compared to their counterparts in France. Additionally, a higher proportion of students in France reported experiencing social pressure to treat this patient than those in the USA.

The legal and cultural differences between the health care systems of the two countries could have influenced students' willingness to treat PWDs. For example, students from the USA school showed more concern about the time required to care for the patient in this scenario compared to those from France. Meanwhile, a larger proportion of students from France felt both social and legal duties to treat the patient, unlike their counterparts from the USA.

6.5 Strengths and Limitations of Studies I-V

Studies I-IV (Balkaran et al., 2022a; Balkaran et al., 2025a; Balkaran et al., 2025b; Balkaran et al., 2022b; Balkaran et al., 2025c) discussed were the first of their kind in their respective populations. Furthermore, Study V (Balkaran et al., 2025c) was the first to compare two universities from different geographic locations with different cultural and health care practices using the validated and standardised international iADH toolbox survey (Faulks et al., 2017). Study I (Balkaran et al., 2022a) included DHCPs, dental therapists, HCPs, caregivers, and self-advocates, forming a diverse group of participants who provided their perspectives through the qualitative design. This inclusion is rare in research concerning disabilities, as it involves both PWDs, who are typically absent or excluded from health research (Rios et al., 2016; Faulks, 2023), and their proxies. Although the qualitative design limits the transferability of the results, trustworthiness, concentrating on the credibility, transferability, and confirmability of the data, was employed to address validity concerns (Lincoln & Guba, 1985, p. 289). This approach enabled rich, detailed accounts from participants and facilitated a nuanced understanding of

complex issues that are not easily captured by quantitative methods. However, the relatively small, purposively selected samples may limit transferability, and the findings reflect participants' perspectives at a particular point in time. As with all qualitative research, the results are interpretive in nature and should not be generalised beyond the study context; rather, they should be viewed as providing depth, insight, and direction for future research.

Studies II and III (Balkaran et al., 2025a; 2025b) investigated accompanying adults as proxies for OHRQoL and DFA through multinomial logistic regression analyses. This thesis also explored data from children with and without disabilities who provided their own reports on OHRQoL and DFA. This is particularly important because children with disabilities are often marginalised in research, despite their ability to participate without modifications (Rios et al., 2016). Both studies used cross-sectional surveys and regression analyses to conduct exploratory research examining associations among multiple variables. Regression analyses enabled adjustment for potential confounders, strengthening the interpretation of the observed associations. However, the relatively small sample sizes limited statistical power and, in some cases, resulted in wide CIs. The use of convenience sampling may have introduced selection bias and limited generalisability. Additionally, the cross-sectional design precludes causal inference, meaning that findings should be interpreted as associations rather than cause-and-effect relationships.

Furthermore, Studies II and III (Balkaran et al., 2025a; 2025b) used proxies, and in health-related quality of life studies, this has been problematic, with poorer parent–child agreement on subjective aspects such as cognition, emotion, and pain than on physical domains such as mobility, self-care, and speech (Khadka et al., 2019). While parents and caregivers may not fully reflect subjective experiences, especially the emotional and psychological impacts central to OHRQoL when children are not with them, this thesis found that the OHRQoL results from children and proxies were similar, consistent with findings by Jokovic et al. (2004). Further, the type of disability experienced by the child may have affected the OHRQoL results, as various disabilities, such as autism, can affect the Functional Limitations dimension owing to sensory issues, which may lead to difficulties with eating and chewing. In contrast, patients with physical disabilities may have comparatively higher Psychological and Social impacts.

Study IV (Balkaran et al., 2022b) revealed that participants maintained a consistent interest in the workshop even after a year had passed, which bodes well for SCD. However, it was not possible to use a validated instrument to evaluate participants' perceptions and the course's local significance. Furthermore, because of COVID-19 restrictions in T&T, where the government enforced social distancing measures and prohibited gatherings to curb the spread of the virus (Daily Express, 2020), the follow-up survey was conducted online.

Additionally, the mixed methods in study IV combined survey data and open-ended questions, which allowed for both quantitative assessment and qualitative insight within a single research design. This approach strengthened the findings by enabling quantitative data to be explored alongside participants' perspectives, which provided greater depth and contextual understanding than either method alone. The integration of qualitative responses helped to clarify and enrich the interpretation of survey results and is consistent with established mixed-methods research practices in health and education research. However, limitations include relatively small sample sizes, which may restrict generalisability, and variability in the depth of responses to open-ended questions. The reasons for any non-responses were not determined, which could introduce bias. In addition, as data were collected at a single time point, the design does not allow for causal inference, and the findings should be interpreted as descriptive and exploratory rather than explanatory.

Study V (Balkaran et al., 2025c) was the first to utilise the iADH toolbox (Faulks et al., 2017) to compare two universities from different geographic locations with unique cultural and health care practices. This shows the value of this standardised international instrument for cross-institutional comparison. A limitation noted is the absence of data to examine participants' status before and after their experience with these curricula, which may mean differences reflect pre-existing traits rather than educational effects. Since the data were collected once, causal conclusions are limited. Also, reasons for any non-responses were not ascertained. Additionally, this thesis acknowledges that self-reported intentions may not always align with corresponding outcome behaviours. However, according to TPB, intention precedes actual behaviour. Specifically, Ajzen (1991) demonstrated that the more positively an individual evaluates a behaviour, the greater their determination to engage in it. Despite its limitations, the study offers important exploratory insights and demonstrates the potential of the iADH toolbox (Faulks et al., 2017) for future long-term and outcome-based research. Given the overall positive response of the participants, this appears to be a positive predictor of their behaviour.

The results of this thesis support the inclusion of mandatory, structured SCD content in undergraduate programs, with specific learning goals focused on patient-centred care, communication, behavioural management, and understanding psychological aspects such as dental anxiety. These measures aim to reduce educational variability, boost clinician confidence, and improve the quality and fairness of oral health services for individuals with disabilities.

Additionally, this thesis highlights ongoing issues with access to dental care for PWDs and advocates for integrated, accountable models across primary and specialist services, citing examples from existing models, such as those experienced in Australia (Lim et al., 2021). Recognising oral health as a fundamental right fosters a more inclusive society (Gallagher & Fiske, 2007; Britton & Bradley, 2021).

Participants' experiences show that relying on general dental practices without sufficient training, time, or systemic backing risks perpetuating inequalities throughout life, rather than addressing them (Northridge et al., 2020). Therefore, routine monitoring and evaluation of SCD models are vital to ensure they meet patient needs and effectively reduce disparities. Furthermore, workshop insights emphasise that clinician behaviour, including attitudes, confidence, and willingness to adapt, significantly influences access to care, highlighting the need for policies and workforce strategies focused on behaviour change and professional development, alongside structural reforms, to achieve equitable dental care for PWDs.

The findings from the quantitative analyses presented in this thesis should be interpreted with caution due to limited sample sizes. These restrictions may have limited the choice of statistical analyses, and in some cases, the CIs were wide, likely because of small sample sizes. Consequently, although some results were statistically significant, the broad CIs indicate that these findings should be viewed as preliminary. Larger, adequately powered studies are needed to confirm these associations and to obtain more precise and reliable estimates.

6.6 Policy Implications and Recommendations

6.6.1 Policy Implications

Given that many oral diseases are preventable, it is surprising that vulnerable groups still suffer significantly due to health disparities (Watt et al., 2019). In Study I (Balkaran et al., 2022a), participants suggested implementing more inclusive social programmes that support PWDs, including subsidised or free dental care at the policy level. Developing this framework for dental services should involve consultations with PWDs, their caregivers, DHCPs, and other HCPs based on a needs assessment (Faulks, 2023). Such a shift could improve access to regular dental care, which may help reduce the risk of DFA developing in childhood or adolescence (Seligman et al., 2017). Additionally, offering financial incentives to dental practitioners, similar to France's system where dentists have a legal duty to care for all patients, could be beneficial (Camiat et al., 2023). Increased access to routine dental check-ups may help reduce the tendency for symptomatic use of dental services, often driven by ongoing avoidance, which can lead to persistent or worsening dental anxiety (Fu et al., 2023).

International policies should also include dental outreach programmes that provide comprehensive oral health education in settings such as community centres, schools, and institutions, which can benefit PWDs and their caregivers. This was highlighted in Study II (Balkaran et al., 2025a), where OHRQoL was found to be

significantly poorer in children with disabilities compared to their counterparts without disabilities. This suggests that the significance of oral health and its effects on OHRQoL can be better understood and prioritised by caregivers through enhanced awareness, enabling them to appreciate the importance of maintaining healthy oral hygiene and dietary practices for both themselves and PWDs (Faulks, 2023).

Participants in Study I (Balkaran et al., 2022a), including a self-advocate, suggested that teledentistry could also be used to disseminate dental health education to PWDs and their caregivers, promoting healthy dentitions. Additionally, it may help effectively triage patients with disabilities through remote exams and the assistance of their caregivers, and has been a valuable tool (Inquimbert et al., 2024). Teledentistry might reduce transportation costs and help dentists, patients, and caregivers prepare for treatment by setting mutual expectations. Another approach to eliminate transportation barriers is to implement mobile dental clinics (Menon et al., 2025). Such measures would facilitate access to dental services for society's most vulnerable members, such as PWDs facing mobility challenges or in circumstances where transportation is inconvenient, time-consuming, and costly.

6.6.2 Policy Recommendations

When PWDs do receive dental care, they are significantly less likely to receive preventive and restorative dental treatments and are often given exodontia, unlike the general population (Wilson et al., 2018; Watt et al., 2019). There may be a component of DFA which results in delayed dental attendance until exodontia or more complex treatment is required, owing to the level of untreated dental decay. HCPs should assess and address patients' DFA. Evaluating the DFA enhances care and reduces barriers stemming from misconceptions about dental fear.

This thesis highlights significant gaps in policy, education, and clinical practice regarding the oral health care of PWDs and suggests ways to improve. The findings support enhancing national SCD frameworks, integrating comprehensive SCD training into dental curricula, and aligning these with international standards. Emphasising the importance of meaningful clinical exposure, communication skills, and psychological factors, the research can guide future educational and training reforms. Overall, this thesis advocates for enhancements that augment preparedness and encourage equitable oral health care for PWDs. Since PWDs and their caregivers continue to encounter persistent barriers such as stigma, restricted access, and variable quality of care. Additionally, DHCPs frequently feel inadequately prepared due to deficiencies in education and training, and discrepancies in educational frameworks lead to inconsistencies both within and across countries.

Although a general dentist can typically provide most dental treatments, their limited experience with PWDs often hinders these patients' ability to access dental care as easily as their counterparts without disabilities. This underscores the importance of establishing a dedicated special needs clinic for undergraduate clinical training to enhance access to dental care for this population and ensure regular attendance. It also emphasises the need for improved access to adequate dental services that offer prevention and aim to deliver dental treatment in the most comfortable manner possible, thereby minimising the development of DFA and improving their OHRQoL. Furthermore, clinics that provide accommodations for PWDs, including specialised equipment and trained HCPs, should be established to facilitate referrals from general dental services when complex care is necessary.

Our research suggests that SCD should be included in international policies. These policies should also globally advocate for the training of all HCPs in treating PWDs, since a multidisciplinary team approach is often required for the holistic management of PWDs with complex treatment needs. When training dentists, schools can utilise existing SCD curricula, such as the guidelines for an 'Undergraduate Curriculum in Special Care Dentistry' developed by the iADH, thereby allowing SCD to be internationally benchmarked (Dougall et al., 2014). This would ensure that the delivery of SCD is standardised, akin to that in all other disciplines in dentistry, with respect to core competencies. This education should also extend to all allied HCPs, who should be adequately trained to treat and promote oral health in PWDs.

Finally, longitudinal studies are recommended for future research to compare PWDs and those without, particularly as there is limited research in this field worldwide to address the existing paucity in this area. Longitudinal studies are also recommended for future research to compare the students from different universities and locations with respect to their SCD education. These studies can then evaluate whether students' intentions to treat PWDs have been reflected in their practice, based on the patients they have treated after graduation from institutions that provide SCD with both didactic and clinical curricula.

7 Summary/Conclusions

Recognising the barriers to accessing oral health care will help clinicians, public health officials, and policymakers modify current practices and develop effective programs and resources to eliminate obstacles and enhance oral health outcomes. HCPs, DHCPs, and caregivers have emphasised the need for more undergraduate and postgraduate training regarding the treatment and management of PWDs. Dental outreach has been promoted to increase awareness and access to dental care. Culturally appropriate national policies tailored to each country are essential for promoting equity among this vulnerable population.

These research studies aimed to explore the challenges PWDs face in accessing dental care and to examine the barriers and facilitators to oral health care for PWDs. The following main conclusions are drawn from the results of the individual studies:

I. Caregivers and allied HCPs frequently encounter challenges in providing dental treatment for PWDs. Respondents voiced a need for improvements in the delivery and accessibility of oral health services for PWDs. Enhancing HCPs' education, strengthening social policies, and promoting health initiatives are essential.
II. OHRQoL was poor among the children attending the UWI dental clinics, particularly those with disabilities. Nevertheless, the oral impacts reported occasionally, daily, or very often in the domains of 'Psychological Discomfort' and 'Psychological Disability' were more significant among children without disabilities. Delayed attendance and costs may have contributed to these findings.
III. Moderate levels of DFA were observed in the child population of T&T. Children with disabilities exhibited significantly higher moderate levels of anxiety than those without. Consistent dental attendance using DFA-minimising methods is recommended to mitigate the development and persistence of DFA in this population.
IV. Dental workshops and continuing education on SCD are greatly needed and could positively impact dental services for PWDs by enhancing the skills of trained HCPs.

V. Dental students expressed a positive willingness to treat patients with disabilities in the given scenario. However, variations between universities were evident in their behaviour outcomes, subjective norms, and motivation to comply. These differences could be attributed to the legal and societal variations in health care obligations across countries, as well as the levels of clinical exposure to PWDs.

Our research from three international universities suggests that SCD should be incorporated into the undergraduate curriculum using a benchmarked curriculum. Furthermore, international policymakers should involve PWDs in their research to gain a broader understanding of the challenges and factors that promote access to oral health care for PWDs. Better access to dental services, including preventive treatments, could increase dental attendance among PWDs, help reduce DFA, and improve their OHRQoL.

Based on the findings across the five studies, several recommendations can be made to strengthen oral health care for PWDs, improve professional preparedness, and support more equitable access to care.

Recommendations for dental practice include implementing a person-centred care approach across the lifespan, incorporating prevention strategies, behavioural support, and personalised communication for PWDs and their caregivers. Enhancing collaboration among DHCPs, caregivers, and allied HCPs to improve care for PWDs. Expanding clinical interactions with PWDs through community outreach and disability partnerships to develop clinician skills. Employing standardised assessments of dental anxiety in routine care to facilitate better pain management and treatment planning.

Recommendations for dental education include making SCD mandatory in undergraduate curricula and following guidelines such as the iADH, ADEE, and CODA standards. Increasing supervised clinical exposure to PWDs to improve attitudes, confidence, and willingness to care after graduation. Training students in communication and behavioural management for complex patients. Promoting continuing professional development in SCD for practising dentists, especially where undergraduate training is scarce.

Policy recommendations involve developing or enhancing national educational and accreditation standards for SCD to mitigate variability in training quality. Allocating resources to ensure accessible oral health services in underserved communities where PWDs encounter barriers. Advocating for strategies that acknowledge oral health as an integral component of overall health for PWDs, in alignment with global health equity principles.

Recommendations for future research include conducting multi-country or cross-cultural studies on SCD to explore how contextual factors shape access to care and

educational practices. Using longitudinal designs to better understand causal pathways, particularly regarding psychological predictors of dental pain. Expand research that includes the voices of caregivers, HCPs, and PWDs themselves to build a more inclusive evidence base. Evaluating the implementation and impact of SCD educational frameworks to determine best practices for preparing future clinicians.

These recommendations come with caveats and limitations. While this thesis offers valuable insights, it also has some constraints. Most research was conducted within a single national and cultural context, limiting its broader applicability. Although the final study included two groups of dental students from different countries, cross-cultural comparison remained limited. All studies involved small sample sizes, reducing statistical power and resulting in wider CIs, especially in regression analyses. The cross-sectional design prevents causal conclusions, rendering the findings exploratory. Additionally, the qualitative results reflect participant perspectives and may not be widely generalizable. Despite these limitations, this thesis advances our understanding of oral health care for PWDs and suggests directions for future research.

Future Research Questions include:

- How can national and international dental education frameworks be strengthened to ensure consistent and mandatory teaching in SCD across dental schools?
- What types of clinical experiences most effectively improve dental students' attitudes, confidence, and competence in treating PWDs?
- How do cultural, social, and health-system contexts shape the experiences of PWDs, caregivers, and HCPs in accessing oral health care?
- To what extent does DFA predict dental pain and treatment avoidance in PWDs?
- What is the long-term impact of enhanced SCD education on clinical behaviour and practitioner confidence to care for PWDs after graduation?

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List of Figures, Tables and Appendices

Figures

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Appendices

Appendices

Appendix 1a. Semi-structured interview schedule for caregivers and health professionals.

1. The semi-structured questionnaire posed to the caregivers would comprise the following questions:

I. What are the main challenges experienced when attending the dentist with a person with special needs? What are the main challenges experienced when treating a person with special needs?

II. How often does your loved one with special needs attend the dental clinic, and why?

III. Has COVID-19 affected the dental attendance of your loved one with special needs?

IV. What do you wish dental health care providers would know when treating a person with special needs?

V. What expectations do you have when attending for dental care with a person with special needs?

2. The semi-structured questionnaire posed to the health care providers would comprise the following questions:

I. What are the main challenges experienced when treating a person with special needs?

II. How often do persons with special needs attend the dental clinic, and why?

III. Has COVID-19 affected the dental attendance of a person with special needs?

IV. What do you wish a person with special needs or their caregivers would know before they are treated?

V. What expectations do you have when treating a person with special needs?

Appendix 1.b. Consent to participate in interview schedule on the challenges experienced in the dental care of persons with special needs: a qualitative study among health professionals and caregivers.

THE UNIVERSITY OF THE WEST INDIES
ST. AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
CAMPUS RESEARCH ETHICS COMMITTEE
TELEPHONE: (1-868) 662-2002 ext. 82755 E-mail: campusethics@sta.uwi.edu

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CONSENT TO PARTICIPATE IN RESEARCH

Complete Protocol Title: The challenges experienced in the dental treatment of persons with disabilities- perspectives of health professionals and caregivers

Principal Investigator: Ramaa Balkaran

Co Investigator(s): Professor Jorma Virtanen, , , , , , , , ,

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1. Identification of project

a. What is the purpose of this research?
To explore the challenges faced by oral health care professionals and caregivers of persons with Special Needs

b. How long it will take to complete this project?
3 months

c. Why am I selected for this research?
Your responses as an oral health care professionals and caregivers of persons with Special Needs shall will help us to explore the challenges faced in dental treatment and also help in recommending health policies for dentists.

d. Why is this document for obtaining informed consent important?
This document is an invitation for you to either consent or decline to participate in the research after understanding thoroughly about the research and is also a legal document which governs your participation in this research.

2. Description of Procedures

a. What am I expected to do in this study?
We need you to understand the implications of this study and once you are satisfied, we will enroll you. We need you to complete an online interview which will be conducted by RB and should take between 45 minutes to 1 hour to complete

b. Which procedures are investigational, which are routine? What is the expected duration, how frequently I have to participate and where will the activities take place?
N/A

c. How many participants are involved in the study approximately?
15

3. Risks and Discomforts

a. What are the risks or discomforts that may result from my participation in the study?
None, it's an online interview

b. What help and treatments are available if any adverse reactions occur? How can I access them? Is there any compensation available if serious adverse effects occur?
N/A

c. Are there any potentially beneficial treatments or procedures that are withheld for the purpose of the study?
No

4. Termination of Research

a. Are there any anticipated circumstances under which the study/participation may be terminated by the researchers without regard my consent?
None

5. Benefits

a. What are the benefits to me (and the wider society) by this study?
The results will assist the policy makers in identifying areas in which subjects require more knowledge and assist in providing support to healthcare providers and caregivers of persons with special needs

6. Alternatives

a. Does this study involve more than minimal risk? Are there any appropriate alternative procedures or courses of treatment that might be advantageous to me?
No. N/A

b. Do I have the right to pursue the alternatives?
N/A

7. Confidentiality

a. How will confidentiality be maintained regarding my data? Who will have access to the data, how the data will be reported and /or published?
Participants' identity will not be identified in anyway to anyone apart from RB who will be conducting the online face-to-face interview. After the interview, the information will be transcribed into text using initials of the interviewee and only the contents of the interview and demographics will be shared with the research team for analysis. The information to be collected during this study will be confidential and will be strictly used for research purposes only. The data will be stored on a "password protected" database with Dr. Balkaran as the gate-keeper, for 5 years.

8. Cost and Payments

a. Are there any costs involved and are there any compensations provided?
None

9. Freedom to Withdraw

a. Do I have the freedom to withdraw from the study anytime?
Yes, participation is voluntary and you are free to withdraw at any time

b. Will withdrawing from the study have any impact on my treatment?
N/A

10. Opportunity to ask questions

a. Do I have to right to ask questions anytime during the study? Whom should I contact?
Yes you have the right to ask questions at any point in time during this study. You can contact the Campus Research Ethics Committee by email at Campusethics@sta.uwi.edu or the Principal Investigator at ramaa.balkaran@sta.uwi.edu

CONSENT

I have read and understood this explanation. The researcher has also explained the study to me. I have had a chance to ask questions and have them answered to my satisfaction. I agree to take part in this study. I have not been forced or made to feel like I had to take part.

By signing this document, I agree that I have read and received a copy of this document.

I must sign this Consent Form. I will be given a signed copy of the form to keep.

Print Name of Subject

_____

Signature of Subject Date

INVESTIGATOR'S STATEMENT AND SIGNATURE

I have explained the purpose of the research, the study procedures, including those that are investigational, the possible risks and discomforts, and the potential benefits, and have answered all questions regarding the study to the best of my ability. In my opinion, the participant understands these issues and has voluntarily agreed to participate in the study.

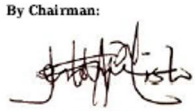
Signature of Person conducting the informed consent discussion Date

---

Role of person named above in the research project

Signature of Second Witness Date

By Chairman:



This document was approved by Campus Ethics Committee on:
March, 1 2021
This document expires on:
March, 1 2022

Appendix 2.a. Questionnaire on OHRQoL and DFA for the accompanying adults.

ORAL HEALTH RELATED QUALITY OF LIFE AND DENTAL FEAR OF CHILDREN AND ADOLESCENTS AGED 6-18 YEARS OLD WITH AND WITHOUT SPECIAL NEEDS– PARENTS' FORM

FORM NO: _____ **AGE OF CHILD:** _____

DATE: _____ **SEX OF CHILD:** _____

ETHNICITY Afro Caribbean ☐ Indo Caribbean☐ Caucasian☐ Chinese☐ Mixed☐ Other☐

DISABILITY OF CHILD

_____

_____

PARENT/ GUARDIAN Mother ☐ Father ☐ Caregiver ☐

1. **Has your child visited a dentist in the past 2 years and when was their last visit?**

   <1 YR ☐ *1 YR* ☐ *2 YR* ☐ *ONLY IN PAIN/ EMERGENCY* ☐ *NEVER* ☐

2. **How would you rate your child's oral health?**
   Excellent ☐ *Very Good* ☐ *Good* ☐ *Fair* ☐ *Poor* ☐

3. **What is the reason for this dental visit for your child?**
   Pain☐ *Filling* ☐ *Cleaning* ☐ *Check-up* ☐ *Other*☐

IN THIS SECTION WE WILL ASK SOME QUESTIONS ABOUT YOUR CHILD'S ORAL HEALTH RELATED QUALITY OF LIFE DURING THE LAST MONTH.

4. **Has your child had trouble pronouncing any words because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

5. **Has your child felt that their sense of taste has worsened because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

6. **Has your child had painful aching in their mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

7. **Has your child found it uncomfortable to eat any foods because of problems with their teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

8. **Has your child been self-conscious because of their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

9. **Has your child felt tense because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

10. **Has been your child's diet been unsatisfactory because of problems with their teeth or mouth, during the last month**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

11. **Has your child had to interrupt meals because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

12. **Has your child found it difficult to relax because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

13. **Has your child been a bit embarrassed because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

14. **Has your child been a bit irritable with other people because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

15. **Has your child had difficulty doing their usual jobs because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

16. **Has your child felt that life in general was less satisfying because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

17. **Has your child been totally unable to function because of problems with their teeth or mouth, during the last month?**
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

IN THE NEXT SECTION, WE WILL ASK SOME QUESTIONS ABOUT YOUR CHILD'S FEELINGS WHEN VISITING A DENTIST DURING THE LAST MONTH.

18. **If your child went to your Dentist for TREATMENT TOMORROW, how would he/she feel?**

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

19. **If your child were sitting in the WAITING ROOM (waiting for treatment), how would he/she feel?**

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

20. **If your child were about to have a TOOTH DRILLED, how would he/she feel?**

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

21. **If your child were about to have your TEETH SCALED AND POLISHED, how would he/she feel?**

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

22. **If your child were about to have a LOCAL ANAESTHETIC INJECTION in his/her gum, above an upper back tooth, how would he/she feel?**

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

Appendix 2.b. Questionnaire on OHRQoL and DFA for Children.

ORAL HEALTH RELATED QUALITY OF LIFE AND DENTAL FEAR OF CHILDREN AND ADOLESCENTS AGED 6-18 YEARS OLD WITH AND WITHOUT SPECIAL NEEDS

FORM NO: _____ **AGE:** _____

DATE: _____ **SEX:** _____

ETHNICITY
Afro Caribbean ☐ **Indo Caribbean** ☐ **Caucasian** ☐ **Chinese** ☐ **Mixed** ☐ **Other** ☐

DISABILITY

_____

_____

IN THIS SECTION WE WILL ASK SOME QUESTIONS ABOUT YOUR ORAL HEALTH RELATED QUALITY OF LIFE.

1. **Have you had trouble pronouncing any words because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

2. **Have you felt that your sense of taste has worsened because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

3. **Have you had painful aching in your mouth during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

4. **Have you found it uncomfortable to eat any foods because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

5. **Have you been self-conscious because of your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

6. **Have you felt tense because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

7. **Has been your diet been unsatisfactory because of problems with your teeth of mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

8. **Have you had to interrupt meals because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

9. **Have you found it difficult to relax because of problems with your teeth or mouth, during the last month?**
   Very Often☐ *Fairly Often*☐ *Occasionally*☐ *Hardly Ever*☐ *Never*☐ *Don't Know*☐

10. Have you been a bit embarrassed because of problems with your teeth or mouth, during the last month?
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

11. Have you been a bit irritable with other people because of problems with your teeth or mouth, during the last month?
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

12. Have you had difficulty doing your usual jobs because of problems with your teeth or mouth, during the last month?
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

13. Have you felt that life in general was less satisfying because of problems with your teeth or mouth, during the last month?
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

14. Have you been totally unable to function because of problems with your teeth or mouth, during the last month?
Very Often☐ Fairly Often☐ Occasionally☐ Hardly Ever☐ Never☐ Don't Know☐

IN THE NEXT SECTION, WE WILL ASK SOME QUESTIONS ABOUT YOUR FEELINGS WHEN VISITING A DENTIST.

15. If you went to your Dentist for TREATMENT TOMORROW, how would you feel?

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

16. If you were sitting in the WAITING ROOM (waiting for treatment), how would you feel?

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

17. If you were about to have a TOOTH DRILLED, how would you feel?

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

18. If you were about to have your TEETH SCALED AND POLISHED, how would you feel?

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

19. If you were about to have a LOCAL ANAESTHETIC INJECTION in your gum, above an upper back tooth, how would you feel?

Not Anxious ☐	*Slightly Anxious* ☐	*Fairly Anxious* ☐	*Very Anxious* ☐	*Extremely Anxious* ☐

Appendix 2.c. Consent and Assent to Participate in OHRQoL and DFA of Children and Adolescents Aged 6-18 Years Old with and Without Disabilities

THE UNIVERSITY OF THE WEST INDIES
ST. AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
FACULTY OF MEDICAL SCIENCES
SCHOOL OF DENTISTRY
Telephone: (868) 645-3232/50 Ext. 4112/4115 Fax: (868) 645-3823

PARENT/GUARDIAN CONSENT

Complete Protocol Title: Oral Health Related Quality of Life and Dental Fear of Children and Adolescents Aged 6-18 Years Old with and Without Special Needs

Principal Investigator: Dr. Ramaa Balkaran

Your child/ ward is being asked to be in a research study. We ask that you read this form and ask any questions that you may have before allowing your child to participate in this study.

1. **What is the purpose of this research?**
   To investigate whether the oral-health-related quality of life (OHRQoL) and dental fear varied among children aged 6-18 years-old with and without special needs.
2. **How will children be selected for this research?**
   All children with special needs (6-18 years old), attending the dental clinic during the period of the study (May 2022- December 2022) will be invited to participate in the study.
3. **Approximately how many participants will be involved in the study?**
   200
4. **What do you expect my child to do in this study?**
   Respond to an international standardized survey
5. **How much time will it take for my child/ward to participate in this study?**
   15-20 minutes
6. **How frequently will my child have to participate and where will the activities take place?**
   Once at the UWI Special Needs Dental Clinic/ Paediatric Dental Clinic
7. **What are the risks or discomforts that may result from my child's participation in the study?**
   No more than minimal risks of answering questions on their dental health and feelings on dental treatment
8. **What help and treatments are available if any adverse reactions occur? How can you access them? Is there any compensation available if serious adverse effects occur?**
   None this study involves answering a questionnaire, so no adverse reactions will occur
9. **What are the benefits to my child (and the wider society) by this study?**
   The results will assist the policy makers in identifying areas in which subjects require more knowledge and assist in providing support to the dentists
10. **What if I don't want my child/ward to be in the study?**
    Participation is voluntary and it does not affect your rights to accessing care
11. **Can my child be withdrawn from this study after agreement to participate?**
    Yes, at any point in the study you are free to withdraw from participation
12. **Do I have the right to see and copy of my child's research information?**
    Yes
13. **Who should I contact if I have any questions to ask concerning my child's/ward's participation?**
    Principal Investigator at ramaa.balkaran@sta.uwi.edu, 6453232 Ext 2157 or the Campus Ethics Committee at Campusethics@sta.uwi.edu
14. **How will confidentiality be maintained regarding my child's data? Who will have access to the data and how will the data be reported and /or published?**

Participants' identity will not be identified in anyway and questionnaires will be identified by numerical code. Subject identifiers will be maintained after analysis and then coded. The code book will be stored in a locked cabinet in the office of Dr. Ramaa Balkaran in Room 151 of the UWI School of Dentistry and the code book will be destroyed after the data has been entered into a database. The data will be stored on a 'password protected' database with Dr. Balkaran as the gate-keeper, for 5 years.

15. **Are there any costs involved and are there any compensation provided?**
    None

Before deciding if you want your child to be in the study, ask any questions you may have. You are also free to ask any questions during the study. If you sign your name below, it means that you agree to allow your child to take part in this research study.

Print Name of Parent/ Guardian

Signature of Parent/ Guardian Date

Assent Consent

1. Why is this study to be done?
   To investigate whether the oral-health-related quality of life (OHRQoL) and dental fear varied among children aged 6-18 years-old with and without special needs during the period of the study (May 2022-December 2022).
2. What will happen to me during the study?
   You will be asked to complete a questionnaire
3. Can anything bad happen to me?
   No
4. Can anything good happen to me?
   Your dentist will have a better idea how to treat you at the next dental visit based on your answers
5. How much time will this take?
   15-20 minutes
6. What if I don't want to be in the study? Can I drop out at any time?
   Yes. Participation is voluntary and you can drop out at any time
7. Will anybody know that I am in this study?
   No. All results will be anonymous and no identifiers will be used in the publication of the findings

Before deciding if you want to be in the study, ask any questions you may have. You are also free to ask any questions during the study. If you sign your name below, it means that you agree to take part in this research study.

Print Your Name Date

Your Signature Age

Appendix 3.a. Pre-workshop Questionnaire.

Pre workshop questionnaire- An assessment of the practitioners' interaction with patients with Special Needs

This questionnaire is targeting all attendees at this Special Needs dentistry workshop. Completion of this survey is optional for all persons, however, the knowledge gained will get useful insight on the delivery of workshop and future learning activities.

Your privacy is important. Participants' identity will not be identified in anyway. The information collected during this study will be confidential and will be strictly used for research purposes only.

The study involves completing the attached questionnaire. Your participation will take approximately 10 minutes. By continuing to the next page, you indicate your consent and willingness to take part in the survey. Thank you for your participation

Answer all questions that apply

1. Age _____
2. Gender? Male ☐ Female ☐
3. What is your ethnicity?

Afro Caribbean	☐
Indo Caribbean	☐
Caucasian	☐
Chinese	☐
Mixed	☐
Other	☐

4. What program are you/ or were you studying?

DHDT ☐ DDS ☐ DSA ☐ MBBS ☐

5. If you are a student, what year are you currently enrolled in at the dental school?

Year 1 ☐ Year 2 ☐ Year 3 ☐ Year 4 ☐ Year 5 ☐ Intern/Resident ☐

6. If you are a graduate, what year did you graduate?

2019	2018	2017	2016	2015	2014	2013	2012	2011	2010
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2009	2008	2007	2006	2005	2004	2003	2002	2001	2000
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

1999	1998	1997	1996	1995	1994
☐	☐	☐	☐	☐	☐

7. What is your main reason for attending today's workshop?

8. How many patients with Special Needs do you treat in a week?

9. What difficulties do you face as a practitioner?

Appendix 3.b. Post-workshop Questionnaire.

An evaluation of the Special Needs Workshop

This anonymous questionnaire is targeting all participants who contributed in a survey at the Special Needs dentistry workshop organized by UWI, 2019. Completion of this survey is fully voluntary. Your feedback is greatly appreciated and will be taken into account in developing future Special Needs education.

Your privacy is important. Participants' identity will not be identified in any way. The information collected during this study will be confidential and will be strictly used for research purposes only. The following link will take you to the survey

https://s.surveyplanet.com/t4kCAP8iz

The study involves completing the attached questionnaire. Your participation will take approximately 10 minutes. By continuing to the next page, you indicate your consent and willingness to take part in the survey.

Please answer all questions that apply

Thank you for your participation!

Dr. Ramaa Balkaran
Lecturer in Special Needs Dentistry, Coordinator Special Needs Dental Clinic
School of Dentistry, Faculty of Medical Sciences

Please answer all questions that apply

1. Age _____

2. Gender? Male ☐ Female ☐

3. What is your ethnicity?
   - Afro Caribbean ☐
   - Indo Caribbean ☐
   - Caucasian ☐
   - Chinese ☐
   - Mixed ☐
   - Other ☐

4. What program are you/ or were you studying?

   DHDT ☐ DDS ☐ DSA ☐ MBBS ☐

5. If you are a student, what year are you currently enrolled in at the dental school?

   Year 1 ☐ Year 2 ☐ Year 3 ☐ Year 4 ☐ Year 5 ☐ Intern/Resident ☐

6. If you are a graduate, what year did you graduate?

2019	2018	2017	2016	2015	2014	2013	2012	2011	2010
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

2009	2008	2007	2006	2005	2004	2003	2002	2001	2000
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

1999	1998	1997	1996	1995	1994
☐	☐	☐	☐	☐	☐

Please answer the following on the scale of:
1 strongly disagree ‖ 2 disagree ‖ 3 neutral ‖ 4 agree ‖ 5 strongly agree

7. My overall assessment of the Special Needs dentistry workshop was positive

   1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

8. The Special Needs dentistry workshop was well arranged

   1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

9. The professor was well prepared

   1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

10. The learning objectives of the Special Needs dentistry workshop were appropriate

    1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

11. The learning objectives of the Special Needs dentistry workshop were met

    1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

12. I will be able to apply these skills to my practice

    1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

13. The amount of time scheduled was exactly what was needed to meet the learning outcomes

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

14. The lecturer demonstrated thorough knowledge of Special Needs dentistry

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

15. My knowledge and/or skills on Special Needs dentistry has greatly increased as a result of this workshop

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

16. I would recommend this Special Needs dentistry workshop to colleagues

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

17. Which part of the Special Needs dentistry workshop did you find most interesting?

_____

_____

_____

Appendix 4.a. Questionnaire on self-reported behavioural intent used at ATSU.

The following survey is for research conducted by the Department of Special Care Dentistry at A. T. Still University. The purpose of this research is to increase understanding of change in self-reported behavioral intent as a result of exposure to both didactic and clinical environments in special care dentistry. Your participation is voluntary and will only involve completing the questionnaire. Completing this questionnaire should require 13 minutes of your time. Please do not use any outside assistance while answering these questions. Please answer each question honestly and to the best of your ability. You are not required to identify yourself on the questionnaire. The researchers will not place any codes on the questionnaire that could directly identify you. The results of this research might be published. Any research reports or publications resulting from this research will not reveal your name or identity. Your research record will remain confidential. There are no direct benefits to you for completing this questionnaire.

Unique Identifier

Gender

Male ○ Female ○

What is your graduation year?

2018 ○ 2019 ○ 2020 ○ 2021 ○

Age in Years

What is your family background or the type of environment in which you were mostly brought up?

- ○ Urban
- ○ Suburban
- ○ Rural

What is your ethnic origin?

- ○ Native Hawaiian or Other Pacific Islander
- ○ American Indian or Alaska Native
- ○ Asian
- ○ Hispanic or Latino
- ○ Black or African American

- White
- Other

Socio-professional group of Mother

- Life, Physical, and Social Science Occupations
- Community and Social Service Occupations
- Personal Care and Service Occupations
- Arts, Design, Entertainment, Sports, and Media Occupations
- Management Occupations, Business and Financial Operations Occupations
- Computer and Mathematical Occupations, Business and Financial Operations Occupations
- Computer and Mathematical Occupations
- Food Preparation and Serving Related Occupations
- Installation, Maintenance, and Repair Occupations
- Protective Service Occupations
- Healthcare Support Occupations
- Building and Grounds Cleaning and Maintenance Occupations
- Construction and Extraction Occupations
- Architecture and Engineering Occupations
- Office and Administrative Support Occupations
- Sales and Related Occupations
- Education, Training, and Library Occupations
- Farming, Fishing, and Forestry Occupations
- Healthcare Practitioners and Technical Occupations
- Legal Occupations
- Production Occupations
- Transportation and Materials Moving Occupations
- Other

Socio-professional group of Father

- Life, Physical, and Social Science Occupations
- Community and Social Service Occupations
- Personal Care and Service Occupations
- Arts, Design, Entertainment, Sports, and Media Occupations
- Management Occupations, Business and Financial Operations Occupations

- Computer and Mathematical Occupations Business and Financial Operations Occupations
- **Computer and Mathematical Occupations**
- Food Preparation and Serving Related Occupations
- **Installation, Maintenance, and Repair Occupations**
- Protective Service Occupations
- **Healthcare Support Occupations**
- Building and Grounds Cleaning and Maintenance Occupations
- **Construction and Extraction Occupations**
- Architecture and Engineering Occupations
- **Office and Administrative Support Occupations**
- Sales and Related Occupations
- **Education, Training, and Library Occupations**
- Farming, Fishing, and Forestry Occupations
- **Healthcare Practitioners and Technical Occupations**
- Legal Occupations
- **Production Occupations**
- Transportation and Materials Moving Occupations
- **Other**

Principal source of finance during dental studies

- **Grants/Scholarships**
- Parents
- **Work**
- Loan

Environment in which you live or lived as a dental student:

- **Living independently i.e. alone, in student accommodation, in shared accommodation, or with a partner**
- Living with parents

Have you ever worked with people with a disability?

- **No**
- paid work
- **occasional unpaid work**
- long term or regular unpaid work

Have you ever worked with people in marginalized groups?

- ○ **No**
- ○ paid work
- ○ **occasional unpaid work**
- ○ long term or regular unpaid work

Does your immediate social circle (family, friends…) include anybody with a disability?

- ○ **No**
- ○ Yes

Does your immediate social circle (family, friends…) include anybody from a marginalized group?

- ○ **No**
- ○ Yes

Are you a passive member of any charitable association or other group involved with community action?

- ○ **No**
- ○ Yes

Are you an active member of any charitable association or other group involved with community action?

- ○ **No**
- ○ Yes

Have you ever received any teaching regarding people with disability?

- ○ **No**
- ○ Yes

Have you ever received any teaching regarding marginalized groups?

- ○ **No**
- ○ Yes

Please answer this questionnaire as HONESTLY as you can. questionnaire is ANONYMOUS and will not count towards an We would simply like your opinion. Anonymous data may b with the aim of evaluating and improving these questionnair thanks.

Do you have a family member with an intellectual disability?

Yes	No
○	○

A patient with intellectual disability:

You receive a phone call from the carer of an adult with Down syndrome living in sheltered housing. She says that the patient has lost a restoration in an upper front tooth.

1. **Assuming that the treatment required was within your clinical competence,** would you provide care for this patient?

No	Yes
○	○

2. How difficult was it for you to make this decision?

Not at all difficult 1	2	3	4	5	6	Extremely difficult 7
○	○	○	○	○	○	○

3. If I were to provide care for this patient:

	Extremely likely 1	2	3	4	5	6	Extremely unlikely 7
A. It would take too long	○	○	○	○	○	○	○
B. It would make the patient anxious	○	○	○	○	○	○	○
C. I would not manage to provide quality care	○	○	○	○	○	○	○

	Extremely likely 1	2	3	4	5	6	Extremely unlikely 7
D. It would disrupt the organisation of my practice	○	○	○	○	○	○	○
E. I would not be able to communicate effectively	○	○	○	○	○	○	○
F. It would make me anxious	○	○	○	○	○	○	○
G. It would not be safe for me and my team	○	○	○	○	○	○	○

4. The following outcomes would be:

	Extremely important 1	2	3	4	5	6	Extremely unimportant 7
a. Not taking too long over treatment	○	○	○	○	○	○	○
b. Not making the patient anxious	○	○	○	○	○	○	○
c. Managing to provide quality care	○	○	○	○	○	○	○
d. Not disrupting the organisation of the practice	○	○	○	○	○	○	○

	Extremely important 1	2	3	4	5	6	Extremely unimportant 7
e. Being able to communicate effectively	○	○	○	○	○	○	○
f. Not making the dentist anxious	○	○	○	○	○	○	○
g. Keeping the dentist and the dental team safe	○	○	○	○	○	○	○

5.

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
a. Most people who are important to me would expect me to treat this patient	○	○	○	○	○	○	○
b. Legally, I am expected to treat this patient	○	○	○	○	○	○	○
c. Other dentists would expect me to treat this patient	○	○	○	○	○	○	○

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
d. My colleagues and dental team would expect me to treat this patient	○	○	○	○	○	○	○
e. I would feel under social pressure to treat this patient	○	○	○	○	○	○	○
f. My other patients would expect me to treat this patient	○	○	○	○	○	○	○
g. This patient would expect me to treat him/her	○	○	○	○	○	○	○

6.

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
A. Most people who are important to me think I should treat this patient	○	○	○	○	○	○	○
B. Legislation exists to oblige me to treat this patient	○	○	○	○	○	○	○

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
C. Other dentists think I should treat this patient	○	○	○	○	○	○	○
D. My colleagues and dental team think I should treat this patient	○	○	○	○	○	○	○
E. Society thinks I should treat this patient	○	○	○	○	○	○	○
F. My other patients think I should treat this patient	○	○	○	○	○	○	○
G. This patient thinks I should treat him/her	○	○	○	○	○	○	○

7.

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
a. The approval of people close to me is important	○	○	○	○	○	○	○
b. My legal obligation is important to me	○	○	○	○	○	○	○
c. The approval of other dentists is important to me	○	○	○	○	○	○	○
d. The approval of my colleagues and dental team is important to me	○	○	○	○	○	○	○
e. The approval of society is important to me	○	○	○	○	○	○	○
f. The approval of my other patients is important to me	○	○	○	○	○	○	○
g. The approval of this patient is important to me	○	○	○	○	○	○	○

8.

	Strongly disagree 1	2	3	4	5	6	Strongly agree 7
a. It would be easy for me to treat this patient	○	○	○	○	○	○	○
b. I am confident that I could treat this patient	○	○	○	○	○	○	○
c. The decision to treat this patient is mine alone	○	○	○	○	○	○	○
d. No factors beyond my control affect my decision to treat this patient	○	○	○	○	○	○	○
e. I have sufficient experience to treat this patient	○	○	○	○	○	○	○

9. How would the following influence the likelihood of your treating this patient?

	Much more likely to treat 1	2	3	4	5	6	Much less likely to treat 7
a. Not working at a loss	○	○	○	○	○	○	○
b. Not feeling rushed	○	○	○	○	○	○	○
c. Not making my regular patients wait longer for treatment	○	○	○	○	○	○	○
d. Not having to modify my usual treatment techniques	○	○	○	○	○	○	○
e. Having adequate training to treat this patient	○	○	○	○	○	○	○

Appendix 4.b. Questionnaire on self-reported behavioural intent used at Université Clermont Auvergne.

INSTRUCTIONS AU RÉPONDANT

Veuillez répondre à ce questionnaire le plus HONNETEMENT possible. Ce questionnaire est anonyme, ne sera pas noté et ne servira pas pour votre évaluation. Seul votre avis nous importe. Les données anonymes pourront être échangées seulement pour évaluer les questionnaires et éventuellement les améliorer. Nous vous remercions de votre participation.

DONNEES DEMOGRAPHIQUES

1) Homme Femme

O O

2) Année de naissance : _ _ _ _ _ _ _ _

3) Quel est votre environnement familial ou le type de milieu dans lequel vous avez majoritairement grandi

o rural (< 2000 habitants)

o semi-urbain (<2000 habitants mais exerçant des activités non agricoles)

o urbain (> 2000 habitants)

4) Catégorie socio-professionnelles des parents.

	5)Mère	6)Père
Agriculteur exploitant	O	O
Artisan, commerçant ou chef d'entreprise	O	O
Cadre ou profession intellectuelle supérieures ex. professeur agrégé, médecin, chercheur...	O	O
Profession intermédiaire ex. instituteur, infirmier(e), employé ex. fonction publique, technicien, agent de maitrise...	O	O
Ouvrier ex. chauffeur...	O	O
Retraité	O	O
Autres personnes sans activité professionnelle ex. Etudiant, forain, gens du voyage, personne au foyer, chômeur...	O	O
Décédé	O	O

5) Principales sources de revenus pendant les études (plusieurs réponses possibles)

o Bourse

o Parents

o Travail

o Emprunt

o Autre – précisez:.....

6) Mode de vie étudiante actuelle :

o Indépendant par ex. seul, dans une résidence universitaire, en colocation, ou en couple.

o Chez vos parents

7) Actuellement vous êtes:

o Un étudiant en chirurgie-dentaire en _ _ _ _ année dans un cursus de 6 années

o Un étudiant de 3ème cycle (interne, master, doctorat) précisez la formation :

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

o Un étudiant en formation continue professionnelle de (précisez): _ _ _ _ _ _ _ _ _ _

8) Si vous êtes chirurgien-dentiste diplômé, depuis combien d'années avez-vous passé votre thèse d'exercice : _ _ ans

9) Si vous êtes chirurgien-dentiste diplômé, comment exercez-vous ? (plusieurs réponses possibles):

o Dentiste omnipraticien

o Dentiste spécialisé en _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ (écrire votre spécialité)

o Dentiste libéral

o Salarié d'un service hospitalier ou hospitalo-universitaire

o Salarié d'un centre de santé (caisse de sécurité sociale, mutuelle, association)

o Autre, précisez: _

EXPERIENCE PERSONNELLE

1) Avez-vous déjà travaillé avec des personnes en situation de handicap? (Plusieurs réponses possibles)

O Non

O Travail rémunéré

O Bénévolat ponctuel / stage non-rémunéré

O Bénévolat régulier ou de longue durée

O Autre, précisez:_ _

2) Avez-vous déjà travaillé avec des personnes appartenant à un groupe marginalisé? (Plusieurs réponses possibles)

O Non

O Travail rémunéré

O Bénévolat ponctuel/ stage non-rémunéré

O Bénévolat régulier ou de longue durée

O Autre, précisez:_ _

3) Dans votre entourage proche (famille, amis…) y-a-t-il une ou plusieurs personnes en situation de handicap?

Non Oui

O O

Si oui précisez: _

4) Dans votre entourage proche (famille, amis…) y a-t-il une ou plusieurs personnes appartenant à un groupe marginalisé?

Non Oui

O O

Si oui précisez: _

5) Etes-vous un membre passif d'une association caritative ou autre groupe impliqué dans une action communautaire? (n'importe quelle action, pas nécessairement reliée au handicap ou à la marginalisation) (passif = membre cotisant ou adhérent mais pas actif)

Non Oui

O O

Si oui précisez: _

6) Etes-vous un membre actif d'une association caritative ou autre groupe impliqué dans une action communautaire? (n'importe quelle action, pas nécessairement reliée au handicap ou à la marginalisation) (actif = impliqué dans le fonctionnement d'un groupe ou participant à des interventions)

Non Oui

O O

Si oui précisez: _

7) Avez-vous déjà reçu un enseignement concernant les personnes en situation de handicap?

Non

Oui, en tant qu'étudiant en chirurgie dentaire

Autre, précisez:_ _

8) Avez-vous déjà reçu un enseignement concernant les personnes appartenant à un groupe marginalisé?

Non Oui,

O O

en tant qu'étudiant en chirurgie dentaire

Autre, précisez:_ _

INSTRUCTIONS AUX REPONDANTS

Veuillez répondre à ce questionnaire le plus HONNETEMENT possible. Ce questionnaire est anonyme, ne sera pas noté et ne servira pas pour votre évaluation. Seul votre avis nous importe. Les données anonymes pourront être échangées seulement pour évaluer les questionnaires et éventuellement les améliorer. Nous vous remercions de votre participation.

Questions en lien avec le scénario choisi:

1. En supposant que vous ayez les compétences cliniques requises, prendriez-vous en charge ce patient?

Non	Oui
O	O

2. A quel point était-il difficile pour vous de prendre cette décision?

Pas du tout difficile	1	2	3	4	5	6	7	Extrêmement difficile
	O	O	O	O	O	O	O	

3. Si j'étais amené à soigner ce patient :

A Cela prendrait trop de temps

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O		

B Cela rendrait le patient anxieux

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

C Je n'arriverais pas à réaliser des soins de qualité

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

D Cela dérangerait le fonctionnement de mon cabinet

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

E Je n'arriverais pas à communiquer efficacement

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

F Cela me rendrait anxieux

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

G Ce ne serait pas sans danger pour moi et mon équipe

Extrêmement probable	1	2	3	4	5	6	7	Extrêmement
improbable	O	O	O	O	O	O	O	

4. Jusqu'à quel point les conséquences suivantes seraient souhaitables:

a Ne pas prendre trop de temps pour les soins

Extrêmement souhaitable non souhaitable	1 O	2	3 O	4 O	5	6 O	7 O	Extrêmement

b Ne pas rendre le patient anxieux

Extrêmement souhaitable non souhaitable	1 O	2 O	3	4 O	5 O	6	7 O	Extrêmement

c Réussir à réaliser des soins de qualité

Extrêmement souhaitable non souhaitable	1 O	2 O	3 O	4 O	5	6 O	7 O	Extrêmement

d Ne pas déranger le fonctionnement du cabinet

Extrêmement souhaitable non souhaitable	1 O	2 O	3 O	4 O	5	6 O	7 O	Extrêmement

E Etre capable de communiquer efficacement

Extrêmement souhaitable non souhaitable	1 O	2 O	3 O	4 O	5 O	6 O	7 O	Extrêmement

f Ne pas rendre le dentiste anxieux

Extrêmement souhaitable non souhaitable	1 O	2 O	3 O	4 O	5 O	6 O	7 O	Extrêmement

g La non mise en danger du dentiste et de son équipe

Extrêmement souhaitable non souhaitable	1 O	2 O	3 O	4 O	5 O	6 O	7 O	Extrêmement

5.

a La plupart des personnes qui sont importantes pour moi attendraient de moi que je soigne ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

b Légalement, on s'attendrait à ce que je soigne ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

c D'autres dentistes s'attendraient à ce que je soigne ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

d Mes collègues et mon équipe s'attendraient à ce que je soigne ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

e La pression sociale me pousserait à soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

f Mes autres patients s'attendraient à ce que je soigne ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

g Ce patient s'attendrait à ce que je le soigne

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

6.

A La plupart des personnes qui sont importantes pour moi pensent que je dois soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

B J'ai l'obligation légale de soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

C D'autres dentistes pensent que je devrais soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

D Mes collègues et mon équipe pensent que je devrais soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

E La société pense que je devrais soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

F Mes autres patients pensent que je devrais soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord

G Ce patient pense que je devrais le soigner

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

7.

a L'approbation des personnes proches de moi est importante

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

b Les obligations légales sont importantes pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

c L'approbation des autres dentistes est importante pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

d L'approbation de mes collègues et de mon équipe est importante pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

e L'approbation de la société est importante pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

f L'approbation de mes autres patients est importante pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

g L'approbation de ce patient est importante pour moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

8.

a Il me serait facile de soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

b Je me sens confiant pour soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

c La décision de soigner ce patient ne revient qu'à moi

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

d Aucun facteur indépendant de ma volonté ne peut affecter ma décision de soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

e J'ai suffisamment d'expérience pour soigner ce patient

Pas du tout d'accord	1	2	3	4	5	6	7	Tout à fait d'accord
	O	O	O	O	O	O	O	

9. A quel point les situations suivantes influenceraient la probabilité pour vous de soigner ce patient?

a Ne pas travailler à perte

Beaucoup plus enclin à soigner	1	2	3	4	5	6	7	Beaucoup
moins enclin à soigner	O	O		O	O	O	O	

b Ne pas se sentir pressé par le temps

Beaucoup plus enclin à soigner	1	2	3	4	5	6	7	Beaucoup
moins enclin à soigner	O	O	O	O	O	O	O	

c Ne pas faire attendre plus longtemps mes autres patients pour leur soins

Beaucoup plus enclin à soigner	1	2	3	4	5	6	7	Beaucoup
moins enclin à soigner	O	O	O	O	O	O	O	

d Ne pas avoir à changer mes techniques habituelles de soins

Beaucoup plus enclin à soigner	1	2	3	4	5	6	7	Beaucoup
moins enclin à soigner	O	O	O	O	O	O	O	

e Avoir une formation adéquate pour soigner ce patient

Beaucoup plus enclin à soigner	1	2	3	4	5	6	7	Beaucoup
moins enclin à soigner	O	O	O	O	O	O	O	

Appendix 5. Ethical Approvals from the University of the West Indies Ethics Committee.

THE UNIVERSITY OF THE WEST INDIES
ST. AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
CAMPUS RESEARCH ETHICS COMMITTEE
TELEPHONE: (1-868) 662-2002 ext. 82755 E-mail: campusethics@sta.uwi.edu

March, 1 2021

Ramaa Balkaran
Professor Jorma Virtanen
School of Dentistry
Faculty of Medical Sciences
Email: ramaa.balkaran@sta.uwi.edu

Dear Ramaa Balkaran,

Ref: CREC-SA.0820/03/2021

Title: The challenges experienced in the dental treatment of persons with disabilities-perspectives of health professionals and caregivers

I am pleased to advise that your application for research on the above captioned topic has met the criteria for Exemption from Review from the Campus Research Ethics Committee, St. Augustine.

Sincerely,

Professor Jerome De Lisle
Chair
Campus Research Ethics Committee

THE UNIVERSITY OF THE WEST INDIES
ST. AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
CAMPUS RESEARCH ETHICS COMMITTEE
TELEPHONE: (1-868) 662-2002 ext. 82755 E-mail: campusethics@sta.uwi.edu

June, 8 2022

Ramaa Balkaran
School of Dentistry
Faculty of Medical Sciences
Email: ramaa.balkaran@gmail.com

Dear Ramaa Balkaran,

Ref: CREC-SA.1609/05/2022

Title: Oral health related quality of life and dental fear and in children aged 6-18 years old with and without special needs

I am pleased to advise that your application for research on the above captioned topic has been approved on behalf of Campus Research Ethics Committee, St. Augustine.

Approval is valid for one (1) year.

Sincerely,

Professor Jerome De Lisle
Chair
Campus Research Ethics Committee

THE UNIVERSITY OF THE WEST INDIES
ST AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
CAMPUS RESEARCH ETHICS COMMITTEE
TEL.: (1-868) 662-2002 ext. 82755 E-mail: campusethics@sta.uwi.edu

October 10 2019

Dr. Ramaa Balkaran (Dr. Anushka Maharaj)
School of Dentistry

Faculty of Medical Sciences,

St Augustine

The University of the West Indies

Eric Williams Medical Sciences Complex

Champs Fleurs,

Trinidad, West Indies
Email: ramaa.balkaran@sta.uwi.edu

Dear Dr. Ramaa Balkaran,

Ref: CREC-SA.0073/11/2019

Title: Audit of attendance at a Special Needs Dentistry workshop

I am pleased to advise that your research on the above captioned topic meets the criteria for waiver of Ethics Protocol as per the guidelines in the UWI Policy and Procedures on Research Ethics.

Sincerely,

Surendra Arjoon (Prof.)
Chairman
Campus Ethics Committee

THE UNIVERSITY OF THE WEST INDIES
ST. AUGUSTINE, TRINIDAD AND TOBAGO, WEST INDIES
CAMPUS RESEARCH ETHICS COMMITTEE
TELEPHONE: (1-868) 662-2002 ext. 82755 E-mail: campusethics@sta.uwi.edu

November, 29 2020

Ramaa Balkaran
Dr. Anushka Maharaj
School of Dentistry, Faculty of Medical Sciences, The University of the West Indies
Email: ramaa.balkaran@sta.uwi.edu

Dear Ramaa Balkaran,

Ref: CREC-SA.0600/11/2020

Title: An evaluation of the Special Needs Workshops

I am pleased to advise that your application for research on the above captioned topic has met the criteria for Exemption from Review from the Campus Research Ethics Committee, St. Augustine.

Sincerely,

Professor Jerome De Lisle
Chair
Campus Research Ethics Committee

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YLIOPISTO
UNIVERSITY
OF TURKU

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