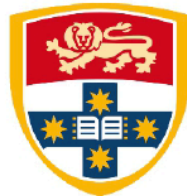


**Presentation of acute odontogenic infections to tertiary  
hospitals with intellectual disabilities; Is it the lack of  
awareness, motivation or insufficiencies in health system -  
A retrospective study**

Rasheedunisa Begum Abdul Jamee  
(Rasheeda Jamee)

BDS; FRACDS (GDP)

A thesis submitted to fulfill requirements for the degree of  
Master of Philosophy



THE UNIVERSITY OF  
**SYDNEY**

Faculty of Medicine and Health  
The University of Sydney

February 2023

## **Declaration of originality**

This is to certify that to the best of my knowledge the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes. I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged accordingly. I certify that if my candidature is successful, this thesis will be lodged with the Director of University Libraries and made available for immediate use.

Rasheeda Jamee

28<sup>th</sup> of February 2023.

## **Supervisor's statement**

As a supervisor for the candidate upon which the thesis is based, I can confirm the authorship attribution statements are correct.

Supervisor name: DR RAHENA AKHTER

Date: 03/03/2023.

## Acknowledgement

The completion of this study would not have been possible without my supervisors support and guidance. **Dr. Rahena Akhter** and **Prof. Vesna Miletic**, with their immense wealth of knowledge, provided endless support that carved a purpose and direction for my research;

Dr. Akhter, thank you for being my lead supervisor, you went above and beyond in providing the timely guidance. Your mentorship stood as a beacon of light in this long journey that underwent many twists and turns.

Dr. Miletic, I am very much thankful to you for agreeing to be my supervisor in my mid-candidature, you gave me words of assurance during some turbulent times.

I will remain always grateful to you both, for the support and guidance that you offered me through each stage of my candidature and made me reach this final stage of thesis writing and submission. I have to remind myself that it is the constant feedback and encouragement from my supervisors, shaped this thesis to reach its final stage. I am grateful to you both for what I got to learn, made me achieve one of my career goals of doing Masters by Research.

I would like to thank the team at Westmead Records section, each and every one of them who helped me collect the data by organising dental records even at a short notice. I would like to express my gratitude to Westmead Ethics team and Westmead Centre of Oral Health to grant me access for my studies without which this study would not be completed. I must also say my sincere thanks to The University of Sydney for accepting me as a student of research and providing the support. It's an honour to be a student of world renowned University.

I hold immense gratitude towards my two lifelong coaches, for their influence shaped my career:

My previous line manager at QLD Health, **Dr. Irina Leonida**, who created endless opportunities and widened my scope of practise. She has set herself as a shining example to aspire and to become like her, one day.

My current employer at NSW Health, **A/Prof. Ravi Srinivas**, who made me what I am today by supporting my career ambitions; supporting this research, fellowship at RACDS, just to name a few out of many. This journey would not be possible without his presence and support that he offers behind the scenes.

No words can explain and I am indebted to them both, forever!

I will fall short if I don't extend my heartfelt gratitude towards my dear friend and my colleague **Dr. Khanh Thi Nguyen**, who re-establishes my confidence when its shaken, provides assurance and encourages me with her kind words.

Last but not the least, I have to mention that my family has been very supportive with all my endeavours:

My husband **Kaja**, has been very tolerant and co-operative towards my career ambitions and supported every decision of mine, including the decision to pursue my first job at Roma, a small mining town in Far West Queensland.

My little daughter **Aayesha**, has been a blessing, hope and joy; without her, my life would have lost its purpose. I love her more each and every day as she emerges to be a kind, beautiful and confident young lady.

My parents **Abdul Jamee**, **Naseema** and my brother **Hafeez**, though they live in different country, their prayers and encouraging words has been the strength that I get to finish this thesis in Australian grounds.

I am thankful to everyone above, if not expressed now, when can it be?!

And most importantly, **The Almighty**.

# Table of Contents

Declaration of originality .....	2
List of Abbreviations .....	9
List of figures and Tables.....	10
Abstract .....	11
Chapter 1	
Dental Caries and Periodontal Disease .....	12
1.1 Dental Caries.....	13
1.1.1 Definition .....	13
1.1.2 Pathophysiology of Dental Caries .....	13
1.1.3 Epidemiology of Dental caries .....	16
1.2 Periodontal disease.....	17
1.2.1 Definition .....	17
1.2.3 Epidemiology of Periodontal Disease.....	19
1.3 Management .....	19
1.3.1 Dental caries management .....	19
1.3.2 Periodontal disease management.....	21
1.3.3 Progression of dental infection.....	22
1.4 References .....	25
Chapter 2: Literature review	
Dental caries and periodontal disease status in children and adolescents with cerebral palsy – a systematic review .....	28
2.1 Introduction.....	29
2.1.1 Oral health in patients with cerebral palsy .....	30
2.1.2 Cause of dental disease in patients with cerebral palsy .....	30
2.2 Aim.....	31
2.3 Materials and methods.....	31
2.3.1 Search Strategy.....	31
2.4 Study selection and data extraction.....	32
2.4.1 Assessment of the study quality .....	33
2.4.2 Search outcome .....	33
2.5 Results .....	35
2.6 Discussion.....	36
2.7 Conclusion .....	41

2.8 References .....	42
Chapter 3	
Dental treatment in patients with intellectual disability.....	45
3.1 Introduction.....	46
3.1.1 Definition .....	46
3.2 Biopsychosocial Model .....	46
3.3 Challenges in treating patients with intellectual disability.....	48
3.3.1 Barriers in providing dental care .....	48
3.3.2 Transition from adolescence to adult dental care .....	49
3.3.3 Establishing effective communication .....	49
3.3.4 Accessibility to the dental offices.....	50
3.4 Dental pain management in patients with intellectual disability .....	52
3.5 Treatment modalities for patients with intellectual disability .....	53
3.5.1 Treatment with 50% nitrous oxide/oxygen for outpatient dental treatment.....	53
3.5.2 Treatment under Conscious sedation .....	54
3.5.3 Treatment under General Anaesthesia .....	54
3.6 References .....	55
Chapter 4	
Referral pathways in NSW health .....	58
4.1 Introduction.....	59
4.2 Referral pathways .....	59
4.3 Responsibility of the referring clinician.....	60
4.4 Who can be referred to SN specialist? .....	60
4.5 References .....	62
Chapter 5	
Research Project .....	63
Presentation of acute odontogenic infections to tertiary hospitals with intellectual disabilities; Is it the lack of awareness, motivation or insufficiencies in health system - a retrospective study .....	64
5.1 Introduction.....	64
5.1.1 Disease Background .....	64
5.1.2 Rationale for performing the study.....	65
5.2 Aim.....	66
5.3 Hypothesis .....	66
5.4 Materials and Methods .....	67

5.4.1 Design/Study Type .....	67
5.4.2 Subjects .....	67
5.4.3 Study participants .....	68
5.4.4 Inclusion criteria .....	68
5.4.5 Exclusion criteria .....	68
5.4.6 Information on consent .....	69
5.5 Statistical considerations .....	69
5.6 Results .....	70
5.7 Discussion.....	78
5.8 Recommendations .....	82
5.9 Conclusion .....	83
5.10 References.....	84
Learning outcomes.....	88
Appendix 1 : NSW Health Oral Health Specialist referral form .....	90
Appendix 2 : Patient Questionnaire form.....	91



## List of Abbreviations

ADL	Activities of Daily Living
ASA	American Society of Anesthesiologists
CAMBRA	Caries Management by Risk Assessment.
CHD	Coronary Heart Disease
CP	Cerebral Palsy
GDP	General Dental Practitioner
GP	General Physician
GMFCS	Gross Motor Function Classification
HCC/PC	Health Care Card/Pension Card
HRQoL	Health Related Quality of Life
ICF	International Classification of Functioning, Disability and health
ID	Intellectual Disability
IDD	Intellectual and Developmental Disability
ICDAS	International Caries Detection and Assessment System
LHD	Local Health District
NOS	Newcastle Ottawa study
OHQoL	Oral Health Quality of Life
OHT	Oral Health Therapist
SCD	Special Care Dentist
SCU	Special Care Unit
SDH	Sydney Dental Hospital
SN	Special Needs
WCOH	Westmead Centre of Oral Health
WHO	World Health Organisation

# List of figures and Tables

## Figures

1. Pathology of Dental Caries
2. Factors involved in caries development
3. Pathology of Periodontal disease
4. Progression of Dental Caries
5. Progression of Periodontal Disease
6. Progression of Periapical infection
7. Anatomical spaces
8. Common Dental Emergencies and the treatment protocol
9. Newcastle Ottawa Study
10. PRISMA 2020 flow diagram
11. Rosenberg & Gorter adaption of the ICF (WHO 2001)
12. Rosenbaum & Gorter adaption of ICF (2012)
13. Communication triad
14. Diaco Bay in a dental office
15. Pictorial representation of referral pathways in New South Wales
16. Reasons for referrals based on underlying medical conditions/concerns
17. Source of referrals
18. Reasons for referral based on dental concerns
19. Compliance noted in the referrals
20. ADLs
21. The treatment outcome

## Tables

1. The median of mean prevalence of caries among continents  
(Chan Tamrakar et al., 2021)
2. Rosenbaum & Gorter F-words (2012)
3. FRAME framework Espinoza & Heaton (2016)
4. Association between reasons of referral and independent variables

## **Abstract**

Dental caries and periodontal disease are the most common dental diseases that affect all groups and sects of population resulting in poor oral health. Patients with intellectual disability (ID) have been greatly affected due to these two diseases leading to poor oral health quality of life. The sequelae of these two diseases not only leads to loss of tooth structure but prior to the tooth loss, an individual suffers with dental pain due to infection with localised and systemic effects. In patients with ID, as the expression of pain is diminished or overlapped with challenging behaviours, they often get misdiagnosed. Most often these patients present to the primary clinician with acute symptoms of pulpitis or facial swelling with or without an exacerbation of un-cooperative behaviour that leads to a referrals to a tertiary hospital.

In chapter 1, this thesis draws a basic understanding of two major oral diseases affecting the oral system – dental caries and periodontal disease. In order to understand how these two diseases affect patients with ID as a whole and the reasons behind referrals to tertiary hospitals, this thesis initially draws light on one single intellectual disability – Cerebral Palsy and on a single age group – children and adolescents with an assumption that dental caries and periodontal disease is highest; this is discussed as a systematic review in Chapter 2.

Further in chapter 3, this thesis discusses about patients with ID and on ways to provide dental treatment in a holistic way. It also discusses the challenges, treatment modalities and options around dental management of ID patients. In chapter 4, referral pathways are discussed to seek further dental treatment under specialist care, where he/she can be seen in three different locations in Sydney metropolitan area.

In the final chapter 5, this thesis discusses the research project, that is to understand the reasons behind referrals as categorised as acute condition either with a facial swelling or a dental abscess or simply change in behaviour that is assumed to be related to dental discomfort. This research is a retrospective study, where the data were collected from existing 91 dental records that were randomly picked. Appropriate ethics was sought and the data were analysed and discussed in chapter 5. This is followed by discussion of results and recommendations with concluding remarks to overcome this prevailing problem of referrals with acute odontogenic infection in ID population.

**Chapter 1**  
**Dental Caries and Periodontal Disease**

## **1.1 Dental Caries**

Dental caries is a multifactorial chronic disease where the carious lesion develops due to the combined action of behavioural, psychological and environmental factors (Machiulskiene et al., 2020). It affects all age groups where an individual can be affected early in childhood as an infant, a toddlers or in adulthood with changing behaviour and lifestyle pattern, some are environmentally triggered while others can be a super-imposed effect of other medical condition.

### **1.1.1 Definition**

*Dental caries is a biofilm-mediated, diet modulated, multifactorial, non-communicable, dynamic disease resulting in net mineral loss of dental hard tissues* (Fejer-skov 1997; Pitts et al., 2017)

### **1.1.2 Pathophysiology of Dental Caries**

The loss of integrity of tooth structure occurs by acids produced by the dental biofilm. A healthy dental biofilm is the presence of microbiota that lives synergistically causing no harm to the host (Marsh 2016). While on occasions, the synergism is lost, leading to breakdown of tooth structure by the presence of acid producing bacteria such as *Streptococcus mutans*, *Bifidobacteria* and *lactobacilli*. In people who consume fermentable carbohydrates with frequent sugar exposures, these bacteria are higher in number causing demineralisation of the tooth structure.

Cariou lesion develops where biofilms remain undisturbed for long periods thereby forming a niche where the plaque grows and forms a cavity which harbours further growth of acid producing bacteria. The biofilm fluid is the key where exchange of minerals take place.

Fluoride in the biofilm is directly proportional to the anti-cariogenic effect. Fluoride is available as reservoir from the external fluoride resources like dentifrices, mouthwashes and varnishes (Walsh 2000), (Marinho et al., 2002, 2003).

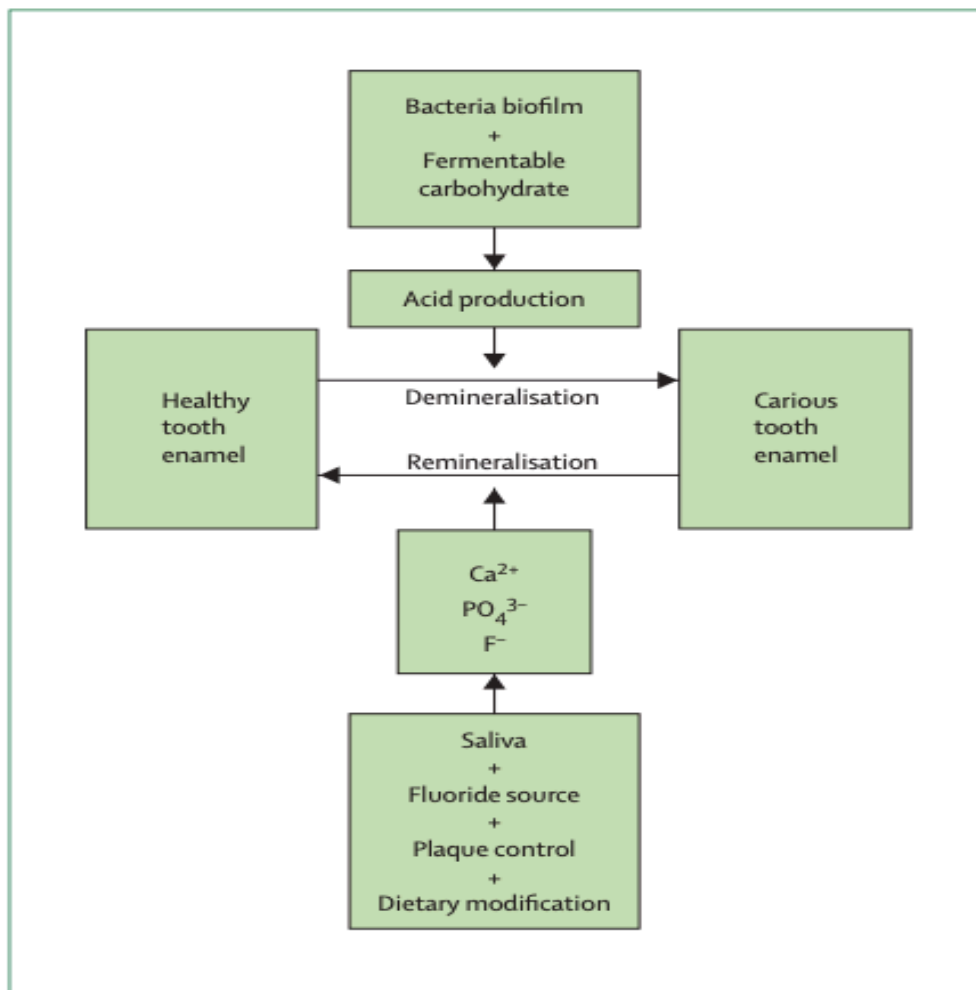


Figure 1 : Pathology of Dental Caries (Selwitz et al., 2007).

The behavioural and psychological factors are based on ineffective plaque control directly related to the frequency of brushing and using interdental aids. If pathogenic bacteria are not cleared on regular basis, in addition to frequent sugar exposures, it leads to the growth of more cariogenic bacteria in the mouth. The sugar exposures can be a direct intake of sweetened food or even presence of sugar in the form of medication. Special health care conditions limiting water intake quadruples the effect.

The environmental factors that have direct influence over the caries rate are: water fluoridation, access to dental care products and access to dental services. These have direct effect on contributing to the caries rate in an individual.

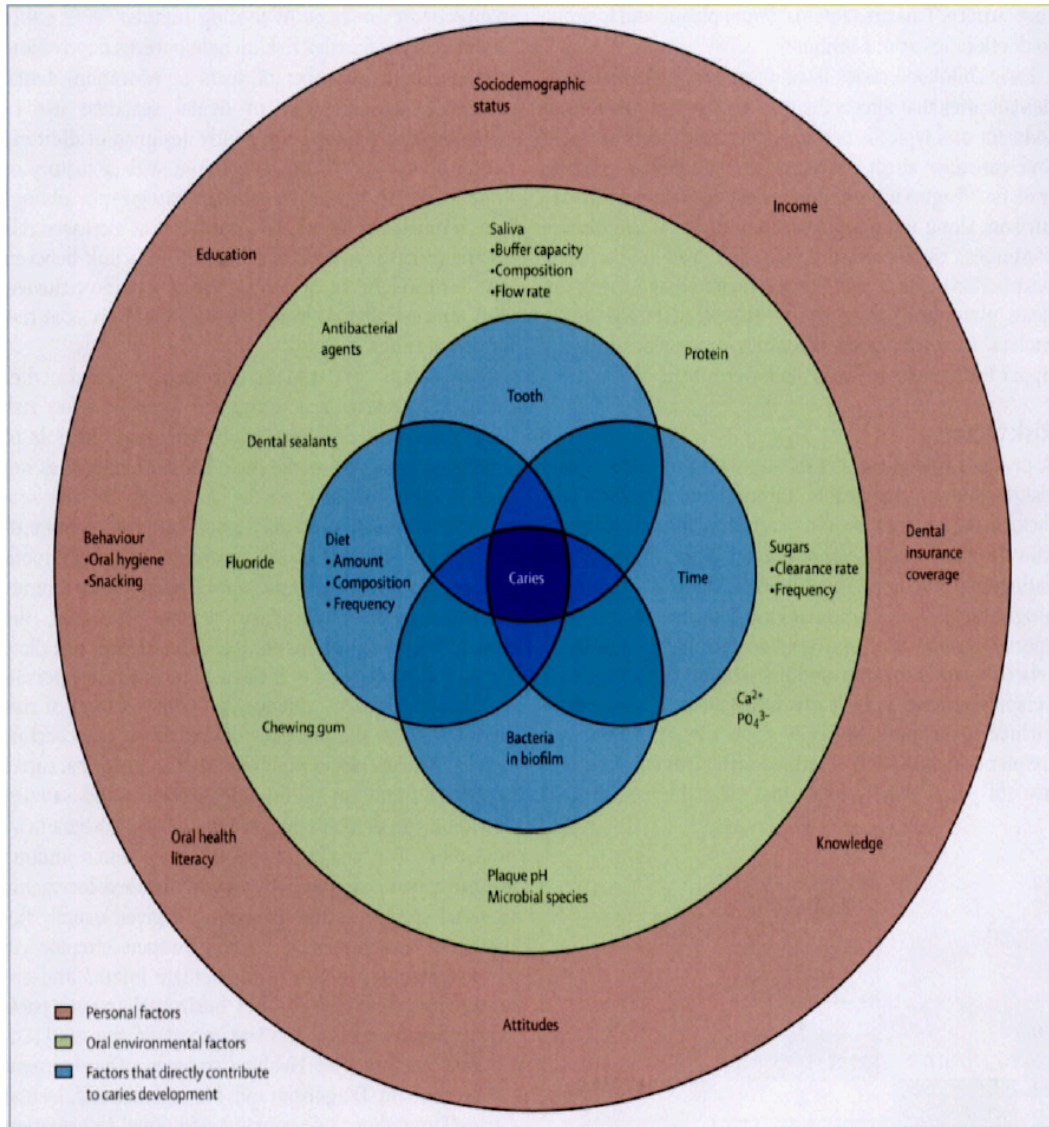


Figure 2: Factors involved in caries development. Selwitz et al., 2007

In addition to the behavioural, psychological and environmental factors, other common risk factors are directly related to the genetics, salivary flow, socio-economic status, awareness about oral health also take direct part in controlling this very common dental disease. The disease is halted or slowed down in initial stages but when inner tooth structure is involved, the dental caries has to be managed or treated, which if not provided may lead to loss of tooth,

risks of dental infection by the presence of acute or chronic symptoms and flare-ups that may include involvement of deep or inner tissue space infections (Selwitz et al., 2007).

### **1.1.3 Epidemiology of Dental caries**

Globally, there is noted decline of dental caries from primary to permanent dentition and also marked decline with increasing age of the individual. In primary dentition, caries presence is more on smooth surfaces but there is transition to pit and fissure caries in permanent dentition (Selwitz et al., 2007)

Previously, it was believed that children who live in rural areas have higher caries incidence than children living in metropolitan areas. There is a cross-sectional study (Ha et al., 2020) that compares caries rate in children living in rural and urban areas. High consumption of sugar drinks was directly related to the caries rate in primary dentition. Also other factors that influence are : water fluoridation and frequency of dental visit. This study confirms that the caries rate is more in children living in rural areas than living in urban areas mainly due to access to dental services in addition to water fluoridation.

It is noted that there was a steep decline in caries experience in both primary and permanent dentition between 1977 and 1983 (Mejia et al., 2011). Between 1980 to 1990, 6 year old had more dental caries than 12year old. However, in 2001 and 2004 there is increase in DMFT scores; in 2006, there is 28% increase in dft scores in deciduous teeth (Mejia et al., 2011). As based on this study, the increase in caries rate has been proposed to increase in consumption of bottled and tank water than fluoridated tap water, a trend of increased consumption of soft drinks among school children. On the other hand, placement of fissure sealants in permanent teeth than on primary teeth and noted improvement of oral hygiene practices with age than in younger children has also been noted.

The trend noted in adult or ageing population is prevalence of untreated caries with or without root caries. When compared to global comparison, Australia has lowest prevalence (25%) of untreated caries when compared to African and Asian countries Table: 1 (Chan Tamrakar et al., 2021), 47-99% in Vietnam and highest in South Africa 99%. Socio-economic factors and underlying medical conditions like uncontrolled diabetes mellitus play a major part in



reflecting the caries DMFT scores. On contrary, Europe has shown lowest amount of untreated caries with even less than 10% in Finland (Chan Tamrakar et al., 2021).

Location	Median of Untreated Caries Prevalence	Median of Root Caries Prevalence
Global (20 countries, 39 studies)	49%	46%
Asia (5 countries, 20 studies)	66%	46%
Europe (8 countries, 10 studies)	46%	35%
North America (2 countries, 3 studies)	25%	95.3%
South America (1 country, 1 study)	-	74%
Oceania (1 country, 2 studies)	25%	18%
Africa (3 countries, 3 studies)	49%	-

Table 1: The median of mean prevalence of caries among continents (Chan Tamrakar et al., 2021).

## 1.2 Periodontal disease

Gingivitis and periodontitis are both inflammatory diseases caused by bacterial plaque. Gingivitis is a reversible condition of marginal gingiva whereas periodontitis is a non-reversible destructive process resulting in loss of connective tissue, alveolar bone and thereby loss of a the tooth structure. Periodontitis is preceded by gingivitis and not all the cases of gingivitis proceeds to be established periodontitis.

### 1.2.1 Definition

*An inflammatory disease of the supporting structures of the teeth caused by specific microorganisms or groups of microorganisms, resulting in progressive destruction of the periodontal ligament and alveolar bone with pocket formation, recession, or both (Carranza et al., 2011).*

### 1.2.2 Pathophysiology of Periodontal Disease

As similar to dental caries, periodontitis is multi-factorial in origin. Dental plaque of specific microbial species has direct correlation to the disease. Species like *Capnocytophaga* spp are more prevalent in gingivitis. As the disease progresses there is noted shift in the microbiota. The dominance of *Prevotella* spp, *Porphyromonas* spp and *Aggregatibacter Actinomycetemcomitans* occurs in established disease state. In cases of abscess formation secondary to periodontitis, other species like *F.nuceatum*, *Peptostreotococcus* have been noted.

In addition to the presence of plaque bacteria, a susceptible host is necessary for the disease progression (Tatakis et al., 2005).

Modifiable and non-modifiable factors also play a pivotal role in disease progression. Factors like genetic conditions in cases with Down's syndrome, Papillon-Lefevre syndrome determine the host susceptibility. Hormonal changes that occur in females during pregnancy and after menopause have direct impact on periodontal disease and are the non-modifiable risk factors. Modifiable factors are smoking, diabetes mellitus which have a strong correlation to the disease severity. To some extent certain medications increases the incidence of periodontal disease not only by reducing salivary flow and increased bacterial plaque growth but also cause overgrowth of gingiva thereby compromising oral hygiene (Chapple et al., 2017).

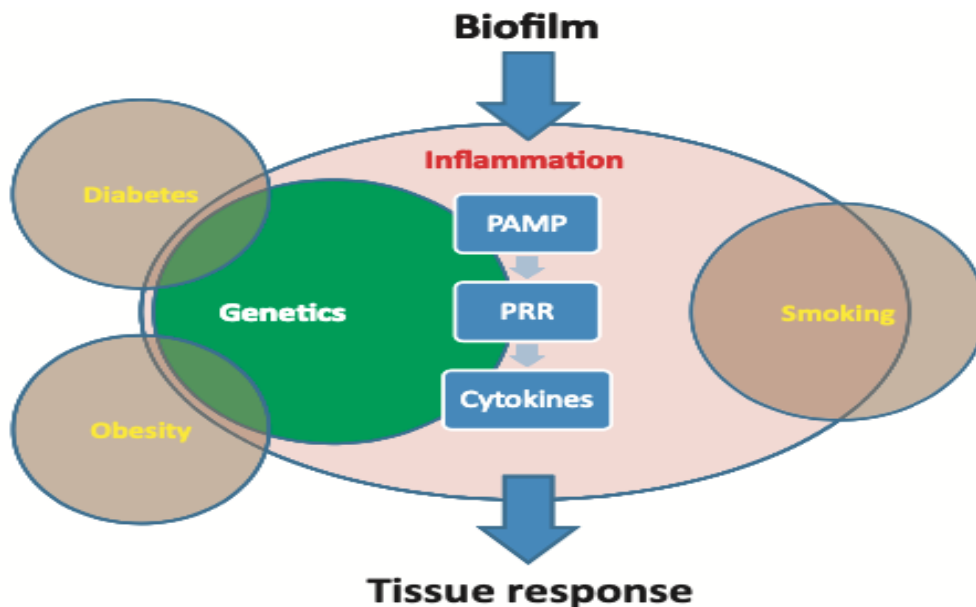


Figure 3: Pathology of Periodontal disease. (Dentino et al., 2013).

On the contrary, poor periodontal status also has detrimental effects on systemic health. Patients with active periodontitis has 1.14 times higher incidence of developing chronic heart disease (CHD) (Cullinan et al., 2009). Increased bacterial load of pathogenic bacteria can contribute to platelet aggregation and thrombus formation thereby causing CHD. When focussing on diabetes mellitus, periodontitis is considered as sixth complication. Diabetic level is controlled by improving periodontal health and vice versa (Cullinan et al., 2009). Chances of preterm birth increases with active periodontal disease. A meta-analysis of five studies

between 1996 and 2002 indicates that pregnant women with periodontal disease had 4.28 times greater risk of preterm birth when compared to healthy women (Cullinan et al., 2009).

### **1.2.3 Epidemiology of Periodontal Disease**

Periodontitis as a combined activity of dental plaque, host response and other related risk factors, the amount of tissue destruction seen through clinical attachment loss and bone loss varies in different forms of disease. The population affected with periodontitis were mainly who completed year 9 schooling or less with prevalence of 1.8 times of moderate to severe periodontitis. The prevalence of periodontitis among Australian population was 22.9%. Over 60% of 75 year old age groups were diagnosed with periodontitis when compared to younger age groups. There is higher incidence of disease in men (26.8%) than women (19%). People who visit dentist for a problem showed higher prevalence of disease (25.1%) to people who visited dentist on regular visits (15.6%) (Australian Research Centre for Population Oral Health 2009). The disease prevalence is also noted to have direct correlation with socio-economic status. People in lower bracket had more active disease when compared to the higher socio-economic status. The contributing factors could be related to smoking, visits to the dentist, affordability to dental treatment which is meagre in people with low socio-economic status.

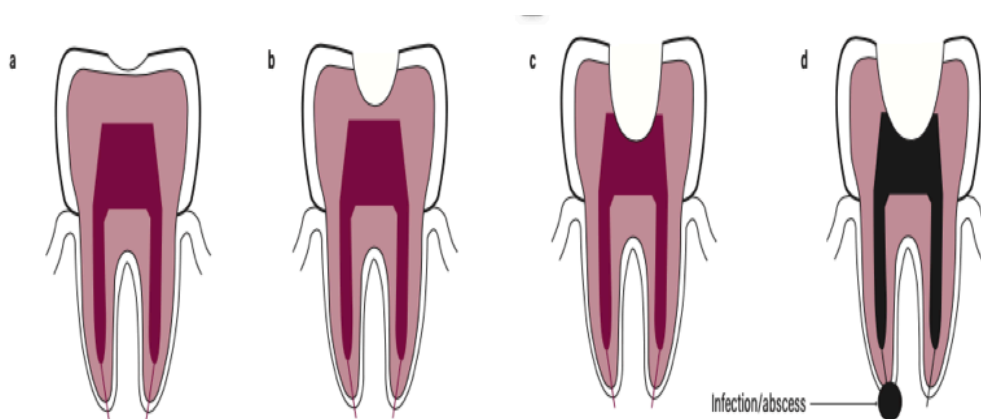
While globally, it has been noticed that there is steady decline in periodontitis, thereby decline in edentulism and increase in teeth retained among all age groups. Especially in United States and Sweden, periodontitis has declined in all age groups (Baelum et al., 2013).

## **1.3 Management**

### **1.3.1 Dental caries management**

With increasing life expectancy, it is expected to have more untreated caries in older population. Polypharmacy, medical co-morbidities and increased demand at aged care facilities have drawn lot more attention towards ageing population of the community. This calls for incorporating dental assessments as a part of routine general health check-ups that caries can be intervened in early stages. Use of silver diamine Fluoride (SDF) is effective measure to control root caries. Also high fluoride toothpaste is also effective in caries management in older population (Chan et al., 2021).

In addition in younger adults, forming a fluoride reservoir by maintaining low levels of fluoride in saliva and plaque reduces the demineralisation of the enamel and dentin tooth structure. Both fluoridated water and fluoride dentifrices play an important role in forming this intra-oral fluoride reservoir (Walsh 2000). Use of topical fluorides in the form of varnishes and gels have been more effective when applied professionally for two or more times in 12 months duration. This has shown a decline in carious teeth requiring treatment in the following year (Jurasic et al., 2022). Cochrane confirms through a meta-analysis that there is 46 % decline in caries rate in permanent dentition and 33% decline in caries rate in deciduous dentition with the help of in-office fluoride varnishes (Marinho et al., 2002). On the other hand, fluoride toothpastes shows reduced caries incidence of 24% in permanent dentition and 37% decline in deciduous dentition (Marinho et al., 2003). Duration of brushing for 2 minutes with fluoridated toothpaste, twice daily also directly correlates to the anti-cariogenic effect (Bradshaw et al., 2013).



- a. Early carious cavity into the enamel.
- b. Carious cavity extending into dentine. Slight pulpal inflammation.
- c. Carious cavity extending into pulp. Marked pulpal inflammation.  
Pulp has died away and become necrotic. Infection/abscess starting to form at the root.

Figure 4 : Progression of Dental Caries (Matthews 2022)

Diet and oral hygiene measures complement each other to prevent and manage dental caries in all age groups. Reducing dietary sugar intake has direct effect on caries reduction rate. Fluoride exposure on the other hand is the key to caries control. This can be achieved by recommending age appropriate Fluoride toothpaste and in cases of patient being high risk to dental caries, high concentration fluoride toothpaste can be recommended like Neutrafluor

5000plus (Evans et al., 2008). In case of xerostomia caused by salivary gland hypofunction, medication induced, head and neck radiation related or associated with systemic conditions like Sjogrens syndrome, in addition to high fluoride toothpaste, certain re-mineralising agents like Tooth mousse or Tooth mousse Plus (Casein Phosphopeptide-amorphous calcium phosphate CPP-ACP) are useful in re-mineralising early carious lesions. In addition, salivary substitutes, modification of diet like reducing alcohol and caffeine can alleviate xerostomia to considerable level (Dost & Farah 2013).

### **1.3.2 Periodontal disease management**

The management of periodontal disease is based on patient level factors, tooth level factors and tooth surface level factors. Patient level factors include attendance to dental clinic and compliance with regular visits, home care measures include oral hygiene measures using tooth brushes and floss. Tooth level factors and tooth surface level factors reflect the response of each tooth to the active periodontal treatment, clinical assessment of bleeding on probing, attachment loss and probing depth. Patients who had active periodontal treatment have shown that teeth lost due to periodontal reasons survived for more than 10years (Tan 2009) when properly maintained. In many parts of world, compromised host defences, limited access to dental care, inadequate supply of oral hygiene aids, compromised oral hygiene measures all correlate to periodontitis. Population based programmes creating awareness, oral health promotion are recommended (Kinane et al., 2017) to overcome this problem.

The periodontal treatment is categorised into two – non surgical and surgical treatment. The diagnosis has to be reached with clinical and radiographic findings. In non-surgical therapy, the combined effect of scaling and root planning along with good personal oral hygiene, has been proven to reduce the inflammation, thereby reducing pocket depth and clinical attachment. For better outcome, this is supplemented with antibiotics and antiseptic drugs, that can be localised or systemic. However, in patients with advanced periodontal disease, periodontal surgery is recommended to gain access to deeper pockets using grafting technique thereby reducing the accumulation of dental plaque and enhancing good oral hygiene.

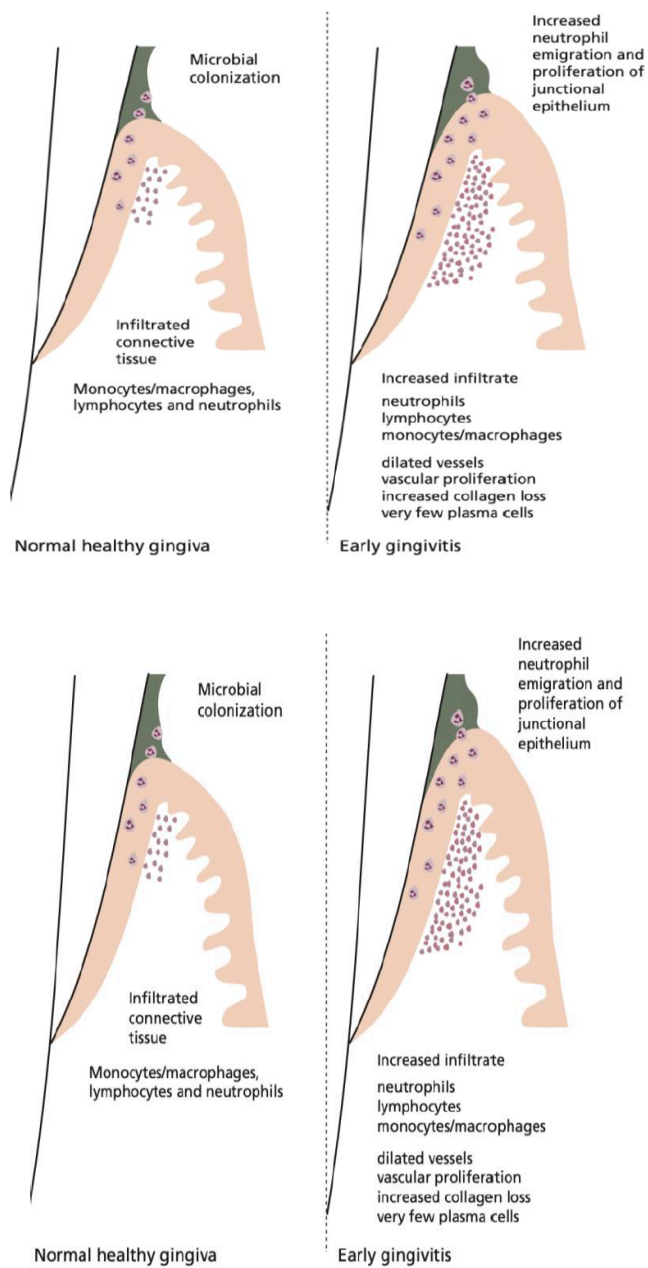


Figure 5 : Progression of Periodontal Disease. Lindhe et al., 2009.

### 1.3.3 Progression of dental infection

Both dental caries and periodontal infections if not treated in initial stages can favour growth of anaerobic bacteria in the dental pulp and periodontal pockets.

## **INTERRELATIONSHIPS OF PERIAPICAL INFECTION**

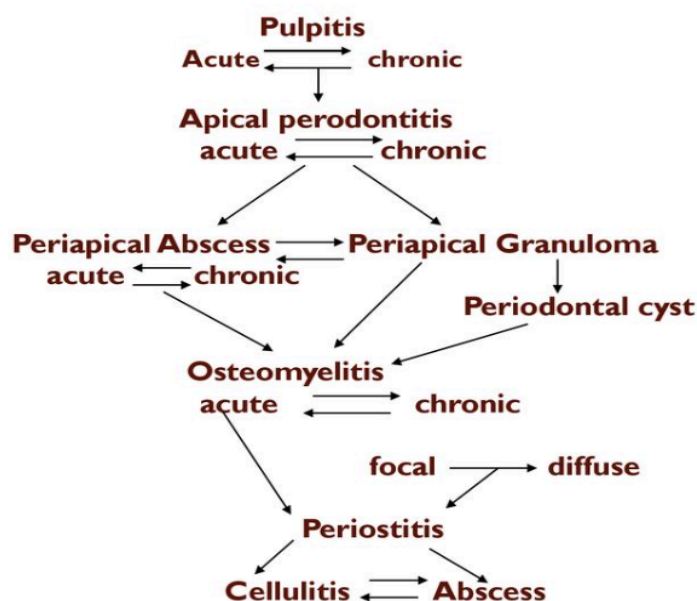


Figure 6: Progression of Periapical infection (Shafer et al., 2012)

The sequelae of infected pulp and periodontal pockets have caused acute and chronic dental infections. The process of infection starts at the apex of the tooth or in the localised area of the tooth. If left untreated, extends beyond the bone to the adjacent tissues. It can spread to the adjacent vestibule and present as localised abscess or to the facial spaces leading to more severe infections. Occasionally, it can travel to lymphatic routes and hematogenous routes presenting as systemic illness with fever, chills and severe nausea, vomiting and evident facial asymmetry with or without trismus. There is a shift of microbiological status in deeper infections that thrive on anaerobic gram -ve bacteria (Ogle 2017)

In cases of delayed presentation of dental infections, the dental infection spreads to deeper tissues risking airway obstruction that require intensive care admissions. These cases are usually treated by maxillofacial surgeons in hospital settings (Vytla et al., 2017).

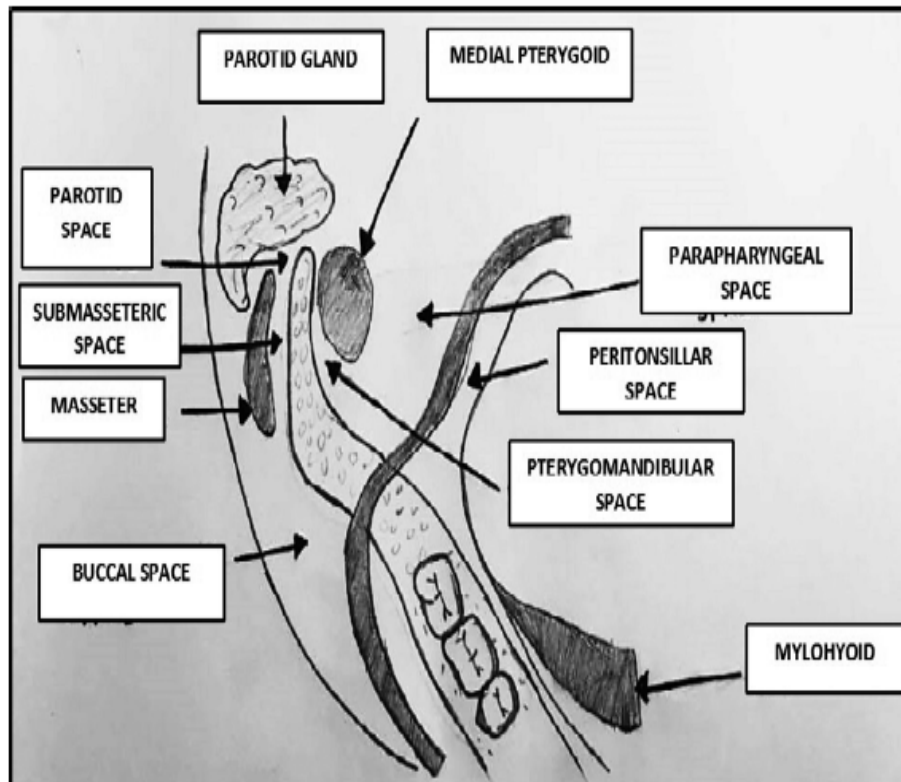


Figure 7 : Anatomical spaces Vytla et al., 2017

Complications that arise from long standing untreated odontogenic infections of either pulpal or periodontal origin can lead to mediastinitis, sepsis and eventually death. The causes can be due to complete dismissal to seek care by the patient or misdiagnosis and/or interim treatment with antibiotics by the clinician without eliminating the cause of infection.

Management of such cases require a thorough investigation that includes appropriate imaging with an OPG to confirm the offending tooth and CT to confirm the extend of the anatomical spaces involved. Surgical management always include extraction of offending tooth, incision and drainage of the abscess allowing decompression of infected deeper spaces. This is often supplemented with intra-venous administration of antibiotics based on culture sensitivity testing and analgesics for pain relief (Vytla et al., 2017).



<b>Common Dental Emergencies</b>				
<i>Diagnosis</i>	<i>Definition</i>	<i>Presentation</i>	<i>Complications</i>	<i>Treatment</i>
Reversible pulpitis	Pulpal inflammation	Pain with hot, cold, or sweet stimuli	Periapical abscess, cellulitis	Filling
Irreversible pulpitis	Pulpal inflammation	Spontaneous, poorly localized pain	Periapical abscess, cellulitis	RCT, extraction
Abscess	Localized bacterial infection	Localized pain and swelling	Cellulitis	I & D and RCT or extraction
Cellulitis	Diffuse soft tissue bacterial infection	Pain, erythema, and swelling	Regional spread	Antibiotics and RCT or extraction
Pericoronitis	Inflamed gum over partially erupted tooth	Pain, erythema, and swelling	Cellulitis	Irrigation, antibiotics if cellulitis also present
Tooth fracture	Broken tooth	Clinical examination and radiography	Pulpitis and sequelae	Fillings, with or without RCT, extraction
Tooth luxation	Loose tooth	Clinical examination and radiography	Aspiration, pulpitis, and sequelae	Splinting, with or without RCT, extraction
Tooth avulsion	Missing tooth	Clinical examination	Ankylosis, resorption	Reimplantation and splinting

*RCT = root canal therapy; I & D = incision and drainage.*

Figure 8 : Common Dental Emergencies and the treatment protocol (Douglass 2003).

## 1.4 References

- Australian Research Centre for Population Oral Health The University of Adelaide South Australia. (2009). Periodontal diseases in the Australian adult population. *Australian Dental Journal*, 54(4), 390–393.
- Baelum, V., & López, R. (2013). Periodontal disease epidemiology - learned and unlearned? *Periodontology 2000*, 62(1), 37–58.
- Bradshaw, D. J., & Lynch, R. J. M. (2013). Diet and the microbial aetiology of dental caries: new paradigms. *International Dental Journal*, 63(s2), 64–72.
- Chan, A. K. Y., Tamrakar, M., Chloe Meng Jiang, Lo, E. C. M., Leung, K. C. M., & Chu, C. H. (2021). A Systematic Review on Caries Status of Older Adults. *International Journal of Environmental Research and Public Health*, 18(20).
- Chapple, I. L. ., Bouchard, P., Cagetti, M. ., Campus, G., Carra, M.-C., Cocco, F., Nibali, L., Hujoel, P., Laine, M. ., Lingstrom, P., Manton, D. ., Montero, E., Pitts, N., Rangé, H., Schlueter, N., Teughels, W., Twetman, S., van Loveren, C., van der Weijden, F., ... Schulte, A. . (2017). Interaction of lifestyle, behaviour or systemic diseases with dental caries and periodontal diseases:: consensus report of group 2 of the joint EFP/ORCA workshop on the boundaries between caries and periodontal diseases. *Journal of Clinical Periodontology*, 44(S18), S39–S51.

- Cullinan, M.P., Ford, P.J., & Seymour, G.J. (2009). Periodontal disease and systemic health: current status: An update in contemporary periodontics. *Australian Dental Journal*, 54.
- Dentino, A., Lee, S., Mailhot, J., & Hefti, A. F. (2013). Principles of periodontology. *Periodontology 2000*, 61(1), 16–53.
- Dost, F., & Farah, C. (2013). Stimulating the discussion on saliva substitutes: a clinical perspective. *Australian Dental Journal*, 58(1), 11–17.
- Douglass, A. B., & Douglass, J. M. (2003). Common dental emergencies. *American Family Physician*, 67(3), 511-6.
- Evans, R., Pakdaman, A., Dennison, P., & Howe, E. (2008). The Caries Management System: an evidence-based preventive strategy for dental practitioners. Application for adults. *Australian Dental Journal*, 53(1), 83–92.
- Ha, D. H., Crocombe, L. A., Khan, S., & Do, L. G. (2021). The impact of different determinants on the dental caries experience of children living in Australia rural and urban areas. *Community Dentistry and Oral Epidemiology*, 49(4), 337–345.
- Jurasic, M. M., Gibson, G., Orner, M. B., Wehler, C. J., Jones, J. A., & Cabral, H. J. (2022). Topical Fluoride Effectiveness in High Caries Risk Adults. *Journal of Dental Research*, 101(8), 898–904.
- Kinane, D. F., Stathopoulou, P. G., & Papapanou, P. N. (2017). Periodontal diseases. *Nature Reviews. Disease Primers*, 3(1), 17038–17038.
- Lindhe J, Lang N, Karring T. *Clinical Periodontology and Implant Dentistry*. Hoboken: Wiley-Blackwell; 2009.
- Machiulskiene, V., Campus, G., Carvalho, J. C., Dige, I., Ekstrand, K. R., Jablonski-Momeni, A., Maltz, M., Manton, D. J., Martignon, S., Martinez-Mier, E. A., Pitts, N. B., Schulte, A. G., Splieth, C. H., Tenuta, L. M. A., Ferreira Zandona, A., & Nyvad, B. (2020). Terminology of Dental Caries and Dental Caries Management: Consensus Report of a Workshop Organized by ORCA and Cariology Research Group of IADR. *Caries Research*, 54(1), 7–14.
- Marinho, V. C., Higgins, J. P., Logan, S., & Sheiham, A. (2002). Fluoride varnishes for preventing dental caries in children and adolescents. *Cochrane Database of Systematic Reviews*, 3, CD002279

- Marinho, V. C., Higgins, J., Logan, S., Sheiham (deceased), A., & Marinho, V. C. (2003). Fluoride toothpastes for preventing dental caries in children and adolescents. *Cochrane Database of Systematic Reviews*, 2016(11), CD002278–CD002278.
- Marsh, P. D. (2016). Dental Biofilms in Health and Disease. *Understanding Dental Caries: 41-52*.
- Matthews, P. (2022). Prevention of dental caries in children and young people. *Nursing Children and Young People*.
- Australian Research Centre for Population Oral Health, The University of Adelaide (2011). Dental caries trends in Australian school children. *Australian Dental Journal*, 56(2), 227–230.
- Ogle, O. E. (2016). Odontogenic Infections. *The Dental Clinics of North America*, 61(2), 235–252.
- Selwitz, R. H., Ismail, A. I., & Pitts, N. B. (2007). Dental caries. *The Lancet (British Edition)*, 369(9555), 51–59.
- Tan, A. (2009). Periodontal maintenance. *Australian Dental Journal*, 54, S110–S117.
- Tatakis, D. N., & Kumar, P. S. (2005). Etiology and Pathogenesis of Periodontal Diseases. *The Dental Clinics of North America*, 49(3), 491–516.
- Vytla, S., & Gebauer, D. (2017). Clinical guideline for the management of odontogenic infections in the tertiary setting. *Australian Dental Journal*, 62(4), 464–470.
- Walsh, L. J. (2000). Preventive dentistry for the general dental practitioner. *Australian Dental Journal*, 45(2), 76–82.

## **Chapter 2: Literature review**

### **Dental caries and periodontal disease status in children and adolescents with cerebral palsy – a systematic review**

## 2.1 Introduction

Cerebral palsy is an intellectual disability (ID) that affects around 1.5 to 4 per 1000 live births (Wyne et al. 2017). In order to understand the disease pattern of dental caries and periodontal disease in ID, the focus is drawn in this systematic review on one particular ID – Cerebral Palsy and one particular age group – children and adolescents. It is also to understand the prevalence of dental caries and periodontal disease and their causative factors in CP children as discussed in the literature. This will further help with the M.Phil research topic to understand the reasons behind the occurrence of acute odontogenic infections in patients with ID in adult age group as it will be discussed in the later chapters of this thesis.

According to the most updated definition, cerebral palsy is *a group of permanent, but not unchanging, disorders of movement and/or posture and of motor function, that are non-progressive interference or abnormality of the developing/ immature brain* (Scully C, Cawson RA, 2005). Cerebral palsy is termed as based on the motor dysfunction (spastic, dyskinetic, ataxic) and the impairment related (hemiplegic, diplegic and quadriplegic). Most cases are spastic subtype (Dougherty, 2009).

Aetiology of cerebral palsy (CP) is complex as it remains undiagnosed until early childhood (Sadowska et al., 2020) For more than 100 years, it was believed that the vast majority of CP cases were related to infant brain hypoxia during labour or in the perinatal period, thus CP incidence was considered to be a measure of obstetric and neonatal care quality. The results of these investigations indicate that, contrary to the previous belief, perinatal pathology is of less importance in CP aetiology. Prenatal factors seem to be responsible for nearly 75%, whereas infant and neonatal period risk factors account for 10% to 18% of all CP cases (Sadowska et al., 2020).

In addition to compromised oral health, other medical conditions existing in CP patients are epilepsy, mental retardation, malnutrition and gastrointestinal complications, speech problems (Sadowska et al., 2020). To evaluate the severity of motor disorders in the course of CP, various scales are applied. One of the most common and easy- to-use is the GMFCS scale, developed by Palisano and his team (Palisano et al, 1997).

There has been numerous studies showing close correlation with increased caries rate and active periodontal disease along with compromised oral hygiene. Some studies in the past show that dental caries and periodontal disease is more in CP population whereas controversial to this statement, some papers have concluded the incidence is less when compared to patients with other disabilities like down syndrome.

The literature has numerous studies conducted on CP individuals analysing the association of caries and periodontal disease that has merged with age, sex, motor function, socio-economic status in one particular demographic area. There is no particular article in the literature that has focussed on various demographic scale in a larger spectrum.

### **2.1.1 Oral health in patients with cerebral palsy**

The stomatognathic region is one of the main systems affected by motor dysfunction in patients affected by CP, which is interrelated with an altered maxillary growth pattern, development of parafunctional habits, malnutrition and poor oral health status due to reduced compliance. As the limitations imposed by the disease, there is limitation in the maintenance of oral hygiene (Miamoto et al., 2010), individuals with CP are at greater risk of developing dental diseases that could be acute, chronic or acute exacerbation of chronic infection that has consequent negative impact on Oral Health and Quality of Life (OHQoL) (Bhowate and Dubey 2005; Santos et al., 2002).

### **2.1.2 Cause of dental disease in patients with cerebral palsy**

Patients with CP face challenging clinical settings for ongoing dental care. Inadequacy of masticatory system causes problems with mastication and problems associated with maintenance of proper oral care (Santos et al., 2010). This is further more complicated with intake of soft mushy diet, sweetened medication suspensions, food thickeners in patients with dysphagia and reduced dental visits for regular dental care. In a study by Santos et al in 2010, about 145 of children with CP were able to correlate with dentist, with 53% need special adaptation and over 33% required general anaesthetic. This data proves that more than half of population of patients with CP have reduced routine dental care when compared to individuals not affected by CP. Studies have also shown that the patients with CP present to the dentist

with acute dental condition that could appear as painful tooth. The problems are not only associated with insufficient care but also with unsuccessful care due to compliance issues. Therefore, the risk of caries and periodontal disease is increased and has a direct correlation although it is noted even in cases with hyper-salivation and totally nil by mouth (PEG fed). This poses a controversial thought.

## **2.2 Aim**

The aim of this study is to conduct a literature search and review of the published studies on the status of dental caries and periodontal disease in children and adolescents with CP. Further, aetiological factors and associated risk factors for prevalence of dental caries and periodontal disease in CP population are to be discussed, thereby directing the focus to optimise care in patients with CP.

## **2.3 Materials and methods**

### **2.3.1 Search Strategy**

A search was done for scientific articles published in journals listed in the following databases: PubMed, Medline, Cochrane Library and Embase until April 2022

The keywords were: “cerebral palsy”, “children”, adolescents”, “dental caries” and “periodontal disease”. The search in all databases was conducted using the following search strategy: ((cerebral palsy) AND ((children) OR (adolescents)) AND ((dental caries) OR (periodontal disease))).

### **2.3.2 Eligibility of studies/ Criteria for selecting articles**

The literature review was based on the PICO question “ what is the status of dental caries and periodontal disease in patients (children and adolescents) affected by CP.

P – Children and adolescents with CP.

I or C – Children and adolescents with no CP.

O- Expected to have more dental caries and periodontal disease in patients with CP.

Based on the PICO question, inclusion and exclusion criteria was developed.

Inclusion criteria were:

- The articles based on English from the year 2010 to current publications as this literature review focuses on more recent publications.
- Clinical studies involving children and adolescents with CP along with dental caries and periodontal disease.
- Risk factors causing dental caries and periodontal disease in CP patients.
- Articles including parents/carer perceptions that is based on evidence based data about dental disease that includes dental caries and periodontal disease.

Exclusion criteria, particularly those related to:

- Data published previous to 2010 as this literature review focuses on more recent publications.
- Non-English articles.
- Articles that had ID in general; not CP as main focus.
- Based on sialorrhea, bruxism and management in CP patients.
- Based on facial trauma, malocclusion, congenital deficits in CP patients.
- Studies that include treatment modalities for dental caries in CP patients.
- Articles based on parental and care givers reports with no evidence based data collection.
- Comparison of dental caries with CP and other ID
- Other systematic reviews and Retrospective studies to simplify the search.
- Letters to editor.

## **2.4 Study selection and data extraction**

Study selection was conducted by 1 reviewer (RJ) and in case of uncertainty another reviewer (VM) was consulted. The reviewer screened the title and abstracts, to determine if the inclusion criteria were met. Secondly, the full papers were analysed. Data were extracted in relation to the participant selection, comparability and outcome, in line with the requirements of the Newcastle Ottawa Study.



### **2.4.1 Assessment of the study quality**

The Newcastle Ottawa study (NOS) (Figure 9) is used in this study type to assess the quality of the articles chosen for this topic. The scores are based on:

- Selection that includes representation and selection of cohorts with exposure rate and the desired outcome unknown at the beginning of the study.
- Comparability of different cohorts groups.
- Outcome at the end of study based on follow up.

The NOS star rating assigns a star for each category with a maximum of nine stars in total. Low star rating as less as 5 is considered as of low quality, whereas NOS score of more than 5 is considered as high quality selection of the article.

### **2.4.2 Search outcome**

The search resulted in 426 records in total, leaving 133 for screening after the duplicate records and non-English records were removed. Records older than 2010 were excluded, leaving 65 records to be assessed for eligibility. After removal of records not related to the topic, parental/caregivers reports, records including other disabilities and systematic review, 18 studies were included in NOS score rating out of which 9 studies have been discussed in this literature review (Figure 10) as studies with low NOS star ratings were not included.

Articles Author and Year	Selection				Comparability	Outcome			Total
	Representative of exposed cohort	Selection of non- exposed cohort	Ascertain ment of exposure	Outcome was not known at the beginning of study		Assessment of the outcome	Follow- up of the cohort after the study	Adequacy of follow- up of cohort	
Castelo et al. 2022	*	*	*	*	*	-	-	-	5
Orsos et al. 2021	*	*	*	*	*	-	-	-	5
Kaushal et al 2021	*	*	*	*	*	-	-	-	5
Castelo et al. 2021	*	*	*	*	*	*	-	-	6
Aurahma et al. 2021	*	*	*	*	*	*	*	*	8
Sruthi KS et al. 2021	*	*	*	*	*	-	*	*	7
Ahmad et al. 2020	*	-	*	*	-	*	-	-	4
Cardoso et al. 2018	*	-	*	*	-	-	-	-	3
Sedky NA. 2018	*	*	*	*	*	-	-	-	5
Rodriguez et al.2018	*	*	*	*	*	-	-	-	5
Hashmi et al. 2017	*	*	*	*	*	*	-	-	6
Wyne at al. 2017	*	-	*	*	*	*	-	*	5
Akhter et al. 2017	*	*	*	*	*	-	*	*	7
Sinha et al. 2015	*	*	*	*	*	*	-	-	6
Cardoso et al. 2014	*	-	*	*	-	*	-	-	5

Figure 9 : Newcastle Ottawa Study.

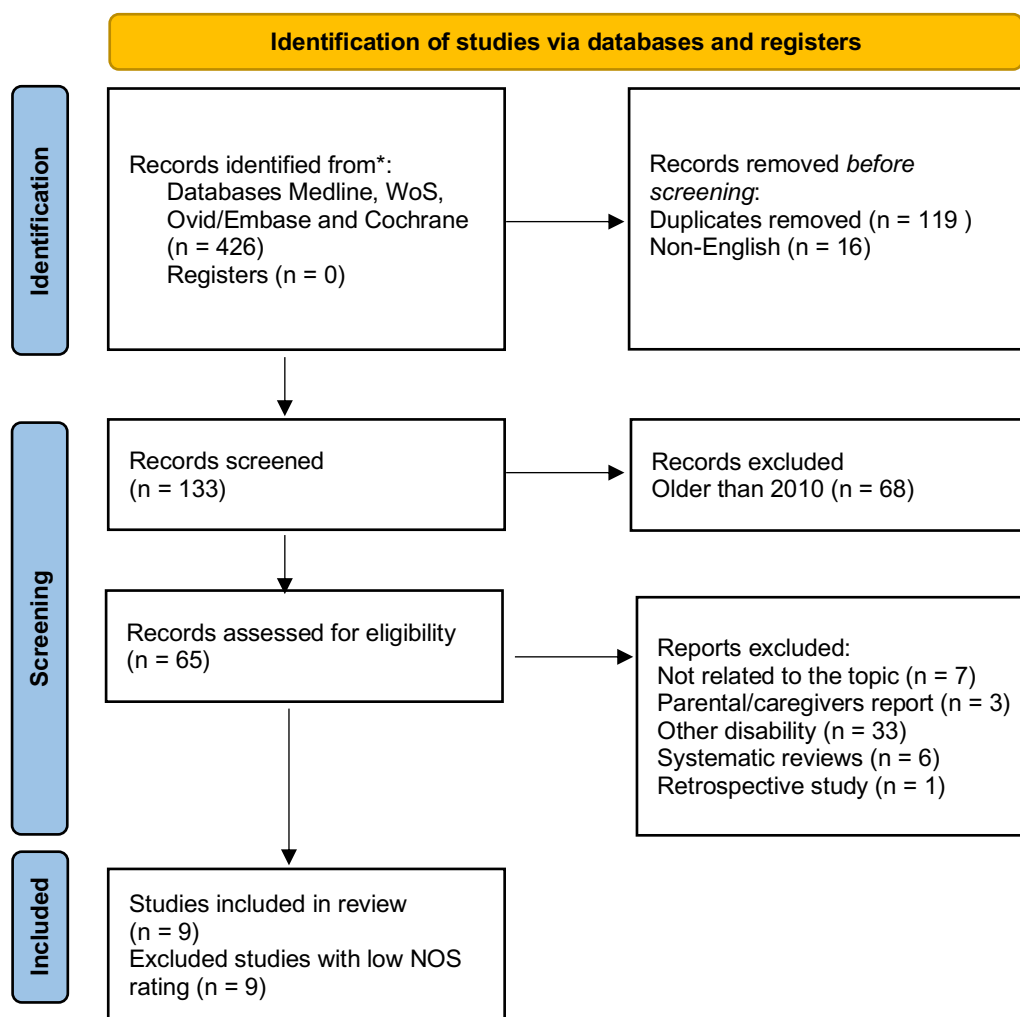


Figure 10. PRISMA 2020 flow diagram.

## 2.5 Results

Out of 9 articles discussed in this literature review, 6 articles discuss about prevalence of both dental caries either by DMFT(defect), ICDAS, CAMBRA and periodontal disease by Gingival index, plaque index or reported bleeding on probing. Only three articles have narrowed their research on dental caries status only. The age groups varied from 1.5 years to 18 years of age with majority of the studies focussing on children from 6 to 14years. The comparison has been consistent in all 9 articles i.e. between two groups – children and adolescents with CP and the other group being children and adolescents with no CP or termed as Normoactive children in some articles.

Five out of six articles confirm the prevalence of dental caries more in CP group. More specifically, the mean DMFT in CP children was higher when compared to non-CP children (Kushal et al., 2021). The treatment need also has been shown to be high in CP children with restorations and extractions (Castelo et al., 2022). In another study that was conducted on a large group of population of around 300 children (Sruthi et al., 2021), mean dmft was higher in CP children when compared to non-CP children. On contrary, an article by Castelo Branco in 2021 confirms the prevalence of dental caries was more in children with no CP. The main reason being the diet as a risk factor. This article draws attention to diet patterns in non-CP children with frequent snacking while it was less reported in CP children.

All the six articles confirm the presence of more gingivitis, periodontal disease in CP children. In the article by Osros et al., 2021, the prevalence of dental disease was compared with GMFCS score. It was confirmed that the dental disease especially gingivitis was prevalent in patients with GMFCS IV and V especially around incisors and mandibular canines when compared to GMFCS II and III.

## **2.6 Discussion**

Number of reasons have been discussed in the articles of interest out of which the reasons can be categorised as systemic, local and social reasons. The systemic reasons are, the presence of mental health issues, developmental delays, systemic conditions like GERD have been identified (Castelo Barncó et al., 2022). One of the main factors that is noted is, majority of these patients are on anti-convulsant oral syrups that are sweetened, in turn increases the dental caries risks in patients with CP combined with epilepsy.

There are various local factors contributing to the prevalence of the disease are the position of the tongue, reduced salivary flow, mouth breathing habit, presence of visible thick biofilm (Castelo Barncó et al., 2021), crowding of teeth is also noted in patients with CP. The social factors mainly depend upon the caregivers knowledge and interest.

Difficulty in maintaining oral hygiene compounded by dependency on carers for tooth brushing, disrupted sleep pattern due to dental pain and inability to express pain along with low socio-economic condition were also noted by some authors. All these contribute to poor

OHQoL in CP children when compared to healthy children (Sruthi et al. 2021). Many of the studies have shown that the prevalence of dental caries and periodontal disease is directly related to the education level of the primary care givers and the socio-economic status of the patient (Castelo Barnco et al., 2021). It is of benefit if there is a good relationship between the primary care givers and dentist, to understand the burden of primary carers in order to manage these patients (Santos et al., 2010). A personal or customised oral hygiene plan will benefit the families and patients with CP that focusses on the oral hygiene measures along with suggestions on oral hygiene aids like mouth props, floss holders, modified toothbrushes to accommodate the disability (Akhter et al., 2017). While formulating the plan, often consideration must be given to the local community water fluoridation as it plays an important role in caries incidence during initial stages of tooth developmental.

When treatment choices are considered, majority of CP patients may not be compliant for normal settings. In such cases, treatment modalities must be extended to general anaesthesia, IV sedation, relative analgesia and oral sedation. When such extensive treatment modalities are considered, there must be consideration not only for comprehensive care but also to formulate regular recalls including, revisiting the customised oral hygiene plan, professional topical application of F1, educating the primary care givers about their role in establishing OHQoL and mainly continuing to keep the bond between the healthcare professional, primary care giver and the patient (Santos et al., 2010).

The first study in the area of interest for this systematic review is Brazil based study by Castelo et al., 2022. As a paired cross-sectional study, this had 121 children and adolescents diagnosed with CP and 121 without CP between the age 6 to 14yrs. As this remains as inclusion criteria, the exclusion criteria was based on few factors like, individuals with fixed orthodontic appliance, who had unerupted first permanent molar, non-compliant to oral examination and care-givers of less time duration. Caries experience with CP was measured as median 9 (range 0-23) and without CP was with median 5 (range 0-28) using bivariate analysis. There was a higher need for teeth that require restorations of more than 2 surfaces in individuals with CP. The consequences of untreated caries resulting in pulp exposure and fistula formation was also higher in CP individuals than without CP. Pulp involvement was median of 8 (range 0-16), fistula formation was with median 11 (range 4-18) when compared to individuals without CP

: pulp involvement median 5 (range 1-20) and fistula formation of median 5.5 (range 2-16). The treatment need was also noted to be high in children with CP, requiring more of three surface restorations, pulp exposures requiring extractions that is consistent with the prevalence of dental caries. The presence of more *S.mutans* and increased indices (DMFS, def-t, GI) and treatment needs all indicate the presence of caries and periodontal disease in children with CP.

In a Hungarian based study conducted by Osros et al., 2021, the caries prevalence and gingivitis was carried out based on GMFCS (Gross Motor Function Classification System) score. The study had 199 participants with mean (SD) age of 9.06 (+/- 3.69). 149 children were from a conductive Practice School and 50 from a school with normal group. The children without motor dysfunction were in two groups and the children with CP were categorised into 5 groups based on GMFS score. It was noted that the children categorised in GMFCS score II and III had more dft and DMFT score with score of 3.00 and 2.42 (df-t) and 2.00 and 1.68 (DMFT) respectively. The restorative index was more in permanent teeth with 27% than in primary teeth of 18.12%. The gingivitis was also high with score of 66.7% in groups with GMFCS IV and V and was more prevalent on all incisors and mandibular canines (above 31%).

A study conducted in India, New Delhi in a tertiary hospital with CP patients conducted by Kushal et al., 2021, had 104 participants, 52 were CP children (case group) and 52 with no CP (control group) with age group of 6-14years. The mean age in case group was 7.03+/-1.57 with majority of males than females. The control group mean age was 55.8% with majority females than males. The initial data collection was based on OHI index, DMFS/defs, Gingival Index (GI). In addition trauma and malocclusion was also recorded for the study purpose. After the initial assessment of the indices, unstimulated salivary samples were collected and sent for microbiological study of *S.mutans*. The salivary samples showed increased *S.mutans* in case group (CP) and was found corresponding to the higher level of DMFS index. The mean DMFS in case group was 1.08+/- 3.16 and control group was 0.14+/-0.76 which shows the caries prevalence being higher in CP children with permanent dentition. The mean defs score was 8.06+/-14.22 in case group and 4.50+/-7.11 in control group indicating the increased prevalence of caries in children with CP with deciduous dentition. The GI index with mean of 1.14 +/- 1.45 in case group was higher when compared to the control group with comparatively low GI index of 7.07 +/- 0.54.

Another study performed by Castelo Branco and his co-authors in 2021, on Brazilian children showed a contradictory outcome. In this cross-sectional comparative study, there were 60 children and adolescents of age group 6-12 years (8.3+/-2.0) and were categorized as CP group (case group) and normoactive (NA) group (control group). There were 30 each in case and control group were paired by gender and age. The dental caries prevalence was compared with International Caries Detection and Assessment System (ICDAS) and the caries risk was assessed by Caries Management by Risk Assessment (CAMBRA) between two groups. In terms of ICDAS codes 5 and 6 (visible cavities in dentine) and ICDAS codes 1 and 2 (active white spots on smooth surface) were considered in addition to restorations performed in the last 3 years along with deep pit and fissures. In primary dentition, there was greater prevalence of ICDAS code 6 in CP children (49.3%) when compared to NA children (41.1%). In permanent dentition, the highest prevalence of ICDAS 2 code was in NA children (64.1%) when compared to CP children (49.8%). This is followed by high prevalence of ICDAS code 1 in NA children (18.3%) and ICDAS code 6 in CP children (38.4%). As per CAMBRA, white spots on smooth surface were more observed in both populations (100% in NA and 93.3% in CP children). The most common risk factor was frequent snacking (93.3% in NA and 90% in CP) and the most common protective factor was F1 toothpaste used twice daily (96.7% in NA and 86.7% in CP).

A comparative cross-sectional study in Jordan by Aburahma et al., 2021, aims at understanding the oral health status and oral hygiene in children with CP to healthy children. This study comprise of 83 CP children and 84 healthy children with age range of 1.5 to 11 years and most of the chosen study participants were less than 6 years of age (mean age 4.9 years); included in this study is a questionnaire for families or caregivers followed by dental exam. Children with CP were dependant on caregivers for oral hygiene measures. Oral hygiene screening was based on Plaque Index, Gingival Index, Sulcus Bleeding Index, Gingival Enlargement Index and Pocket Depth. There was no major difference in dmft scores (CP-3.5 as mean and non-CP was 3.2 as mean) and DMFT scores (CP-0.4% as mean and non-CP- 0.6% as mean) between two age groups. GI was slightly higher in CP group with mean of 0.6 when compared to non-CP with a mean of 0.3. The Pocket depth was sightly high in CP of 1.4 as mean and 1.3 as in non-CP. Regarding oral hygiene practices, CP group reported 58% of no brushing opposed to

non-CP with 25%. In contradiction, CP children had dental visits when compared to non-CP children who did not had the first dental appointment (71%). However, CP children were more likely to seek emergency dental care when compared to non-CP (50% and 29% respectively).

A cross-sectional comparative study conducted in the city of Bangalore, India by Sruthi and her coordinates in 2021, focuses the oral health status and parental perception by comparing between CP and healthy children. This study included 300 children aged 5-15years were categorised as 150 children with CP gender-matched with healthy 150 comparison children. The participants were selected from four special schools and four regular schools on a random basis. The mean caries experience of primary and permanent dentition in CP group was higher when compared to healthy children. The mean dmft in CP children was noted as 2.64 (+/- 3.05) whereas in the healthy group was 1.81 (+/-2.54). The mean DMFT in CP children was 1.86 (+/-2.07) and in healthy group was 1.26 (+/-1.98). Gingivitis was also higher in CP children when compared to healthy children (n=121 in CP and 91 in healthy children).

A Malaysian study by Ahmad et al., in 2019, recruited 93 CP children with a mean age of 12 years, majority of boys (54.8%) than girls (45.2%) for assessment of oral health and nutritional status of the CP population. Approximately, 61.3% of the children with CP had atleast one dental visit in a lifetime. The dietary analysis that was a part of the study showed that the consumption of sugary drinks was higher when compared to other cariogenic food. This information was gathered by face-to-face 24-hour diet recall interview given by the primary care givers. The DMFT/dft score was 0.5- 3.0 as median respectively. The prevalence of caries was noted to be as 81.7% whereas the dental plaque was noted in all 93 participants with majority being mature and acid producing type. All these indicate that the CP children are at moderate risk of caries to develop.

In 2018, Cardoso et al., in his research cross-sectional study, 182 Brazilian children and adolescents were included from the northeast part of Brazil. This study not only discusses the presence of dental caries and periodontal disease but also its implications in OHRQoL (Oral Health Related Quality of Life). The criteria was based on children and adolescents diagnosed with CP, aged 2 to 18years. The HRQoL (Health Related Quality of Life) was discussed based on demographic and socio-economic data that was collected. The type of CP was also obtained



from the medical records. There was a sample loss of around 33 patients out of 182. The findings were not surprising where the prevalence of dental caries was 50.3% and periodontal disease was 84.2%. The impact of dental caries on OHRQoL was 21.6%, affecting females (19.7%) and posterior teeth were affected slightly more than anterior teeth. The periodontal disease remain low around 13.7%. There was reported bleeding with tooth brushing and was considered in association with periodontal disease and reported frequently by caregivers (46%).

In the cross-sectional study conducted by Sedky NA, 2018, in a Hospital for children, Alexandria, Egypt, draws main focus on children only between the age 3 to 12 years, with spastic quadriplegic as mainstream CP population. 62 children were examined out of which 61.35 were boys and 38.75 were girls. The findings were correlating to other research studies. The caries prevalence was 54.8% with more caries noted in mandibular posteriors (85.3%) and maxillary posteriors (73.5%). There was significant poor oral hygiene amongst children of around 53.2% prevalent with the age groups of 7-10 years with severe gingival inflammation of 57.7%. This was in correspondence with lack of oral hygiene maintenance in patients with CP.

## **2.7 Conclusion**

As we discuss the findings of 9 articles that focussed on CP patients in with research performed in different parts of the world, it is stated in majority of articles that the prevalence of dental caries and periodontal disease is high in CP patients. Majority of articles confirm that the caries prevalence is high in CP patients when compared to non-CP patients either with DMFT/dft score, ICDAS and/or CAMBRA studies. The PI score and GI score has been shown higher in CP patients when compared to non-CP patients along with BOP being positive.

All these indicate that the dental caries and periodontal disease is more in CP patients thereby supporting the need to continue with my research topic of analysing the referral reasons with acute odontogenic infections in patients with intellectual disability.

## 2.8 References

- Aburahma, S. K., Mhanna, A., Al-Mousa, S., Al-Nusair, J., & Al Habashneh, R. (2021). Dental health status and hygiene in children with cerebral palsy: A matched case-control study. *International Journal of Paediatric Dentistry*, 31(6), 752–759.
- Ahmad, R., Rahman, N. A., Hasan, R., Yaacob, N. S., & Ali, S. H. (2020). Oral health and nutritional status of children with cerebral palsy in north-eastern peninsular Malaysia. *Special Care in Dentistry*, 40(1), 62–70.
- Akhter, R., Hassan, N. M. M., Martin, E. F., Muhit, M., Haque, M. R., Smithers-Sheedy, H., Jones, C., Badawi, N., & Khandaker, G. (2017). Risk factors for dental caries among children with cerebral palsy in a low-resource setting. *Developmental Medicine and Child Neurology*, 59(5), 538–543.
- Al Hashmi, H., Kowash, M., Hassan, A., & Al Halabi, M. (2017). Oral health status among children with cerebral palsy in Dubai, United Arab Emirates. *Journal of International Society of Preventive and Community Dentistry*, 7(9), S149–S154.
- Bhowate, R., & Dubey, A. (2005). Dentofacial changes and oral health status in mentally challenged children. *Journal of the Indian Society of Pedodontics and Preventive Dentistry*, 23(2), 71–73.
- Cardoso, A. M. R., Gomes, L. N., Silva, C. R. D., Soares, R. de S. C., de Abreu, M. H. N. G., Padilha, W. W. N., & Cavalcanti, A. L. (2015). Dental Caries and Periodontal Disease in Brazilian Children and Adolescents with Cerebral Palsy. *International Journal of Environmental Research and Public Health*, 12(1), 335–353.
- Cardoso, A. M. R., Medeiros, M. M. D., Gomes, L. N., Martins, M. L., Padilha, W. W. N., & Cavalcanti, A. L. (2018). Factors associated with health and oral health-related quality of life of children and adolescents with cerebral palsy. *Special Care in Dentistry*, 38(4), 216–226.
- Castelo Branco, C. M. C., Cabral, G. M. P., Castro, A. M. G. S., Ferreira, A. C. F. M., Bonacina, C. F., Lussi, A., Santos, M. T. B. R., & Diniz, M. B. (2021). Caries prevalence using ICDAS visual criteria and risk assessment in children and adolescents with cerebral palsy: A comparative study. *Special Care in Dentistry*, 41(6), 688–699.
- de Castelo Branco Araújo, T., Nogueira, B. R., Mendes, R. F., & Júnior, R. R. P. (2022). Oral health-related quality of life in children and adolescents with cerebral palsy: paired cross-sectional study. *European Archives of Paediatric Dentistry*, 23(3), 391–398.

- Dougherty, N. J. (2009). A Review of Cerebral Palsy for the Oral Health Professional. *The Dental Clinics of North America*, 53(2), 329–338.
- Jones, M. W., Morgan, E., Shelton, J. E., & Thorogood, C. (2007). Cerebral Palsy: Introduction and Diagnosis (Part I). *Journal of Paediatric Health Care*, 21(3), 146–152.
- Kaushal, D., Kalra, N., Khatri, A., Tyagi, R., Singh, N., Aggarwal, A., & Saha, R. (2021). Oral health status and microbial load of *Streptococcus mutans* in children with Cerebral palsy in a tertiary care hospital in Delhi. *Journal of the Indian Society of Pedodontics and Preventive Dentistry*, 39(2), 214–220.
- Luana Leal Roberto, Mariana Gomes Machado, Vera Lúcia Silva Resende, Lia Silva Castilho, & Mauro Henrique Nogueira Guimarães de Abreu. (2012). Factors associated with dental caries in the primary dentition of children with cerebral palsy. *Brazilian Oral Research*, 26(5), 471–477.
- Miamoto, C. B., Ramos-Jorge, M. L., Pereira, L. J., Paiva, S. M., Pordeus, I. A., & Marques, L. S. (2010). Severity of malocclusion in patients with cerebral palsy: Determinant factors. *American Journal of Orthodontics and Dentofacial Orthopedics*, 138(4), 394.e1–394.e5.
- N. Sedky; Assessment of oral and dental health status in children with cerebral palsy: An exploratory study; *Int Journal of Health Sciences* 2018; Vol 12 (1).
- Orsós, M., Antal, D., Veres, D., Nagy, K., & Németh, O. (2021). Oral Health, Dental Care and Nutritional Habits of Children with Cerebral Palsy during Conductive Education. *The Journal of Clinical Paediatric Dentistry*, 45(4), 239–246.
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology*, 39(4), 214–223.
- Rodríguez, J. P. L., Ayala-Herrera, J. L., Muñoz-Gomez, N., Martínez-Martínez, R. E., Santos-Díaz, M. A., Olvera-Delgado, J. H., & Loyola-Leyva, A. (2018). Dental Decay and Oral Findings in Children and Adolescents Affected by Different Types of Cerebral Palsy: A Comparative Study. *The Journal of Clinical Paediatric Dentistry*, 42(1), 62–66.
- Sadowska, M., Sarecka-Hujar, B., & Kopyta, I. (2020). Cerebral Palsy: Current Opinions on Definition, Epidemiology, Risk Factors, Classification and Treatment Options. *Neuropsychiatric Disease and Treatment*, 16, 1505–1518.

- Scully C, Rawson RA, Neurological disorders I: Epilepsy, stroke and craniofacial neuropathies. In : Medical Problems in Dentistry. 5<sup>th</sup> ed. Elsevier: Churchill Livingstone; 2005. p. 297-8.
- Santos, M. T. B. R., Biancardi, M., Guare, R. O., & Jardim, J. R. (2010). Caries prevalence in patients with cerebral palsy and the burden of caring for them. *Special Care in Dentistry*, 30(5), 206–210.
- Sinha, N., Singh, B., Chhabra, K. G., & Patil, S. (2015). Comparison of oral health status between children with cerebral palsy and normal children in India: A case-control study. *Journal of Indian Society of Periodontology*, 19(1), 78–82.
- Sruthi, K., Yashoda, R., & Puranik, M. P. (2021). Oral health status and parental perception of child oral health-related quality of life among children with cerebral palsy in Bangalore city: A cross-sectional study. *Special Care in Dentistry*, 41(3), 340–348.
- Stang, A. (2010). Critical evaluation of the Newcastle-Ottawa scale for the assessment of the quality of nonrandomized studies in meta-analyses. *European Journal of Epidemiology*, 25(9), 603–605.
- Wyne, A. H., Al-Hammad, N. S., & Splieth, C. H. (2017). Dental caries and related risk factors in Saudi cerebral palsy children. *Neurosciences (Riyadh, Saudi Arabia)*, 22(4), 282–286.

## **Chapter 3**

### **Dental treatment in patients with intellectual disability**

## **3.1 Introduction**

### **3.1.1 Definition**

Developmental disabilities are defined as:

*A group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime (CDC&P).*

Intellectual disability (ID), formerly termed “mental retardation,” is defined by the American Academy of Intellectual and Developmental Disabilities (AIDD) as: *a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. (AIDD)*

People with ID require extreme care with their physical health and mental health. Oral health is basically dependant on awareness of the need of severity of the disease, aetiology, coping mechanisms and residential arrangements of the individual (Raj, et al., 2015). In patients with ID, it is important to understand the diagnosis of the medical condition, its medical and dental implications to improve the OHQoL. By working in a holistic approach, a greater success of the dental treatment is achieved.

## **3.2 Biopsychosocial Model**

There are various models that can be adapted and the most effective one is the Biopsychosocial Model (Nelson et al., 2019). In this approach, in order to classify disability, WHO has developed International Classification of Functioning, Disability and health (ICF). It is a health classification system that utilises information from body, individual and the social factors (Petrovic et al., 2011). It is to understand the health and function of the individual in addition to social, environmental and personal situations that determines the success of the dental treatment.

Rosenbaum and Gorter, (2012) adapted this on children with disability with “F-words”.

Example of the adaptation of ICF table as per Rosenbaum and Gorter is as below:

“F-word”	ICF
Function	Activity Participation
Family	Environment
Fitness	Body structure and function
Fun	Personal factors
Friends	Personal factors Participation

Table 2 : Rosenbaum & Gorter F-words (2012)

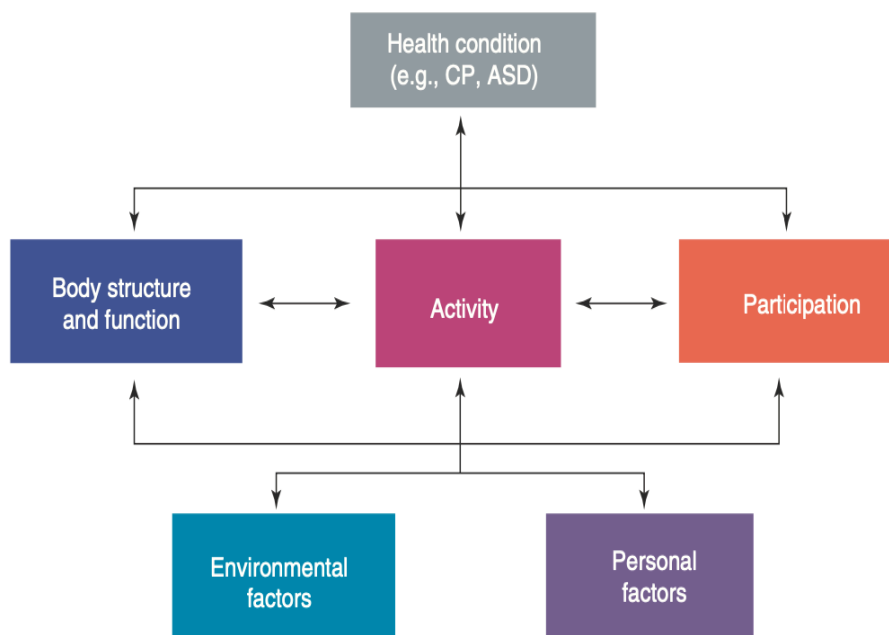


Figure 11 : Rosenberg & Gorter adaption of the ICF (WHO 2001)

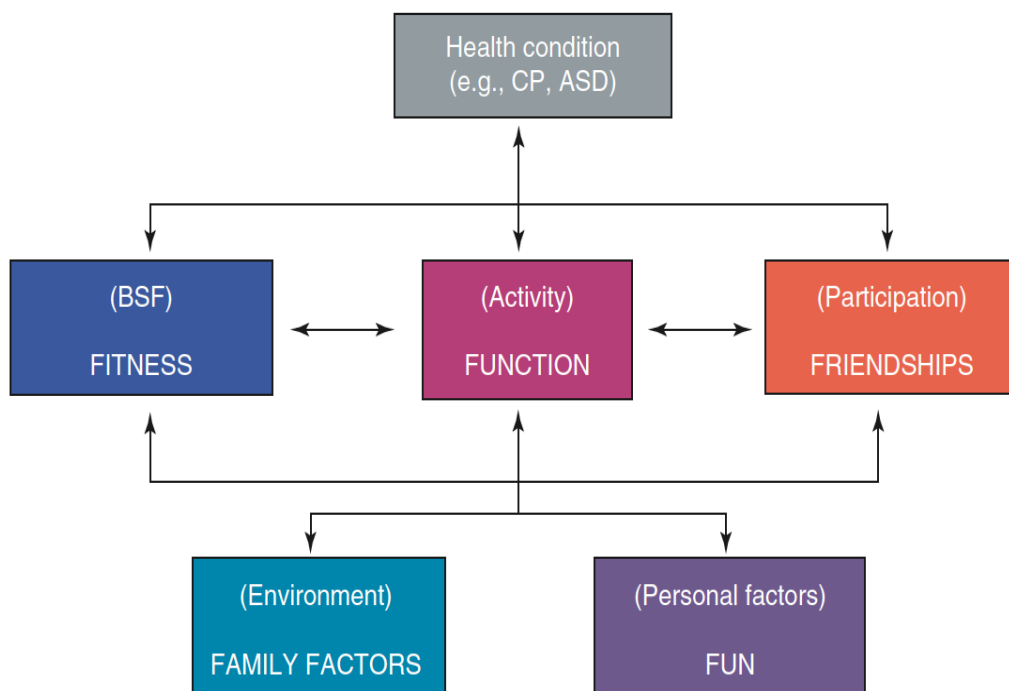


Figure 12 : Rosenbaum & Gorter adaption of ICF (2012).

### 3.3 Challenges in treating patients with intellectual disability

#### 3.3.1 Barriers in providing dental care

Barriers for dental care varies starting from financial barriers, physical barriers and lack of enough healthcare providers to work for ID patients. One of the main barriers in providing treatment for patients with ID is the lack of knowledge, experience and confidence among dental health professionals in Australia. In this approach, in order to classify disability, WHO has developed International Classification of Functioning, Disability and health (ICF). It is a health classification system that utilises information from body, individual and the social factors (Petrovic et al., 2011). The study included 27 clinicians working in four different government funded dental services to take part in research by answering a questionnaire. The main concerns focussed were, lack of confidence in treating the patients with ID and the lack of support provided to them by the health system they worked in. Another barrier that was mentioned was the lack of time and pressure of productivity from the employers (Lim et al., 2021).



Lack of access to the specialist services has also been drawn as one of the main barriers for meeting the oral care demands in patients with ID (Balkaran et al., 2022). Also there is a need to have consistent and experienced team who can respond to the needs of this special sect of population has been a major setback in treating patients with ID.

### **3.3.2 Transition from adolescence to adult dental care**

Transition with time and age of the patient to adult services, does not limit with finding an adult healthcare provider, but also extends to develop an individual the ability to care for him/herself. The goal is to help an individual to continue uninterrupted services from adolescence to adulthood (Mikkelson et al., 2022)

Transition is a difficult phenomenon for children with ID transiting to adult services. Changing of providers, ineligibility to have treatment in hospital settings due to lack of health care card or reimbursement services, longer waiting times in adult services, lack of staff time for transition to take place by handover from one team to the other are the major setbacks in patients with ID having timely treatment (Nowak et al., 2010).

### **3.3.3 Establishing effective communication**

As with patients with ID, there are more needs for an adaption of modified communication style. Communication can be verbal, non-verbal including sign language, facial expressions and gestures. As with the considerable variation in communication, patients with ID are most often not able to clearly express dental pain or discomfort in terms of symptoms, duration of discomfort, resulting in presentation to the dentist with visible and obvious signs of infection. In order to establish communication, sensitivity to patient's intellectual state and compliance must be recognised by the dental team (Espinoza et al., 2016). FRAME mnemonic help the providers in addressing the communication needs of the patients. This was developed by speech pathologists at the University of Washington, Dept of Rehabilitation Medicine.

### **The FRAME framework**

Each letter in the FRAME framework represents a key strategy across a range of communication disorders (Table 3). It helps in establishing communication with ID patients.

F	Familiarize	Figure out how the patient best communicates before proceeding with the appointment. This process may involve becoming familiar with existing strategies or establishing new strategies
R	Reduce rate	Reduce your speaking rate and ask 1 thing at a time to lessen the communication burden on the patient. Allow extra time for the patient to respond
A	Assist with message construction	Acknowledge what information you have understood from the patient, agree on how to resolve communication breakdowns. Actively assist the patient with communication
M	Mix communication modalities	Incorporate different ways of communicating, such as writing, drawing, gestures, pictures, and eye gaze, to help patients improve both understanding and expression
E	Engage the patient	Engage the patient directly. Use family or caregivers as interpreters when needed. Keep your focus on interacting with the patient to respect the patient's autonomy

Table 3 : FRAME framework. Espinoza & Heaton (2016).

### Communication triad

Establishing a good communication with ID patients involves three individuals: the dental provider, the patient and the primary care giver.

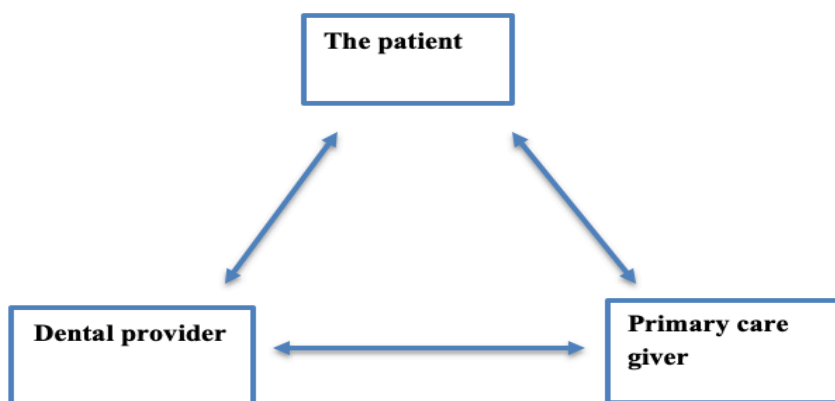


Figure 13: Communication triad

#### 3.3.4 Accessibility to the dental offices

Adopting universal design while designing a dental office to incorporate patient needs is the main challenge in treating patients with ID. Not all dental offices have enough space to

accommodate wheel chairs, diaco bays, ramped curbs at the entry where not only patients with ID but also patients with physical disabilities can be seen. This problem is more faced in urban areas with limited space available for dental offices.



Figure 14: Diaco Bay in a dental office (Lakshmi et al., 2020)

Some of the universal designs that can be include in designing the dental offices are (Nelson et al., 2019):

- Installation of lever handles to reduce dexterity to use.
- Large print and understanding audio and written messages.
- Adjustable volume and light to accommodate sensory sensitivities.
- Restrooms to have disability access.

### **3.4 Dental pain management in patients with intellectual disability**

Patients with ID have medical co-morbidities, defensive behavior, physical limitations that has a direct impact on attempting to examine, diagnose and provide dental treatment. Utilization of The Dental Discomfort Questionnaire (DDQ) helps in monitoring and scoring behaviors related to toothache and pain (Versloot et al., 2006; Maeda et al., 2005). Each question is to be answered from a score of 0 as assigned for “never,” 1 for “sometimes,” and 2 for “always.” Thus, the final score could vary from 0 to 24. It is a descriptive questionnaire to assess the presence of dental pain for both dental professionals and the carers.

In order to decide the treatment modality, it is very important to determine or diagnose the dental pain. As with lack of communication and inability to express, patients with ID misrepresent or get misdiagnosed for behavioral or psychotic problem. It is always ‘a miss’ to relate the change in behavior to be dental related discomfort as patients with ID express pain in atypical pattern. Change in behavior, sleep pattern and refusing to eat or brush teeth must alert the primary care giver to check the possibility of having dental pain.

When managing a patient with ID, it is important to understand baseline behaviour compared to recent changes as reported by the carer. A thorough history taking along with updated medication list is very important. Based on the information gathered, treatment can be provided by non-pharmacological and pharmacological methods. These can be grouped as:

- Communicative management
  - Tell-Show-Do
  - Voice control
  - Positive reinforcement
  - Distraction
- Relative analgesia (RA)
- Conscious sedation
- General anaesthesia

When deciding the behavior management techniques, an order of least restrictive and most effective must be followed. Individual treatment goals must be focused in choosing the treatment modality and the treatment outcomes (Compton et al., 2016).

1	Crying during meals
2	Reaching for the cheek while eating
3	Puts away something nice to eat
4	Crying at night
5	Chewing at one side
6	Problems chewing
7	Bites with molar instead of front teeth
8	Earache at daytime
9	Earache at night
10	Earache during eating
11	Problems with brushing lower teeth
12	Problems with brushing upper teeth

Figure 15 : The Dental Discomfort Questionnaire (DDQ)

### **3.5 Treatment modalities for patients with intellectual disability**

#### **3.5.1 Treatment with 50% nitrous oxide/oxygen for outpatient dental treatment**

It is considered as difficult in providing treatment for patients with ID as an outpatient or for chair side procedure, the risk being aggravation of existing behavioral problems, non-compliance during the treatment. Although treatment under RA has been proven to be successful being mild with rapid onset, reversible and little or no systemic effect. There is a prospective study to evaluate effectiveness of RA with 50% Nitrous Oxide (NO) to Oxygen (Faulks et al., 2007). This study demonstrates that nitrous oxide has been a greater success (91.4%) in patients where previously no co-operation has been noted. The adverse outcomes were minor that included nausea, vomiting, headache, sweating and pallor. When compared to different groups of ID, autistic behaviors have unpredictable response to the inhalational sedation. The benefits of inhalational sedation is that it can be performed by trained non-anesthetists, reduction of exposure for GA sessions, thereby more treatment needs can be met in routine dental visits.

### **3.5.2 Treatment under Conscious sedation**

Conscious sedation is moderate sedation that is drug-induced, produces an altered state of consciousness where individual withdraws from painful stimulus, responds to verbal commands with or without tactile stimulation. The airways and cardio-vascular function remains patent. It is only performed by trained seditionist or anesthetist (Nelson et al, 2019).

With treatment under IV sedation, the most commonly used drug is Propofol. Occasionally, this is used in combination with other benzodiazepines and often combined with administration of nitrous oxide. This is usually given to patients who are highly resistant to dental treatment, exhibiting combative behavior. It has been found to be effective for more than 75% of the patients with ID. Repeated sessions of sedation is possible at immediate time intervals and has shown significant improvement in level of cooperation among the patients with ID (Salerno et al., 2023). The most common post-operative complications include nausea, vomiting, drowsiness, agitation, headache and coughing. There were no deaths or aspiration reported as per the study (Kouchaji et al., 2019). As it is in-office provision of drugs, less dependency is required from the carers in premedication and better control of drug administered by the seditionist.

### **3.5.3 Treatment under General Anaesthesia**

General Anaesthesia is a state of drug-induced loss of consciousness. The patients are not arousable, even with painful stimulation. The ability to independently maintain ventilatory function is often impaired. Cardiovascular function may be also be at reduced rate. This is done with the help of anesthetist where patent airway is maintained along with maintaining positive pressure ventilation because of depressed ventilation or drug-induced depression of neuromuscular function (Nelson et al, 2019).

When treatment under normal setting or conscious sedation fail, then as per the hierarchy of treatment needs, General Anaesthesia (GA) is provided to the individual with ID. GA is the most effective modality of care who have been proven to be difficult in accepting treatment. It is complex and most expensive procedure and has greater side effects (Salerno et al., 2023).

Patients indicated for GA are to be assessed or categorized in accordance with the American Society of Anaesthesiologists (ASA 2008). These are:

- ASA Class 1 Healthy patient
- ASA Class 2 Mild to moderate systemic disease without significant limitations
- ASA Class 3 Severe systemic disturbance without limitations
- ASA Class 4 Life-threatening systemic disorder
- ASA Class 5 Moribund patient not expected to survive >24hrs
- ASA Class E Emergency patient

Patients who are in the category of ASA 1 or 2 are suitable for day-stay anaesthesia.

However, patients in the category of ASA 3 or 4 may need overnight hospital care to ensure that they maintain their airway, tolerating oral food and fluids and are monitored in post-surgery area for supervision.

Due to the risks involved in GA, it must not be the first choice to provide dental treatment, unless the other options discussed above are not feasible. Patients and carers choice and preferences must be taken into account, including medical, dental, social and psychological needs of the individual. There must be significant benefit or the outcome favourable when compared to the risks involved. As the process of GA is stressful for both patients and families, it has to be carefully considered and reserved for individuals who really benefit from the GA session (Aloufi et al., 2022).

### **3.6 References**

- Aloufi, A., Alatawi, F., Hakeem, F. F., & Abed, H. (2022). Factors determining the need for general anaesthesia to deliver dental treatment for adults with intellectual and developmental disabilities. *Saudi Journal of Anaesthesia*, 16(1), 24–28.
- American Association on Intellectual and Developmental Disabilities; The AAIDD Definition of Intellectual Disability is Cited in SSA's Proposed Revision of Medical Criteria for Evaluating Mental Disorders. (2010). *Health & Medicine Week*, 3017–.

- Balkaran, R., Esnard, T., Perry, M., & Virtanen, J. I. (2022). Challenges experienced in the dental care of persons with special needs: a qualitative study among health professionals and caregivers. *BMC Oral Health*, 22(1), 116–116.
- Compton, K., DiGiorgio, C., & Burson, H. (2016). Dental pain management in patients with intellectual disabilities. *Journal of Pain Management*, 9(2), 177–.
- Espinoza, K. M., & Heaton, L. J. (2016). Communicating with Patients with Special Health Care Needs. *The Dental Clinics of North America*, 60(3), 693–705.
- Faulks, D., Hennequin, M., Albecker-Grappe, S., Maniere, M. C., Tardieu, C., Berthet, A., Wolikow, M., Droz, D., Koscielny, S., & Onody, P. (2007). Sedation with 50% nitrous oxide/oxygen for outpatient dental treatment in individuals with intellectual disability. *Developmental Medicine and Child Neurology*, 49(7), 621–.
- Goering, S, 2010, ‘Revisiting the Relevance of the Social Model of Disability’, *American Journal of Bioethics*, vol. 10, no. 1, pp. 54–55
- Kouchaji, C. (2015). Complications of IV sedation for dental treatment in individuals with intellectual disability. *Egyptian Journal of Anaesthesia*, 31(2), 143–148.
- Lakshmi, K & Madankumar, PD, 2020,, ‘Development of modified dental chair to accomodate both wheelchair bound patients and general population’, *Disability and Rehabilitation: Assistive Technology*, vol. 15, no. 4, pp. 467–470
- Lim, M. A. W. T., Liberali, S. A. C., Calache, H., Parashos, P., & Borromeo, G. L. (2021). Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs. *Special Care in Dentistry*, 41(3), 381–390.
- Maeda, S., Kita, F., Miyawaki, T., Takeuchi, K., Ishida, R., Egusa, M., & Shimada, M. (2005). Assessment of patients with intellectual disability using the International Classification of Functioning, Disability and Health to evaluate dental treatment tolerability. *Journal of Intellectual Disability Research*, 49(4), 253–259.
- Mikkelsen, A., Sheller, B., Williams, B. J., Churchill, S. S., & Friedman, C. (2022). Transition to adult dental care from a paediatric hospital dental home for patients with special health care needs. *Special Care in Dentistry*, 42(4), 333–342.
- Nelson & Webb (2019). *Dental Care for Children with Special Needs: A Clinical Guide*. Springer International Publishing AG.



- Nowak, A. J., Casamassimo, P. S., & Slayton, R. L. (2010). Facilitating the Transition of Patients With Special Health Care Needs From Paediatric to Adult Oral Health Care. *The Journal of the American Dental Association* (1939), 141(11), 1351–1356.
- Raj, S. C. B. (2015). Management of oral care among people with intellectual disability. *Research Journal of Pharmacy and Technology*, 8(8), 1068–.
- Rosenbaum, P., & Gorter, J. W. (2012). The “F-words” in childhood disability: I swear this is how we should think. *Child : Care, Health & Development*, 38(4), 457–463.
- Salerno, C., Cirio, S., Zambon, G., Valeria D’Avola, Parcianello, R. G., Maspero, C., Campus, G., & Cagetti, M. G. (2023). Conscious Sedation for Dental Treatments in Subjects with Intellectual Disability: A Systematic Review and Meta-Analysis. *International Journal of Environmental Research and Public Health*, 20(3), 1779–
- Versloot, J., Veerkamp, J. S. J., & Hoogstraten, J. (2006). Dental Discomfort Questionnaire: assessment of dental discomfort and/or pain in very young children. *Community Dentistry and Oral Epidemiology*, 34(1), 47–52.
- World Health Organization. *International classification of functioning, disability and health*, 2001.

**Chapter 4**  
**Referral pathways in NSW health**

## **4.1 Introduction**

When the treatment needs are exceeding the scope of the dentist or if there is no proficiency to accommodate the patient due to the challenges discussed in chapter 3, referral pathways are open for the general public where the patient can be referred to public or private Special Needs (SN) specialist.

For most patients, referral to SN specialist from their primary health care provider can be an easy process arranged by the primary health care provider, either a General Physician (GP) or General Dental Practitioner (GDP). Improving specialist referrals outcomes, 2020 : The Australian financial review, a newspaper article states that, a successful referral is dependent on the relationship between GPs and their patients. If the GP understands the patient well in terms of underlying medical conditions, the referrals become more targeted by referring to the correct specialist. At the same time, the referral quality increases if the GP includes the necessary information, understand the referral process and the duration for the referrals to get into action.

## **4.2 Referral pathways**

With current Oral Health treatment needs in Australia, the referrals to a SN specialists can be from a public or private GDP, a GP, a health specialist of dental or other areas of expertise, an allied health worker like a speech pathologists. Although there are only three tertiary hospitals in New South Wales accepting referrals from patients who hold valid health care card or pension card (HCC/PC), there are multiple private dental offices accepting referrals from private patients.

Tertiary referral centres in NSW are:

- Sydney Dental Hospital (SDH)
- Westmead Centre for Oral Health, Westmead (WCOH)
- The Children's Hospital Westmead, Dental Department, Westmead.

The referrals to tertiary centres are governed by Oral Health Specialist Referral Protocol, a policy directive to establish clear and consistent pathway for eligible residents of New South

Wales to seek specialist oral health services. A referral form is attached to the thesis as Appendix 1.

All eligible adult patients who require specialist services are seen free of charge. The exemption lies with patients who are seen for teaching purposes and patients with special clinical needs as advised by the clinical director of the Local health District (LHD) where a service charge may be applied.

The services that may be requested are:

- An opinion only, about a specific condition.
- Management of a specific condition, upon the acceptance of the referral.
- Ongoing management of a patient whose medical and dental condition requires a specialist management, upon the acceptance of the referral.

### **4.3 Responsibility of the referring clinician**

- Assess the eligibility of the patient to obtain specialist treatment in tertiary hospital.
- Provide all the relevant patient identification details – full name, address, contact details, medicare card numbers, health care card/pension card details.
- A relevant medical history, medications and known allergies.
- Relevant dental records and findings along with reason for referral.
- Inform the patient of waiting times and attempt to provide a relief of pain for interim.

Usually, the receipt of referral will be sent from the specialist services to the referring clinician. This is also followed by advising the referring clinician, the outcome of the consultation appointment along with proposed treatment plan.

### **4.4 Who can be referred to SN specialist?**

The patients who are ID with or without physical disability, not suitable for routine dental care in a routine clinical setting can be referred to the Dept. of Special Care dentistry (SCD). SCD also extends to patients who live in

- Aged care or nursing homes.

- Mental health unit of a hospital.
- People who are homeless.
- Patients with serious medical conditions.
- Patients with syndromes and anomalies.
- Patients with dental phobia.
- Other sensory disabilities who cannot be seen in routine dental clinics.

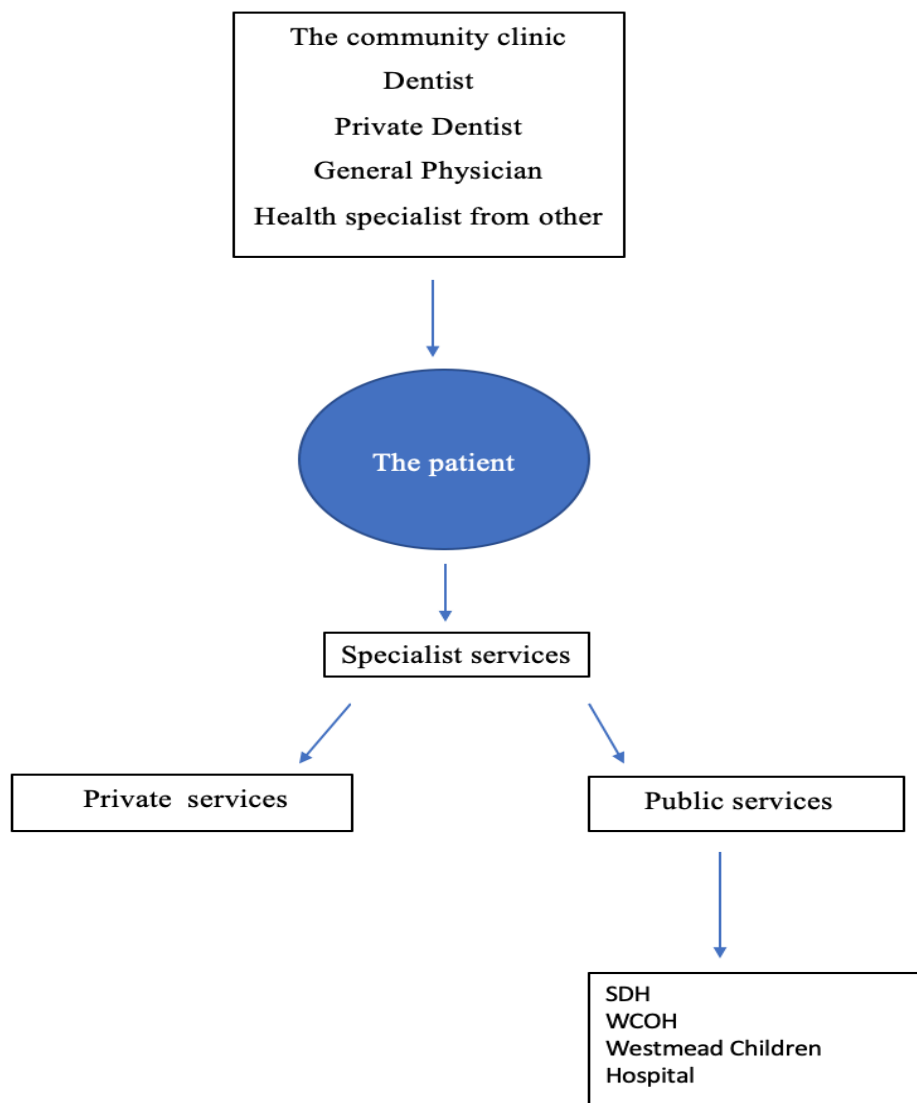


Figure 15: Pictorial representation of referral pathways in New South Wales.

## **4.5 References**

- Improving specialist referrals outcomes 2020, Fairfax Media Publications Pty Limited, Melbourne.
- Oral Health Specialist referral protocols, NSW Health. Nov 2011.

**Chapter 5**  
**Research Project**

# ***Presentation of acute odontogenic infections to tertiary hospitals with intellectual disabilities; Is it the lack of awareness, motivation or insufficiencies in health system - a retrospective study***

## **5.1 Introduction**

Intellectual disability (ID) affects nearly 2.5% of the population (S.M. Alaki et al., 2012) and is defined by the American Association on Intellectual and Developmental delay (AAIDD) as *significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of certain adaptive skills including communication, self-care and social skills manifesting before the age of 18years*. The ID itself can be associated with syndromes and with no syndromes, also can be associated with neurological deficits, cognitive impairment due to chronic illnesses and other medical conditions.

Based on the research there is higher prevalence and experience of dental caries in both primary and permanent dentition in individuals with ID. The burden of untreated dental caries is more in permanent dentition than on primary dentition and appears twice when compared with individuals with no ID (M.Dziwak et al., 2017). It is a known fact that oral hygiene is compromised in patients with ID due to the challenges faced during routine dental care. In addition to this, reliable description of pain may be difficult to predict in individuals with ID, though it is represented with their idiosyncratic behaviours such as moaning, grunting and grimacing which may lead to over-estimation of pain (S.M. Alaki et al., 2012, Dubios et al., 2010). When individuals present to routine dental check-ups, challenges are often with limited compliance, treatment is most often not carried out in periodic fashion increasing the incidence of acute flare up of chronic infections. Often, it necessitates referral to tertiary hospital for treatment to be carried out in GA or IV sedation other than in normal settings.

### **5.1.1 Disease Background**

When ID patients present to the tertiary hospital with acute odontogenic infection with clinical signs that are noticeable (facial swelling, abscess with purulent discharge), they often present along with behavioural changes reported by the caregivers as discussed above. This draws attention towards the use of analgesics along with antibiotics to reduce the symptoms till the



treatment modality is determined (Kouchaji et al., 2015). It also requires informed consent from primary carers, family members or legal guardian in order to perform any treatment. With interim pain management, the risk is high with poly-medication and drug interactions along with adverse effects, necessitating the clinical input from various other specialities like psychiatrist, geriatricians and allied health professionals. The concomitant use of benzodiazepines, most NSAIDS, opioids increases the chances of respiratory depression and depression of central nervous system thereby limiting to the use of paracetamol to be the safest drug of choice although not much of analgesic effect is achieved (Compton et al., 2016).

Although with or without failed attempts of treatment under normal settings, when a patient presents to the tertiary hospital with acute infection, most of the times, the dental treatment is limited to general anaesthesia due to the reasons such as poor compliance, localised collection of abscess where local anaesthesia might not work, or spread of infection to deeper tissues with limitations like trismus. Moreover, environmental factors play a significant role in managing the post-operative care on public health system like : absence of immediate family relying on carers and social workers, transportation services, over-night stay and admission in hospital for good recovery. There is increased severity of ID after every session of GA (Jockusch et al., 2020; Chang et al., 2014; Petrovic et al., 2011; Dougherty et al., 2009).

### **5.1.2 Rationale for performing the study**

Presence of odontogenic infections is more prevalent in individuals with ID for the reasons that the oral health needs are unmet due to impaired cognitive or motor abilities, inability to perform adequate oral hygiene, less awareness amongst care givers and health professionals, fear and anxiety related to non-compliance, limited access due to wheel chair, bed bound and other systemic restrictions like dysphagia, risk of aspiration pneumonia further necessitating treatment beyond routine dental treatment (Petrovic et al., 2011).

To date, there are not many studies that rule out the cause of acute odontogenic infections with flare-ups in ID patients, as the reasons are multifactorial and diverse in nature. The rationale for this research is to find the reasons why such cases occur and why are they not possible in clinical settings other than tertiary hospitals, thereby drawing more light on what can be done to improve health services for individuals with special needs.

## **5.2 Aim**

The aim of this study is

- To understand the reasons why the acute presentations of odontogenic infections occur in individuals with ID. The treatment in tertiary clinics is presumed to be majority under GA by placing them in urgent management category; the aim of this research is to understand the reasons that include severity of ID, compliance, knowledge and motivation among care givers, if limited training among general dentists or limited access in the community clinics for managing patients with special needs and
- The underlying reasons and gaps of why dental treatment was referred to tertiary hospitals for patients with ID assuming that they would possess poor compliance to routine dental care and periodic follow ups.
- The aim is to come up with some recommendations to close the gap either with education tools to the carer and clinician, encouraging regular visits to the dental clinics or equipping dental teams to see patients with ID.

## **5.3 Hypothesis**

The hypothesis of this study is to show :

- The main reasons of referral to tertiary hospitals in patients with ID.
- The health practitioners other than dentist contribute to majority of the referrals.
- The reasons for referral is not just limited to poor compliance.
- The majority of the treatment was not limited to GA, but to normal settings.
- This study also should show the relationship of primary care givers involved in caring the patients, the social history, diet history, history of previous dental treatment and the outcome of the referral.

The final outcome of this study would help the public dental system to identify the gaps contributing to refer ID patients to tertiary hospitals, to understand the reasons behind these gaps and to come up with recommendations in closing these gaps either by training more

clinicians managing special need patients or even by having more access to GA to the community clinics.

## **5.4 Materials and Methods**

### **5.4.1 Design/Study Type**

The study is a retrospective study involving the patients with intellectual disabilities. The study focuses on the reasons behind their presentation to the tertiary hospitals namely, Westmead Centre of Oral Health. As it's a retrospective study there is no direct patient involvement and to collect the data from the patient files with relevant information. As the data is from one centre, the data was collected in MS forms with a questionnaire that was transferred to Microsoft excel. The data is privacy stored by a password protected computer in University of Sydney office at WCOH. The data is restricted to be available to myself and my two supervisors.

### **5.4.2 Subjects**

In total, 91 dental records/files were collected from 91 different patients who presented to the Dept. of Special Care Unit (SCU) at WCOH. The dental records were picked on random basis from the system with the help MRN that were seen at Dept. of SCU. The data collected was de-identified with alphabetical and number coded for privacy reasons and could be matched only based on de-coding the data, accessible only to researchers involved in the study. The files were ranging from the most recent to going back to 15 years old. The reasons to restrict the data collection from files only 15 years older are:

- With advancement in medical field, the treatment modality and approach to patient care may not be applicable to current times.
- The older files are archived, limiting their access.

### **5.4.3 Study participants**

The study participants were men and women referred to the SCU by :

- Private dentist.
- Community dentist.
- Other health professionals.
- GP.
- Health specialist.
- Allied health care worker.
- Mental health specialist from the hospital.
- Miscellaneous 'other' referrals from group homes.

### **5.4.4 Inclusion criteria**

- Individuals over 18 years of age identified with ID.
- Individuals eligible for public dental service under specialist care.

Individuals who presented to the centre with a referral for

- Management of acute dental infection.
- Management of acute facial swelling.
- Management of behavioural issues.

### **5.4.5 Exclusion criteria**

- Individuals with no background of ID.
- Individuals for dental check-ups.
- Individuals who are in course of treatment for GA and IV sedation.
- Individuals with no complete records or clear referral pathway.

The referrals were read thoroughly and the reason for referrals were noted. Though the main aim was to collect the referrals who present with acute dental infections or acute flare ups, it could vary from one of the reasons or a combination of reasons as mentioned above.

These patients had eligible medicare card and Health Care card/Pension card and had issues with compliance, underlying medical condition where it could be just ID or in combination with physical disability and/or deemed not safe to be treated under normal settings either with physiological limitations or physical threat due to ID.

In addition to the above information gathered, certain indicators that would help us draw towards aetiology of dental infection were also focussed and attempts were made to gather from dental record/file. To approach this research in holistic way, information below were also collected:

- Primary carer or the individual living conditions.
- ADL score – Activities of daily living.
- Diet history/ Snacking history.
- Oral hygiene measures.
- Attendance to dental appointments.
- Previous modality of dental treatment.

#### **5.4.6 Information on consent**

As it's a retrospective study, there was no necessity of consent as there is no patient direct involvement. The data collected from the patient files were analysed for research. A consent waiver was obtained with ethics approval due to the following reasons:

- Involvement in the research carried no more than low risk.
- There was no direct patient involvement.
- The collected information was de-identified from the data already present in the patient files.
- It is impractical to obtain consent going retrospectively.
- The data collected were protected with any privacy breach.

The Patient Questionnaire form is attached in the appendix (Appendix 2).

#### **5.5 Statistical considerations**

The data were processed using SPSS (Statistics Package for Social Science, version 24.0 for windows; SPSS Inc., Chicago, IL USA). Reasons for referrals in terms of underlying medical condition, source of referrals and ADLs were analysed using the vertical and horizontal bar charts. Reasons of referrals based on dental concerns, compliance noted in the referrals and the outcome of the referral in terms of treatment has been shown as pie charts. The association between reasons of referral and independent variables such as source of referral, compliance,

ADLs, snacking history, dependency and frequency of toothbrushing, type of toothpaste were assessed using  $X^2$  tests. The significance level was set at  $p < 0.05$ .

## **5.6 Results**

A total of 91 ID patient records were identified from random selection of patient records referred to the Dept of Special care, WCOH. Among them 62.6 % were found as complaint and 37.4% were non complaint patients.

Table 4 shows the association between reasons of referral and independent variables. There is a significant relation found between the change of behaviour in noncompliant ID patients when compared with moderate complaint ID patients (79.3% and 20.0%, respectively,  $P < 0.05$ ). In addition to these findings, Table 4 also shows that acute dental infection is significantly present in individuals who use regular toothpaste (83.9%) than in individuals using high fluoride toothpaste (83.9% and 16.1%, respectively,  $P < 0.05$ ). There is very high significance noted in change of behaviour who are fully or partially dependant on tooth brushing when compared to individuals who are independent in toothbrushing (82.8% and 17.2%, respectively,  $P < 0.001$ ).

Variables and findings		Acute Dental Infection (%)	Change in behavior (%)
<b>Information about referrals</b>			
Source of Referral	Public & Private Dentist + all other referrals	46.8	27.6
	Other health professionals.	53.2	72.4
Compliance	Non-compliance	54.8	79.3 *
	Moderate compliance	45.2	20.7
<b>Social and Diet History</b>			
ADLs	Zero ADLS	45.2	58.6
	Full or partial ADLS	54.8	41.4
Snacking History	Frequent snacking – Non healthy	71.0	72.4
	Healthy snacking	29	27.6
<b>Oral Hygiene habits</b>			
Dependency of toothbrushing	Full or partial support	41.9	82.8***
	Independent	58.1	17.2
Frequency of Tooth brushing	Once or twice daily	37.1	41.4
	Occasional/rare	62.9	58.6
Type of toothpaste	Regular toothpaste	83.9*	65.5
	High Fl toothpaste	16.1	34.5

Significance tested with Chi Square test.

\*<0.05, \*\*<0.01, \*\*\*<0.001

Table 4: Association between reasons of referral and independent variables: source of referral, compliance, ADLs, snacking history, dependency and frequency of toothbrushing, type of toothpaste.

<b>Dental History</b>			
Attendance to the dental appointments	Irregular	53.2	72.4
	Regular	46.8	27.6
Motivation	No motivation	50	27.6
	Motivated	50	72.4*
Dental treatment history Dental treatment hi	GA + IV sedation	22.6	37.9
	Normal setting	77.4	62.1
<b>Treatment outcome</b>			
Treatment provided	Treatment under normal settings	45.2	62.1
	Treatment under GA+IV	54.8	37.9
Long term management plan	Placed in recall	61.3	69
	Refer to primary clinician	38.7	31

Significance tested with Chi Square test.

\*<0.05, \*\*<0.01, \*\*\*<0.001

Table 4 contd: Association between reasons of referral and independent variables: attendance to dental appointment, motivation, dental treatment history, treatment provided and long-term management plan.

Figure 16 showed that 49.5% of the referrals were made to the Dept of Special care mainly due to intellectual disability while 23.1% of the referrals were a combination of intellectual disability along with physical threat to the clinician and 26.4% were a combination of intellectual and physical disability. The remaining 1% were the referrals based just on physical threat to the clinician.



## Underlying medical concern

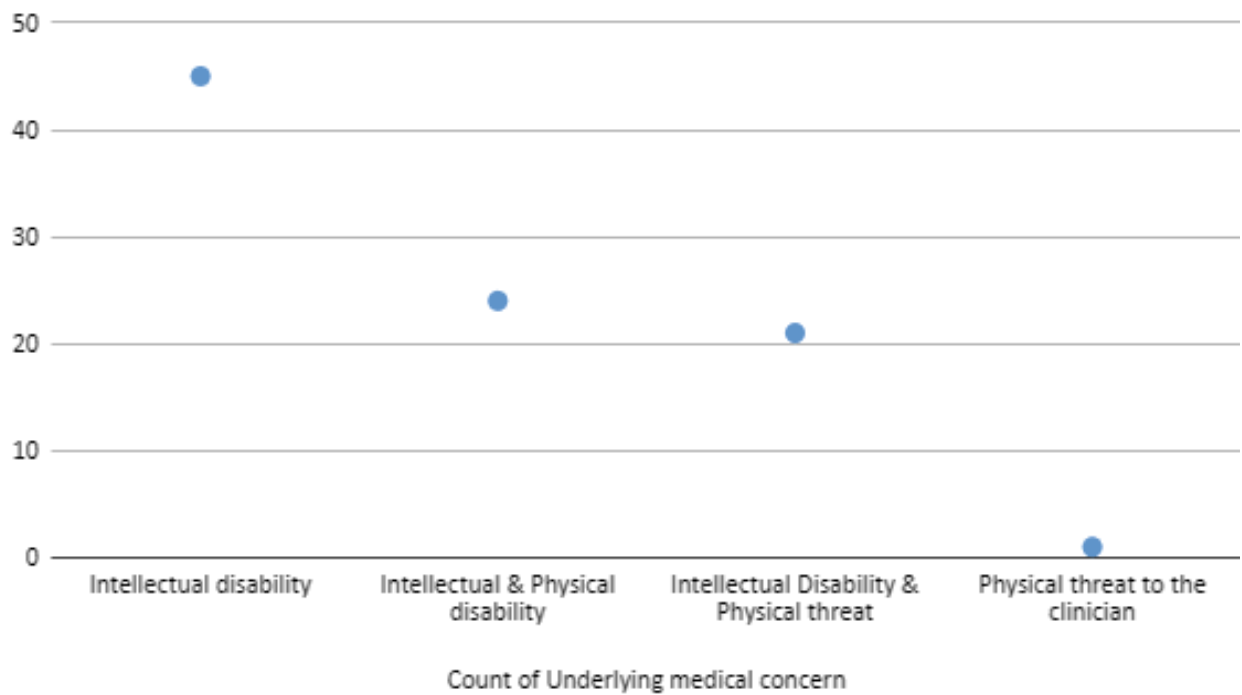


Figure 16: Reasons for referrals based on underlying medical conditions/concerns

Figure 17 showed the source of referrals as 56% of the referrals made from health practitioners like GPs, health specialist from other field of expertise, 24.2% from the General dentist from community clinics while 16.5% were from the private dentist referrals. Other miscellaneous referrals contributed to the least of around 2.2%.

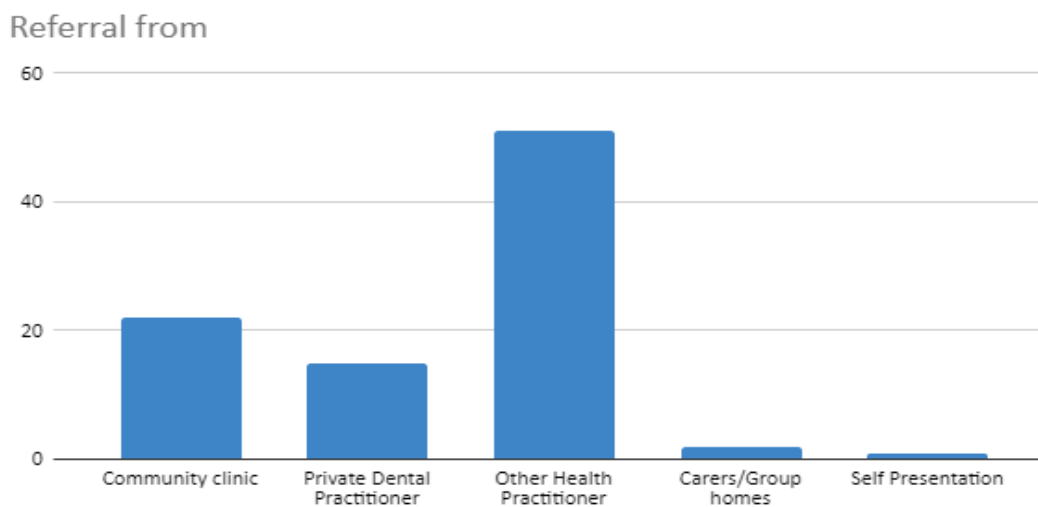


Figure 17: Source of referrals.

Figure 18 showed about the reasons for referral based on dental concerns. The reasons were divided into five categories as the combination of reasons were added to the main concern of the chief complaint. Acute dental infection like pulpitis, localised acute abscess on examination by the primary clinician contributed to around 33%. There were few cases with acute facial swelling of around 13.2%. In patients with ID, there is a significant change in behaviour with dental pain and this was noted as reasons for referral in 28.6% of cases while it appeared in combination with presentation of acute dental infection in 23%. The least 2.2% of cases presented with facial swelling.

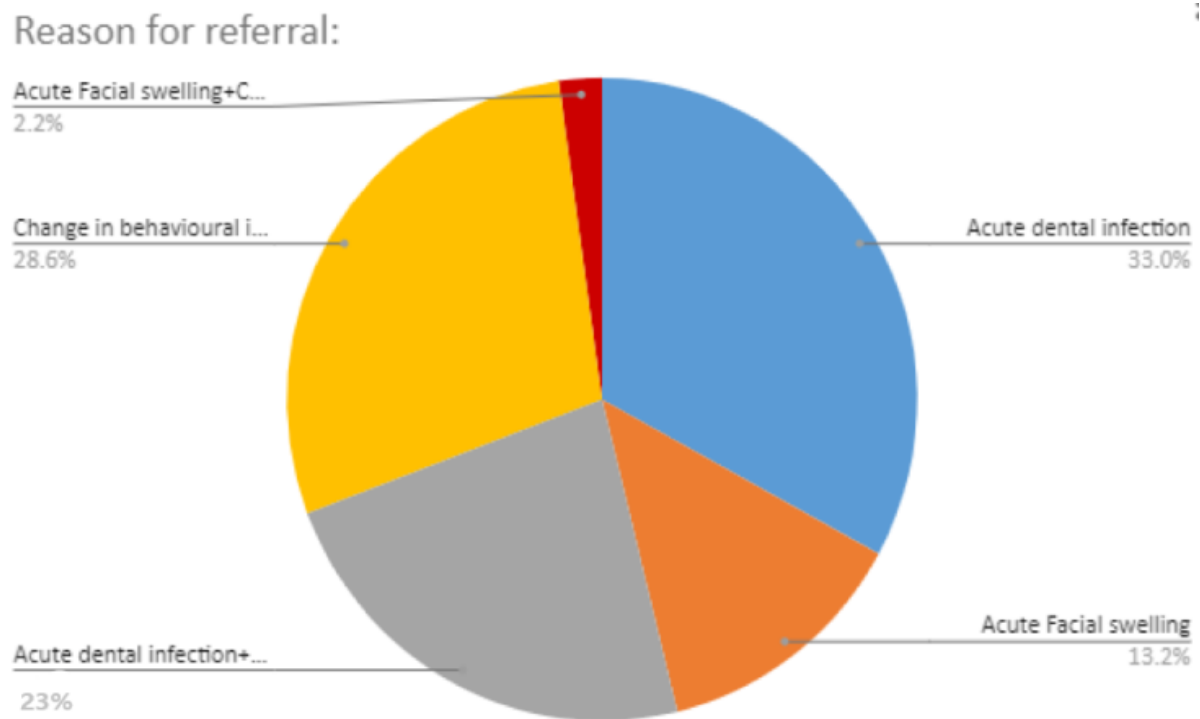


Figure 18: Reasons for referral based on dental concerns.

Figure 19 showed the compliance noted in the referrals. First majority of 39.6% had severe behavioural issues, second majority 37.4% of the referrals were based on moderate compliance while non-compliance was noted in 6.6% of referrals. Physiological limitations like dysphagia, PEG fed, restrictions like bed bound with severe neurological ailments limiting the clinician to

provide treatment also contributed some referrals of around 12%. There were few referrals 4.4% with good compliance.

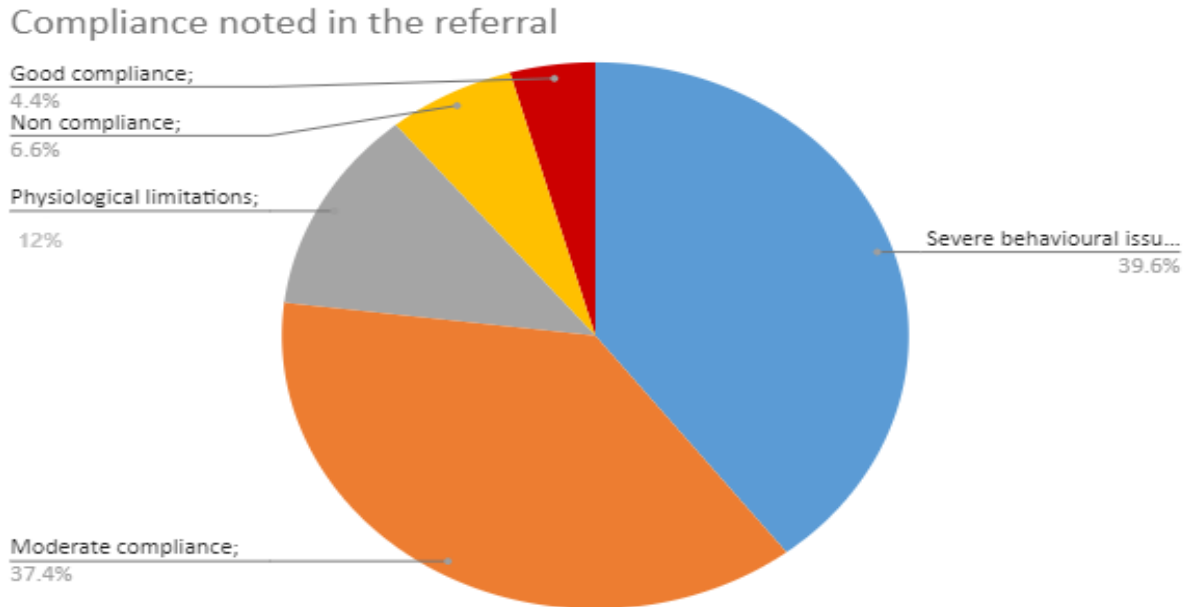


Figure 19: Compliance noted in the referrals.

Figure 20 showed the ADLs. As the questionnaire focussed on social history and tooth brushing technique, 40.7% of the patients referred were independent with ADLs (5/6 and 6/6), 45.1% were independent with tooth brushing. On the other hand, patients who were fully dependant on all activities with 0/6 score were 25.3%. Likewise, patients who needed full support with brushing teeth were more than the other groups and contributed around 30.8%. 42.9% of patients and carers were poorly motivated in terms of oral hygiene and needed motivation that was assessed during the consultation appointment by the oral hygiene therapists. The remaining 57.1% remain as unknown from the data collected.

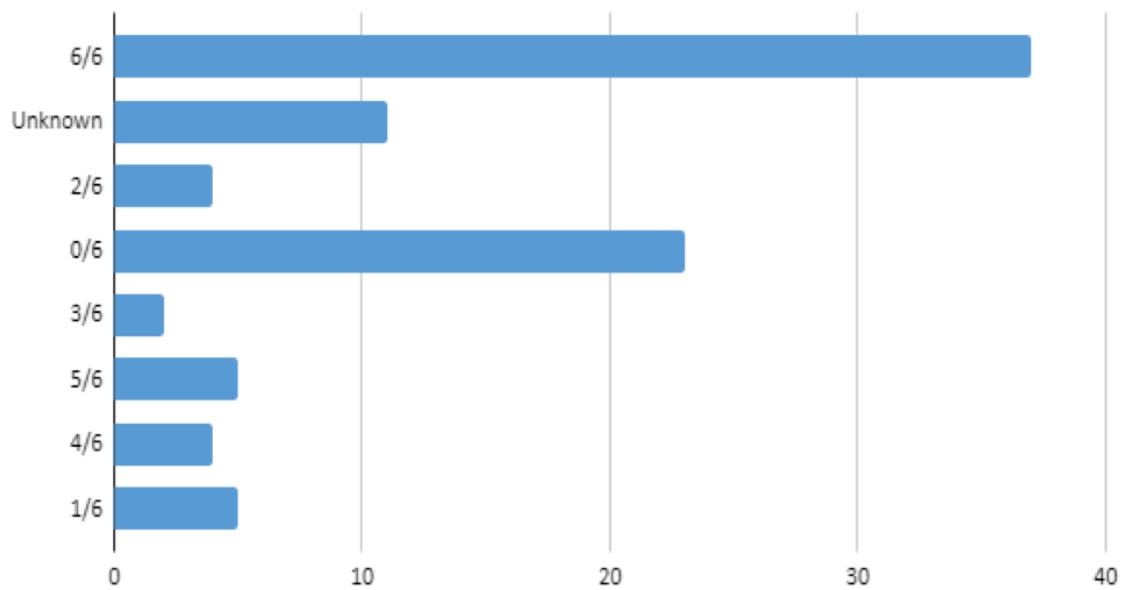


Figure 20: ADLs

Figure 21 showed the treatment outcome, treatment under normal settings was the most offered treatment for patients who were referred, contributing 44%. This was followed by treatment under GA that was around 35.2%. Patients who were seen under IV sedation were 12% while in 4.4% of patients, the treatment was deferred due to medical and social reasons. Two minority groups of 2.2% each for a combination of normal setting followed by GA and combination of IV sedation followed by GA was also provided and the main reason was poor compliance and social issues.

### Count of Treatment outcome

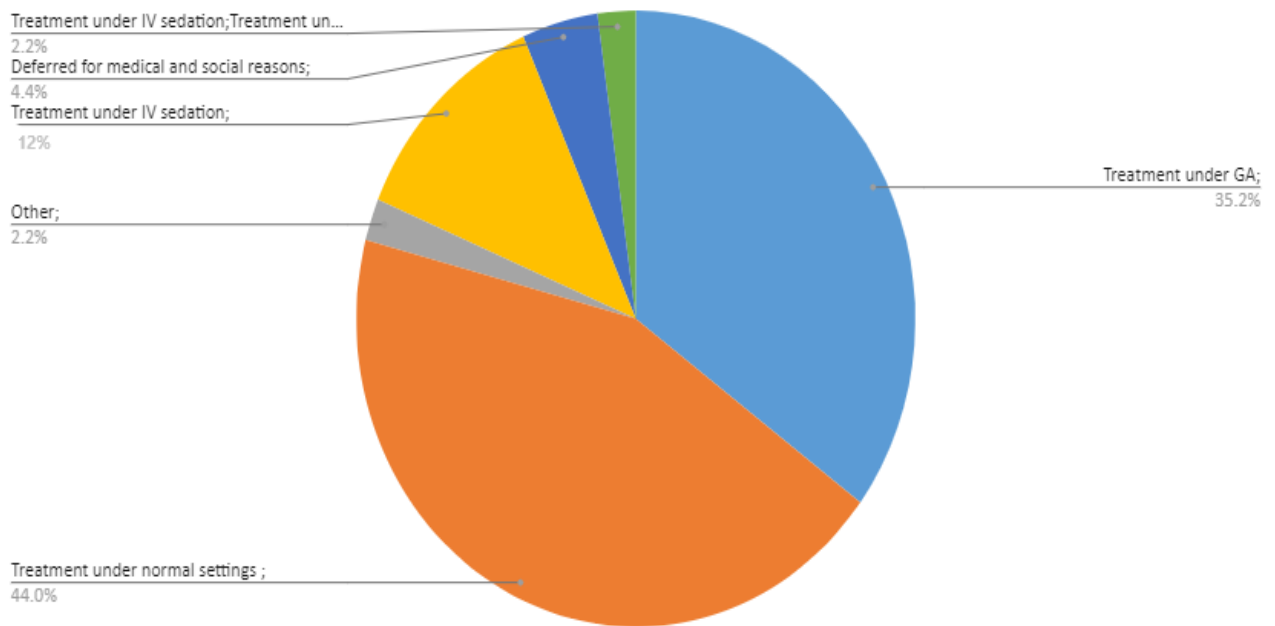


Figure 21 showed the treatment outcome.

Following the treatment majority of the patients were placed in the recall waitlist that contributed to 65.2% while there were less number of patients referred back to the primary clinician (3.4%). The gap of 31.4% of cases were categorised as unknown status.

As to approach the aim of the study in holistic way, the social factors were included. When looked into the social status of the patients chosen for study, majority lived with their immediate families (58.2%), the next majority lived in group homes (25.3%) while the less percentage (12.1%) lived in mental health unit in a hospital. There were some referrals that had not mentioned about social status (4.4%).

In terms of diet history, majority of the cases were having oral intake of food and very few were associated with thickeners and PEG fed. As with the diet, there was a tendency of 41.8% with increased intake of unhealthy snacks, between meals, intake of sugar drinks or coca-cola, snacking with cakes, biscuits more frequently noted during the day. 28.6% had healthy diet and 29.6% had unknown dietary habits. Although living in metropolitan areas of Sydney and majority of referrals being from Sydney, the consumption of fluoridated water was a regular

finding as there was limited proficiency for tank water or rain water. There were no other remarks about intake of medication with sugar but there was more use of thickeners in patients who were placed on modified diet.

From the data, 40.7% were regular attenders to the dental clinics as they were seen as paediatric patients in dental wing at Children's hospital or they happen to be seen by a dentist with previous referrals from other health specialists. 37.3% were irregular attenders and 22% had unclear dental history. However, many cases were not drawing any light, in terms of previous modality of care. Around 31.9% mentioned that the patients were seen under normal settings either in hospital settings or rarely by a general dentist efficient in managing ID patients. 13.2% were seen under GA and 8.8% under IV sedation as reported by the carer who accompanied the patient during consultation appointment. 46.1% are with unknown or unclear dental history in terms of modality of care. Although some patients reported to have deterioration in compliance level as previously they were seen by general dentist in a community clinic or private practice but deemed to be not suitable anymore due to change in clinicians, limited compliance due to ongoing dental discomfort or change in social circumstances of the patient that would reflect on dental treatment or simply because of progressive nature of ID.

## **5.7 Discussion**

As based on the findings of this study, where 91 dental record were collected, majority of the referrals were from other health professionals which reflects the hypothesis of this study. It was noted that the referrals were made from other health specialist for eg: Neurologist, disability physician, Psychiatrist and whomever patient sees for general health reasons contributed to more than half of the number. The reasons could be that there is limited awareness among other health specialist about the waiting times and patient load in tertiary hospitals but also with the presumption that the patient falls under the SN specialist care.

The next majority of referrals come from other LHD community clinics or private dentist that contribute to around 40% of the referrals. The reasons stated in the referrals were "patient with intellectual disability" or medical history with an intellectual or psychological disorder. There were some referrals with noted physical threat to the treating clinician due to non-compliance

and combative behaviour. This contributed to around 24.3% of the referrals. These cases along with acute dental infection are direct referral cases where patient is seen under IV sedation or GA.

Majority of referrals reported to be with noted dental infection that has been prioritised as code 1 and the services at Dept of Special Care try to accommodate these patient at the earliest. As with some of these referrals describe, there was a change in behaviour noted in the patient alarming the carer or the dentist of first point of contact to refer with failed attempt to examine the causative tooth. Change in behaviour with or without other signs like facial swelling, dental infection in total contribute to 59% of referrals. This is supported by a study by Dr. Pradhan in 2013, as it explains that patients who can verbalise their dental problem had their dental treatment received earlier than patients who were not able to communicate.

Majority of the referrals indicate the need for GA although it is universally understood that GAs must be the last resort of treatment when other modalities fail. Most of these patients among 91 cases, were treated under normal settings (41.8%) which is then followed by the next higher numerical figure of 35.2% under GA. Guidelines of American Academy of Paediatric Dentistry (AAPD 2020:19) state that ‘children and adolescents who cannot co-operate due to lack of psychological or emotional maturity and/or mental, physical, or medical disability; the extremely uncooperative, fearful, anxious, child or adolescent; patients for whom the use of GA may protect developing psyche and/or reduce medical risk are indicated for dental GA. It is understood that the same applies for adults of all age groups although in addition to these above given measures, ASA of an individual must be taken into account as there is increased number of co-morbidities in adults, the anaesthetist determines the suitability of an individual for GA.

One of the main aims of the study is to explore the reasons why patients present with acute dental infection or in other words why referrals have mentioned acute condition of dental infection. When we look into the aetiological factors, diet, oral hygiene, frequency and access to the dental care all contribute as an inter-link to the OHQoL of an individual.

The data shows :

- 41.8% of total 91 cases has shown frequent snacking with unhealthy diet and 28.6% has been on healthy diet.
- Tooth brushing was performed independently in 45.1% of 91 cases but the second majority were fully dependant (30.8%). Although majority of patients (45.1%) did brush their teeth occasionally with majority using manual toothbrush and normal toothpaste.
- The first majority being irregular attenders (53.2%). Second majority of the cases (46.8%) were regular attender to the dental services, having said the frequency of dental visits in a year was not discussed in the dental records.
- In addition the primary carers were family members in the study cohort contributing to 58.2% of the population selected. The second highest number were from group homes (25.3%). These figures indicate that majority of patients lived with carer support either one-on-one patient – carer ratio or one carer facilitating the needs of two or three ID patients in a group home.

All the above factors draw towards the knowledge and understanding of oral health amongst carers. Various other studies show that the carers have insufficient training or information in performing routine dental care. One of the main study conducted at Belgium, elaborates the barriers for oral care in an organisation for people with disabilities (Phlypo et al., 2020). In this study 40% of the caregivers were not aware that inter-dental cleaning is a part of their job, while only 14% addressed it as toothbrushing.

In order to emphasis on oral health as a part of general health to the care givers, the most important part is to break down the barriers by promoting oral health education. Also collaboration with the dentist for periodic dental screening in residential or aged care facilities would draw more light where residents are considered as regular attenders. Carer shortages and time restraints have direct impact on oral hygiene measures, while other reasons are not having enough information and training to practice good oral health for ID patients. In this research, it was noted that 42.9% of carers and families needed motivation around oral hygiene practices which was reflective in the study by Waldman and Perlman 2012.

In WCOH, after every consultation appointment, patients and carers are given a session with Oral Health Therapists (OHT), where the OHT assess the dental caries risks of an individual



along with social factors of who is involved in the care, comes up with oral hygiene plan and diet plan. In the oral hygiene plan, the OHT discusses the choice and type of toothbrush, type of toothpaste, demonstrates on either the patient or on a model and also gives instructions on inter-dental using inter-dental brushes. The dietary advice is also given based on the snacking history and number of sugar exposures in a day. The recommended changes are recorded in the dental file and periodically revisited. It is recommended based on a French study (Faulks et al., 2000) for patients with limited cooperation, three sided toothbrush was recommended. For patients with frank resistance, conditioning approach was demonstrated. For patients who were independent with brushing, manual educational program are encouraged where tooth brushing is considered and trained as a life-skill.

When drawing attention to the outcome of the referrals, majority of the patients among 91 cases (41.8%) had treatment under normal settings. The second modality that was noted is treatment under GA (35.2%). This indicates that though the referrals were made stating intellectual disability (49.5%), the treatment was under normal settings but treatment was provided by the clinicians who were employed through the Dept of Special care. As per the dental records, it was identified that the many patients had dental extractions performed under normal settings by an Oral surgeon skilled in seeing ID patients. Similarly, the dental treatment including dental restorations and other necessary treatment were performed by clinicians skilled with special training to accommodate the challenges of ID patients. One of the main reasons for referral to tertiary hospitals is the accessibility to GA theatres. Not all LHDs in the Sydney Urban area have access to GAs; the reasons are unknown. Also working in GAs need credentialing and training that is not commonly available in public hospitals for all clinicians. In addition, if patient has Health Care Card/Pension Card, they are eligible to have free dental treatment under GA versus patients having to pay for GA services in private hospitals. To reduce the burden on GA waitlist, some of the study cohort had the treatment split into GA and IV sedation (2.2%) in WCOH.

On the other hand, WCOH has proficiency for IV sedation and some referrals were indicated directly for IV sedation but mainly the modality was often chosen after the consultation appointment and assessing the patient compliance. Carer's perception and the social circumstances also take part in decision making as GA is a one-of visit to the dentist where all

the necessary treatment is carried out in one session. Although other modalities require multiple visits and relies on various factors like patient compliance on the day, clinician present, the effect of IV medication in that session as there are situations that patient compliance may get altered in one session and remain excellent in other.

The aim of this study was to understand the reasons why the acute presentations of odontogenic infections occur in individuals with ID and the reason for referral to tertiary hospitals. The treatment in tertiary clinics is under GA by placing them in urgent management category; the focus of this research was to understand the reasons that included severity of ID, compliance, knowledge and motivation among care givers, if limited training among general dentists or limited access in the community clinics for managing patients with special needs. The proposed outcome of this research is to come up with some recommendations to close the gap either with education tools to the carer and clinicians, to maintain regular visits to the clinics or equipping dental teams to see patients with ID.

## **5.8 Recommendations**

The referrals that were made to WCOH, by health professionals other than dentist indicating the presence of acute symptoms or signs of dental infection with or without change in behaviour draws more attention on the gaps not only in the dental system state-wide but also on the need to create awareness among other health professionals and carers about waiting times and oral hygiene measures. The health professionals like specialists have to be given factual numbers of waiting list and the unmet demand of increasing referrals. On the same note, the private and public GDPs must also try to expand their expertise in treating patients with ID either by observing clinicians who are skilled in seeing patients or undertaking some training programs. To close the loop, the tertiary hospitals have to offer some programmes that could be available for general dentist to take part. It is not only training the dentists but also it is important to create a dental team who can cater these disadvantaged patients and evolve who can meet the needs of ID patients.

On the other hand, the oral care does not stop at dental office. Oral health programs designed for educating and managing patients with ID must aim not only to residential or aged care homes but also to the family members who are the primary carers. The health promotion and interventions are of great benefit when they are customised (Mac et al., 2013). This can be an

extension of care from their primary clinicians or GPs. These programs can also be introduced in state level similar to ante-natal workshops. The GPs and other health professionals must be educated about the effects of sugar coated medications and modifications must be sought either by the carers or the dental professionals. Although the treatment for ID patients under GA is easier than other modalities, every attempt should be taken to address the main concern under normal setting or inhalational sedation (Geddis et al., 2022).

When dental treatment needs are getting met in either public or private clinics or tertiary hospitals, the treatment must be provided based on the dependency levels as with application of Seattle pathway (Pretty et al., 2014). Patients with severe ID and non-compliance fall under the category of medium or high dependency levels; the aim should be to work on maintaining the strategically important teeth or maintain the functioning units to reduce the bacterial load and to develop effective oral hygiene around functioning teeth.

On the other hand the concept of shortened dental arches would also benefit the patients where the treatment needs are adapted based on problem-solving approach by retaining minimum of four occlusal units (Abuzar et al., 2015).

These concepts of gerontology will benefit patients with severe ID as they both share the same concepts around oral care and thereby reduce the load of treatment needs on ID patients, families and care-givers and eventually reducing the need for repeated GA.

## **5.9 Conclusion**

Dental pain among individuals with intellectual disabilities are noted due to several reasons, including:

- poor oral hygiene.
- the higher experience of dental caries.
- unmet treatment needs.
- The higher prevalence of malocclusion than those without disabilities.

The referral system in NSW where the dependency is only on three tertiary hospitals, must widen where other public hospitals can see patients with ID by providing training the interested

dental practitioners in managing patients with ID and by providing training and credentials for treatment under GA. The education programs must educate the care-givers about importance of oral hygiene and periodic visits to the dentists thereby the dental disease burden is minimised and incidence of acute flare ups are reduced in patients with ID. These major gaps have to be addressed, to reduce the referrals to or redirect the referrals from tertiary hospitals.

## 5.10 References

- American Academy of Paediatric Dentistry. Definition of special health care needs. The Reference Manual of Paediatric Dentistry Chicago, IL. 2020:19.
- Abuzar, M., Humplik, A., & Shahim, N. (2015). The shortened dental arch concept: awareness and opinion of dentists in Victoria, Australia. *Australian Dental Journal*, 60(3), 294–300.
- Aloufi, A., Alatawi, F., Hakeem, F. F., & Abed, H. (2022). Factors determining the need for general anaesthesia to deliver dental treatment for adults with intellectual and developmental disabilities. *Saudi Journal of Anaesthesia*, 16(1), 24–28.
- Australian Research Centre for Population Oral Health The University of Adelaide South Australia. (2009). Periodontal diseases in the Australian adult population. *Australian Dental Journal*, 54(4), 390–393.
- Baelum, V., & López, R. (2013). Periodontal disease epidemiology - learned and unlearned? *Periodontology 2000*, 62(1), 37–58.
- Balkaran, R., Esnard, T., Perry, M., & Virtanen, J. I. (2022). Challenges experienced in the dental care of persons with special needs: a qualitative study among health professionals and caregivers. *BMC Oral Health*, 22(1), 116–116.
- Bradshaw, D. J., & Lynch, R. J. M. (2013). Diet and the microbial aetiology of dental caries: new paradigms. *International Dental Journal*, 63(s2), 64–72.
- Chan, A. K. Y., Tamrakar, M., Chloe Meng Jiang, Lo, E. C. M., Leung, K. C. M., & Chu, C. H. (2021). A Systematic Review on Caries Status of Older Adults. *International Journal of Environmental Research and Public Health*, 18(20), 10662–.
- Chapple, I. L. ., Bouchard, P., Cagetti, M. ., Campus, G., Carra, M.-C., Cocco, F., Nibali, L., Hujoel, P., Laine, M. ., Lingstrom, P., Manton, D. ., Montero, E., Pitts, N., Rangé, H.,

- Schlueter, N., Teughels, W., Twetman, S., van Loveren, C., van der Weijden, F., ... Schulte, A. . (2017). Interaction of lifestyle, behaviour or systemic diseases with dental caries and periodontal diseases:: consensus report of group 2 of the joint EFP/ORCA workshop on the boundaries between caries and periodontal diseases. *Journal of Clinical Periodontology*, 44(S18), S39–S51.
- Compton, K., DiGiorgio, C., & Burson, H. (2016). Dental pain management in patients with intellectual disabilities. *Journal of Pain Management*, 9(2), 177–.
  - Cullinan, M.P., Ford, P.J., & Seymour, G.J. (2009). Periodontal disease and systemic health: current status: An update in contemporary periodontics. *Australian Dental Journal*, 54.
  - Dentino, A., Lee, S., Mailhot, J., & Hefti, A. F. (2013). Principles of periodontology. *Periodontology 2000*, 61(1), 16–53.
  - Espinoza, K. M., & Heaton, L. J. (2016). Communicating with Patients with Special Health Care Needs. *The Dental Clinics of North America*, 60(3), 693–705.
  - Faulks, D., & Hennequin, M. (2000). Evaluation of a long-term oral health program by carers of children and adults with intellectual disabilities. *Special Care in Dentistry*, 20(5), 199–208.
  - Faulks, D., Hennequin, M., Albecker-Grappe, S., Maniere, M. C., Tardieu, C., Berthet, A., Wolikow, M., Droz, D., Koscielny, S., & Onody, P. (2007). Sedation with 50% nitrous oxide/oxygen for outpatient dental treatment in individuals with intellectual disability. *Developmental Medicine and Child Neurology*, 49(7), 621–.
  - Geddis-Regan, A. R., Gray, D., Buckingham, S., Misra, U., & Boyle, C. (2022). The use of general anaesthesia in special care dentistry: A clinical guideline from the British Society for Disability and Oral Health. *Special Care in Dentistry*, 42(S1), 3–32.
  - Ha, D. H., Crocombe, L. A., Khan, S., & Do, L. G. (2021). The impact of different determinants on the dental caries experience of children living in Australia rural and urban areas. *Community Dentistry and Oral Epidemiology*, 49(4), 337–345.
  - Jurasic, M. M., Gibson, G., Orner, M. B., Wehler, C. J., Jones, J. A., & Cabral, H. J. (2022). Topical Fluoride Effectiveness in High Caries Risk Adults. *Journal of Dental Research*, 101(8), 898–904.
  - Kinane, D. F., Stathopoulou, P. G., & Papapanou, P. N. (2017). Periodontal diseases. *Nature Reviews. Disease Primers*, 3(1), 17038–17038.

- Kouchaji, C. (2015). Complications of IV sedation for dental treatment in individuals with intellectual disability. *Egyptian Journal of Anaesthesia*, 31(2), 143–148.
- Lim, M. A. W. T., Liberali, S. A. C., Calache, H., Parashos, P., & Borromeo, G. L. (2021). Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs. *Special Care in Dentistry*, 41(3), 381–390.
- Mac Giolla Phadraig, C., Guerin, S., & Nunn, J. (2013). Train the trainer? A randomized controlled trial of a multi-tiered oral health education programme in community-based residential services for adults with intellectual disability. *Community Dentistry and Oral Epidemiology*, 41(2), 182–192.
- Machiulskiene, V., Campus, G., Carvalho, J. C., Dige, I., Ekstrand, K. R., Jablonski-Momeni, A., Maltz, M., Manton, D. J., Martignon, S., Martinez-Mier, E. A., Pitts, N. B., Schulte, A. G., Splieth, C. H., Tenuta, L. M. A., Ferreira Zandona, A., & Nyvad, B. (2020). Terminology of Dental Caries and Dental Caries Management: Consensus Report of a Workshop Organized by ORCA and Cariology Research Group of IADR. *Caries Research*, 54(1), 7–14.
- Maeda, S., Kita, F., Miyawaki, T., Takeuchi, K., Ishida, R., Egusa, M., & Shimada, M. (2005). Assessment of patients with intellectual disability using the International Classification of Functioning, Disability and Health to evaluate dental treatment tolerability. *Journal of Intellectual Disability Research*, 49(4), 253–259.
- Marinho, V. C., Higgins, J. P., Logan, S., & Sheiham, A. (2002). Fluoride varnishes for preventing dental caries in children and adolescents. *Cochrane Database of Systematic Reviews*, 3, CD002279–.
- Marinho, V. C., Higgins, J. P., Logan, S., & Sheiham, A. (2002). Fluoride varnishes for preventing dental caries in children and adolescents. *Cochrane Database of Systematic Reviews*, 3, CD002279–.
- Marsh, P. D. (2016). Dental Biofilms in Health and Disease. In *Understanding Dental Caries* (pp. 41–52). Springer International Publishing.
- Matthews, P. (2022). Prevention of dental caries in children and young people. *Nursing Children and Young People*.
- Meija, G. C. and D. H. Ha (2011), T. U. of A. (2011). Dental caries trends in Australian school children. *Australian Dental Journal*, 56(2), 227–230

- Ogle, O. E. (2016). Odontogenic Infections. *The Dental Clinics of North America*, 61(2), 235–252.
- Petrovic, B., Markovic, D., & Peric, T. (2011). Evaluating the population with intellectual disability unable to comply with routine dental treatment using the International Classification of Functioning, Disability and Health. *Disability and Rehabilitation*, 33(19-20), 1746–1754.
- Phlypo, I., Palmers, E., Janssens, L., Marks, L., Jacquet, W., & Declerck, D. (2020). The perception of oral health and oral care needs, barriers and current practices as perceived by managers and caregivers in organizations for people with disabilities in Flanders, Belgium. *Clinical Oral Investigations*, 24(6), 2061–2070.
- Pradhan, A. (2013). Oral health impact on quality of life among adults with disabilities: carer perceptions. *Australian Dental Journal*, 58(4), 526–530.
- Pretty, I. A., Ellwood, R. P., Lo, E. C. M., MacEntee, M. I., Müller, F., Rooney, E., Murray Thomson, W., Van der Putten, G.-J., Ghezzi, E. M., Walls, A., & Wolff, M. S. (2014). The Seattle Care Pathway for securing oral health in older patients. *Gerodontology*, 31(s1), 77–87.
- Salerno, C., Cirio, S., Zambon, G., Valeria D’Avola, Parcianello, R. G., Maspero, C., Campus, G., & Cagetti, M. G. (2023). Conscious Sedation for Dental Treatments in Subjects with Intellectual Disability: A Systematic Review and Meta-Analysis. *International Journal of Environmental Research and Public Health*, 20(3), 1779–
- Selwitz, R. H., Ismail, A. I., & Pitts, N. B. (2007). Dental caries. *The Lancet (British Edition)*, 369(9555), 51–59.
- Tan, A. (2009). Periodontal maintenance. *Australian Dental Journal*, 54, S110–S117.
- Tatakis, D. N., & Kumar, P. S. (2005). Etiology and Pathogenesis of Periodontal Diseases. *The Dental Clinics of North America*, 49(3), 491–516.
- Vytla, S., & Gebauer, D. (2017). Clinical guideline for the management of odontogenic infections in the tertiary setting. *Australian Dental Journal*, 62(4), 464–470.
- Waldman, H. B., & Perlman, S. P. (2012). Ensuring oral health for older individuals with intellectual and developmental disabilities: Oral health for the elderly with disabilities. *Journal of Clinical Nursing*, 21(7-8), 909–913.
- Walsh, L. J. (2000). Preventive dentistry for the general dental practitioner. *Australian Dental Journal*, 45(2), 76–82.

## **Learning outcomes**

Learning outcomes of the author of this thesis, Master of Philosophy (in the field of Dentistry) degree can be summarized below:

- To do a Systematic review based from the experience in doing Chapter 2
- To conduct a research project as in Chapter 5 in terms of applying for ethics, data collection and analysis.
- To interpret the result and draw conclusions.
- To understand the ID population and oral health.
- To understand the disease burden in ID population, to recognize the gaps in services to meet the oral health needs of ID patients.

During this course of M.Phil, the author has completed DENT6000 module of study and attended many workshops for thesis writing, on conducting literature review and data analysis with statisticians.

The oral presentations showcased as a part of MPhil study within University of Sydney:


- Dental Caries and Periodontal disease status in children & adolescents with cerebral palsy : A Systematic Review.
- Oral hygiene aids for patients with Intellectual Disability.



### Conferences and presentations:

Conference	Date	Title	Presentation Type
Oral Health Showcase SWSLHD, Sydney	4 <sup>th</sup> of September 2023	Intellectual disabilities, Acute Dental Infections and Tertiary Hospitals : an unsolved paradigm	Oral presentation
IADR – ANZ, Sydney	29 <sup>th</sup> of September 2023		Poster presentation

Appendix 1 : NSW Health Oral Health Specialist referral form

 <b>NSW</b> GOVERNMENT <b>Health</b>	FAMILY NAME		MRN	
	GIVEN NAME		<input type="checkbox"/> MALE <input type="checkbox"/> FEMALE	
	D.O.B. ____/____/____		M.O.	
	ADDRESS			
<b>ORAL HEALTH SPECIALIST REFERRAL</b>				
COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE				
<b>Indicate referral centre (✓)</b>	Sydney Dental Hospital <input type="checkbox"/>	Westmead Centre for Oral Health <input type="checkbox"/>	John Hunter Hospital <input type="checkbox"/>	Other _____
	Postal Address 2 Chalmers St Surry Hills NSW 2010	PO BOX 533 Wentworthville NSW 2145	Locked Bag 1 Hunter Region Mail Centre NSW 2310	_____
<b>Type of Specialist Service Required:</b>				
<b>Patient Information:</b>				
Home number:		Mobile:	Work number:	
Language spoken at home:		Country of Birth:		
Interpreter required <input type="checkbox"/> Yes <input type="checkbox"/> No		Aboriginal Liaison Officer required <input type="checkbox"/> Yes <input type="checkbox"/> No		
Medicare Card No. _____ (please provide all 11 numbers)				
Concession card: HCC or PCC (please circle)		Card No:	Start date:      Expiry date:	
<b>Referring Practitioner</b> <input type="checkbox"/> Medical <input type="checkbox"/> Dental <input type="checkbox"/> Other				
Type: <input type="checkbox"/> General <input type="checkbox"/> Specialist      Specialty _____				
Name:				
Address:				
Telephone:		Fax:	Email:	
Signature:		Date:		
<b>Patient's Medical and Dental Information</b>				
1. Significant <u>medical history</u> : (include any relevant access issues / special requirements / guardianship)				
2. Reason for referral and <u>treatment history</u> : (please ✓ the relevant box below to identify your request)				
I request: <input type="checkbox"/> an opinion <input type="checkbox"/> opinion and management by a specialist <input type="checkbox"/> general care (student only)				
3. Provisional <u>treatment plan</u> :				
4. Enclosures (please identify type e.g. radiograph, reports)				
■ _____ ■ _____ ■ _____				
Office Use Only: Clinic/Dept: _____      Waiting List _____ Date entered: _____      Signed: _____				

SMR010741

Holes punched as per AS2828.1:2012  
BINDING MARGIN - NO WRITING

NH606531 040714

ORAL HEALTH SPECIALIST REFERRAL

SMR010.741

Appendix 2 : Patient Questionnaire form

	<b>Patient de-identified serial number:</b>	
<b>S.NO</b>	<b>Questionnaire:</b>	
<b>1</b>	<b>Patient Details:</b>	
	<ul style="list-style-type: none"> <li>a. Date:</li> <li>b. Location:</li> <li>c. Patient's Identification Number:</li> <li>d. Attends with:</li> <li>e. Transport:</li> </ul>	
<b>2</b>	<b>Referral from:</b>	
	<ul style="list-style-type: none"> <li>a. Community Clinic</li> <li>b. Private Practitioner</li> <li>c. Other health practitioner</li> <li>d. Self-Presentation</li> <li>e. Other (Specify in detail)</li> </ul>	
<b>3</b>	<b>Referral for :</b>	
	<p><b>Reason for referral:</b></p> <ul style="list-style-type: none"> <li>a. Management of acute dental infection</li> <li>b. Management of acute facial swelling</li> <li>c. Management of behavioural issues</li> <li>d. Other (Specify in detail)</li> </ul> <p><b>Patient compliance as noted in referrals:</b></p> <ul style="list-style-type: none"> <li>a. Non-compliance</li> <li>b. Severe behavioural issues</li> <li>c. Physiological limitations</li> <li>d. Moderate compliance</li> <li>e. Good compliance</li> </ul>	
<b>4</b>	<b>Underlying medical concern:</b>	
	<ul style="list-style-type: none"> <li>a. Intellectual disability</li> <li>b. Physical disability</li> <li>c. Physical threat to the clinician</li> <li>d. GMFCS scale</li> <li>e. MACS scale</li> </ul>	

Appendix 2 : Patient Questionnaire form (Contd)

<b>5</b>	<b>ADLS:</b>	
<b>Katz Index of Independence in Activities of Daily Living</b>		
<b>ACTIVITIES POINTS (1 OR 0)</b>	<b>INDEPENDENCE: (1 POINT) NO supervision, direction or personal assistance</b>	<b>DEPENDENCE: (0 POINTS) WITH supervision, direction, personal assistance or total care</b>
BATHING POINTS: _____	Bathes self completely or needs help in bathing only a single part of the body.	Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.
DRESSING POINTS: _____	Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes	Needs help with dressing self or needs to be completely dressed.
TOILETING POINTS: _____	Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	Needs help transferring to the toilet, cleaning self or uses bedpan or commode.
TRANSFERRING POINTS: _____	Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable.	Needs help in moving from bed to chair or requires a complete transfer.
CONTINENCE POINTS: _____	Exercises complete self control over urination and defecation.	Is partially or totally incontinent of bowel or bladder.
FEEDING POINTS: _____	Gets food from plate into mouth without help. Preparation of food may be done by another person.	Needs partial or total help with feeding or requires parenteral feeding.
<b>TOTAL POINTS = _____ 6 = High (patient independent) 0 = Low (patient very dependent)</b>		
<b>6</b>	<b>Primary carer:</b>	
	<ul style="list-style-type: none"> <li>a. Immediate Family:</li> <li>b. Extended family:</li> <li>c. Group Home:</li> <li>d. Mental Health Unit in Hospital</li> <li>e. Other (Specify in detail);</li> </ul>	
<b>7</b>	<b>Diet History:</b>	
	<p><b>Diet Type:</b></p> <ul style="list-style-type: none"> <li>a. Oral</li> <li>b. PEG</li> <li>c. NG</li> <li>d. TPN</li> <li>e. Combination</li> </ul> <p><b>Snacking History:</b></p> <ul style="list-style-type: none"> <li>a. Frequent snacking</li> <li>b. Healthy snacking</li> <li>c. Nil by mouth</li> <li>d. Any medication with sugar</li> <li>e. Fluoride in drinking water</li> </ul>	

Appendix 2 : Patient Questionnaire form (Contd)

<b>8</b>	<b>Oral Hygiene:</b>	
	Dependency on brushing teeth: a. Independent b. Under supervision c. Partial support d. Full support Oral Hygiene habits: a. Frequency b. Toothbrush type c. Toothpaste type d. Any adjunct aids	
<b>9</b>	<b>Attendance to the dental appointments:</b>	
	a. Regular b. Irregular c. Unknown	
<b>10</b>	<b>Previous modality of dental treatment:</b>	
	a. GA b. Sedation – Oral/inhalational/IV sedation c. Normal settings d. Unknown	
<b>11</b>	<b>Oral Health understanding and motivation assessment:</b>	
	a. Very motivated b. Needs motivation and understanding c. Poor understanding and no motivation d. Unknown	
<b>12</b>	<b>Outcome of referral:</b>	
	a. Treatment under GA b. Deferred for medical and social reasons c. Other (Specify in detail)	
<b>13</b>	<b>Long term management plan:</b>	
	a. Referral to the primary clinician b. Placed in recall waitlist c. Other (Specify in detail)	
<b>Comments</b>		