

Oral health in an urban, Aboriginal and Torres Strait Islander community in Queensland, Australia and the development of a culturally specific health-related quality of life measurement tool

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Bachelor of Public Health

**Submitted in fulfilment of the requirement for the degree of
Doctor of Philosophy**

School of Public Health and Social Work

Faculty of Health

Queensland University of Technology

2020

Key Words

Australia, Aboriginal, children, dental caries, First Nations, Indigenous, oral health, quality of life, Torres Strait Islander, urban, wellbeing

Acknowledgement of Aboriginal and Torres Strait Islander peoples

My colleagues involved in the research presented in this thesis and I would like to acknowledge and pay our respects to the Traditional Custodians of the land in which this research took place, primarily the Turrbal, Jaggera and Gubbi Gubbi people. We also acknowledge the many nations and cultural groups that have contributed to this work.

Throughout this thesis, both Aboriginal and/or Torres Strait Islander peoples are referred to as 'First Nations' or 'Indigenous' people. In the first four publications associated with this thesis project, the term 'Indigenous' was chosen for sake of brevity, but also to recognise the shared experience of colonisation experienced by Aboriginal and Torres Strait Islander people, despite having different cultures and heritage. However, social preference in culturally appropriate terminology has evolved over the duration of the PhD project and thus the final publication utilises the term 'First Nations' to represent both Aboriginal and/or Torres Strait Islander people. The term 'First Nations' is thought to better acknowledge the sovereignty of the Aboriginal and/or Torres Strait Islander people in Australia.

When reading this thesis, it is important to understand that the work is not intended to be representative of, or generalisable to all Australian First Nations people. The studies provide some insight into the experiences of participants, readers should be cautioned against homogenising the findings to be reflective of all Australian First Nations people.

Abstract

Background

Oral diseases are a global public health concern. According to the Global Burden of Disease study, approximately 3.5 billion people around the world are affected by oral disease, the most common disease being dental caries. Dental caries is a decay of the tooth in the oral cavity which can cause pain, tooth loss and affect quality of life. Dental caries follows a social gradient and disproportionately affects individuals and populations that are marginalised and/or have lower socio-economic status.

Within Australia, Aboriginal and Torres Strait Islander (hereafter respectfully referred to as First Nations) populations experience worse oral health than their non-Indigenous counterparts. Despite being acknowledged as a priority population by the Australian Government's National Oral Health Plan since 2004, data on the oral health of First Nations peoples are lacking, particularly for preschool aged children and those living in urban areas. Likewise, there is limited understanding of how First Nations Australians perceive their experiences related to the oral health of their children and themselves. At present, there are limited opportunities to evaluate the experiences and implications of oral health for First Nations Australian children because a health and wellbeing measure has yet to be developed or validated for use with First Nations Australian children. How health and wellbeing is defined and perceived is thought to be different across cultures and as such, health metrics that are culturally specific and appropriate are required.

Thus, this thesis aimed to a) identify the prevalence of caries and the associated risk factors and indicators amongst urban First Nations Australian children aged less than five years b) understand the impact of child oral health on urban First Nations families and c) develop and validate a culturally specific parent-proxy health-related quality of life (HR-QoL) tool for use with First Nations Australian children.

Methods

To achieve the stated objectives, data were collected from three studies. The first study was part of a larger research project: a prospective cohort study of children aged less than five years registered with a primary health care service in Caboolture, Queensland. Comprehensive demographic, epidemiological, socio-economic, cultural and clinical data pertaining to oral health and respiratory health were collected on each child at baseline and monthly for 12 months. A basic oral examination of dentulous children to explore the presence of decayed, missing and filled teeth (dmft) was performed. Descriptive analyses of the baseline characteristics related to oral health were performed and a backwards stepwise logistic regression model was planned to identify potential associations with dmft status.

The second study utilised yarning circles and face-to-face interviews to document the experiences of parents/carers of urban, First Nations children. Participants were recruited from the first study and through word of mouth. The information collected was transcribed and analysed thematically. Codes and themes were confirmed by myself and two participants.

The third study was conducted over two phases. The first phase was a qualitative investigation of the concepts which First Nations Australian parents/carers of chronically ill children deemed to represent child HR-QoL. Participants were recruited through word of mouth and via established social and professional networks in Queensland and the Northern Territory of Australia. Yarning circles and face-to-face interviews were used to document the perspectives of parents/carers and the information collected was transcribed and analysed thematically and placed into a concept map.

The second phase of the third study involved piloting a survey developed from the HR-QoL concepts garnered in the first phase. The draft survey was piloted for appropriateness and acceptability, and then tested for validity with a larger population recruited primarily from the Queensland Children's Hospital.

Participants also completed comparison scales including a generic Quality of Life measure, the PedsQL 4.0 and the Spence Childhood Anxiety Scale. The scales were then repeated by a sub-set of participants four weeks later.

Results

Study 1 resulted in 180 children enrolled and 111 children receiving an oral examination, of whom 14 (12.6%) (mean age 35 months) were estimated to have dmft >0. There was a high prevalence of socio-economic, dietary and behavioural risk factors/indicators present for children. Due to the small sample size, a stable regression model to identify independent predictors of dmft could not be achieved.

The findings of Study 2 indicated that oral health is an important issue for urban First Nations families and maintaining oral health to a desired standard is having emotional, physical and financial impacts. The themes identified were financial concerns, worry about the future and juggling multiple priorities; all of which were inter-related and cyclical. Additional findings unrelated to the initial objective of study was the oral health experiences of mothers in the study. The women shared their personal narratives on the topic of oral health which were reflective of different time points in their life: growing up, as an adult and as a mother/carer. Although women were trying to support their oral health across their life-course, they faced a number of barriers, including a lack of information and the costs of accessing dental care. The teenage years and pregnancy were reported as important time periods for oral health support.

The first phase of Study 3 established that HR-QoL is defined as more than just physical, social and psychological wellbeing. Family and social support are valued aspects of HR-QoL, as is knowledge, communication and the relationship with the health system. Participants described the importance of being heard and their voice trusted and valued by health practitioners. Racism and prejudicial behaviour had negative impacts on HR-QoL.

The second phase of Study 3 established a tool that was both acceptable and appropriate for use with First Nations Australian families within the sample tested. Of the 263 parents/carers enrolled to participate in the validation, 163 participated, completing either the paper-based or online survey. The survey was completed by 46 of the 163 participants four weeks later. The novel HR-QoL tool demonstrated good internal scale reliability, with Cronbach alpha coefficients of ≥ 0.7 . Good test-retest reliability was observed for the overall scale ($r=0.753$; Confidence Interval (CI): 0.593-0.856). The novel HR-QoL was moderately to strongly correlated to the PedsQL, with Pearson's coefficients of $r=0.681$ for ages two to four years and $r=0.651$ for ages five to 12 years suggesting acceptable convergent validity against comparison measures. Divergent validity was not demonstrated against the Spence Anxiety Scales, the novel HR-QoL tool being moderately correlated to both the preschool ($r=-.466$) and school age ($r=-.535$) scales.

Conclusion

The findings of this thesis contribute new knowledge to the area of urban First Nations Australian health and wellbeing. Overall First Nations Australians are disproportionately affected by poor oral health and yet prior to this thesis there were no contemporary data on the oral health experiences of preschool aged children living in urban areas, nor any understanding of how their families were coping with their oral health. The findings of this study demonstrate that urban First Nations children continue to be adversely affected by preventable oral disease and this has implications for them and for their family's quality of life.

Given these challenges, there was a need for culturally specific screening tools that can evaluate the oral health and wellbeing of First Nations Australians. This thesis has resulted in the first validated culturally-specific parent-proxy general HR-QoL tool which can inform the development of disease specific tools, such as those needed in oral health contexts.

Thesis format

This thesis is the culmination of three studies and the five corresponding articles that have been published or submitted for publication at appropriate journals. The

articles have been arranged to ensure a logical flow throughout the thesis.

Although the articles are presented as they have been published, they have been reformatted using the Vancouver referencing style and reconfigured to Word so as

to ensure a consistent format for readers. Furthermore, tables and figures have

been numbered sequentially as they appear in the thesis.

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List of publications

Published papers included in this thesis

1. Bitten K, Johnson NW, Hall KK, Anderson J, Toombs M, King N, O'Grady KAF. Risk factors for oral health in young, urban, Aboriginal and Torres Strait Islander children. Australian Dental Journal. 2019 Mar;64(1):72-81.
2. Bitten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF. Impact of oral health on Australian urban Aboriginal and Torres Strait Islander families: a qualitative study. International Journal for Equity in Health. 2019;18(1):34.
3. Bitten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF. Yarning about oral health: perceptions of urban Aboriginal and Torres Strait Islander women. BMC Oral Health. 2020;20(1):1-12.
4. Bitten K, Newcombe PA, Chang AB, Sheffield JK, O'Grady KA, Johnson NW, King N, Toombs M. Concepts of Health-Related Quality of Life of Australian Aboriginal and Torres Strait Islander Children: Parent Perceptions. Applied Research in Quality of Life. 2020 May 6; 1-19.

Submitted manuscripts included in this thesis

5. Bitten K, Jones L, Newcombe P, Chang AB, Sheffield JK, O'Grady KAF, Johnson NW, Bell AM, Ross G & Toombs M. Development and validation of a parent proxy health-related quality of life survey for Australian First Nations children. Submitted to Quality of Life Research April 18th, 2020.

Other publications produced during candidature

1. Toombs M, Nasir B, Kisely S, Kondalsamy-Chennakesavan S, Hides L, Gill N, Beccaria G, Brennan-Olsen S, **Bitten K**, Nicholson G. (2020) 'Protocol for a randomised controlled trial of an Australian Indigenous model of mental health care based on transdiagnostic CBT co-designed with Indigenous Community.' BJPsych Open. 2020;6(3):e39.

List of Presentations

1. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Risk factors for dental caries: prevalence in young, urban, Aboriginal and Torres Strait Islander Children. Oral presentation at Children's Health Symposium, November 1st, 2017 in Brisbane, Australia
2. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Risk factors for dental caries: prevalence in young, urban, Aboriginal and Torres Strait Islander Children. Oral presentation at Public Health Prevention Conference on May 2nd, 2018 in Sydney, Australia
3. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Impact of dental caries in young, urban, Aboriginal and Torres Strait Islander Children. Oral presentation at Public Health Prevention Conference on May 2nd, 2018 in Sydney, Australia
4. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Impact of dental caries in young, urban, Aboriginal and Torres Strait Islander Children. Oral presentation at Centre at Children's Health Symposium on June 1st, 2018 in Brisbane, Australia
5. Bitten K, Newcombe PA, Chang AB, Sheffield JK, O'Grady KF, Johnson NW, King N, Toombs M. Concepts of health-related quality of life of Australian Aboriginal and Torres Strait Islander children: parent perceptions. Poster presentation at International Meeting on Indigenous Child Health in Calgary, Canada on March 22nd to 24th 2019
6. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Risk factors for dental caries: prevalence in young, urban, Aboriginal and Torres Strait Islander Children. Poster presentation at International Meeting on Indigenous Child Health in Calgary, Canada on March 22nd to 24th 2019
7. Bitten KL, Johnson NW, Hall K, Anderson J, Toombs M, King N, O'Grady KA. Impact of dental caries in young, urban, Aboriginal and Torres Strait Islander Children. Poster presentation at International Meeting on Indigenous Child Health in Calgary, Canada on March 22nd to 24th 2019
8. Bitten K, Newcombe PA, Chang AB, Sheffield JK, O'Grady KF, Johnson NW, King N, Toombs M. Concepts of health-related quality of life of Australian Aboriginal and Torres Strait Islander children: parent perceptions. Oral presentation at Children's Health Symposium on August 29th, 2019 in Brisbane, Australia

List of abbreviations

ADA	Australian Dental Association
ADG	Australian Dietary Guidelines
AIHW	Australian Institute of Health and Welfare
ABS	Australian Bureau of Statistics
CDHS 2010	Child Dental Health Survey 2010
CI	Confidence Interval
DMFS	Decayed Missing and Filled Surfaces
DMFT	Decayed Missing and Filled Teeth
ECC	Early Childhood Caries
HR-QoL	Health-Related Quality of Life
ICDAS	International Caries Detection and Assessment System
NCOHS 2012-2014	National Child Oral Health Study 2012-2014
NHMRC	National Health and Medical Research Council
OR	Odds Ratio
QoL	Quality of Life
SD	Standard Deviation
SE	Socio-Economic
SiC	Significant Caries Index
SSB	Sugar Sweetened Beverage
WHO	World Health Organization

Statement of original authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

[QUT Verified Signature](#)

Kaley Batten

August 19th, 2020

Acknowledgements

To the many participants who shared their time, stories, insights and knowledge with me, thank you. I feel privileged to have worked alongside you. Your passion and vision for better quality health care has inspired and created this body of work. Thank you for sharing with me.

They say it takes a village to raise a child, the same could be said for a PhD student. I am incredibly grateful to my exceptional supervisory team: A/Prof Kerry-Ann O’Grady, A/Prof Maree Toombs, Emeritus Prof Newell Johnson, Prof Neil King and A/ Prof Peter Newcombe. I am so very thankful for all your mentorship and guidance the past three years. You have been kind, supportive and generous with your time and expertise. Thank you.

Kerry-Ann, sitting in such close proximity to a student is a brave move and a testament to your ethos and dedication to your flock. You are a wonderful teacher and it has been a pleasure to be your student. I cannot thank you enough for always being in my corner and going above and beyond to help me reach my goals. Thank you.

Prof Anne Chang and A/Prof Jeanie Sheffield. Thank you both for sharing your time, skills and wisdom along the way and in facilitating the health-related quality of life project.

My sincere thanks to both the RiOAR and CAARG teams. What luck to land in with such a kind, funny and clever crew. Your good company, mateship and support has been invaluable. I have learned so much from everyone. Thank you, Dr Kerry Hall for your hard work in establishing the oral health study and trusting me to work with a community that you hold dear. Thank you, Gregg Ross and Anna-Maria Bell for taking me under your wings and helping me to become a part of the hospital community – and for the many yarns – work related and not.

Bradley, Angel and Vincent. Thank you for keeping the home fires burning and supporting my curiosity and development. You are wonderful men and I love you. My in-laws, Therese and Peter, there are no words to express my gratitude for your unwavering logistical and emotional support. Thank you. Canucks, the village that

you are, and my parents (Mom, Fadja and Dale), grandparents and Aunty Kelly.
Thank you for the love you put in and for cheering me on.

This PhD is dedicated to my mum, Lisa, who loved me enough to give me wings,
even though they would inevitably carry me away from her. ♥

Funding

Funding for Study 1 and Study 2 was provided through a Queensland Children's Medical Research Institute Project Grant, UQ Foundation Research Excellence Award, and a Queensland University of Technology Indigenous Health start-up research grant and support from the NHMRC Centre for Research excellence in Lung Health of Aboriginal and Torres Strait Islander Children (1040830). Study 3 was funded by a Children's Hospital Foundation Early Career Fellowship grant (50227), QUT Child and Adolescent Health Program Funding Support and Public Health and Social Work Higher Research Degree Funding Support.

During my PhD I was fortunate to have been supported by a Supervisor Scholarship, a scholarship from a Children's Hospital Foundation Early Career Fellowship grant (50227) and a travel grant from the Children's Hospital Foundation (50256) and a QUT Faculty of Health scholarship.

Prologue

The seed for this project was planted long before I had the privilege to become involved. In 2012 my primary supervisor, A/Prof Kerry-Ann O'Grady and the now Dr Kerry Hall were collaborating with an Aboriginal owned and operated primary health care clinic in Caboolture, Brisbane. As part of her PhD project, Dr Hall was investigating respiratory illness in young First Nations children. The clinic would be the primary study and recruitment site. In discussions with the clinic and other community members, it became apparent that oral health was also an important issue for the wider community, yet there was little information on the scope or severity of the health problem, particularly for the youngest community members.

With this information, the Respiratory Infection Outreach and Research (RiOaR) team launched the prospective cohort study titled 'Tooth and Lung Sickness in Murri Kids' (TLISM) in February 2013 and completed recruitment in October 2015. Amongst the respiratory investigations, basic clinical investigations into the prevalence of decayed, missing and filled teeth were undertaken for First Nations children under the age of five, and data were collected on participant demographics, health history, culture, and potential oral health risk factors.

In 2016, I came to speak to A/Prof O'Grady about what a Masters project might look like. I had completed my Bachelor of Public Health in 2015 and after a year of working in research administration, I realised that I wasn't finished learning. I approached A/Prof O'Grady because since studying, the 'health-space' I felt most comfortable in and the space I wanted to make a difference in was reflective of home. Growing up in Canada on unceded Coast Salish land, the consequences of colonisation were familiar to me. My childhood best friends were First Nations women and I had heard their family stories of hardship and resilience: family being put into residential school, culture and traditions lost, people moving forward in spite of history and circumstance. I realised these experiences are shared in

Australia. Although our cultures and countries are different, many of the barriers experienced by First Nations people globally are the same.

A/Prof O’Grady suggested a number of possible projects that I could get involved in, and I went with what was familiar. Like Australia, Canada does not have publicly funded dental care and growing up, my family and I felt the impact of that. As a small child I suffered from caries in my baby teeth and went on to have a mouth full of silver fillings. Because my mum could not afford to go to the dentist herself, oral health education was limited and we learned together, after the fact.

In 2017 I commenced a Masters of Public Health (Research) to process the oral health data A/Prof O’Grady and Dr Hall had collected, with a view to articulating to a PhD if the community interest was there for additional research. We knew that the community had more to say about oral health and so we organised for a qualitative study to complement the quantitative findings. This research was very well received and there was considerable interest in launching a school dental screening service and health promotion/education intervention into the local high schools on advice from local elders. However, achieving the level of stakeholder engagement within the time frame of a post graduate degree proved challenging. Resources were sourced for the community to use, but in late November 2017 a decision needed to be made about whether to go ahead with the project given insufficient buy-in from all stakeholders and with the feasibility of completing the trial within the timeframe of a PhD. However, we felt it prudent to continue on with a project, given the relationships that had been fostered. It was decided that I would change my focus to another area, Health-Related Quality of Life (HR-QoL).

A number of HR-QoL issues arose during our qualitative oral health investigations that warranted more research in their own right. It was also something that had been discussed with the Australian Research Centre for Population Oral Health early

on in my study. The director of the Indigenous Oral Health Research Unit, Professor Lisa Jamieson, indicated that HR-QoL was a top priority for oral health research in Australia and yet the work had yet to be done. There was no measurement tool in Australia to measure HR-QoL for First Nations Australians, in general or for oral health. Given our findings, it was decided that I would take over research that had been commenced by one of my other supervisors, A/Prof Maree Toombs. A/Prof Toombs and others had begun qualitative investigations into HR-QoL years previously, but like many projects can, it had lost its momentum. With our latest findings and funding from the Children's Health Foundation, we re-established the study.

Fast-forward, and although we have not fully validated an oral health specific HR-QoL measure, we have contributed much needed data on the topic of oral health for young, urban First Nations children and their families, and have laid a foundation for First Nations Australian HR-QoL measures generally. There is much work to be done, but it is a solid start.

1 INTRODUCTION

This section outlines the context and rationale of this thesis. It provides a short background on the research topics, the aims and main objectives of the studies and the settings in which the research took place.

1.1 BACKGROUND

The process of colonisation has had deleterious effects on the health and wellbeing of First Nations Australian people.¹ While there have been efforts to understand and address the damage that has been caused, there remains large gaps in data and culturally respectful understanding to progress health issues at a population level. In a research context, this insufficiency can be attributed to a number of factors including, but not limited to:

- a) Research and health services have a history of paternalism. Historically and in many contemporary settings, a solution has been assumed without consultation or understanding of the individual/patient/stakeholder/community;²
- b) The majority of research has taken place in rural and remote locations, despite First Nations Australians predominantly living in urban locations³ and;
- c) Inadequate and insufficient identification of First Nations Australians within overall population metrics.⁴

One area of health that has been raised as an area of concern for First Nations Australians is oral health. As mentioned previously, community members in northern Brisbane shared their desire for more oral health information and resources. According to community leaders, oral health was a major health issue for the community and yet there were limited empirical data to lobby for change and

increase resources. The community appraisal of the status of oral health for First Nations Australians is supported in the available literature.

However, data on the prevalence of caries experienced by First Nations Australian children are lacking.⁴ Of the studies undertaken, few provide data on children under five years of age or for those outside a school environment.⁴ There are limited data on urban locations, and in national collections the states of New South Wales and Victoria have been left out regularly, as has Indigenous status across Australia due to inconsistencies in reporting and study design. Few studies have attempted to measure the relationship between caries and potential risk factors.⁴ Risk factors for different populations may vary, particularly between urban, rural and remote populations. Caries prevalence in urban First Nations children is less than that of rural and remote populations.⁵ However, it is still considerably higher than that of non-Indigenous populations, even when children are from affluent areas.⁵ While some risk factors have been well studied, such as the impact of diet, others have not, particularly coming from low-income and racially diverse families.⁶⁻⁸

Additionally, there is very little qualitative research in regard to the oral health of First Nations Australians overall. Of the studies undertaken, only one has aimed to understand the impacts of oral health from the perspective of parents and carers.⁹ Research and program development have a history of Euro-centrism and paternalism within First Nations populations.¹⁰ Those in positions of power have intervened without consultation, collaboration or understanding.¹⁰ Failing to recognise First Nations perspectives is at the very least an impediment to progress and worst, harmful.⁹ According to the research, participants have reported a number of different barriers to care, including discrimination and services that are not family friendly.^{9, 11} There are also impacts on child and family HR-QoL.

HR-QoL does not have a standardised definition, but is typically modelled on the World Health Organization's definition of health, which suggests that health is not just absence of illness, but the state of complete physical, emotional and social wellbeing.¹² This notion of HR-QoL has always been open to interpretation and remains a subjective concept, influenced by a person's conceptualisation of health, environment and culture. Yet, it is most typically attributed with being comfortable with your physical function and being able to participate in life at a physical, social and emotional level i.e. being able to work or go to school, eat, sleep, and engage with friends and family. Within an oral health context, First Nations Australian people experience considerable inequities in their lived environment which has implications for oral HR-QoL. For example, in qualitative studies First Nations Australians report avoiding professional prophylactic care and delaying treatment when needed because of the cost.^{11, 13} These circumstances and others can result in poor oral health which can be debilitating and prevent individuals from participating in their life as they normally would.

While there is an interest in better understanding the oral health specific HR-QoL experiences of First Nations Australians, we are unable to do so. This is because there has yet to be a validated instrument to measure HR-QoL in this population, let alone a disease specific measure.¹⁴ In order for health psychometrics to be effective, they must incorporate concepts determined by the populations to which they are applied.¹⁵ It is suggested that available instruments do not adequately capture those concepts which are reflective of HR-QoL as determined by First Nations Australians.¹⁴ Family, community, and connection are all concepts attributed to the health and wellbeing of First Nations Australians, yet they are not typically included in available measures. Those working in the wellbeing space for First Nations Australians advise that, not only do measures need to be created that include established concepts, as those mentioned above, but more research is needed to properly understand what other values may be relevant and incorporated into tools.¹⁶ This would entail engaging with First Nations Australian people that have experienced ongoing deficits to their health, such as that of

chronic illness, to understand what aspects of their life are influenced by health and what that means for their quality of life.

1.2 AIM, OBJECTIVES AND RESEARCH QUESTIONS

1.2.1 Aim

The aim of this thesis was to better understand the oral health of status of young urban First Nations Australian children, understand the impacts of oral health from the perspective of their parents and carers, and develop a way to measure the HR-QoL impacts experienced by children. To facilitate this aim, three studies addressing specific objectives and research questions were undertaken.

1.2.2 OBJECTIVES

STUDY 1: Investigating the prevalence of caries and risk factors and risk indicators for oral health

1. To determine the prevalence of known risk factors and risk indicators for dental caries in urban First Nations children aged zero to five years registered with a primary health care practice in Brisbane, Queensland.
2. To determine the prevalence of decayed, missing and filled teeth in a population of urban First Nations children aged zero to five years registered with a primary health care practice in Brisbane, Queensland.
3. To determine what socio-cultural, environmental and physiological factors are associated with dental caries.

STUDY 2: Exploring the impact on families

4. To determine the impacts of child oral health on urban First Nations families from the perspective of parents and carers.

STUDY 3: Develop and validate a health-related quality of life measurement tool

5. To develop and validate a generic HR-QoL tool for use with First Nations children aged zero to 12 years

1.2.3 RESEARCH QUESTIONS

Study 1: Among First Nations Australian children aged less than five years living in an urban area in Australia:

- a) What is the prevalence of decayed, missing and filled teeth (dmft) due to dental caries?
- b) What known risk factors and risk indicators are prevalent?
- c) What socio-cultural, environmental and physiological risk factors and risk indicators are associated with having dmft?

Study 2: According to parents and carers that have cared for First Nations Australian children aged less than five years living in an urban area of Australia, what are the impacts of child oral health on families?

Study 3, Phase 1:

- a) According to First Nations Australian parents and carers of children aged less than 18 years with a chronic illness, what concepts are representative of HR-QoL for First Nations Australian children?
- b) According to professionals in the field of First Nations Australian child health, what concepts are representative of HR-QoL for First Nations Australian children for inclusion in a draft survey tool on HR-QoL?

Study 3. Phase 2:

- a) According to First Nations Australian parents and carers of children aged less than 13 years, is the formulation of a draft survey tool on HR-QoL applicable and appropriate to be used with a wider population?

In a population of parents and carers of First Nations Australian children aged less than 13 years:

- b) What are the latent factors of a draft HR-QoL survey tool?
- c) Does the draft HR-QoL survey tool demonstrate internal consistency?
- d) Does the draft HR-QoL survey tool demonstrate test-retest reliability?
- e) Does the draft HR-QoL survey tool demonstrate known-group validity?
- f) Does the draft HR-QoL survey tool demonstrate convergent validity?
- g) Does the draft HR-QoL survey tool demonstrate divergent validity?

1.3 SETTING

The setting for this thesis varied between studies. The first two studies were conducted in Caboolture, a northern suburb of Brisbane, Queensland. According to the 2016 Australian National Census, 4.8% of Caboolture's population of 67,460 people identified as First Nations Australians. The First Nations population being higher than the rest of Queensland (4.0%) and of Australia overall (2.8%).¹⁷ An Aboriginal owned and operated primary health care clinic located on the main street of Caboolture was the primary recruitment site for the first study. The clinic hosted general medical practitioners, First Nations Health Workers and midwives; as well as being affiliated with a dental clinic within the same building complex. The clinic was open to everyone, but also offered First Nations specific health services and thus had a large First Nations population. Of the clinic's 11,229 registered clients,

59% identified as First Nations Australians. The first study operated from within the clinic premises, recruiting eligible participants as they utilised the clinic services.

Participants for the second study were recruited from the same participant group as the first study, using the contact details provided by the participant. The details of Study 2 were also shared through word of mouth through the clinic, so that anyone that did not participate in the first study could have the opportunity.

The third study had two phases: 1) developing the tool and 2) validating the tool. The first phase involved gathering perspectives from First Nations Australian parents and carers. To do this, both personal and professional networks were used. Participants from Study 1 and 2 were approached to participate as well as people from other areas including Toowoomba and Darwin.

Toowoomba is a regional area of South East Queensland, approximately 120 kilometres west of Brisbane with a population of 149,512 people, 3.9% of whom identify as First Nations Australians.¹⁸ Participants were recruited through professional connections with Carbal Medical Services. Carbal Medical Services is an Aboriginal Health Corporation. They have two clinics; one is in the Toowoomba city centre and one in the town of Warwick, which is 30 minutes' drive from Toowoomba.

Darwin is a port city in the Northern Territory of Australia. It has one of the highest proportions of First Nations Australian residents of any capital city in Australia; 8.7% of the population's 136,828 people identify as First Nations Australians.¹⁹ The Darwin Hospital draws many people from the surrounding regions to Darwin for health care, including remote and very remote locations in northern Australia and the islands north of Australia. Participants were recruited via professional connections with the Menzies School of Health Research. Menzies is a large research institute based on the Darwin Hospital complex.

The second phase of the third study was undertaken primarily at the Queensland Children's Hospital, which is the only tertiary children's hospital in Queensland. Like Darwin, along with locals, people from all other regional, rural and remote areas are referred and transferred to the hospital for the facilities and/or specialist care. The hospital runs numerous outpatients' clinics which include, but are not limited to dermatology, otolaryngology, audiology, physiotherapy, ophthalmology, psychology, orthopaedics, general paediatrics, cardiology and oncology. The hospital provides for patients needing day procedures, short stays and longer care. Participants were recruited in collaboration with the First Nations Liaison officers at the hospital from outpatient clinics and wards.

1.4 SUMMARY

- There are insufficient contemporary data on the prevalence of caries and the associated risk factors and risk indicators experienced by urban First Nations Australians, particularly children under the age of five years.
- Little is known about the impact of child oral health on urban First Nations families from the perspective of parents and carers; only one study has been previously published.
- There is a limited understanding of how oral health is perceived and experienced from the perspective of urban First Nations Australians, particularly women. Research suggests there may be barriers to oral health care specific to First Nations Australian women and families.
- First Nations Australian perceptions of health and wellbeing have been found to be different to non-Indigenous Australians. A better understanding of how HR-QoL is perceived by First Nations Australians is needed before disease specific psychometrics can be developed and applied.

1.5 SIGNIFICANCE OF THE RESEARCH

The negative effects of colonisation have been long-lasting and are evident in the health disparities experienced by First Nations Australians compared to their non-Indigenous counterparts.¹ In order to address these inequities, a better understanding of the current health experiences which are important to First Nations Australians is needed.²⁰ Oral health is one area of health where there are limited contemporary data.⁴ In reviewing the available literature on the oral health of First Nations Australian children, de Silva et al advise that there are currently insufficient data to *'inform the development of policies and programs to address the oral health differences in Indigenous populations living contemporary lives in metropolitan areas'*.⁴ Although an overall disparity is evident, there are no current data on the prevalence of dental caries for First Nations Australian children aged less than five years.⁴ Likewise, there are very little data on risk factors and risk indicators for poor oral health experienced by young, urban First Nations Australian children.²¹

This research presents the first data in over 10 years⁴ which describes the prevalence of dental caries amongst young urban First Nations Australian children in one urban setting and reports the prevalence of risk factors and risk indicators for dental caries experienced by the population. The findings of these investigations can be used to inform resource provision and health promotion within urban settings. They add to the understanding of the risk factors specific to very young children. Adding to the body of knowledge of age and culturally specific risk factors is likely to result in more effective oral health policies and programs which are urgently needed for this priority population.

In addition to these quantitative oral health investigations, this research includes the first qualitative study in Queensland (and the second qualitative study in Australia overall)⁹ to investigate First Nations Australian child oral health from the perspective of parents and carers. The study highlights the impacts of child oral

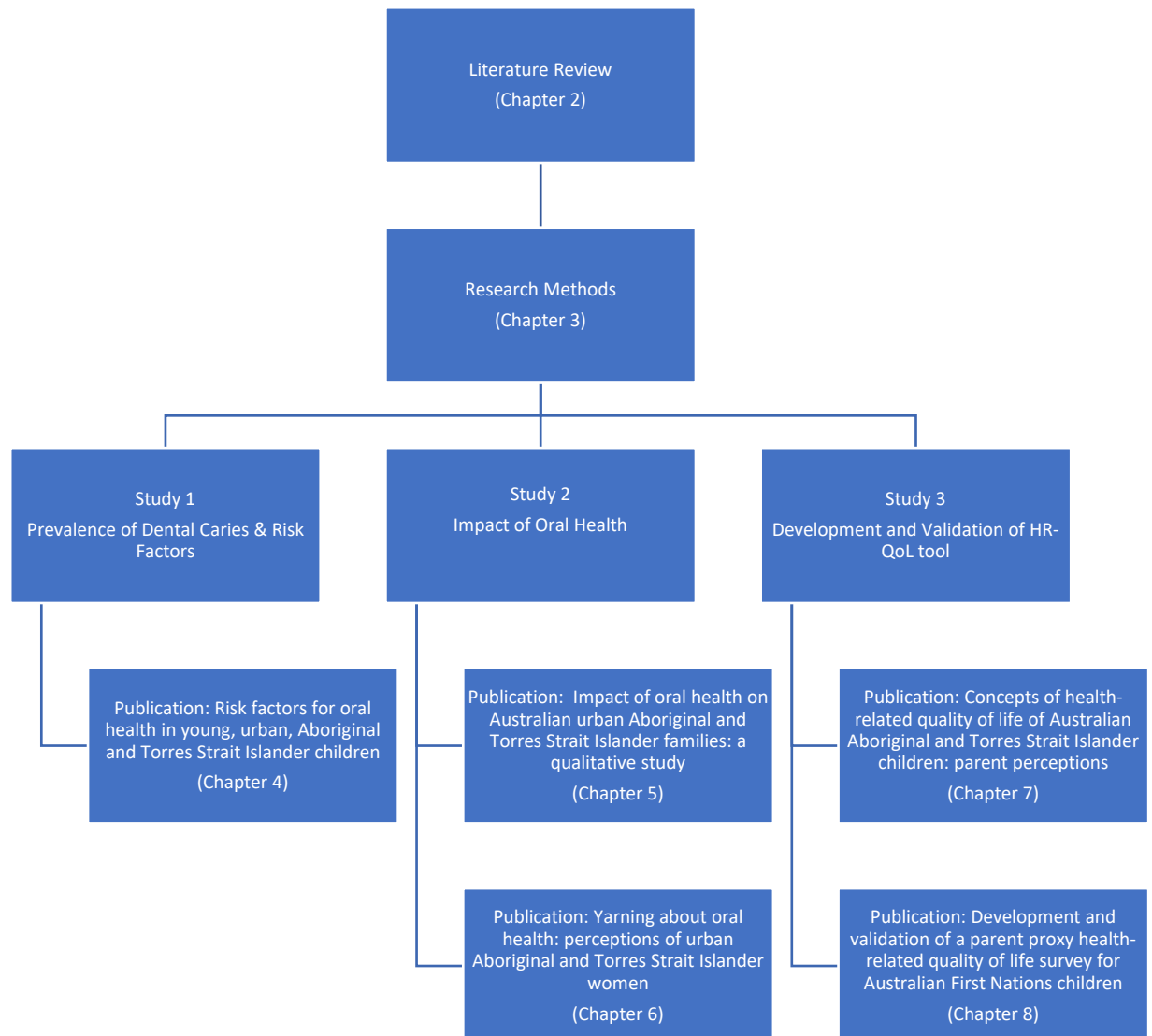
health on families from the perspective of parents and carers and provides a platform for First Nations Australian parents and carers to share their thoughts on oral health. Understanding the complexity of oral health issues as well as the social context in which they occur is considered necessary for progressing the health of First Nations Australians.⁹ As has been mentioned previously, there has been a history of insufficient consultation with First Nations Australians with respect to their health needs and experiences and this has resulted in inappropriate services and poor uptake of interventions.²² An understanding of First Nations Australian perspectives with respect to oral health is needed to inform the delivery of current oral health services and form new ways of supporting vulnerable populations.⁹ The incorporation of First Nations Australian experiences and ideas is likely to result in health care and health promotion that is more relevant and equitable for First Nations Australians.

In Study 3, we aimed to address health equity via the development of a culturally specific HR-QoL measurement tool. As has been highlighted, health care should be reflective of the population it aims to serve and at present there is yet to be a validated tool for investigating the HR-QoL of First Nations Australian children.¹⁴ Patient reported outcomes and experience measures are now commonplace within clinical and research settings, providing health professionals valuable insight into patient's subjective health status.¹⁴ Understanding a patient's experiences can be used to inform treatment options and tailor health services to both individuals and populations.¹⁵ However, First Nations Australians are not adequately represented in the available measures. This research not only defined which concepts should be included in child HR-QoL measurement tools according to First Nations Australians parents and carers but determined whether a culturally specific tool is more effective in measuring HR-QoL than available measures in one small sample. This work is significant because it provides a foundation for future disease-specific and age-specific tools to be developed, increasing the opportunity for health metrics to be utilised appropriately and effectively with First Nations Australians and potentially other Indigenous populations globally.

1.6 OUTLINE OF THIS THESIS

This thesis consists of nine chapters, five of which are/will be publications (four currently published, and one submitted April 18th, 2020). Figure 1 outlines the research studies and associated publications and chapters.

Figure 1. Diagram of research studies and publications included in thesis



Chapter 2 is a review of the existing literature relevant to the three studies included in the thesis. It provides an overview of the study topics generally and where possible describes what is known about the topic in a First Nations Australian context. It includes a summary of the existing research describing the prevalence of caries and the associated risk factors. It also describes what is known about the impact of oral health on children, families and women and discusses some of the ways that impact is perceived and measured. The chapter provides a brief introduction into the practice of measuring quality of life and the considerations relating to cultural perceptions of health that need to be made when developing a psychometric HR-QoL tool. This chapter is my own work with minor editing by my supervisors.

Chapter 3 describes the study design and methods used in the three studies included in this thesis. As the methods for each study are included in Chapters 4 to 8 as part of the manuscripts for publication, this chapter provides an overview of the methods as well as any supplementary details that were unable to be included into the publications because of word count limitations. This chapter is my own work, with minor editing by my supervisors.

Chapter 4 is the first publication and describes the results of the analysis of oral health data collected during Study 1. The investigation focused on the prevalence of caries and associated risk factors in young, urban First Nations children. For this chapter I was responsible for cleaning and analysing all the data and producing the first and final versions of the manuscript. I received guidance on the planning and interpretation of the statistical analysis from my supervisors.

Chapter 5 is the second publication and describes the primary results of Study 2, which was a qualitative investigation of the impact of child oral health on urban First Nations families. This chapter reports on the initial research question, which aimed

to understand from the perspective of parents/carers how child oral health impacted on family life. For this chapter I was responsible for conceptualising, developing and facilitating the qualitative study; developing study materials, collecting, cleaning, transcribing and analysing the data; and preparing the first and final manuscript. Guidance on cultural protocols and interpretation of data was provided by my supervisors and co-authors. I also received assistance from a co-author in transcribing a portion of the data.

Chapter 6 is the third publication and describes the secondary results of Study 2. The data collected in this chapter were opportunistic and reflected the oral health experiences of the participants in Study 2. Although this chapter does not answer a specific research question, it reports on the topics that are important to the participants. As previously described, I was responsible for all aspects of Study 2 and received advice from my co-authors and supervisors in the preparation and publication of these additional findings specifically. I was responsible for the first and final version of the manuscript.

Chapter 7 is the fourth publication and describes the qualitative findings of Phase 1 of Study 3, which qualitatively investigated how First Nations Australian parents and carers perceive child HR-QoL. This phase of the study had previous ethics approval and thus I was responsible for updating the ethics and study protocol, facilitating additional data collection, data cleaning and analysing the data. I was responsible for the first and final version of the manuscript. Guidance on cultural protocols and interpretation of data was provided by my supervisors and co-authors.

Chapter 8 is the fifth publication and describes the findings of Phase 2 of Study 3, which aimed to statistically validate a novel culturally specific HR-QoL measurement tool based on the findings of the qualitative study in Phase 1. This chapter also describes the steps taken to develop the tool and the results of the statistical

validation. The premise for this phase of the study had been conceptualised previously and thus I was responsible for establishing and facilitating the study, designing the study materials, collecting, cleaning and performing basic analysis of the data. Assistance analysing and interpreting the statistical validity of the tool was provided by a statistician, and my supervisors and co-authors. I was responsible for the first and final version of the manuscript.

Chapter 9 summarises the study findings as they relate to each research question and thesis overall. The chapter addresses the strengths and limitations of the studies included in the thesis and discusses the implications of the findings and directions for future research. This chapter is my own work, with minor editing by my supervisors.

2 LITERATURE REVIEW

This section provides a summary of the available literature on the study topics. It is organised in study order with reference to the three overarching topics of this thesis:

- 1) investigating the prevalence of dental caries and the associated risk factors;
- 2) understanding the impact of oral health and;
- 3) developing and validating a HR-QoL tool for First Nations children.

All three studies are focused on First Nations Australian populations and thus the review aims to reflect the available culturally specific literature. However, given the specificity of the population, the literature is supplemented with relevant international studies giving a global and national context for the data.

2.1 WHAT IS DENTAL CARIES?

Dental caries is a disease of the oral cavity and are associated with significant morbidity. If untreated, caries can have physical, emotional and psychological consequences. In children and adolescents, the pain associated with caries can influence sleep, growth, development, behaviour, learning and well-being²³, while the physiological impact of the caries can lead to a loss of dentition, hospitalisation and long-term consequences to both oral and general health.²⁴ The following section discusses the disease and its pathogenesis in more detail, as well as how the disease is measured for epidemiological purposes.

2.1.1 PATHOGENESIS OF DENTAL CARIES

Dental caries, commonly referred to as tooth decay or cavities, is the most common type of dental disease.²⁵ Dental caries develop over time via the presence of

bacteria and fermentable carbohydrates in the mouth. The combination of these properties forms what is commonly known as dental plaque. Dental plaque works to demineralise enamel which covers the crowns of teeth, initially by subsurface demineralisation. Caries will first present itself as a white lesion on the tooth. If the dental plaque is not removed, and the lesion is left to progress, the tooth can develop a cavity when the thin, remaining surface layer fractures. This leaves the tooth open to infection, which initially damages the dentine – the core tissue of the tooth. Bacteria eventually reach the neurovascular tissues of the dental pulp, causing inflammation and pain, which is usually severe. Infection can spread to surrounding soft tissues and bone, and even to distant parts of the body²⁶, which is why it is common practice to remove a decayed tooth. If caries is detected at the pre-cavitation stage, there is the opportunity to halt the carious process and support the tooth to re-mineralise. This is done through oral hygiene practices, especially the use of fluoridated toothpastes and by professional application of topical fluorides and remineralising agents. It is possible by fracture of undermined enamel for a cavity to become “self-cleaning” and for the lesion to arrest, particularly in children. Usually, however, cavities need filling; decayed tissue is removed, and the cavity filled with an impermeable restorative material – traditionally a metal amalgam, more usually today a “tooth coloured” resin or cement. This is designed to stop bacteria from entering and causing further decay, eliminate pain, and restore form and function.^{25, 27, 28}

2.1.2 MEASUREMENT OF CARIES

The established method for measuring the cumulative incidence of caries is the ‘DMFT-index’. The index refers to the number of Teeth that are Decayed, Missing or Filled. When measuring deciduous teeth, primary or baby teeth as they are also called, the index is written in lower case, dmft. Each tooth is given a number and the sum is an indicator of the caries load.^{25, 28} DMFT/dmft scores are commonly used in research to describe the prevalence of dental caries in a population. Sometimes a more sensitive count of individual tooth *Surfaces* is used – DMFS/dmfs. Although these are commonly used for epidemiological purposes, it is important to

recognise that caries is a process, with many phases operating over many months or years, and the index is only able to measure cumulative effects at the particular point in time when the observations are made.²⁹ The most common guidelines for use of these indices come from the World Health Organization (WHO) which regards a surface as carious when it has an overt cavity. Therefore, from an epidemiological perspective we may be underestimating the true prevalence of caries. Furthermore, a simplistic DMF/dmf index does not differentiate between past, present and future activity of the caries process, although it is well known that past caries experience is the strongest predictor of future activity available.³⁰

Contemporary indices, notably the International Caries Detection and Assessment System (ICDAS)³¹, seek to improve measures by counting pre-cavitated lesions and past restorations on each tooth surface separately, but for comparative purposes it is still necessary to rely on the basic DMF/dmf tools.

2.1.3 CARIES SEVERITY

Similar to the progression of caries, the dmft/DMFT index falls short in describing the burden of disease within a population.³² Because the dmft/DMFT looks at the average or mean of caries prevalence, it does not highlight those in the population that may be experiencing a disproportionate amount of dmft/DMFT.³² The Significant Caries Index (SiC) was created to highlight these individuals. Developed by WHO collaborator, Dr Douglas Brattall, the SiC was first published in 2000.³³ To determine the SiC index, individuals are sorted by their dmft/DMFT score; one third of those with the highest dmft/DMFT score are separated as a sub-group. The mean is then taken from that high score sub-group and that mean score represents the SiC index.³³ This is different to the dmft/DMFT index because the SiC index is not looking at the entire population, but the 'tail' of the distribution: one-third of the population with the highest dmft/DMFT scores. While this method assists in determining those in a population that may be vulnerable, it is not reported as frequently in the literature as the dmft/DMFT index.

2.1.4 SUMMARY

Dental caries is the visible representation of a disease process within the mouth. The disease develops over time via the presence of bacteria and fermentable carbohydrates in the mouth. Left untreated, caries leads to cavities in the tooth surface and eventual decay of the entire tooth. The disease is measured by counting the signs of decay, evaluating the visible lesions, cavities, and/or missing teeth as a result of the associated decay. The way the disease is measured can vary and can affect the comparability of epidemiological studies; caution should be used when interpreting data from different countries and/or time points.

2.2 PREVALENCE OF DENTAL CARIES

The chronic and cumulative nature of caries is a contributing factor to the prevalence of caries. This section describes the disease from a global perspective and then discusses the populations where the disease is most prevalent, inclusive of First Nations Australian populations. Where there are limited data on the prevalence of caries in terms of age or population, similarly aged or similar global populations are used for reference.

Dental caries is considered a global public health problem according to the WHO. The WHO estimates that 60-90% of the world's population is affected by the disease.³⁴ According to a 2015 systematic review investigating the global burden of caries, 2.4 billion people in 2010 were affected by untreated caries, making caries the most prevalent condition worldwide.³⁵ In the early 1970s epidemiological studies established that caries were more prevalent in industrialised countries as opposed to less wealthy countries.³³ This difference was attributed to the impact of the 'Western Diet' on oral health.³⁶ In more recent times, oral health has improved in many industrialised countries because of advances in oral public health, such as toothbrushing with fluoridated toothpaste, topical fluoride applications and deliberate water fluoridation.³³ However, less-developed countries and less-

privileged populations within industrialised nations have experienced an increase in the prevalence of caries.^{33, 37}

It has been well documented that caries follows a social gradient.³⁸ In 1997, the WHO published a document that evaluated the oral health of children and adults from countries with a range of oral health care systems; ranging from demand-based private systems to public oral health care systems. Also factored into this global analysis were socio-economic and socio-behavioural indicators for caries.³⁸ The WHO asserted that even in countries that had comprehensive oral health systems and a commitment to health promotion, social inequalities in oral health were prevalent.³⁸ Experts in oral public health attribute this social gradient to 'upstream' factors such as wealth, education and broader environmental conditions.^{38, 39}

More recent commentary on the disparities of oral health suggests that little has changed since the WHO investigations. In 2019, global leaders in oral health research, Peres et al described oral disease as '*a sensitive clinical marker of social disadvantage*' and an '*indicator of population ill health linked to deprivation*'.⁴⁰ Data published in 2015 from 329, 798 participants across 155 studies globally since 2000 reported the association between socioeconomic position and caries.⁴¹ The meta-analysis found the those with higher numbers of DMFT were more likely than those with lower numbers of DMFT to have lower levels of: education (Odds Ratio (OR) = 1.29, 95% Confidence Interval (CI) 1.14-1.45), income (OR = 1.4, 95% CI 1.19-1.65) and occupational background (OR = 1.2, 95% CI 1.03-1.65).⁴¹ Within Australia, according to a nationally representative sample of adults aged 35 to 54 years, those who have completed less schooling (year nine or less) have a higher average of DMFT (17.4 teeth) than adults who have completed more schooling (year 10 or more, 14.1 DMFT).⁴² Similarly, Australian children from lower income families have a higher prevalence of dental caries in their deciduous teeth (36%), than children from higher income families (18%).⁴²

The social gradient is particularly evident amongst Indigenous populations globally. In countries that have been colonised, the Indigenous populations continue to be adversely affected by the colonial process and experience inequities across all aspects of life, inclusive of health.⁴³ Jamieson et al⁴⁴ reported data from Australia, New Zealand and Canada for adults aged >18 years and concluded that within all three nations, Indigenous adults experienced a greater oral health burden than non-Indigenous adults; described below in Table 1. The Australian data used for comparison in this study were from Australia's National Survey of Adult Oral Health, conducted between 2004 and 2006. Although a similar scale contemporary study has yet to be completed, other studies indicate the burden of oral health remains.⁴⁵

Table 1. Mean prevalence of decayed teeth, missing teeth and filled teeth in adults aged >18 years in Australia, New Zealand and Canada

	Decayed Teeth >0 Prevalence % (95%CI)	Missing Teeth >0 Prevalence % (95%CI)	Filled Teeth >0 Prevalence % (95%CI)
Australia			
First Nations	48.6 (32.0-65.2)	78.5 (65.8-91.2)	84.2 (65.0-103.4)
Non-Indigenous	22.6 (20.89-4.4)	59.0 (55.3-62.7)	91.0 (89.8-92.3)
New Zealand			
Maori	49.7 (44.6-54.8)	64.7 (59.5-69.9)	91.9 (89.1-94.8)
Non-Indigenous	34.4 (31.2-37.7)	45.6 (41.0-50.2)	91.3 (89.7-92.9)
Canada			
Indigenous*	35.0 (20.3-49.6)	50.8 (30.2-71.4)	94.6 (89.6-99.6)
Non-Indigenous	18.7 (16.9-20.6)	43.8 (40.3-47.3)	92.8 (91.6-94.1)
Estimates adjusted for age and sex; 95 % confidence interval in parentheses; * Representative of First Nations, Metis and Inuit peoples. Source: Jamieson LM, Elani HW, Mejia GC, Ju X, Kawachi I, Harper S, et al. Inequalities in Indigenous Oral Health: Findings from Australia, New Zealand, and Canada. Journal of Dental Research. 2016;95(12):1375-80.			

Parker et al⁴⁶ reviewed the oral health of Indigenous children in Australia, New Zealand, Canada and the United States and like Jamieson et al⁴⁴, also surmised that irrespective of the country, Indigenous children fared worse when it came to their oral health.⁴⁶ An example of the national disparities can be seen in Table 2.

Table 2. Mean prevalence of decayed, missing and filled teeth in children in Australian, New Zealand and Canada

	Decayed Teeth >0 Prevalence	Missing Teeth >0 Prevalence	Filled Teeth >0 Prevalence
Australian children aged 5 years			
First Nations	2.49 (0.09)	0.27 (0.04)	0.44 (0.04)
Non-Indigenous	0.72 (0.01)	0.05 (0.00)	0.22 (0.00)
Australian children aged 15			
First Nations	1.54 (0.23)		0.96 (0.15)
Non-Indigenous	0.58 (0.02)		1.12 (0.03)
*Standard Error in parentheses; Source: Jamieson LM, Armfield JM, Roberts-Thomson KF. Oral health of Aboriginal and Torres Strait Islander children: Australian Institute of Health & Welfare, Dental Statistics and Research Unit; 2007.			
New Zealand children aged 5-17 years			
Maori	0.2 (0.1-0.3)	1.7 (1.3-2.2)	1.5 (1.1-1.9)
Pacific	0.2 (0.0-0.3)	1.4 (1.0-1.7)	1.2 (0.9-1.5)
European/Other	0.1 (0.0-0.2)	1.1 (0.8-1.4)	1.0 (0.7-1.2)
*95% Confidence Interval in parentheses; Source: Ministry of Health. 2010. Our Oral Health: Key findings of the 2009 New Zealand Oral Health Survey. Wellington: Ministry of Health.			
Canadian children aged 6-11 years			
Indigenous*	0.57 (0.20-0.95)		3.82 (2.18-5.47)
Non-Indigenous	0.26 (0.21-0.32)		1.53 (1.28-1.77)
*95 %Confidence Interval in parentheses; * Representative of First Nations, Metis and Inuit populations. Source: Health Canada. 2010. Report on the Findings of the Oral Health Component of the Canadian Health Measures Survey 2007–2009. Ottawa. Health Canada.			

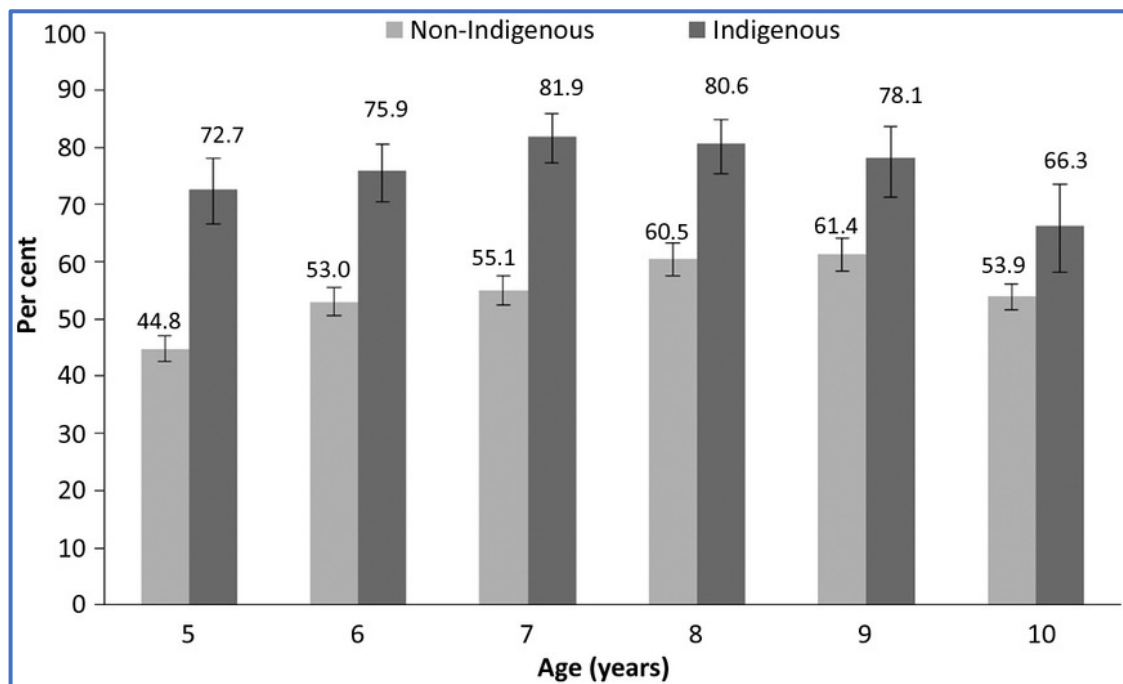
The United States reports similar data. A seminal study of a community-based sample of American Indian and Alaskan Native preschool children in the United States indicated that over 62% of American Indian and Alaskan Native children aged two to five years had experienced caries, compared to 25% of Caucasian children.⁴⁷ The mean score (3.7 teeth) for decayed and filled teeth was also three times higher in American Indian and Alaskan Native children compared to Caucasian (1.2 teeth). The generic ethnicity of the non-Indigenous children is specified because the study also examined the caries experience for African-American and Hispanic children, who also experienced a greater burden of caries than Caucasian children, but less than American Indian and Alaskan Native children (a difference of 32% and 42% respectively).⁴⁷ Indigenous Canadian children also experience worse oral health than other minority populations.⁴⁸ Shi et al⁴⁸ reported Indigenous Canadian children aged five to eight years were more likely to have caries and higher levels of DMFT than the majority of other populations measured (Table 3).

Table 3. Prevalence of caries and DMFT with respect to ethnic background in Canada

Ethnic background of child as described in study	Caries prevalence, DMFT
Indigenous* Canadian	81.9%, 5.5
White	49.2%, 2.0
Latin American	54.1%, 2.2
Black	58.3%, 2.8
South Asian	60.2%, 2.9
Chinese	70.0 %, 3.7
Filipino	76.1%, 5.2
Arab	81.9%, 4.7
Representative of First Nations, Metis and Inuit populations. Source: Shi C, Faris P, McNeil DA, Patterson S, Potestio ML, Thawer S, et al. Ethnic disparities in children's oral health: findings from a population-based survey of grade 1 and 2 schoolchildren in Alberta, Canada. BMC Oral Health. 2018;18(1):1.	

Within Australia, according to the Child Dental Health Survey 2010 (CDHS) which examined 103,387 children aged five to 15 years across six states and territories, the percentage of First Nations children with $dmft > 0$ was higher than non-Indigenous children between the ages of five and ten years as seen in Table 4. Of the children who participated, 6.8% were First Nations and 89.3% non-Indigenous; 3.9% of children did not state their First Nations status.⁴⁹ The National Child Oral Health study 2012-2014 had similar findings.⁵⁰ First Nations children (44%) aged five to ten years were more likely to have higher levels of untreated decayed teeth (3.5 mean, CI 2.5-4.5) compared with non-Indigenous children (26%) of the same age (1.2 mean, CI 1.0-1.3).⁵⁰

Table 4. Percentage of Australian children with $dmft > 0$



Source: Australian Research Centre for Population Oral Health. Oral health of Australian Indigenous children compared to non-Indigenous children enrolled in school dental services. Australian Dental Journal. 2014;59(3):395-400.

2.2.1 PREVALENCE OF CARIES IN YOUNG CHILDREN

In addition to affecting older children and adults, caries is also prevalent in younger children. In synthesising data from 72 reports globally, Tinanoff et al⁵¹ observed 17% mean caries prevalence for children aged one year which increased to 36% in those aged two years and progressed with the age of the child: three years 43%, four years 55%, and five years 63%.⁵¹ The disease is considered the most common chronic disease of childhood within Australia⁵², yet data on very young children (children aged less than 5 years) remain limited. Routine population data are only collected for children that are school-aged. Nevertheless, available data suggest the burden of caries is not improving and First Nations children are affected disproportionately.⁴ A 2016 study demonstrated that between 1989-2007, the prevalence of caries in the deciduous dentition of Australian children had increased by 28%.⁵³ The CDHS reported that 74.4% (95% CI 70.4-78.0) of First Nations children aged five to six years had caries compared to 48.9% (95% CI 47.2-50.5) of non-Indigenous children (Table 5).⁴⁹ However, in the National Child Oral Health Study 2012-2014 (NCOHS 2012-2014) a decrease in the caries prevalence in both groups was reported,⁵⁴ with 51.9% (95%CI 41.9–61.7) of First Nations children experiencing caries compared to 33.1% (95%CI 30.7–35.5) of non-Indigenous children (Table 5). Although there was a decrease in prevalence of caries for both groups in the latter study, First Nations children still experienced a disproportionate amount of caries. Moreover, the mean dmft was twice that of non-Indigenous children (5.9 mean dmft vs 2.5 mean dmft respectively).⁵⁴ The authors of the study noted the discrepancy between the two studies and suggested this may reflect the methods of surveillance. CDHS 2010 utilises school dental services data and hence may be somewhat inflated.⁵⁴ It was postulated that the CDHS 2010 may include more high-risk children and children who are seen on an urgent care basis, which by default would be more likely to have more severe caries. Location sampling may also influence the differing results in the studies.⁵⁴ The CDHS 2010, which reported a higher prevalence, included in their sample rural and remote locations, special schools and small schools with <50 children. In contrast, the NCOHS 2012-2014 did

not, but did include data from New South Wales and Victoria, which the CDHS 2010 did not.⁵⁴

Table 5. Prevalence of caries in Australian children aged 5 to 6 years as reported in state/national health studies

Children aged 5 to 6 years	First Nations	Non-Indigenous
Child Dental Health Survey 2010		
	74.4% (95%CI 70.4-78.0)	48.9% (95%CI 47.2-50.5)
National Child Oral Health Study 2012-2014		
	51.9% (95%CI 41.9–61.7)	33.1% (95%CI 30.7–35.5)
Queensland Child Oral Health Survey 2010-2012		
	72.6% (95%CI 44.1-71.3)	38.3% (95%CI 34.2-42.5)

A federal government initiative in the Northern Territory reported the prevalence of caries in First Nations children aged one to three years had decreased from 73% in 2009 to 43% in 2017.⁵⁵ The program provided ancillary funding to the state-based oral health program for children aged zero to 16 years, providing both preventative (application of full-mouth fluoride varnish and fissure sealants) and clinical (tooth extractions, diagnostics, restorations and examinations) services. It is thought that the program has contributed positively to the reduced prevalence of caries. However, the authors also suggest it could be due to the sample of children changing (as children move in and out of the service provision area) and acknowledge the burden of disease is still high compared to national population estimates.⁵⁵

In 2014, a systematic review reported the percentage of First Nations children aged four to six years with caries from three studies in Queensland as ranging from 61% to 90.2%.⁴ Arrow's study of First Nations children aged five to ten years in Western Australia reported a mean dmft of 2.54 compared to a mean dmft of 1.37 of non-Indigenous children⁵⁶ and Smith et al's study conducted across seven Aboriginal communities in New South Wales found 40% of the children assessed had caries.⁵⁷

In northern New South Wales, Dimitropoulos et al⁵⁸ reported the mean dmft/DMFT of school children aged five to 12 years across three communities to be 5.3, three times higher than that experienced by non-Indigenous children in New South Wales. Kroon et al's trial to investigate the efficacy of active (individualised) and passive (community water fluoridation) oral health interventions in the Northern Peninsula Area of Far North Queensland found that children aged four to 12 had 4.5dmft (4.6SD) in 2004 prior to any interventions and 3.0dmft (2.9 Standard Deviation(SD)) in 2017 post-interventions.⁵⁹ Jamieson et al's⁶⁰ trial of an oral health promotion program for First Nations families in South Australia recruited mothers and their young children between February 2011 and May 2012. Of the 436 children included in the study, 22% of children at two years of age had caries prevalence and, the mean number of decayed teeth was 0.75.⁶⁰ The investigators completed a follow up of children at three years of age and found that 29.7% of those children involved in the early intervention arm of the trial had decayed teeth, compared with 37.7% of children who received a delayed intervention.⁶⁰

While population level data on very young children remains limited, the caries experience of older children and adults assists in filling the gap in knowledge. Globally, we see a continuing increase in caries experience with age, continuing long into adulthood.⁶¹ The DMFT for adults aged 35 to 44 years old in most industrialised countries including Australia is greater than 13.9.⁶² Although it would make sense that the prevalence of caries would grow with age and permanent dentition, it is worth noting that there is no clinical reason why the disease needs to progress. Caries is preventable and the disease trajectory can be halted.⁶¹ This increase in caries with age demonstrates that it is not only a disease of childhood, but one that typically begins in childhood and remains chronic well into adulthood and throughout the lifespan.⁶¹ This is due to the recession of the gingival margin with age and this recession is exacerbated by poor oral hygiene. The process exposes the enamel-cementum junction and thereby renders the tooth particularly vulnerable for cariogenic bacteria and decay.⁵¹

2.2.2 SUMMARY

Dental caries is the most common chronic disease across the globe. The disease is cumulative, often beginning in the first years of life and progressing into adulthood. Following a strong social gradient, the disease is most prevalent in populations that experience socio-economic disadvantage. Indigenous populations globally have been shown to have higher levels of caries than their non-Indigenous counterparts. Within Australia, despite the high prevalence of the disease amongst First Nations Australian populations, there remains limited contemporary data on the prevalence of dental caries in young, urban First Nations Australian children. This thesis aims to address this gap in Chapter 4 by reporting on the prevalence of dental caries experienced by young, urban First Nations Australian children in one urban setting.

2.3 RISK FACTORS

The ubiquitous nature of caries globally suggests risk factors for the disease are common. This section describes the commonly attributed risk factors for caries. As well as the social and environmental factors known as risk indicators, which do not necessarily increase risk for the disease directly but are a conduit for a cariogenic environment and behaviours.

At an individual level, the literature indicates there are five main risk factors for caries.⁶³

1. Excessive volumes of dental plaque, due to inadequate tooth cleaning;
2. Frequency of fermentable carbohydrates taken into the mouth;
3. Frequency of exposure to dietary acids in addition to bacterial acids;
4. Absence or impediment of natural protective factors such as saliva, and;
5. Inadequate exposure to fluoride.⁶³

While this list appears limited, the conditions that influence these factors are not. In the era of evidenced-based medicine, we now understand that individual behaviours are determined by wider socio-ecological conditions as demonstrated in Figure 2.⁶⁴ Those working with Indigenous populations that have previously been colonised suggest that, like systemic health, oral health is influenced by historical inequities.^{39, 65} Historically and up until the 1970s, First Nations Australians were considered to have good oral health, even better than their non-Indigenous counterparts.⁶⁶ Pre-invasion, there was negligible sugar in the First Nations diet and populations took part in protective health behaviours, such as exclusive breastfeeding and the home-cooking of traditional, whole foods.⁶⁷ Post-colonisation many people were forced into government mandated camps and their provisions consisted of cariogenic foods, high in fermentable carbohydrate, such as white flour and sugar.⁶⁷ Families were separated and the health behaviours that had previously protected them were lost due to policies imposed by the Australian Government.¹ The negative impacts of these policies have been transgenerational and have manifested in present-day social determinants.^{1, 68} The WHO explains social determinants as the conditions in which 'people are born, grow, work, live and age.'⁶⁹ First Nations people experience significant disadvantage across all of these conditions^{46, 70} and this disadvantage is strongly associated with the development of caries.^{8, 71}

Figure 2. Determinants of oral health

Structural environment	Social environment	Health behaviours and individual factors
• socio-economic status • living conditions • education • employment • access to timely health supporting services: food, care, transport • equitable social and health policies • exposure to fluoride	• family norms • cultural norms • health literacy • self-efficacy • beliefs and attitudes • peer groups • identity	• eating • drinking • smoking • drugs/alcohol • injury • preventative oral health habits • age • sex • biological factors

Source: adapted from Rogers⁶⁴

2.3.1 DIET

One way that disadvantage influences caries is through diet. The 'Western Diet' is heavy in sugars and the evidence for the relationship between sugar and caries is robust.⁷² Those from low-income backgrounds tend to be more negatively affected by the 'Western Diet'⁷³; consuming more sugary beverages and discretionary foods more often and protective and nutritious foods less often.^{74, 75} The Australian Dietary Guidelines (ADG) refer to 'discretionary foods' as foods that have little nutritional benefit but are high in fat, salt and sugar.⁷⁶ Sebastian and Donnelly⁷⁷ explain that the impact of economic disadvantage on diet for First Nations Australians is multi-level; there are geographic, socio-economic, social and environmental factors to be considered. A recent review of nutrition barriers for First Nations Australians concluded that the underlying causes of food insecurity were: 'low income and unemployment, inadequate housing, overcrowding, lack of educational opportunities, transport, high food costs, cultural food values, food and nutrition literacy, knowledge and skills'.⁷⁸ For example, at a systemic level, transport can be a major impediment to accessing healthy food. Many First Nations people

do not have access to personal transport.⁷³ In a qualitative study with First Nations Australians with type 2 diabetes, participants explained that they often relied on others with a car to get them to the grocery store.⁷³ Similarly, insufficient funds can lead to power and gas being cut off, which in turn affects safe food storage and cooking facilities.⁷⁷ Thus, takeaway and processed meals are often considered a safer, as well as a more convenient, option.⁷⁷

In 2012-2013, First Nations Australians were reportedly consuming 41% of their daily energy intake from discretionary foods and had low levels of fresh fruit and vegetable consumption.⁷⁹ On average, First Nations people consume 1.8 serves of vegetables per day and 1.2 serves of fruit (inclusive of juice and dried fruit) compared to non-Indigenous people who consume on average 2.7 serves of vegetables and 1.5 serves of fruit.⁷⁹ According to a qualitative study of First Nations Health Workers in Western Australia, fruit and vegetables were expensive and many people had family and community responsibilities that affected their budget.¹¹ A participant explained, that they 'never know who is going to turn up at the door hungry'.¹¹ Another observed that a bag of chips is more affordable than a bag of apples.¹¹ These environmental conditions are compounded by general societal changes. There is an increased availability of 'fast food' in Australia as well as more intensified marketing of sugary and processed foods.⁸⁰

2.3.2 SUGAR SWEETENED BEVERAGES

Although the 'Western Diet' in general has been associated with decay, sugar-sweetened beverages (SSB) in particular are most commonly regarded as the cause of the rise of caries in recent times.⁸⁰⁻⁸² Consumption of carbonated beverages rose 240% from 1959 to 1999 in Australia.⁸² On average, there are ten teaspoons of sugar in a typical SSB, above the recommended daily limit of six teaspoons for adults, as advised by the WHO.⁸³ Australians have been ranked as some of the highest consumers of SSB, placing in the top ten globally.⁸³ A 2007 national survey suggested that 47% of Australian children aged two to 16 years had a SSB daily, 25%

having soft drink daily. Australian children that had an annual household income of <\$40,000 consumed 60% more SSB than those with a household income of > \$80,000.⁸²

In 2012-2013, data from the Australian Bureau of Statistics' (ABS) National Aboriginal and Torres Strait Islander Health Survey indicated that 67% of free sugars (those added to food and present in honey, syrups and fruit juices) consumed by First Nations people were from beverages, the majority from soft-drinks and sport/energy drinks.⁸⁴ A recent survey investigating the oral health behaviours of 149 First Nations preschool children in Sydney found that approximately 40% of children were regularly drinking cordial or juice between the ages of zero and 24 months, with water becoming a more popular choice as the children aged. The authors postulate that juice is likely still perceived as a healthy way of getting nutrients into younger children, whereas, soft-drink consumption was rarely consumed in the first two years, but became more popular as children aged.²¹

Likewise, findings from the Longitudinal Study on Indigenous Children (LSIC) in 2008, demonstrated that consumption of SSB for children aged zero to three years increased with age; 29.3% of children aged zero to 12 months had consumed any SSB, compared with 65.7% of children 38 to 36 months.⁸⁵ The findings varied between geographical locations: with consumption by children aged zero to three months significantly lower in urban area (36.3%), compared to regional (49.7%) and remote (62.8%) areas.⁸⁵ This is in contrast to ABS (2012-2013) data which suggests First Nations people in non-remote locations consumed on average 12 grams more sugar daily than those living in remote areas.⁸⁴ Likewise, a 2014 study of First Nations children aged four to seven years found that compared to children living in remote areas, children in urban areas were more likely (OR = 3.18, 95%CI: 1.55-6.55) to consume SSB.⁸³ In regional New South Wales, 64.1% of the 78 children aged five to 12 years who completed an oral health survey reported that they regularly

consumed sugary drinks. The authors did not provide context for what constituted regular consumption.⁵⁸

The effect of SSB on the health of children has become a primary concern for researchers and clinicians globally.⁴⁰ However, within the context of oral health, representative sampling of First Nations Australian children remains limited, as do data on very young children, with much of the focus being on obesity and other comorbidities influenced by sugar consumption. A longitudinal study of Queenslanders aged less than 12 years found that in 2003, children who drank soft-drink between meals had three to four times the risk of tooth extraction (OR=4, 95%CI: 1.99-8.17).⁷⁴ In 2008, this likelihood decreased to an OR of 2.8 (95%CI: 1.31-6.06).⁷⁴ The results of this study may not be representative of all urban First Nations children because of the restrictive sampling technique and sample size. Only families with a telephone number available in the White Pages (Australian Telephone Directory) or the Association of Market and Social Research Organisation database were included for random sampling. Surveys were discontinued if the potential participant was not the principal caregiver of the child and the study was limited to approximately 1500 respondents. Armfield et al's⁸² 2013 study found a consistent dose-response association between caries in 16,508 Australian children aged five to 16 years drinking SSB.⁸² In contrast to the Queensland study mentioned previously, this study was much larger and utilised the school dental service in Queensland, South Australia, Victoria and Tasmania to sample students randomly by birthdate, which potentially provides a more generalisable context for urban First Nations families. However, like the Queensland study, it was reliant on retrospective self-reported dietary data and was dependent on active participation.⁸²

A 2015 study in New South Wales had insufficient data to report on Indigenous identity, but suggested that nearly 50% of adolescents aged 14 to 15 years drank one or more cups of SSB per day;⁸⁶ those who did not consume SSB regularly had a

significantly lower DMFT score.⁸⁶ Consumption of SSB by urban First Nations adolescents may well be higher than the results in this study because the sample was stratified by socio-economic status. Like Armfield et al's study⁸², this study utilised schools' dental services as a platform for sampling, but stratified based on social-disadvantage of schools, aware that the prevalence of caries would likely be higher from economically disadvantaged cohorts and skew the results.⁸⁶ Despite this, the study found that students who were less wealthy drank more SSB than wealthier students. Likewise, students whose mothers had less education drank more SSB than those with more education.⁸⁶ According to the National Child Oral Health Study 2012-2014, First Nations children who drank two or more cups of SSB day had 24.5% more decayed surfaces in their deciduous dentition and 17.9% in their permanent dentition than First Nations children who drank less than two cups a day.⁸⁷

While representative data of all children are limited, public health advocates believe that there is enough evidence to suggest that population level approaches, such as a tax on SSB, are warranted.⁸⁸ In the context of oral health, a recent cost analysis of a 20% tax on SSB within the United Kingdom concluded that taxation could prevent approximately 1,030,163 (95%CI 1,027,903-1,032,423) caries lesions in the population and save €159.01 (AU\$256.01) million (95%CI 158.67-159.35) on dental expenditure.⁸⁸ These findings are broadly supported by an Australian study which considered the benefits of the same tax for general health gains, and found 175,300 (95%CI 68,700; 277,800) health-related life years could be gained, as well as healthcare cost savings of AU\$1,733 million (95%CI \$650m; \$2,744m) over the lifetime of the population.⁸⁹

2.3.3 EXPOSURE TO FLUORIDE

There have been few other studies that have looked at what factors may mitigate the effects of SSB.⁸² A 2013 Australian study is believed to be the first to demonstrate that greater exposure to water fluoridation significantly reduced the

association between SSB and caries in both the deciduous and permanent dentition of children aged five to 16 years.⁸² Fluoride is touted as a 'public health breakthrough', and its efficacy in strengthening tooth enamel and decreasing the incidence of caries has been confirmed in many studies.^{34, 90} Globally, the use of fluoride in public drinking water began in the 1940s and has been endorsed by the WHO since the 1960s.³⁴ Australia first started using fluoride in public drinking water in 1953.⁹¹ However the coverage was not uniform and, up until 2008, Queensland had been a notable exception to the practice.⁹¹

Although there has been substantial investigation into the efficacy of water fluoridation for childhood caries globally, there is also now a number of contemporary Australian studies at a population level which demonstrate the benefits. The 2010 Child Dental Health Study of 97,809 Australian schoolchildren found there was a 51% difference in caries experience between children from areas with fluoridated water compared to those in non-fluoridated areas.⁹² A similar benefit was found for 24,664 children who participated in the National Child Oral Health Study 2012-2014.⁹³ Even when controlling for socio-economic status, children who had at least some lifetime exposure to fluoride had fewer caries than those who had no exposure. For example, children aged five to eight years with no exposure to fluoride had a mean of 2.1 dmfs (95%CI 1.83-2.40), compared to children with exposure of >0% to 50% (1.7dmfs, 95%CI 1.41-2.10) and exposure of >50% to <100% (1.27dmfs, 95%CI 1.01-1.59).⁹³ The benefits of exposure to fluoride during childhood were also highlighted in findings from the Longitudinal Study of Australian Children (LSAC), which has been evaluating child oral health in seven waves since 2002. A difference in caries experience was found for children living in areas with established water fluoridation compared with those children living in non-fluoridated and recently fluoridated areas.⁹⁴ However, the authors acknowledge that these notable geographic differences may also be due to differences in state resources and policy.

Research shows that although fluoride is not a panacea for child oral health, it does appear to have quantifiable public health benefits that extend to First Nations children. Of the First Nations children who participated in the Child Dental Health Survey 2010, there was a 23.4% difference in mean dmft scores for children living in fluoridated (mean dmft, 3.2) compared to non-fluoridated (mean dmft, 4.1) areas.⁹² At the time of the study, Queensland had only just begun mandatory water fluoridation treatment in December 2008, with dissemination continuing to 2010. For areas that had only recently begun fluoridation, which includes the Caboolture area where my study takes place, the researchers coded the areas as non-fluoridated. Thus, these results may not be generalisable to my study population. However, a study from a nearby location with a very similar socio-economic situation also demonstrated the benefits of fluoride.⁹⁵ In the Logan-Beaudesert district, there was a 19% reduction in caries experience in children aged four to nine years in the 36 months post fluoride (a mean of 4.5 dmft decreased to 3.66 after fluoride).⁹⁵ The authors explain that although this study did not demonstrate as large an effect as other studies, it was likely due to the shortened duration of fluoride exposure compared to other locations, as well as the high level of other risk factors within the community.⁹⁵

A study in the Northern Peninsula of Far North Queensland demonstrated that the introduction of fluoridated water into five rural communities was significantly associated with a decrease in caries.⁹⁶ In 2004, the prevalence of caries within the communities was measured.⁹⁶ Children aged six to 12 years were reported to have caries experience more than twice the average of other children in Queensland. In 2005, fluoridation of the water supply commenced in the aforementioned five communities. Seven years later in 2012, researchers again investigated the prevalence of caries within the communities and reported a substantial decrease in caries.⁹⁶ Pre-fluoride, six-year old's had a mean decay score of 5.2, post-fluoride that decreased to 3.4, $p < 0.05$. Statistically significant decreases in dmft were found for all children aged four to nine years.⁹⁶ The most recent analysis of data from the

study indicates that the mean dmft has decreased by 37.7% between the pre-fluoride and post-fluoride follow up.⁵⁹

Additionally, the latest analysis of data collected during the National Child Oral Health Study 2012–14 demonstrates the importance of fluoride, particularly for First Nations children that are more financially disadvantaged.⁹⁷ Do et al⁹⁷ investigated whether water fluoridation could reduce race and income related inequality related to caries amongst children aged five to 14 years. While they found that fluoride reduced the levels of caries in all children, First Nations children still experienced higher levels of dmfs than non- First Nations children. The greatest difference in caries experience was found in the deciduous dentition with respect to income levels. First Nations children from the lowest income quartile living in fluoridated areas had 2.9 less dmfs, compared with First Nations children in the same quartile in non-fluoridated areas.⁹⁷

The benefit of fluoride also transcends its method of delivery. Daily toothbrushing with fluoridated toothpaste is well accepted for its anti-caries effect⁹⁸, as is the topical application of fluoride by dental professionals for those designated as being at high risk of caries.⁹⁹ However, despite the empirical evidence praising fluoride, its use is questioned by many. An analysis of English language tweets on Twitter between 2009 and 2017 found that the ratio of positive words to negative words in discussion of fluoride was 2.25:1.¹⁰⁰ Negative tweets regarding fluoride commonly included the words ‘poison’, ‘waste’ and ‘bad’ and although fluoride was not found to be a popular topic on Twitter, there are notable spikes in tweets during fluoride policy changes within the United States, suggesting it remains a contentious issue for some.¹⁰⁰ Within Queensland, a survey was conducted on the Gold Coast shortly after the fluoride program was mandated in 2008 and aimed to understand locals’ perceptions of fluoride.¹⁰¹ Thirty percent of the 500 people surveyed associated fluoride with a health risk and 45% said they were concerned about this risk.¹⁰¹ Other surveys in Queensland on fluoride approval conducted between 1997 and

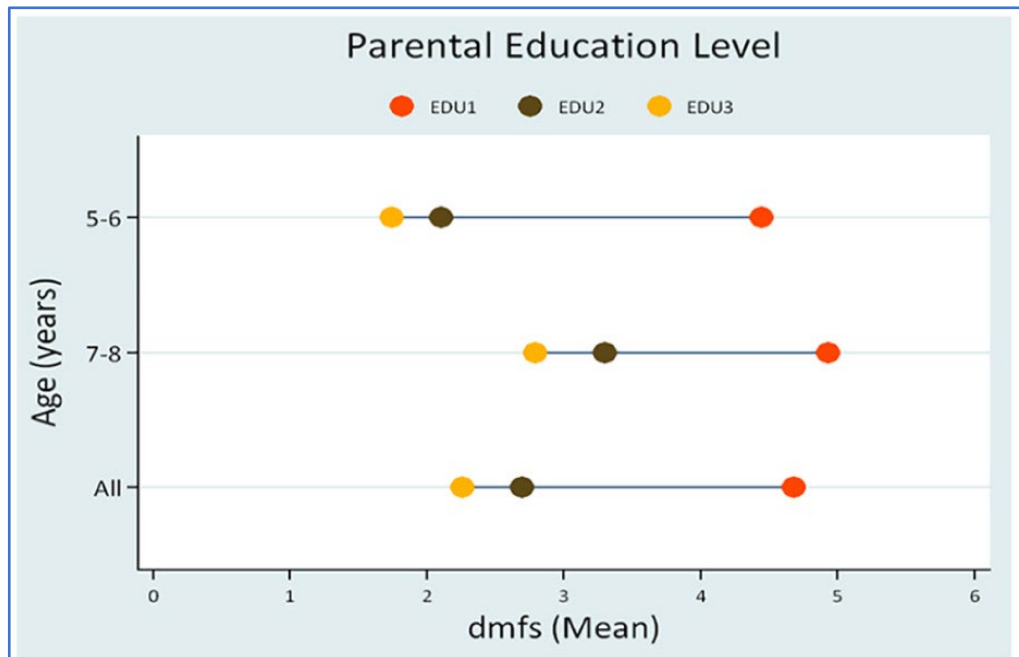
2007 demonstrated that approval ranged from 60% to 73.4%.¹⁰¹ Anecdotally, when perusing the local online media on fluoride, the comments section of news articles indicate that those who are opposed to fluoride do so vehemently.

2.3.4 EDUCATION

The relationship between oral health and level of education is important when considering risk factors for dental caries. This is reflected in numerous studies that show a general correlation between dental disease experience and personal and/or parental education levels.¹⁰²⁻¹⁰⁴ Other studies show that food choices are linked to dietary knowledge and education levels.¹⁰⁵ Research shows that adults with low levels of oral health literacy have poorer oral health themselves and are less likely to seek dental care for their children.¹⁰⁶

Health literacy, the ability to synthesise health messages and adapt them to behaviours, typically depends on education.⁷⁶ A 2016 systematic review investigating the impact of parent-related factors of caries in the permanent dentition of children aged six to 12 years demonstrated that education has been inversely related to caries in numerous studies.¹⁰⁷ In examining Australian population data, researchers report similar findings; children with parents with lower levels of education have more caries than children with parents with higher levels of education as seen in Figure 3.¹⁰² Presently, First Nations peoples tend to have lower levels of formal education than non-Indigenous people.⁵ Yet education, or the lack thereof, must be considered in a wider socio-ecological context. Like other determinants of health, the level of education a person achieves is often influenced by their socio-economic (SE) status and more complex environmental conditions.⁷⁰

Figure 3. Average number of decayed, missing, or filled tooth surfaces (dmfs) of the deciduous dentition according to parental education level: EDU 1: school, EDU 2: vocational training, EDU 3: university

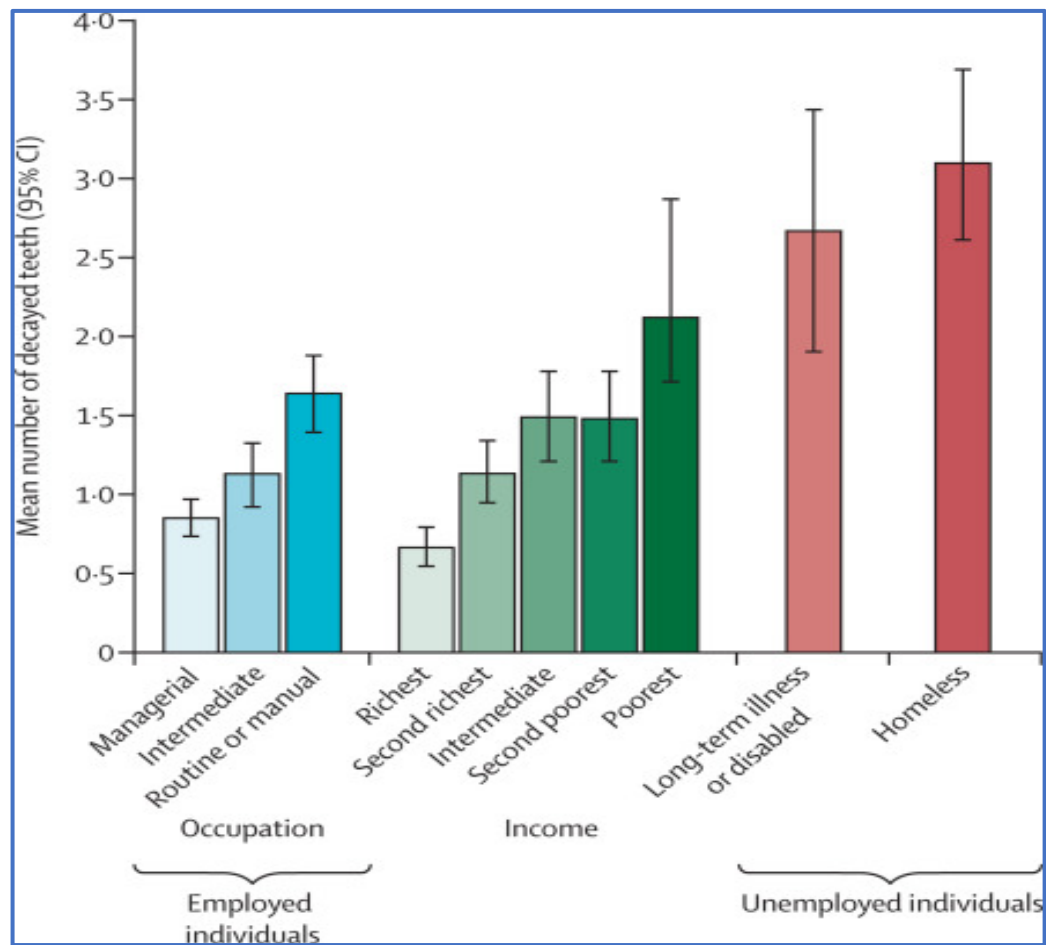


Source: Peres MA, Ju X, Mittinty M, Spencer AJ, Do LG. Modifiable Factors Explain Socioeconomic Inequalities in Children's Dental Caries. *Journal of Dental Research*. 2019;98(11):1211-8.

2.3.5 SOCIO-ECONOMIC STATUS

More so than any other factor, income stands out as the key indicator of oral health.¹⁰⁸ The social gradient is evidenced in research globally, Schwendicke et al⁴¹ suggest the association between SE status and oral health is potentially stronger in developed countries. A visual representation of the gradient can be seen in Figure 4.

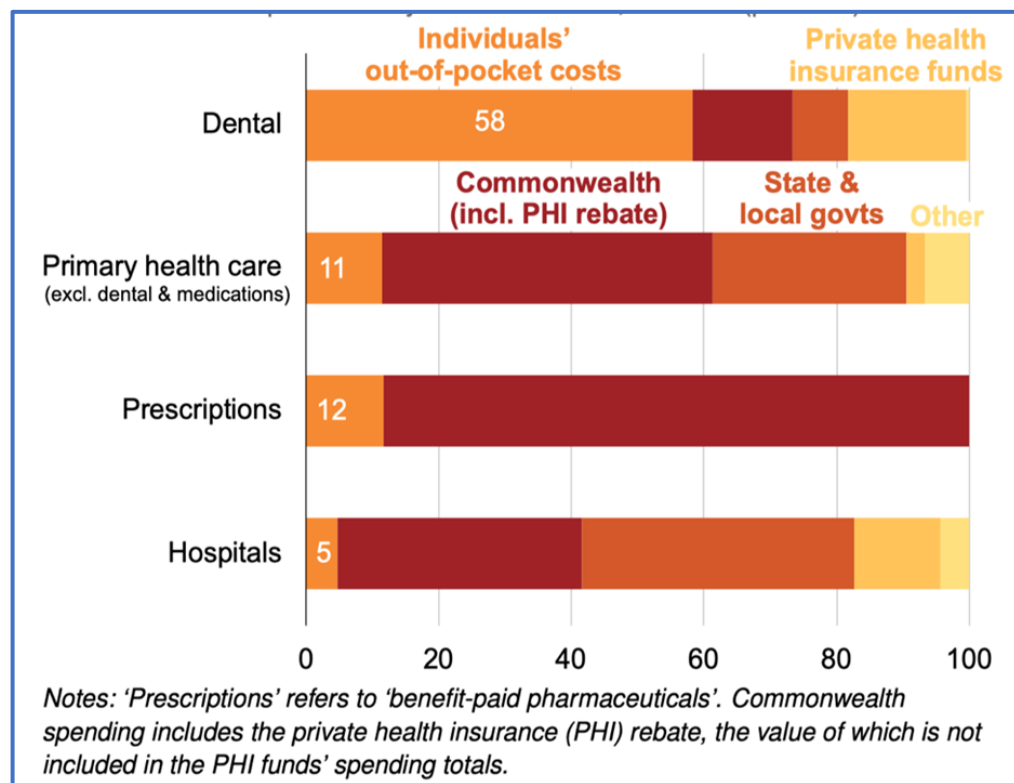
Figure 4. Mean number of decayed teeth among male adults aged 16 to 65 years in England, Wales, and Northern Ireland



Source: Peres MA, Macpherson LMD, Weyant RJ, Daly B, Venturelli R, Mathur MR, et al. Oral diseases: a global public health challenge. The Lancet. 2019;394(10194):249-60.

Despite the glut of data demonstrating SE disparities in oral health, researchers examining the relationship between income and oral health advise that a '*lack of clarity and consensus on causal pathways through which income, or income inequality, affects oral health outcomes remains*'.¹⁰⁸ Of the potential factors affecting the disparity, the out of pocket cost of professional oral health care is often raised (Figure 5). Compared to other health services, oral health care is the mostly costly for patients.¹⁰⁹

Figure 5. Patient out of pocket costs in Australia 2016-2017 (by percentage)



Source: Duckett S CM, Swerissen H. Filling the gap: a universal dental care scheme for Australia [Internet] Victoria: Grattan Institute; 2019 [Available from: <https://grattan.edu.au/report/filling-the-gap/>].

The National Dental Telephone Interview Survey 2010 reported that cost was a major barrier to Australians accessing services and those in the lowest income bracket were the least likely to receive preventative oral health care such as plaque and calculus removal, and fluoride treatments.¹¹⁰ The difference in uptake of professional care by income status can be seen in symptom reporting as well. Australians in lower income quartiles are more likely to report experiencing toothache than those in higher income quartiles.¹¹¹ In analysing the relationship between toothache and income between 1994 and 2013, researchers found the difference in toothache prevalence between low and high income quartiles grew from 38% to over a 100%.¹¹¹ It is speculated that this increase is likely due to the worsening of toothache for those in the lowest income quartile, given that toothache levels in the higher income quartile remained stable over time.¹¹¹ Many Australians will avoid dental treatment until it becomes an emergency. This is

despite government initiatives to mitigate cost barriers for disadvantaged people. According to Schwarz, those who are disadvantaged are more likely to report avoiding services because of cost (41%), as opposed to those who are affluent (17%).¹¹²

Although a public dental care system exists, it is stipulated by eligibility criteria which varies by State and Territory.¹¹² In Queensland, adults must have a concession card, which is provided on application by a national social services agency such as Centrelink or the Department of Veterans' Affairs.¹¹² For children and adolescents aged two to 17 years; a national program, The Child Dental Benefits Schedule (CDBS), provides a \$1000 voucher per eligible individual every two years (child must be eligible for Medicare and be of a family that receives Family Tax Benefit A) which can be used in public or private dental services. Services are limited to basic prevention and treatment options including clinical examinations, diagnostic radiography, tooth cleaning and fillings.¹¹³ According to a recent poll, 26% of eligible parents were unaware they were eligible for the CDBS.¹¹⁴ State provided oral health services in Queensland for children and adolescents have traditionally been provided through the School Dental Service, with services available on school grounds or mobile dental clinics.⁵⁴ Over time, these services have changed in their regularity and some locations have moved into hospital and/or clinic sites. Currently, the State Health Department advises that services for children/adolescents should be provided at least once every two years¹¹³, in accordance with Australia's National Oral Health Plan 2015-2024.¹¹⁵ School dental services are delivered to students up to year ten and only children that have returned a consent form signed by a parent/carer can receive care.¹¹⁰

First Nations Australians are entitled to use Aboriginal Community Controlled Health Services (ACCHS). However, like the State services, ACCHS operate using the CDBS voucher and have options for private service.¹¹⁰ These services vary by location. It is believed that the public health system only covers treatment for 20%

of concession card holders.¹¹⁰ Any care required outside of the CDBS limits (e.g., orthodontics), needs to be undertaken privately.¹¹⁵ Private oral health services can be subsidised at the time of presentation by an individual's private health insurance. However, only 20% of First Nations adults living in non-remote areas are thought to be privately insured compared to 57% of non-Indigenous adults.¹¹⁶

As mentioned previously, the relationship between disadvantage and oral health is complex. Even when considering objective factors such as wealth, research demonstrates that there are more factors to consider. A 2016 study investigated caries in Australian children by neighbourhood economic characteristics and demonstrated that while children from affluent areas had lower levels of caries compared to those in less affluent areas, First Nations children still had higher DMFT scores than their non-Indigenous counterparts, despite living in the same area.⁵ The authors noted that 46.8% of First Nations children lived in poor neighbourhoods compared with 26.7% of non-Indigenous children.⁵ Given this information, other oral health experiences for First Nations children may also be inferred. Neighbourhood liveability (as defined by the Neighbourhood Liveability scale which evaluates local neighbourhood safety, cleanliness, local parks quality, lighting and roads/footpaths)¹¹⁷ has been found to be a significant predictor of both caries and dental injury in Australian children, with Queensland having the highest odds of caries and injury experience.⁹⁴ For First Nations Australians, poverty and disadvantage must be considered in the context of colonisation and the additional barriers that are in place because of transgenerational inequities.⁶⁵ These barriers to oral health can be behavioural and environmental.

Crowded housing is related to poverty and has been found to be associated with an increase in caries prevalence in young children.^{107, 118} Warren et al¹¹⁸ posit that crowded housing may be a conduit for cariogenic behaviours, particularly for very young children. They suggest inconsistent oral health habits, having a variety of carers and/or the need to pacify children with sweetened foods may contribute to

increased risk.¹¹⁸ A qualitative study of First Nations Health Worker's perceptions of oral health indicated that when there were many people in the house, people did not feel confident using their toothbrush in case someone else had used it.¹¹ Approximately one in four First Nations people live in crowded housing.¹¹⁹ First Nations families can also be transient and spend time moving between relatives and friends' houses.¹¹⁹ This instability can impede oral health habits.¹¹ Having access to your own toothbrush is one issue; another is not having the means to buy a toothbrush and toothpaste regularly. Research in a remote First Nations community in the Northern Territory reported that there were low levels of brushing, late onset of toothpaste utilisation for children and low levels of toothpaste utilisation overall.¹²⁰ This is despite the community receiving regular visits from the Northern Territory school dental service. The authors suggested that the cost of toothpaste coupled with parent's/carer's limited awareness of preventative measures could be contributing to the low levels of use.¹²⁰ In a qualitative study, participants indicated that cost was a major issue for preventative health measures.¹¹ One participant explained that First Nations people had other economic priorities besides going to the dentist, such as paying for living costs and food; oral health was only a priority if there was pain.¹¹

2.3.6 RISK FACTORS IN YOUNG CHILDREN

In addition to the more general risk factors for caries, young children can experience challenges to their oral health that are more specific to their age and circumstance. Caries in children aged less than five years are referred to as Early Childhood Caries (ECC). ECC have not been as well researched as caries in general.¹²¹ However, there are a number of known risk factors and risk indicators associated with this age group.⁷¹ Arguably, the most well known risk factor for ECC is the practice of going to sleep with a bottle of milk or formula. The practice has been so widely regarded as cariogenic, that ECC is also commonly known as 'bottle caries'.¹²² A 2012 systematic review found ten studies that demonstrated nocturnal feeding with a bottle was significantly associated with increased caries risk in children aged zero to six years.⁷¹ The review acknowledged two studies that did not find an association

between bottle-feeding and caries. Both papers addressed the same study population: taking place in Belgium and evaluating oral health data on 1250 three year old children for caries in relation to smoking and other factors.¹²³ Although a relationship between bottle-feeding and caries was not found, the authors did find a significant relationship between nocturnal drinking and caries (OR = 8.7, 95%CI: 1.61-47.68).¹²³ Moreover, drinking any SSB in a bottle is associated with an increased risk of caries.^{7, 71}

In addition to the sugar from milk or SSB, it is hypothesised that the duration of the fluid in the mouth also contributes to risk.⁷¹ Drinking SSB between meals is associated with an increased risk of caries, as is persistent sucking or sipping at a bottle.^{71, 124} A 2003 study of young children in Brisbane indicated that consuming juice, cordial and soft-drink in a bottle not only significantly increased the prevalence of caries (OR=1.6, 95%CI=1.2-2.0, $p<0.00$), but also increased the severity of the caries.¹²⁵ Similarly, in a cross-sectional study of 2515 children aged four to five years in Brisbane, researchers found sleeping with a bottle and sipping from a bottle to be statistically significant risk factors for increased risk of caries (OR=1.9, 95%CI:1.5 - 2.4 and OR=1.6, 95% CI:1.2 - 2.0 respectively).¹²⁵ The Australian Dietary Guidelines advises that children aged less than 12 months should not be consuming fruit juice or fruit drinks, nor should children be consuming sweetened beverages in a bottle, with the practice strongly linked to caries.⁷⁶

Bacterial and maternal factors have also been associated with caries in very young children.^{7, 51, 71, 126, 127} A 2013 systematic review reported that habits whereby the mother's saliva - or that of another major carer - is shared with the child (kissing on the lips, sharing cutlery, licking a dummy/pacifier) favours colonisation of a child's mouth with potentially cariogenic bacteria if they have poor oral health themselves, especially untreated decay.¹²⁸ Soon after birth, a child's mouth begins being colonised by microbes, including those which are known to be cariogenic. It is thought that mothers are the first to infect their children with these microbes.¹²⁸ As

well as transmission, the levels of cariogenic bacteria the mother harbours has been found to be associated with the child's risk of caries.¹⁰⁷ With this risk factor established, contemporary research appears to be invested in improving the oral health of mothers and understanding how to prevent mother-child transmission of mutans streptococci, and delay colonisation and caries in young children.¹²⁹

2.3.7 CHILD HEALTH

A physician in Canada previously suggested that medication should be considered a 'sweet snack' in regards to its impact on dental caries.¹³⁰ His rationale was that in addressing the palatability of drugs for children, liquid formulations with high levels of sugar were often used.¹³⁰ Tablets that are swallowed do not pose the same risk, but are used less often.¹³¹ Nevertheless, recent investigation of the relationship between medicine and caries in adults provides evidence that irrespective of the formula, those consuming more prescription medication have higher levels of caries.¹³² Children with chronic illness such as heart disease, asthma, epilepsy and chronic infections are at increased risk for caries because of the regularity of their treatment.¹³⁰ A 2006 study of young Brisbane children found that 35% of children who had taken medication for more than one month had caries compared to 26% who had not.¹³³ First Nations people experience considerable disadvantage in regards to their overall health. In addition to experiencing greater amounts of disease than non-Indigenous people, they also experience earlier onset of disease.¹

A meta-analysis that analysed the relationship between asthma medication and caries risk in 18 studies demonstrated that asthma medication doubles a child's caries risk.¹³⁴ Asthma is thought to affect 18% of First Nations Australians, with the rate increasing with age; First Nations people have 1.9 times the prevalence of asthma as non-Indigenous people.¹¹⁶ Those living in urban areas are thought to experience more asthma than those living remotely.³ Further, otitis media is a common childhood illness caused by infection. It can lead to hearing loss, deafness and can contribute to learning difficulties.¹¹⁶ Treatment typically includes

antibiotics. Paediatric formulations of antibiotics often have high concentrations of sugar and have been documented as a potential risk factor for caries.¹³⁵ First Nations children are 2.3 times more likely to have otitis media as non-Indigenous children.¹¹⁶ It is thought that 12% of the First Nations population have chronic ear and or hearing problems.¹¹⁶ However, in a qualitative study, it was pointed out that medical professionals do not always explain the associated risks of illnesses in relation to oral health to First Nations people.¹¹ Feigal, Jensen and Mensing¹³⁶ advocate that practitioners need to be aware of the cariogenic potential of the medications they prescribe (specifically liquid form) and educate their patients in turn to prevent caries.¹³⁶

As the requirement of medication can impact on caries, so too can other health conditions, whether they require medication or not. In particular, children with conditions that affect their sensory abilities, behaviour and cognition, such as Autism Spectrum Disorder (ASD), experience additional challenges in maintaining their oral health.^{137, 138} The challenges related to ASD are incredibly varied between children, but within an oral health context have been attributed to a number of factors including but not limited to:

- The inability and/or lack of desire to mimic oral health behaviours. Young children typically imitate those around them and have desire to grow up and display self-help skills. Whereas some children with ASD lack this motivation;¹³⁷
- Restricted diet and/or atypical eating habits. Hypersensitivity to foods and textures is common with those with ASD and could potentially increase exposure to cariogenic foods and eating behaviours e.g. holding foods or liquids in the mouth for extended periods of time¹³⁹, and;
- Behavioural issues. Children with ASD can struggle with compliance, hyperactivity, sensory defensiveness and self-injury which can affect a parent's ability to establish positive oral health behaviours in the home; as well as the uptake of professional preventative care.¹⁴⁰

2.3.8 SUMMARY

While the individual and behavioural risk factors for dental caries such as toothbrushing and limiting sugar are often front of mind, the disease must be considered within the wider social and environmental conditions within which it exists. Research has demonstrated that there is a complex interplay of factors attributable to the disease manifesting and progressing in individuals and populations. First Nations Australians may be more susceptible to the disease process because of these social and environmental factors. Young children can also experience vulnerabilities specific to their age group as they are exposed to a cariogenic environment through their diet, behaviours and health conditions. Yet there are limited data relevant to very young children. This thesis aims to address this gap in Chapter 4 by reporting on the prevalence of oral health risk factors and risk indicators experienced by young, urban First Nations Australian children.

2.4 IMPACT OF ORAL HEALTH

In the context of this project, the term ‘impact’ has been used because it is a broad term and its meaning is subjective to the person and context of their situation. In the qualitative component of my study, we are endeavouring to understand from the perspective of parents and carers what they perceive the impact of oral health to be. This section describes the way impact can be perceived and measured and how oral health impacts on children, families and women.

Impact can be interpreted in a number of ways, for instance qualitative studies can report the impact subjectively. Participants may refer to different impacts, such as cost, emotional toll or time.⁹ Alternately, impact is also commonly interpreted as the impact on Quality of Life (QoL). In academia, QoL has had several interpretations. Traditionally, QoL referred to the normative standard of living for an individual using objective social indicators such as wealth or access to resources.¹⁴¹ Contemporary QoL has evolved to include subjective experiences. In health, these indicators are reflective of the WHO definition of health, which

suggests that health is not merely the absence of disease, but '*a state of complete physical, mental, and social well-being*'.¹⁴¹ A large body of research has been devoted to the development of tools to measure these aspects of well-being. What these tools are and the rationale for measuring QoL will be discussed in greater detail in section 2.5. The following sections use both informal and formal measures (such as QoL measurement tools) to discuss the impact of oral health.

2.4.1 IMPACT ON YOUNG CHILDREN

As has been discussed previously, dental caries is not only the most common chronic condition for young children, but is also the most common issue with respect to a child's oral health in general.⁴⁰ Other oral health issues do occur, such as malocclusion (a misalignment of the teeth), periodontal diseases, cleft lip and palate, and traumatic dental injury, to name a few.¹⁴² However at a population level, caries arguably has the most deleterious effect on child oral health compared to other issues, particularly for young children.¹⁴³ In young children, the pain of caries can affect their ability to eat, influence weight and development, affect sleep, affect their behaviour and impact on their ability to learn.¹⁴⁴⁻¹⁴⁶ These disturbances can be escalated by the severity of caries^{147, 148} and the location of the caries, with caries located in the front teeth reported to be a greater burden than caries located in other areas of the mouth.¹⁴⁹ This is attributed to the visibility of the teeth, as well as the loss of function.¹⁴⁹

Based on both parent-proxy and child-reported data, dental caries have been shown to significantly impact on child QoL when measured.¹⁵⁰⁻¹⁵³ Measurement is typically across a number of different domains that reflect the potential impact to QoL. Although there are too many tools to list here, the Early Childhood Oral Health Impact Scale (ECOHIS) provides an example of a common proxy measure utilised in oral health. The questions and related domains are outlined in Figure 6.

Figure 6. An example of questions in the Early Childhood Oral Health Impact Scale

■ Child impacts		
■ 1. How often has your child had pain in the teeth, mouth or jaws?	}	Symptoms
■ How often has your child ... because of dental problems or dental treatments? —		
■ 2. Had difficulty drinking hot or cold beverages	}	Function
■ 3. Had difficulty eating some foods		
■ 4. Had difficulty pronouncing any words		
■ 5. Missed preschool, daycare or school		
■ 6. Had trouble sleeping	}	Psychology
■ 7. Been irritable or frustrated		
■ 8. Avoided smiling or laughing	}	Social interaction
■ 9. Avoided talking		
■ Family impacts		
■ How often have you or another family member ... because of your child's dental problems or treatments? —	}	Parent distress
■ 10. Been upset		
■ 11. Felt guilty		
■ 12. Taken time off from work	}	Family function
■ How often has your child had dental problems or dental treatments that had a —		
■ 13. Financial impact on your family?		

Source: Arrow P, Klobas E. Evaluation of the Early Childhood Oral Health Impact Scale in an Australian preschool child population. Australian Dental Journal. 2015;60(3):375-81.

To the best of our knowledge, there is no research that explores the impact of caries on the QoL of First Nations children specifically. This may be because there is yet to be a validated culturally appropriate tool developed for measuring QoL in relation to oral health for First Nations Australians. Within First Nations culture, the definition of well-being is holistic and includes a number of factors including cultural, spiritual and social well-being.¹⁵⁴ Present tools are not culturally specific, but when used in adult populations, have shown that many First Nations Australian adults experience poor oral health-related QoL.¹⁵⁵⁻¹⁵⁸ A study of young First Nations adults (aged 18 years) who participated in Wave 3 of the Aboriginal Birth Cohort Study in the Northern Territory found that an increased caries experience was associated with higher levels of anxiety and those who were dissatisfied with their dental appearance also had lower levels of mental health.¹⁵⁴

Despite being utilised less frequently, qualitative investigations provide non-scripted insight into how children are impacted by their oral health. Children aged five to 15 years articulated that dental caries negatively impacted their life; affecting sleep, their ability to eat and function at school.¹⁵⁹ A study in the United Kingdom found that of children receiving treatment for their caries, 26% had missed time off school because of pain.¹⁶⁰ Along with pain, children describe feeling 'tired', 'grumpy' and 'annoyed'.¹⁵⁹ These descriptions align with parent reflections on their child's caries experience, with pain commonly manifesting in emotional output. Mothers in Syria used terms such as 'disturbed' and 'angry,' and that caries affected their child's psyche.¹⁶¹ Parents of young children with caries in their front teeth have explained that their children expressed feelings of shame related to the appearance of their teeth¹⁴⁹; sharing with their parents that they did not want to smile for pictures or play with friends because of their teeth. They also shared experiences of being outcast at school and on the playground because of their appearance.¹⁴⁹

The way caries negatively impact on children does not vary much with increasing age; function and aesthetics remain important.^{159, 162} Adolescents in the United Kingdom who were satisfied with their physical appearance reported better QoL in relation to oral health.¹⁶³ In Brazil, those that had received orthodontic treatment reported better QoL compared to those who hadn't had treatment or were in the midst of treatment.¹⁶⁴ A New Zealand study found that psychosocial factors (self-esteem, psychological well-being, somatisation, and self-perception scores for body image) were significant predictors of oral HR-QoL, even more so than socio-demographic and clinical factors.¹⁶⁵

Although there is evidence that children are impacted at every age with oral health issues, consideration needs to be given to the challenges in adequately understanding the impact of oral health on very young children. Despite numerous studies reporting the oral HR-QoL of young children, often these studies have utilised surveys which seek the parent's perception and not the children. This is

because the child is typically too young to respond to the survey themselves.¹⁶⁶ At present, there appears to be no validated oral health QoL survey for children under the age of five years¹⁶⁷, nor do there appear to be any qualitative studies of young children. By the time children are aged seven to eight years, they are thought to have the skills to conceptualise, for an adult's understanding, what they perceive to be the impacts to their QoL.^{166, 167} However, prior to that it is left to a proxy. Studies have shown that parents are not always a reliable indicator of their child's oral health status; being unaware that their child is experiencing poor oral health^{168, 169} and demonstrating less agreement with their child in emotional and social domains than in physical domains.¹⁷⁰

2.4.2 IMPACT ON FAMILY UNIT

Little has been written about how a child's oral health impacts on the family unit, particularly from the perspective of the parents and carers. Only one study in Australia has specifically investigated oral health from the perspective of First Nations Australian families.⁹ This qualitative study, undertaken in 2014, included 52 carers of young First Nations children, mostly mothers from Perth, Western Australia. Interviews and focus groups were used to collect the data. Although the study population is similar demographically to our study population, the investigation did not specifically investigate the impact of oral health on families, but addressed factors such as diet, motivation, services and barriers. The study revealed that cost, lack of family-friendly services and discrimination were all considered barriers to care.⁹ Participants also shared their frustration at how dental issues escalated to emergencies, which they felt were dangerous and stressful.⁹

First Nations children are twice as likely to be hospitalised for oral health problems and are more likely to require tooth extraction and receive general anaesthetic than non-Indigenous children.¹⁷¹ This not only exposes children to the potential risks of surgery and anaesthesia, but the increased risk of infection and increased use of antibiotics.¹⁶⁰ No information could be found on the number of repeat visits for

patients in Australia, but a study in north-west England suggested that 12 to 37% of patients had required repeat interventions using general anaesthetic.¹⁷² A 2010 systematic review indicated that both child and family QoL increased following dental treatment under general anaesthetic.¹⁷³ The same has been found for First Nations Australian children¹⁷⁴ and other children globally.¹⁷⁵ A 2018 meta-analysis¹⁷⁵ of studies completed in Asia, America, Europe, the Middle East and Oceania which investigated the relationship between treatment under general anaesthetic and QoL, found that treatment significantly increased child oral health QoL by up to three months.¹⁷⁵

Supporting a child with their oral health takes an obvious toll on parents. Internationally, studies have shown that a child's poor health affects parent well-being^{144, 150, 176-178} and the worse a child's caries are, the worse the parents' QoL is going to be.^{150, 177, 179} A number of studies report a trend of parents feeling 'bad', 'guilty' and 'upset' with respect to their child's oral health status.^{176, 178, 180-182} Carvalho and colleagues explain that parents often feel responsible and that their child's caries could have been avoided.¹⁸³ Parent distress coupled with child irritability (due to their oral discomfort) can contribute to conflict in the home.¹⁷⁸ Yet there are few studies that aim to understand in greater detail the wider effects of child oral health on family life.

The available literature indicates the impact of oral health issues extends to work and school. In the United States, it is estimated that 117,000 hours of school time is lost per 100,000 children per year.¹⁴⁸ The time lost is attributed to utilisation of dental services, which are typically only available in school hours.¹⁴⁸ Ribeiro and colleagues asked parents of preschool children: *'How often has your child had dental problems or dental treatments that had a financial impact on your family?'*¹⁸⁴ Parents who perceived their child to have poor oral health were more likely to report experiencing a financial impact.¹⁸⁴ The authors noted that there was no correlation between socio-economic status and financial impact. However other

studies have found increased caries experience to be associated with decreased family activity and parent working hours.¹⁵⁰ The cost of oral health, as has been discussed previously, is a considerable challenge for families. Wong et al¹⁷⁴ explained that parents would often administer pain medication and antibiotics and forgo dental treatment until the situation is acute and the child needs clinical intervention.¹⁷⁴ Both parents and children have commented on the logistical challenges associated with administering pain medication at school.¹⁵⁹ Pain that cannot be managed often requires an acute intervention¹⁸⁵; and within Australia, dental extractions and tooth restoration are the most common cause of hospital admission for children aged one to 14 years.⁶³

Durey et al⁶⁵ argue that the modern medical communities focus on individual behaviour as the cause of caries contributes to a rhetoric that ignores the 'structural inequalities' in oral health, such as education, access and cost.⁶⁵ This sentiment is supported by another study¹⁸⁶, which describes the barriers suggested by First Nations people as being cost, waiting times and culturally insensitive services.¹⁸⁶ Further, a qualitative study revealed a reason behind the feelings of apprehension felt by First Nations people attending oral health services¹¹; participants described feeling judged by the dentist and having their health behaviours questioned. Apprehension around sending children for care was related to transgenerational trauma and fear that parents would be seen as ill-equipped and have their children taken away.¹¹ First Nations Australians in South Australia explained that many older First Nations Australians grew up on missions and were regularly told what to do and forbidden to participate in their heritage. This meant that many people did not learn about their oral health and the effects of the introduced colonial diet until it was too late.¹⁸⁷

2.4.3 MATERNAL ORAL HEALTH

One outcome of engaging parents and carers to understand impacts of child oral health is also discovering the parents' experience of oral health as an individual.

Oral health is critical to normal human function, allowing people to breathe, eat, socialise and exist in their environment without pain, discomfort or embarrassment.⁴⁰ Yet the mouth can be vulnerable to disease and damage which can have physiological, psychological, emotional and socio-environmental consequences.⁴⁰ While this review has largely focused on young children and one specific disease (caries), with increasing age, other oral health conditions and risk factors/indicators also become prevalent.¹⁸⁸ For example, one of the most common oral health conditions is periodontal disease. Periodontitis, which starts as gingivitis, is a chronic inflammation of the surrounding tissues which support teeth. Along with insufficient levels of oral hygiene, other behavioural and physiological factors are associated with increased risk of disease, including tobacco smoking and comorbidities such as cardiovascular disease and diabetes.⁴⁰ Like caries, periodontal disease is chronic and often requires timely professional treatment; the outcomes of which are variable. Pain, loss of function, tooth loss and decreased aesthetics are common side effects of both caries and periodontitis.⁴⁰ Other conditions of concern include cancer, craniofacial disorders, injuries, and various infections.⁴⁰

While the requirements to support oral health as we age are largely homogenous (keep the mouth clean, use fluoride, limit sugar, avoid drugs and alcohol, and visit the dentist regularly), the way oral health is experienced is not. Like children, women and more specifically mothers, can have oral health experiences that are specific to them and their circumstances.¹⁸⁹ For instance, women are physiologically different to men and can experience numerous hormonal changes during their lifespan which interact with their oral health status. Similarly, oral health can be influenced by behaviours related to women's traditional gender roles such as being the primary carer of children and responsible for domestic duties which include but are not limited to: grocery shopping, cooking meals and facilitating family health care.¹⁸⁹⁻¹⁹¹ The intensity of these roles can be heightened as many women are the single head of the family and typically earn less than their male counterparts.^{189, 190} According to the Grattan Institute's latest report on oral health, women at nearly

every age are more likely (20%) to avoid the dentist because of the cost than men (16%).¹⁰⁹

Understanding how women experience oral health across their life course has important implications, not only for them, but for those they care for as well.¹⁹¹ Despite this fact, there is limited literature on the oral health experiences of women, from the perspective of women, particularly First Nations Australian women.¹⁹² What we do know is primarily focused on physiological variations; puberty, menses, pregnancy, and menopause all influence women's oral health. The fluctuation of sex hormones (estrogen and progesterone) change the oral environment and can increase inflammation and bacterial colonisation, putting women at increased risk of caries and periodontitis amongst other conditions.¹⁹³ The relationship between oral health and pregnancy specifically has garnered attention. This is likely because a women's oral health during pregnancy has implications not only for her, but for her delivery and the health of her child.¹⁹⁴ Poor oral health during pregnancy has been linked to low birth weight, preeclampsia and preterm birth.¹⁹⁴ Although no causal pathway has been discovered, it is hypothesised that bacteria and inflammation due to caries and periodontitis factor in significantly to the cause.¹⁹⁴ Indeed, pregnancy exacerbates conditions such as gingivitis, periodontitis and caries¹⁹⁵, which is potentially the source of the common notion that you 'lose a tooth with every child'.¹⁹⁵ While poor oral health during pregnancy is not inevitable, studies give credibility to the old adage, finding parity related to tooth loss.¹⁹⁶ The same relationship has not been found with fathers.¹⁹⁵

Like other oral health issues, tooth loss is a greater problem for those that are less financially privileged.³⁹ According to an Australian survey, 47% of First Nations Australian adults are missing at least one tooth (excluding wisdom teeth) and 5% report total tooth loss. The loss of all teeth is more common in those aged 55 years and over.¹⁹⁷ Tooth loss not only affects mouth function, but often has negative consequences for QoL, mental and emotional health, as well as employability.^{198, 199}

There is considerable social stigma related to the mouths appearance and those that experience poor oral health report feeling ashamed and limited socially; to the extent that they do not attend job interviews and/or their regular employment.¹⁹⁸ A 2010 study from the United States estimated that the loss of each tooth costs a person \$720 US per annum in wages.²⁰⁰ First Nations Australians (43.7%) are reported to have worse self-reported oral health than their non-Indigenous (9.2%) counterparts.^{156, 201} The disparity is considerably larger than what has been found between Indigenous and non-Indigenous populations in New Zealand and Brazil.²⁰² Despite this burden, a 2016 study found only 28.4% of the 945 First Nations Australian adults surveyed were dissatisfied with their dental appearance. The authors hypothesise that the finding is likely a result of community normalization whereby people are resigned to poor oral health.⁶⁶

2.4.4 SUMMARY

The impact of oral health has implications at a number of levels. Within a family, the oral health of a child, not only affects the health of the child, but has widespread consequences for the entire family. These consequences can be physical, emotional and financial. The relationship between a family's QoL and child oral health is well documented. There is however limited research and data on the impact of oral health for First Nations Australian populations. Despite evidence of poor oral health experienced by many First Nations Australians, little is known from their perspective. This thesis addresses this gap in Chapters 5 and 6 by exploring qualitatively the impact of oral health from the perspective of First Nations Australian women. Chapter 5 reports on the impact of child oral health on families and Chapter 6 addresses the thoughts and experiences of women specifically.

2.5 MEASURING QUALITY OF LIFE

As has been discussed, oral health can have a considerable impact on a person's life and several objective and subjective implications for QoL. Within contemporary

healthcare, improving QoL is no longer just a side-effect of care, but is increasingly seen as a measurable outcome that assists in understanding the efficacy of an intervention and patient health outcomes.²⁰³ This section describes why HR-QoL should be measured, how it is typically measured and some of the cultural considerations that need to be made in terms of developing a tool that reflects the populations it aims to serve, in this case First Nations Australians. As well as a brief overview of the existing research which describes the values of First Nations Australians with respect to health and wellbeing.

2.5.1 WHY MEASURE QUALITY OF LIFE?

Firstly, there has been shift in the way the medical community understands health. We are endeavouring to move away from a biomedical model of thinking, whereby health is binary and you are either healthy or not.²⁰³ The biomedical approach is potentially useful if you have a disease which can be diagnosed and cured, but it is less desirable in accommodating the complexities of health and medical treatment. For instance, we know that not all treatments are harmless.²⁰³ Certainly, within oral health, the implications of diagnosis and treatment are not always favourable. There are barriers to treatment to be considered and just because a tooth is removed or decay found, does not necessarily mean a patient's QoL has improved. In contrast, the 'Outcome Model' endeavours to acknowledge these complexities in health and works to address health holistically.²⁰³ We have become more focused on people living longer and feeling better. This is evidenced at an epidemiological level with the creation of the Quality Adjusted Life Years measurement (QALY). As a society, we acknowledge that the length of life is not necessarily indicative of a quality life.²⁰³ This notion is pertinent to the secondary reason why QoL is now considered an important outcome to measure.

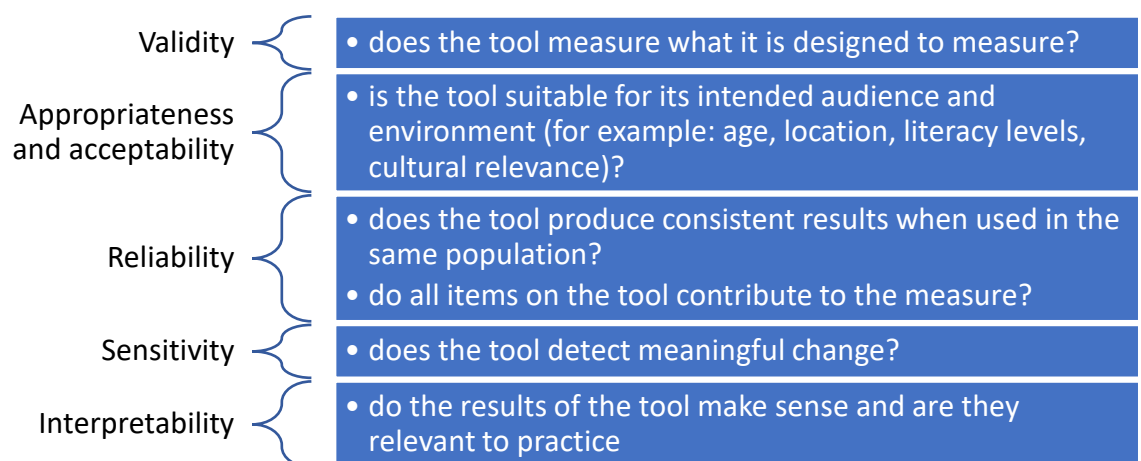
In the present day, the nature of diseases we are dealing with, inclusive of oral health diseases, are predominantly chronic. A binary outcome of healthy or not does not fit the scope of disease that predominates in modern times and wealthier

countries. Much of the health burden people experience is ongoing and is associated with other comorbidities.²⁰³ A cure may not be achievable, thus improving the QoL of an individual becomes a very important aspect of any intervention or treatment available.

2.5.2 DEVELOPING A MEASUREMENT TOOL

The most common way of measuring HR-QoL is via a questionnaire-style survey.²⁰⁴ Although HR-QoL does not have a universal definition, there is consensus that it is multifactorial and includes domains outside the biomedical model of health.²⁰⁵ Surveys are conducive to the subjective nature of HR-QoL and can be adapted to include the multiple domains that need to be addressed, such as social and emotional indicators as well as subjective physical functioning and symptoms.¹⁴¹ In developing psychometric tools there are a number of factors (as seen in Figure 7) to consider before and during development, and an established methodological process to ensure the scientific merit of the tool.

Figure 7. Factors to consider in the development of a psychometric tool



Source: adapted from Higginson and Carr²⁰⁶

The general concept is that questions are developed under each domain of the survey topic and a scale used to create measurable responses.²⁰⁷ How the questions and scale are determined depend on who will be administering the survey, who will

be responding to the survey and the goal of the measurement.²⁰⁸ For instance, there are many situations where a proxy is required. If a patient is too unwell or the individual is young, then caregivers or parents may be the proxy.²⁰⁹ The questions and response scale should be considerate of the participant's age, literacy and environment. Likewise, the cultural heritage of the participant undergoing the survey should be considered during the formation of the tool.^{15, 210}

In defining QoL, the WHO acknowledged that QoL is an 'individual's perception of their position in life in context of their culture and value systems'.²¹⁰ When designing the questions, there is the potential for ambiguity, embarrassment and confusion, which may lead to error or a lack of response.²⁰⁷ Despite efforts to keep surveys unbiased, the majority of the tools have been developed in English, using Western constructs of health, which can be in discordance with other cultural perceptions of health.^{15, 211}

By 2011, there were over 6600 research articles that referred to QoL in their abstract.²⁰⁵ A 2017 paper acknowledged that for HR-QoL specifically, over 900 measurement tools had been registered in a single international patient-reported outcome and HR-QoL instrument database.²¹¹ The tools developed have been diverse and address health generally, specific diseases, ages, cultures and proxy needs (such as parent for child). Yet presently, to the best of our knowledge, there is no tool developed for evaluating the HR-QoL of First Nations people within Australia; for oral HR-QoL or any other health context.¹⁴

2.5.3 CULTURAL PERCEPTIONS OF HEALTH

Some HR-QoL instruments have been adapted to make them more relatable to different cultures.¹⁴ However, adaption of an existing HR-QoL measurement tool for First Nations Australians is considered inappropriate.¹⁴ This is because First Nations perceptions of health have been shown to be different from Anglo-centric

perceptions of health.¹⁴ A 2016 systematic review aimed to identify studies that measured HR-QoL in Indigenous populations globally or had validated a tool to use with Indigenous populations.¹⁴ A total of 32 papers were determined eligible for review: 16 studies were from the United States, five from Canada and three each from New Zealand and Australia. Of the 32 studies reviewed only four reported a tool to be successfully validated and none were for First Nations Australians. Some studies had attempted to adapt tools through minor language adjustments and it was noted by the authors that the approach was insufficient for Indigenous populations, inclusive of First Nations Australians.¹⁴ For example, an exploratory study²¹² with a population of Aboriginal Canadians discovered that ‘social, cultural and land use factors were most important to the health and wellbeing of the sample’. These concepts are not typically represented in available tools and thus changing the language does not suffice.¹⁴ Another study²¹³ found that the SF-12, a commonly used short-form questionnaire for people with chronic health conditions, was not well received by First Nations Australians with type 2 diabetes living in a rural location. The tool was not user friendly and the First Nations Health Workers who were required to administer it; felt that their clients were providing them with answers they wanted to hear, as opposed to using their own judgement.²¹³

Although HR-QoL is considered multi-faceted and extends past the bio-medical notion of health, First Nations people are believed to value factors outside of the individualised Anglo-centric dimensions that have been established.¹⁴ In 1989 the National Aboriginal Health Strategy Working Party published a report where they described ‘*health as not just the physical well-being of the individual, but the social, emotional and cultural well-being of the whole community including attributes of social justice, well-being and equity*’.²¹⁴ Since this report there has been considerable research into the health and wellbeing of First Nations Australians and while there has been limited investigation into HR-QoL specifically, others^{16, 215} have suggested much can be inferred from related concepts that have been researched, such as wellbeing. For this reason, I will provide a brief overview of the related

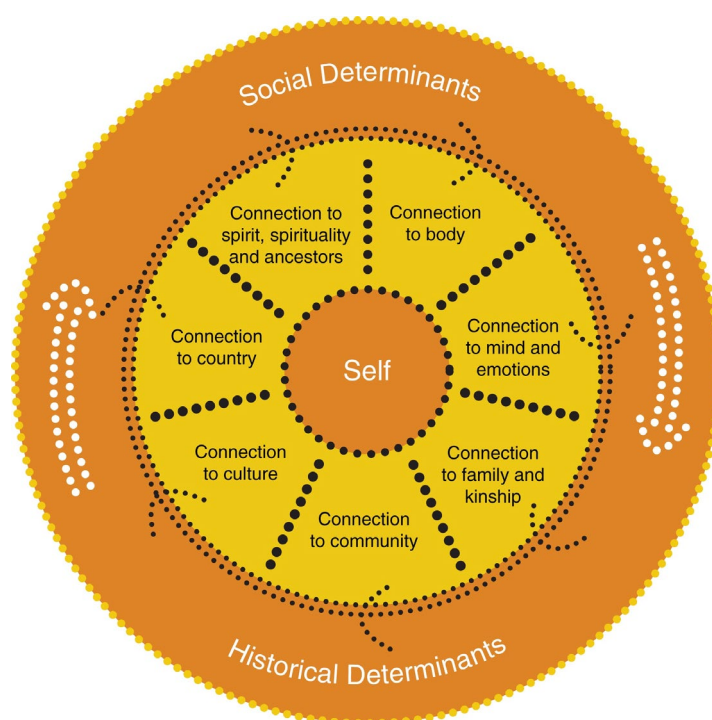
research and frameworks that have developed with respect to First Nations Australian wellbeing.

2.5.4 FIRST NATIONS AUSTRALIAN PERCEPTIONS OF HEALTH AND WELLBEING

The concept of wellbeing, like HR-QoL, is subjective and although it is often described in research and even measured, its definition is difficult to pin down. In 2012, Dodge et al²¹⁶ offered a definition, which they suggested had a universal application which transcended a person's age, culture and gender: *'stable wellbeing is when individuals have the psychological, social and physical resources they need to meet a particular psychological, social and/or physical challenge.'*(p.30)²¹⁶ The universality of this definition is arguably because of its non-specificity. There is considerable scope for cultural interpretation of the indicators. At the same time that Dodge and colleagues were discussing a universal definition of wellbeing, work was being done in Australia to define social and emotional wellbeing for First Nations Australians.²¹⁷ The federal government had partnered with the University of Western Australia to facilitate the National Empowerment Project (NEP) which was collaborating with eight communities to identify what factors were negatively impacting on the social and emotional wellbeing of First Nations Australians.²¹⁷ Social and emotional wellbeing is certainly more specific than general wellbeing, and unlikely to represent all the necessary values related to HR-QoL. However, within the context of defining health and wellbeing, it provides insight into how different or not First Nations Australians perceive domains that are already commonly included in health and wellbeing measures, for example, the PedsQL^{4.0} Inventory.²¹⁸ The inventory includes generic and disease specific HR-QoL measures to be used with children in clinical and research settings and utilises four domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items).²¹⁸ These items and their respective domains were developed in the mid-1990s by synthesising the available adult QoL literature and surveying parents and children aged eight to 18 years with cancer from three major paediatric cancer centres in the United States.²¹⁹ The inventory is now used globally, having been translated and validated in numerous languages.²²⁰

According to Gee et al²²¹, there are seven domains that reflect social and emotional wellbeing for First Nations Australians, all influenced by historical and social determinants, seen in Figure 8. Professor Pat Dudgeon and colleagues facilitated the NEP and undertook consultation with the eight communities to identify the domains.²²¹ The authors note the artist's representation of the model delineates the domains, when they should actually be interpreted as overlapping and interconnected.²²²

Figure 8. Domains of social and emotional wellbeing in Australian First Nations peoples



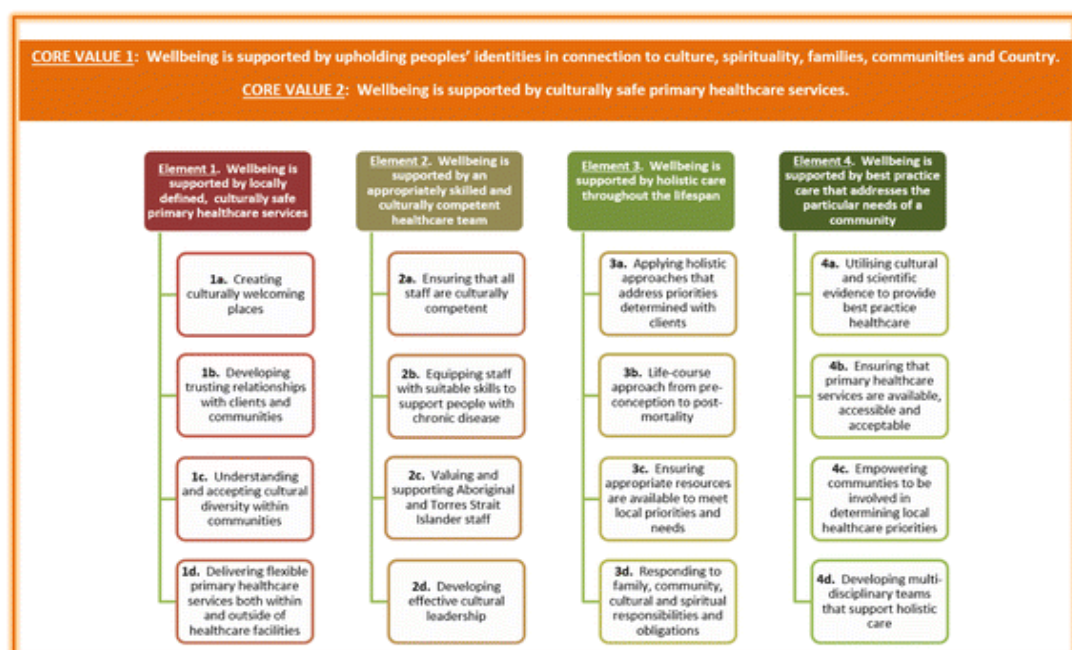
Source: Gee, G., Dudgeon, P., Schultz, C., Hart, A., & Kelly, K. (2014). Aboriginal and Torres Strait Islander social and emotional wellbeing. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*

While the domains have similarities to emotional and psychological domains in generic representations of health and wellbeing, there are additional concepts, such as 'Connection to Country' that have not traditionally been reflected in available measures.¹⁴ In 2017 Le Grande et al²¹⁵ reviewed the available social and emotional

wellbeing instruments for use with First Nations Australians.²¹⁵ Twenty-two instruments were evaluated. These consisted of tools that had not been validated with First Nations Australians, those that had been adapted, and those that had been specifically developed for First Nations Australians. Upon critically reviewing each tool for its merit and applicability, the authors advised that First Nations developed tools should be utilised and any tool that had been adapted for use with First Nations Australians should be viewed with caution.²¹⁵ This is because existing tools fail to incorporate concepts important to First Nations Australian notions of health and wellbeing, thus providing an insufficient measure of how First Nations Australians may actually be faring.²¹⁵

Davy et al's²²³ framework for the wellbeing for First Nations Australians with chronic disease was published in a similar time frame as the Le Grande et al review.²¹⁵ As can be seen in Figure 9, the wellbeing of First Nations Australians is not an individual concept, but can be understood in how the individual is connected to their identity, culture, spirituality, family, community and country.²²³

Figure 9. Framework for wellbeing for First Nations Australians with chronic disease



Source: Davy C, Kite E, Sivak L, Brown A, Ahmat T, Brahim G, et al. Towards the development of a wellbeing model for Aboriginal and Torres Strait islander peoples living with chronic disease. BMC Health Services Research. 2017;17.

In June 2019 a comprehensive literature review on the topic of First Nations Australian wellbeing was published.¹⁶ The authors synthesised 95 manuscripts with the aim of better understanding the domains of wellbeing and QoL of First Nations Australians. Literature was reviewed from inception to June 2017 and updated in March 2019. The authors found there to be nine broad interconnected dimensions which are briefly described below.

1. Autonomy, empowerment and recognition

Much of the colonial process has involved removing the rights of First Nations people to assimilate them into the dominant invading culture. At the outset this was done with physical force and later with government policy. There was little agency for First Nations people as children were forcibly removed from their families, forced into schools, forced into work and forbidden their customs.¹ In 1989 the National Aboriginal Health Strategy Working Party (NAHSWP)²²⁴ explained:

“Prior to colonisation Aboriginal peoples had control over all aspects of their life. They were able to exercise self - determination in its purest form. They were able to determine their “very - being, ” the nature of which ensured their psychological fulfilment and incorporated the cultural, social and spiritual sense (NAHSWP, 1989, p. ix).”

In their search Butler et al found that for First Nations Australians, control over their own lives was an essential component of everyday wellbeing.¹⁶ Having knowledge and being able to have a say for themselves and their community was highly valued within a health and wellbeing context.¹⁶ As well as having recognition and equity as a person in the wider Australian population.¹⁶

2. Family and community

Butler et al¹⁶ explain that in some communities, when asked how someone is doing, individuals will explain in the context of how their family and wider community is getting along, as in their wellbeing is intricately linked to their community structure

and its wellbeing as a collective. Unlike Anglo-centric norms which espouse the immediate or 'nuclear' family as being the core family related to the individual, the structure of family and meaning of family has a broader definition for First Nations Australians.²²⁵ Kinship is used to describe the wider structure and understanding of First Nations Australian families.²²⁵ Not only are these larger family groups valued as any family would be, but social and familial relationships are prioritised within First Nations Australian cultures.²²⁵ According to the 33 articles which referenced family in a wellbeing context, Butler et al explain that family and community provide connectedness, social capital and a sense of identity which supports a feeling of belonging.¹⁶

3. Culture, spirituality and identity

First Nations Australians have been documented as one of the world's oldest populations, with evidence of civilisation hypothesised to date back a potential 100 000 years.⁶⁷ The survival of the culture throughout history and colonisation has been attributed to the dedicated participation and adaptation of First Nations Australians in passing on knowledge and their First Nations identity.²²² Butler et al found that understanding heritage, being involved in culture and having an First Nations identity was integral to wellbeing.¹⁶

4. Country

To appreciate the importance of Country, it is useful to look outside the Anglo-centric understandings of what a country/home/place is and respect the cultural understandings of Country and its implications for health from the perspective of First Nations Australians.²²⁶ For example, Love et al²²⁷ describe some of the negative health implications of being away from country:

'if your spirit is not free to wander the spirit world and you are removed from your Country, dreaming place or spirit for extended periods of time, an illness called 'longing for, crying for, or being sick for Country' can develop. Hence,

maintaining a healthy spirit can also assist with physical health as the physical body will heal once the spirit is healed.'(p.182)²²⁷

Moreover, a person's country is described as being more than where they came from or their heritage. Within First Nations Australian cultures, there is a symbiotic relationship with the land whereby people take care of the land and the land cares for them.²²⁶ This is actualised in active custodianship and living directly from the land, as well as connecting through fishing, camping, story-telling, gathering food, walking and practising land management, amongst other things.¹⁶ Since colonisation, there have been barriers in nurturing this relationship. Research has demonstrated that those from the Stolen Generation have worse health and wellbeing than those that were not Stolen, a contributing factor being the removal of the person from their Country and land.¹⁶ An exemplar of the relationship between Country and wellbeing is the model (Figure 10) developed by an Aboriginal community near Melbourne, Australia.²²⁶ Featured in the model is the visual representation of the Country that community members identify with as their own and is symbolic of the struggle of being urbanised but also needing to connect to Country.²²⁶

Figure 10. Rumbalara Aboriginal Cooperative model of wellbeing.



Source: Kingsley, J., Townsend, M., Henderson-Wilson, C., & Bolam, B. (2013). Developing an Exploratory Framework Linking Australian Aboriginal Peoples' Connection to Country and Concepts of Wellbeing. *International Journal of Environmental Research and Public Health*, 10(2), 678-698.

5. Basic needs

Basic needs refer to the essential factors for supporting life.¹⁶ Butler et al¹⁶ explain that in many of the papers they reviewed, First Nations Australians described 'the pressure to fulfil basic needs' for life, such as: food, money, housing and access to services. Many First Nations Australians experience disadvantage across the social determinants of health and this disadvantage is attributed with decreased levels of wellbeing.¹⁶

6. Work, roles and responsibilities

Work and responsibilities have implications for wellbeing. Butler et al¹⁶ found that work, particularly work that involved supporting a person's own heritage or community was connected to wellbeing. There is a responsibility to culture and

educating younger generations and being able to follow through with these responsibilities that is attributed with wellbeing. Work that separates people from their Country, family and/or responsibilities is attributed with decreased wellbeing.¹⁶

7. Education

A complex relationship between education and wellbeing was reported in the literature reviewed by Butler et al. According to Butler et al there is a tension between formal schooling and cultural knowledge in community settings.¹⁶ In the literature there appeared to be a perceived need to prioritise one form of education over the other and this made the relationship to wellbeing unclear. It was recognised that education is associated with paid work which has benefits to wellbeing. However, there are also drawbacks, particularly for children in remote communities that may have to travel or board for their schooling. Some studies reported that the ideal situation would be to have formal education opportunities that recognise and utilise First Nations ways of knowing; incorporating language, song, dance and other relevant cultural practices into the teaching space.¹⁶

8. Physical health

As has been mentioned, First Nations Australian perceptions of health and wellbeing differ from non-Indigenous perceptions. The literature reviewed by Butler et al also supports this notion.¹⁶ They describe physical health '*as an integrative concept that is dependent on the functioning of broader parts of life rather than merely the physical state of the body.*' (p.142) Nonetheless there is a relationship to wellbeing, but it is culturally-bound and complex.¹⁶ It is evident in the literature that the lower levels of physical health experienced by many First Nations Australians is associated with decreased levels of wellbeing attributed to transgenerational inequities. These factors are interlinked and should not be viewed independently but in the wider context of colonisation.¹⁶

9. Mental Health

There is considerable conflation between wellbeing and mental health. However, Butler et al suggests that there is some delineation within the literature as mental health impacts on overall wellbeing.¹⁶ Many First Nations Australians experience high levels of decreased mental health which is attributed to transgenerational trauma, overall disadvantage across life factors and the stress associated with these socio-environmental conditions.¹⁶ Having a strong sense of identity and connection to culture is associated with resilience and increased levels of mental health. Butler et al¹⁶ note that a number of studies have demonstrated that culturally specific mental health care should be utilised as Western approaches do not typically consider the social and cultural context of mental health and can be inappropriate and unsupportive; *'the quality of social relationships, community processes and social context was said to be more relevant to a collectivist culture, where the wellbeing of the whole community is paramount and essential for wellbeing of the individuals that comprise it'*.¹⁶

In September 2019 another review²²⁸ was published on the topic of First Nations Australian health and wellbeing. This review was conducted as part of a national research study called Mayi Kuwayu Study.²²⁹ The study is being facilitated by the Australian National University. The overall aim of the study is to understand how First Nations Australian culture is connected to health and wellbeing.²²⁹ As part of the study, the research team undertook a literature review to present the available evidence which describes which cultural factors are important to First Nations Australians in relation to health and wellbeing. The review included 284 articles from 1990 to 2017. Like Butler et al,¹⁶ the authors determined that there were a number of culturally specific domains related to wellbeing. They also observed that the domains overlap and the concepts are interconnected. They suggest six domains;²²⁸

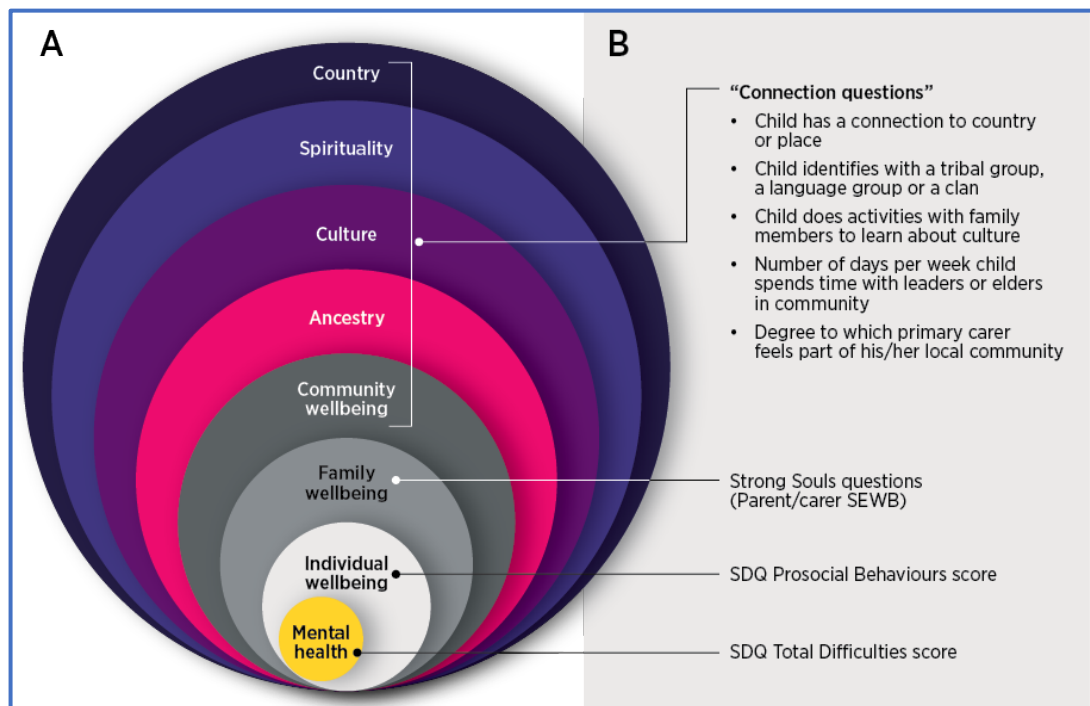
- Connection to Country
- Indigenous beliefs and knowledge
- Indigenous language
- Family, kinship and community
- Cultural expression and continuity
- Self-determination and leadership

It is outside the scope of this thesis to systematically analyse all of the similarities and differences of domains proposed in the literature with respect to the domains of First Nations Australian health and wellbeing. However, anecdotally it is evident that there are similar concepts and values being repeatedly reported and described. Since the publication of these reviews, there appears to be no new literature which investigates the definitions of health and wellbeing for First Nations Australians. Yet, a limitation of the existing reviews is that they do not delineate children from adults with respect to defining health and wellbeing for First Nations Australians. Compared to the overall population of First Nations Australians, there is very limited research on how First Nations Australian children perceive their health and wellbeing.²³⁰

In 2017 Priest et al²³⁰ published data from focus groups completed with 31 urban, First Nations Australian children aged eight to 12 years. They reported that like adults, First Nations Australian children have a holistic view of their health and wellbeing. Family and their First Nations identity was highly valued in terms of how they perceived their health.²³⁰ The findings mirrored Priest et al's²³¹ earlier work with 25 parents and carers of First Nations Australian children that aimed to develop a conceptual framework of child health and wellbeing. According to the framework, social and historical determinants play a role in child health and wellbeing, as do connection to family, country and culture.²³¹

The Longitudinal Study of Indigenous Children (LSIC) provides some insight into child perceptions as well.²³² The study commenced in 2008 with First Nations Australian preschool aged children and has been collecting health and wellbeing data since.²³² The study investigators suggest that the social and emotion wellbeing (SEWB) of First Nations Australian children is *'dependent upon family and community wellbeing and connection to ancestry, culture, spirituality and country. Mental health is important but not central to the child's SEWB'*.(p.5)²³² As part of their investigations into what factors promote the SEWB of First Nations Australian children, the authors have created a model, Figure 11. Like adult conceptions of health and wellbeing and Priest et al's findings²³¹, the LSIC reports a number culturally specific domains.

Figure 11. (A) Conceptual framework for social and emotional wellbeing (SEWB) of Indigenous Australian children; and (B) variables from LSIC chosen as outcome measures to operationalise the concept of SEWB



Source: Marmor, A., & Harley, D. (2018). What promotes social and emotional wellbeing in Aboriginal and Torres Strait Islander children?: Lessons in measurement from the Longitudinal Study of Indigenous Children. *Family Matters*(100), 4.

2.5.5 SUMMARY

There is considerable evidence to demonstrate that many First Nations Australians perceive health and wellbeing differently to non-Indigenous Australians. Available research indicates that there are not only culturally specific understandings of health, but also values that are not typically reflected in Anglo-centric definitions of health. At present there are no HR-QoL or wellbeing measures that adequately and/or validly measure the HR-QoL of First Nations Australians. This thesis addresses this gap in Chapter 7 and 8 by establishing which concepts are important to First Nations Australians when considering their children's HR-QoL and trialling a culturally-specific HR-QoL tool to investigate its validity with a First Nations Australian population.

2.6 CONCLUSION

Since the colonisation of Australia, First Nations Australian people have experienced considerable barriers to achieving high levels of health and wellbeing. The colonial process has eroded social and cultural determinants of health, undermining First Nations Australians' ability to participate in work, education and their own cultural traditions and identity.¹ These factors have resulted in widespread disadvantage and poor health for many First Nations Australians. One area of health that is in noticeable deficit compared to non-Indigenous Australians is oral health.⁴² Unlike the rest of the body systems, oral health is not included under Australia's publicly funded medical system and is siloed into a private, treatment focused industry.¹¹² These conditions along with historical determinants have resulted in low levels of oral health for First Nations Australians.⁶⁵

Despite the notable challenges experienced by First Nations Australians with respect to their oral health, there are gaps in the knowledge for health policy. Preschool aged First Nations Australian children are not typically included in national oral health data collection and there have been limited studies that have addressed the oral health of First Nations Australian children under the age of five

years.⁴ Likewise, the experience of oral health from the perspective of First Nations Australians has rarely been recorded.⁹ In order to address the health disparities of First Nations Australians, policy and programs need to be informed by the people they aim to serve. Patient reported outcome measures are considered necessary for the advancement of patient health care¹⁵ and yet First Nations Australian values are not currently reflected in available measures.¹⁶ At present, there is not a valid culturally-specific tool to investigate how First Nations Australians are faring with respect to their oral HR-QoL or general HR-QoL.^{14, 16} This thesis aims to address the aforementioned gaps in data, knowledge and HR-QoL metrics, making a novel contribution to the field of First Nations Australian health and wellbeing.

3 RESEARCH METHODS

Three studies were conducted for this thesis. This chapter explains the methods used to conduct each study. Study 1 and 2 have some overlap as they involve the same study population. Study 3 is presented separately and described in two phases: development and validation. All methods are also discussed in the five forthcoming chapters which relate to the published (and soon to be published) findings of the studies.

3.1 STUDY 1: INVESTIGATING CARIES IN CHILDREN AGED LESS THAN FIVE YEARS

This study was part of a larger research project titled 'Tooth and Lung Sickness in Murri Kids' (TLSIM). The study was a prospective cohort study of children aged less than five years registered with a primary health care service in Caboolture, Queensland; the full study protocol has been previously published.²³³ The TLISM study commenced in February 2013 and completed recruitment in October 2015. Comprehensive demographic, epidemiological, socio-economic, cultural and clinical data pertaining to oral health and respiratory health were collected on each child at baseline and monthly for 12 months. My evaluation and analysis of the oral health data were retrospective and began in February 2017. The findings of this study have been published and are available in Chapter 4.

The primary objectives of my analysis were to:

1. Determine the prevalence of known risk factors and risk indicators for dental caries in urban First Nations children aged between zero and five years registered with a primary health care practice in Brisbane, Queensland.
2. Determine the prevalence of decayed, missing and filled teeth in a population of urban First Nations children aged zero and five years registered with a primary health care practice in Brisbane, Queensland.

3. Determine what socio-cultural, environmental and physiological factors were associated with dental caries.

3.1.1 STUDY DESIGN

To address objectives one to three, a cross-sectional analysis of data collected at baseline in the cohort study was undertaken. As the oral health data had not been previously utilised for any other study purposes, it had not been cleaned or prepared for analysis. Preparations for this study involved going through the study workbook to determine the variables required, cleaning the data and preparing it for analysis.

3.1.2 PARTICIPANTS

In the original cohort study, participants were eligible if they were registered as a patient with the clinic, aged under five years, provided written consent from a parent/carers and were willing and able to complete the protocol requirements. They were ineligible if they planned on leaving the area within 12 months. For my analyses, only First Nations children were included in the analysis provided they had been eligible for the cohort study.

3.1.3 DATA COLLECTION

The quantitative data were collected from 2013 to 2015 by the now Dr Kerry Hall and fellow researchers. The study duration for each participant was 12 months from baseline. Researchers administered a paper-based questionnaire via interview at baseline. Follow-up interviews were conducted monthly for 12 months via phone, email or home visit. Data collected at baseline included demographic, cultural, general medical history, brief prenatal and antenatal history and oral health behaviours of the child and parent/carers. In addition to the questionnaire, participants also took part in an oral examination which measured their dmft score.

The oral examination was basic, limited by the child's age and acceptance of the examination to be conducted. Infants and younger children were held in their parent's arms with their head tilted back. Older children sat in a chair independently. With the use of a moveable overhead light, a dental hygienist or the researcher who had been trained by the hygienist, visually inspected the mouth and used a gloved hand and mirror when possible (younger children sometimes did not accept the use of the mirror) to look and feel for the number of teeth present and/or erupting and whether teeth had cavities present, had been filled or were missing as a result of decay. Teeth were considered present if they had erupted through the gum and could be exposed to saliva, food and microflora. Teeth were marked as having decay if cavitation to the dentine was visible to the naked eye. Plaque levels and non-cavitated lesions were not counted. As there were only two examiners and one taught the other, they were not calibrated. Decayed, missing and filled deciduous teeth (dmft) were noted on a data collection sheet based on the 'dmft index' criteria proposed by the World Health Organization.²³⁴ Follow-up data collected attendance at dental clinics over a 12-month period as well as dental symptoms such as toothache.

3.1.4 DATA ANALYSES

Descriptive analyses were performed for all children with proportions presented by children with and without deciduous teeth present. Further analyses were performed on data from children who had deciduous teeth present and had undergone an oral examination. Due to the small sample size, whether children with deciduous teeth present had any evidence of dmft was dichotomised as either 'yes' having dmft or 'no' not having any dmft; proportions were presented by dmft status, 'dmft=yes' or 'dmft=no'. Chi-squared and Fisher's exact (for variables with cell counts <5) statistics were used to look for differences in both the teeth present and not yet present groups and dmft 'yes' or 'no' groups.

We undertook a backwards stepwise logistic regression to examine what risk factors and risk indicators with a p-value of less than 0.2 in univariate analyses were independently associated with children having observed dmft in the oral examination. A backwards stepwise logistic regression allows you to look at all potential factors within the model and gradually eliminate factors that are not significant. However, due to the small sample size, the model was not stable, and we had to abandon further analysis. All analyses were conducted using Stata 13.1 software (Stata Corp, College Station, TX, USA).

3.1.5 ETHICS

The study received ethical approval by Queensland Children's Health Services Human Research Ethics Committee (HREC/12/QRCH/169), the Medical Research Ethics Committee of the University of Queensland (2012001395) and the Human Research Ethics Committee of the Queensland University of Technology (1300000741). As I was not involved at the commencement of the study, an amendment to the study investigator list was made to include me in the ethics application and was approved.

3.2 STUDY 2: INVESTIGATING IMPACT ON FAMILIES

Given the interest of the community involved in Study 1, it was decided that a qualitative study would be appropriate in order to better understand oral health from the community perspective. The study used semi-structured interviews and focus groups (yarning sessions) with parents/carers of children who had participated in Study 1 and was open to others in the community that were eligible and wanted to participate. The findings related to the study's first objective (Chapter 5) and second objective (Chapter 6) have been published.

The primary objective was to:

1. Determine the impacts of child oral health on urban First Nations families from the perspective of parents and carers.

A secondary objective arose during the study because of the participatory nature of the study. This was to:

2. Report the perceptions and oral health experiences of urban First Nations women.

3.2.1 THEORETICAL FRAMEWORK

Perhaps more than other research methods, many qualitative methods require at least some reflection of how the researcher is going to collect, handle and report the data. This is because the researcher is often used as a tool for collection and analysis (unlike statistical software), leaving the participants and the data they produce vulnerable to whatever approach that the researcher may have.²³⁵ For First Nations populations in particular, there has been a cultural hegemony associated with research. Colonial privilege has historically led to imbalances of power, exploitation and misinterpretation of First Nations experiences.^{2, 236} As a white woman, I was conscious that although I may have the best intentions, there were privileges and paradigms that I brought as a white researcher that could be harmful. To try and minimise harm and conduct research in a culturally sensitive way I chose to follow a social constructionist perspective and use data collection methods that are considered culturally acceptable to First Nations Australian people, such as yarning.

Like social constructionism, yarning for research is concerned with allowing the participant to socially create their own data.^{237, 238} It involves relationship building with the participant prior to data collection to try and alleviate some of the power imbalance that is naturally present between researchers and participants²³⁸, let alone in situations when there is a dominant culture (white colonial researcher investigating an Indigenous culture) looking in. Moreover, during data collection

there is shared dialogue and an expectation that the researcher is there to share their own stories and knowledge as well.

My approach was guided by the principles of Participatory Action Research (PAR). PAR is in contrast to the historical positivism and paternalism of social research and instead endeavours to distribute power and engage participants as researchers themselves.²³⁹ The central tenets of PAR come from a strong background of collaboration and advocacy, whereby research can be used to progress change and support social and community agendas.²³⁹ Given the rationale for commencing the study was because of community interest, it was important to provide the study population with as much say as they wanted, with respect to how the data were produced, analysed and interpreted.

In addition to these principles, my research was conducted under the guidance and supervision of a First Nations Australian researcher, and First Nations Australian colleague. Associate Professor Maree Toombs, my supervisor, and Dr Kerry Hall, my colleague and study predecessor, assisted at each step of the study to provide cultural oversight and input during the data collection and analysis process. Their involvement assisted in countering cultural bias, as well providing an additional perspective on the data. Dr Hall's involvement in particular is discussed in greater detail in section 3.2.5 and 3.2.6.

3.2.2 STUDY DESIGN

Yarning circles and face-to-face interviews were used to achieve the study objectives. The experiences were audio recorded and analysed thematically.

3.2.3 SETTING

Participants were recruited from the study population of the original study, 'Tooth and Lung Sickness in Murri Kids'. Dr Kerry Hall, the lead investigator of the TLSIM study provided support by sharing the study plans with the community and assisting

with recruitment. Contact was made through the participant's preferred contact method established in the original study. This was typically via text message and/or phone call. The study was also advertised at the primary health care clinic and those that had not previously been involved in Study 1, were invited to participate. This was done through word of mouth at the clinic, through fellow researchers and the clinic staff.

3.2.4 PARTICIPANTS

Participants were eligible if they were or had previously been the parent/carer of a First Nations child aged less than five years and were able to provide written consent.

3.2.5 DATA COLLECTION

Data were collected by what is commonly referred to as narrative enquiry. Narrative enquiry uses a person's stories and life experiences to create data.²⁴⁰ Within Australia, a culturally accepted way of facilitating narrative enquiry is by having a yarn.²³⁸ In research, a yarn is akin to a semi-structured interview or focus group. However, there is another aspect to be understood, which can be challenging to articulate: yarning is a cultural practice. Oral traditions have historically been the main form of transmitting knowledge and information within many Indigenous cultures, including Australia.²³⁸ Thus, when yarning is conducted there are some customs to follow, which roughly translate to manners and ways of respecting the sanctity of engaging someone or a group to share their stories and knowledge.

For this research project, I am indebted to Dr Kerry Hall who had established the TLISM study. Dr Hall had established relationships with the majority of the participants and so was able to introduce myself and the qualitative project to the study community. This meant that by the time I had scheduled the research yarn, there was a familiarity between participants and myself. When the yarns took place,

to establish rapport and provide additional context to the participants, I shared my own experiences of oral health, both as a young girl and as the mother to two boys. The yarns began with a starting question such as, “can you tell me about what oral health is like for your family?” and then followed the narrative of the participant. Questions were available to prompt the dialogue if needed, such as “what are some of the things you find easy or hard when it comes to oral health for your kids?”.

In this process, participants shared their thoughts related to the initial research question concerning the impact of child oral health on families, as well as their own personal experiences of oral health as individuals; sharing what oral health was like for them as children and throughout their life as they became mothers. This was not anticipated and as a result a second objective was developed to progress the data that had been collected opportunistically.

3.2.6 DATA ANALYSES

Narrative sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea). The data were then coded with the assistance of NVivo 11.4 (QSR International Pty Ltd. Version 11.4.1.1064) (a qualitative data analysis software). Analysis was guided by Braun and Clarke’s ‘6 Steps’²⁴¹, which does not use a specific lens or theory to guide the analytical process, but provides a framework to follow.²⁴¹ This includes becoming familiar with the transcripts, initial coding, searching for themes, reviewing themes, defining the themes and writing them up.²⁴¹ This process was supplemented by participants’ contribution to the coding and theming steps. Participant involvement in qualitative analysis is necessary to uphold collaborative research agreements, as well as a method to support the validity of the data.^{242, 243} Upon reviewing the transcripts, I inductively coded the data and printed the coded transcripts to paper. These codes were informed by personal notes made after the yarning sessions and informal discussions with Dr Hall.

The transcripts were then brought separately to two participants who had expressed interest in participating in the analysis process. All other participants were offered the opportunity and either declined or were unreachable upon three contact attempts. The participants and I used the transcripts, along with blank pieces of paper ('Post-It Notes'), for any additional information and to place the codes into initial themes. This process was iterative and prompted by a discussion of the yarning sessions and sharing ideas about the data that arose and potential themes. For instance, some concepts were not repeated individually within the group sessions, but consensus was given by participants by way of agreement and affirmations. Like codes were grouped together and once established, it was discussed whether the themes were relevant or not in terms of the study's objective, which was to understand the impact of child oral health on families. This was both a tactile (moving the post-its into themes) and verbal (discussing ideas) collaboration that aimed to acknowledge the participants as experts on their own lives and counteract the sub-conscious bias that can occur with non-Indigenous participation in research.²

Some themes were leftover in the analysis process and although they did not fit the original objective, the participants, Dr Hall and I agreed that they were representative of the participants' personal stories as women and important, nonetheless. Given the amount of data collected, the findings were prepared in a separate manuscript submitted for publication, which can be seen in Chapter 6.

3.2.7 ETHICS

The study was approved by the ethics committees of the Queensland Children's Health Services (HREC/17/QCRH/94) and the Queensland University of Technology (Reference: 1700000462).

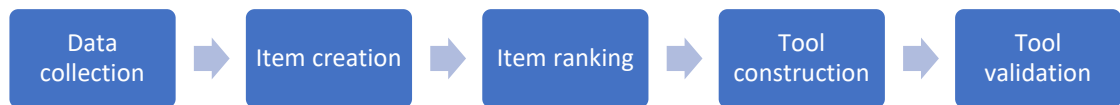
3.3 STUDY 3: DEVELOPING A HEALTH-RELATED QUALITY OF LIFE MEASUREMENT TOOL

The overarching objective of Study 3 was to:

1. Develop and validate a generic HR-QoL tool for use with First Nations children aged zero to 12 years.

There are a number of steps involved in creating a psychometric tool, each which produces new knowledge in and of itself (Figure 12). As such, it is much like a mixed methods study. However, given the variation in settings and participants across the steps, I feel it is best described as two phases: Phase 1: development, and Phase 2: validation. The qualitative findings from Phase 1 have been published (Chapter 7) and the results of the development process of the tool and subsequent validation have been submitted for publication (Chapter 8).

Figure 12. Stages in the development of a psychometric tool



The research questions for Study 3 correspond to the different steps of the study process and phase of the study:

Phase 1:

- a) According to First Nations Australian parents and carers of children aged less than 18 years with a chronic illness, what concepts are representative of HR-QoL for First Nations Australian children?
- b) According to professionals in the field of First Nations Australian child health, what concepts are representative of HR-QoL for First Nations Australian children for inclusion in a draft survey tool on HR-QoL?

Phase 2:

- c) According to First Nations Australian parents and carers of children aged less than 13 years, is the formulation of a draft survey tool on HR-QoL applicable and appropriate to be used with a wider population?
- d) What are the latent factors of a draft HR-QoL survey tool?
- e) Does the draft HR-QoL survey tool demonstrate internal consistency?
- f) Does the draft HR-QoL survey tool demonstrate test-retest reliability?
- g) Does the draft HR-QoL survey tool demonstrate known-group validity?
- h) Does the draft HR-QoL survey tool demonstrate convergent validity?
- i) Does the draft HR-QoL survey tool demonstrate divergent validity?

3.3.1 PHASE 1: DEVELOPMENT

The rationale for developing an entirely new tool was because the available evidence suggests that established tools are ineffective and inappropriate.¹⁴ This meant we needed to start at the beginning and find out what concepts were important to the population the tool aims to serve. The most effective way of doing this was by opening up a dialogue with a sample of the population and leaving the topic open for discussion and interpretation.

3.3.1.1 Study design

Similar to Study 2, this phase of Study 3 used narrative enquiry. Yarning sessions were used to understand the meaning of HR-QoL as it pertained to parents and carers of First Nations children who had experienced a chronic illness.

3.3.1.2 Theoretical framework

In contemporary thought, HR-QoL is a subjective phenomenon, experienced by an individual.¹⁵ This interpretation of HR-QoL, as previously discussed in section 2.5.4 of the document has evolved from its more objective beginnings, where QoL was denoted by objective social indicators such as wealth or access to resources. Because of this evolution, narrative enquiry has become an appropriate research approach to facilitate data collection and one theory in particular resonates with its investigation: Phenomenology. Phenomenology is concerned with understanding a person's experience through their eyes, understanding how they experience a phenomena in this case HR-QoL.²⁴⁴ Phenomenology is in contrast to the positivist approaches that have dominated science, which hold that reality is independent to people's perspectives.²⁴⁵ A phenomenological approach is considered compatible with First Nations methods, such as yarning and ways of knowing associated with First Nations Australians²⁴⁶, because the oral traditions of yarning and story-telling provide a platform for participants to express their experiences of the phenomena.

The expression of the phenomena is however not the end point. Interpretation of the phenomena is needed. At present, there are no validated guiding theories that are applicable to non-Indigenous researchers working within a First Nations health context. Thus, I am unable to say that I have used one particular, appropriate, theory to guide my analysis. What I can say is that I have approached this study, as I have Study 2, cognisant of my whiteness and the lens that I look through.

In recent times, there has been much more attention drawn to how whiteness influences research and specifically analysis.²⁴⁷ Evans et al²⁴⁷ explain that: *'Whiteness is hidden as the normative way of life by which all other cultural ways of being are measured; it forms the taken for granted and hidden framework that gives meaning to events, social actions, and phenomena; and, it privileges White people over all others in such spaces'*(p.898). The actions I have taken to challenge these unconscious biases have been both formal and informal. Formally, I have engaged

with my supervisor, A/Prof Maree Toombs, a First Nations Australian researcher, and we yarned at length about the project and findings as they arose. She provided cultural mentorship and the opportunity to check my interpretation of phenomena. Informally, I tried to educate myself as much as possible on First Nations Australian experiences, perspectives, and ways of knowing. The advent of social media has made access to different people, communities and cultures far more accessible than ever before. There is somewhat of a bias in who you choose to follow or which content you choose to read, but it is now widely accepted that it is a non-Indigenous person's responsibility to educate themselves on how to be an ally and advocate (challenging their colonial bias), and as such there is considerable information to be accessed. For example, Celeste Liddle²⁴⁸, Amy Thunig²⁴⁹, Tiddas for Tiddas²⁵⁰, Elaine Crombie²⁵¹, IndigenousX²⁵², all provide discourse on contemporary issues from a First Nations Australian perspective. While this tutelage is of course informal and does not solve any issues of bias, I felt that it was important to describe as it informs who I am as a white researcher with colonial heritage in Australia.

3.3.1.3 Setting

As has been previously mentioned, Study 3 was undertaken under the direction of my supervisor, A/Prof Maree Toombs. She and colleagues commenced data collection in Toowoomba and Brisbane, recruiting participants via personal and professional networks developed through Carbal Medical Services in Toowoomba and affiliated studies in Brisbane. I engaged with my network in Brisbane and travelled to Darwin in the Northern Territory, to engage with families that had a relationship with the Menzies School of Health Research.

3.3.1.4 Participants

At each time point, participants were recruited via word of mouth. Parents and carers were eligible if they identified as being of Aboriginal and/or Torres Strait Islander descent and were, or had been, the carer of an First Nations child aged less than 18 years with a chronic illness (defined as any condition which affected the child's daily life and required them to attend the doctor and/or hospital

regularly).²⁵³ The study protocol was explained verbally and through a written plain language statement that was provided to potential participants. Signed consent was obtained.

3.3.1.5 Data collection

During data collection, A/Prof Toombs and I spent time with participants getting to know each other over morning or afternoon tea before commencing the research yarn. This involved sharing information about ourselves, including personal information in the context of HR-QoL, discussing why we were conducting the research and how we related as mothers in caring roles.

As HR-QoL was not a concept or phrase that everyone was familiar with, we utilised questions to prompt discussion around ‘health and wellbeing’. For example, asking ‘*how can you tell when your child is sick or unwell?*’ prompted discussion around some of the attributes of wellness as perceived by parents and carers. Likewise, asking ‘*what are some ways you know your child is feeling good and you know their quality of life is good?*’ provided talking points that we could explore further with participants. All yarning sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea).

3.3.1.6 Data analysis

The recordings were transcribed by a transcribing service (Smart Docs., Lexical Ventures, Brisbane, Australia). The data were entered into the software package NVivo 11.4 (QSR International Pty Ltd. Version 11.4.1.1064) and coded by myself. Definitions of health and wellbeing as described by participants were coded first, with like codes grouped together and then further refined into specific concepts which were illustrated on a concept map (see Chapter 7, Figure 14). Remaining data were coded and organised thematically before being refined into more specific concepts to be placed on the concept map. All data were included on the concept map regardless of volume or repetition by participants. Codes were cross-checked

by A/Prof Toombs for interpretation and accuracy and then further discussion was had before finalisation of the concept map.

3.3.1.7 Item generation

From the qualitative investigations, 'items' or 'questions', as I prefer to think of them (as they become that eventually), were selected for inclusion into a draft survey. For this process, I relied heavily on the concept map I had created to ensure that I included all concepts that were raised by participants (see Chapter 7). This included using variations on wording and approaching the item/question in a different way so as to ensure that each concept/value was well represented in the survey. The item generation process was consultative between myself and the research team involved in the project. This included my supervisory team and Associate Professor Jeanie Sheffield, an experienced psychologist and researcher who has contributed to the development of a number of psychometric tools previously. As well as Professor Anne Chang, a paediatric respiratory physician with considerable experience working with First Nations children in urban, regional, and remote settings. I drafted the concepts into rough questions and the group deliberated over the relevance of the question and whether it was reflective of the concept on the concept map. The refining process happened over three meetings and decisions were informed by professional experience and literature on HR-QoL tools. However, we aimed to prioritise the concept map over any literature or opinion as we felt that it was important to not be swayed by the status quo.

3.3.1.8 Item ranking

Once the items/questions were determined they were formatted into a document with a ranking scale. This part of the validation process was informed by Polit and Beck.^{254, 255} Each item could be ranked from 1 (Do not use) to 4 (Definitely Keep) to determine an item validity content index (I-CVI). This document was then disseminated to a panel of nine people which included First Nations Australian academics, First Nations Health Workers, and clinicians that work closely with both First Nations Australian paediatric and adult populations. A rationale for the survey,

as well as directions on how to rank the items effectively was provided. These documents are presented in Appendix A.

Of the nine contacted, six professionals participated in the ranking. Of the three that did not participate, one returned the form with only written feedback, one did not return the form until much later and the index was not utilised and one did not return the form at all. Guided by Polit and Beck^{254, 255}, six professionals were considered to be adequate to inform the I-CVI. The I-CVI score was determined by summing the percentage of agreement between the panel: items were included upon >79% agreement and removed if <69%. All others were to be iteratively reviewed until a resolution had been reached.²⁵⁵ However, there was a consensus amongst the professionals and no items needed to be returned to professionals for consultation. The ranking process effectively reduced the number of items from 52 to 39.

3.3.1.9 Tool construction

Once the items were finalised, they needed to be formulated into questions that could be answered using a Likert-type scale. Feedback from the professional panel suggested that the five-point scale: (0) Never to (5) Almost Always, would be most appropriate. Question wording was checked with the research team via group meetings and modified where needed for comprehension. Although it was not a deliberate approach, most questions were positively framed. For example, by asking 'does your child sleep through the night?', a child with better HR-QoL would respond higher on the scale. Conversely with a negatively worded question, 'the medical staff talk down to you', a child with better HR-QoL would respond lower on the scale. There is some debate²⁵⁶ about the inclusion of both positively and negatively worded questions, with empirical evidence^{256, 257} supporting both approaches: 1) all questions in one direction, or 2) questions in both directions. The latter is thought to reduce method effects, which refers to the tendency '*to respond to questionnaires based on other criteria than their alleged content, resulting in systematic variance that is irrelevant to the study or the concept the researcher is*

*attempting to measure’ (p.196).*²⁵⁷ In layman’s terms, the inclusion of a negatively worded item is thought to act as ‘cognitive speedbump’ when answering questions, so that an acquiescent person answering the question has to consciously check in with what they are answering.²⁵⁷ For this tool it was decided that the focus should be on question comprehension and so clarity of the questions was prioritised over wording them in any particular direction. The final draft tool and associated participant information and consent form can be viewed in Appendix B.

3.3.1.10 Materials

Another step in the validation process is comparing the tool against other measures to examine convergent validity and divergent validity. Convergent validity is concerned with the tool correlating highly with other tools that measure the same constructs.²⁵⁸ In this instance, we were interested in finding a tool that measured HR-QoL in an First Nations Australian population, and if not possible a generalisable population. Another criteria was the age the tool targeted. The data to inform the novel HR-QoL tool was believed to best represent children aged zero to 12 years, as that was the age range of children that were represented during the qualitative investigations to determine the items/domains of HR-QoL. A systematic review of available HR-QoL measures with First Nations Australians was undertaken. When this resulted in no relevant items, the review was expanded to include other Indigenous populations globally. Unfortunately, there were no validated parent-proxy HR-QoL tools for Indigenous populations available at the time.¹⁴ For this reason it was decided to use a tool that had demonstrated good reliability and validity in numerous populations, the ‘PedsQL^{4.0}’.²⁵⁹ The Pediatric QoL Inventory 4.0 (PedsQL)²⁵⁹ is a 23 item parent-proxy measure of child HR-QoL. It has a 5-point Likert-style scale (0 = never a problem to 4 = almost always a problem). Another reason for choosing the tool was because the inventory caters to a large age group (2 to 4, 5 to 7, 8 to 12, and 13 to 18 years) including relative proxy measures.

To examine divergent validity, we were interested in finding a tool that would not correlate with HR-QoL but was still in the realm of health. Like the aforementioned tool, this process also proved challenging. In this case, catering to the age groups and need for a proxy tool were the greatest barriers. Because the items in the novel tool were specific to children aged zero to 12 years, we were concerned with finding a tool to reflect this age range, and one that would not be inappropriate or offensive. For example, the tools available tend to be geared to older children and adolescents and reflect mental health and/or behavioural screening.²⁶⁰ One tool that was considered because of its age applicability was the Strengths and Difficulties Questionnaire (SDQ). It has previously been used with general and First Nations Australian populations²⁶¹, as well as adapted for First Nations Australians in the Western Australian Aboriginal Child Health Survey.²⁶² However, the questions relate to difficult psychological attributes and behaviour, and as such, can be considered quite negative. This perception was reported in a study that examined the face validity of the tool with an First Nations Australian population in Sydney, Australia²⁶¹, and in a study with a Maori population in New Zealand.^{263, 264} Moreover, upon emailing the administrator of the SDQ, it was indicated that the adapted tool had also been rejected by some Aboriginal community members during the Western Australian Aboriginal Child Health Survey and was no longer available for modification. If we wanted to use the tool, we needed to use the whole tool as it was. Given our inability to find a tool had been used with First Nations populations that would be both applicable (in terms of age and topic) and acceptable, we chose to utilise a tool that, for lack of a better description was more 'gentle' in the questions it asked and would be applicable to both preschool and school-aged children, i.e. the Spence Children's Anxiety Scale (SCAS-P).

The SCAS-P parent-version²⁶⁵ is a scale designed to measure anxiety in a children. There are two versions of the scale, for preschool children and for school-aged children. The preschool scale consists of 28 items that ask parents to report on the frequency of which an item is true for their child. Each item is rated on a five-point scale from 0 'not at all' to 4 'very often true'. The scale has been validated for

Australian children aged two and a half to six years.²⁶⁶ The school aged version consists of 44 items and has been validated for Australian children aged six to 18 years. The parent is asked to rate on a 4-point scale (never, sometimes, often or always), how often each of the items happens to their child.²⁶⁵

To investigate other correlations to the novel parent-proxy HR-QoL, we also utilised a parent wellbeing scale. The Kessler Psychological Distress Scale²⁶⁷ is a ten-item scale investigating whether a person has been experiencing the anxiety or depression in the past four weeks. The tool has been used with general Australian adults previously, and adapted versions of the scale (the Kessler 5 & 6) validated with First Nations Australian adults.²¹⁵ Given parents of the children we would be recruiting may or may not identify as First Nations Australians, we opted to use the generic tool, the Kessler 10.

We also collected a single item measure which reflected the parent/carers perception of their child HR-QoL. Participants were invited to indicate on a numerical scale from 1 (terrible) to 10 (excellent) how they would rate their child's HR-QoL.

3.3.1.11 Ethics

This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/16/QRCH/281) and the Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (HREC 2017-2866).

3.3.2 PHASE 2: VALIDATION

This part of Study 3 involved piloting the tool for appropriateness and acceptability, and then evaluating the psychometric properties of the tool. Although they are

essentially separate tasks, both tasks were done within the same setting and so are described as such.

3.3.2.1 Study Design

This study involved a pilot phase whereby participants were recruited to complete a survey and provide any feedback on the tool; and then a larger prospective study phase that recruited parents/carers of First Nations children in different settings. A subset of participants completed a follow up survey at four weeks from baseline.

3.3.2.2 Setting

Queensland Children's Hospital: was the primary recruitment location of the study. The recruitment process was made possible by the collaboration of the First Nations Liaison Officers, Mr Gregory Ross and Ms Anna-Maria Bell. Mr Ross and Ms Bell are responsible for supporting the First Nations Australian children and their parents that visit the hospital. As there are only two of them to support the entire hospital, much of their workload is prioritised to those children who are inpatients and staying in the hospital overnight and for extended periods. At the beginning of the project, I was introduced to Mr Ross and Ms Bell who have an office on the main floor of the hospital. This office is open to the public and provides an opportunity to engage with First Nations Australian families attending the hospital. At the beginning of the project I spent considerable time in the office with Mr Ross and Ms Bell to familiarise myself with the hospital community and give the same opportunity to the hospital community to meet me. Mr Ross and Ms Bell began introducing me to potential participants and later supported me to approach potential participants independently through the hospital's inpatient wards and outpatient clinics.

Carbal Medical Services Toowoomba and Warwick: Additional recruitment took place in primary health care clinics in two regional towns West of Brisbane. These clinics provide culturally specific primary health care to First Nations Australians

residents. Participants were recruited from the waiting rooms of the respective clinics and during the clinic's 'Mums & Bubs' sessions.

3.3.2.3 Participants

Pilot phase: Parents/carers were eligible if they identified as First Nations, were caring for a First Nations child aged less than 13 years with a chronic health condition (physical, behavioural, mental) and provided written informed consent.

Validation: Both First Nations and non-Indigenous parents/carers were eligible if they were caring for a First Nations child aged less than 13 years. Both parents/carers of children who had a chronic health condition (physical, behavioural, mental) and did not have a chronic condition were eligible. Children in the care of State services were not eligible.

3.3.2.4 Procedure and data collection

In addition to the novel HR-QoL tool and associated comparison measures, demographic, cultural, health and wellbeing data were collected for both participants and the child they were completing the study survey on. With respect to measuring the reliability and validity of the tool, certain procedures were undertaken to assist in answering the research questions. For instance, to investigate known-group validity, a question which asked whether the child had a health condition or not was included. Known-group validity refers to the ability of a tool to discriminate between two groups.²⁶⁸ We hypothesised that children with a health condition would have worse HR-QoL, than children without a health condition. However, with hindsight the scope of our recruitment was too large, and we were unable to adequately distinguish groups for analysis. These challenges are explained further in the Discussion in section 9.2.4. To investigate aspects of the tool's reliability, a re-test option was created for participants. Participants were asked to complete the novel survey and comparison measures four weeks after baseline.

Initially a paper-based survey (Appendix B) was created to collect the participant details and their answers to the surveys. However, in response to participant feedback early on in data collection during the validation phase an online version (www.surveymonkey.com) of the survey was developed. The initial screening process for the paper-based survey involved inviting potential participants to complete the survey in their own time. The survey and consent form were supplied and the participant had the option to complete the survey in their own time and for it be collected at a time that suited them while in the hospital or to mail back the survey and consent form using a reply paid envelope.

Pilot-phase: participants were invited to participate and give their feedback on completing the survey. They could give verbal feedback and were encouraged to write their feedback on the survey itself. Once feedback was received for 12 participants, the tool would be modified using the feedback to progress the validation. However, no changes to the content were advised and so only formatting changes were made.

Validation phase: As mentioned, the initial screening phase involved providing potential participants with a paper-based survey and consent form. This was undertaken for the first 30 participants before the online option became available to all participants. Potential participants were then offered the option to take the paper-based survey for completion and consent at a time that suited them or provide written consent for the online survey at the time of recruitment and complete a short demographic details page which would inform which survey would be sent out. The majority of participants chose to complete the consent form and have the online survey sent to them via text and/or email. An age-specific survey would then be sent out with a three-digit code that was linked to the participants screening information.

On the paper-based form, participants were asked on the consent page whether they would provide consent to be contacted in four weeks' time to complete the survey again. On the online version, participants were able to indicate after they had completed the survey, whether or not they would consent to being contacted again in four weeks' time.

3.3.2.5 Data Analysis

Descriptive statistics were performed for all demographic, cultural, health and wellbeing characteristics and presented using means and standard deviations for normally distributed data and medians and interquartile ranges for non-normal distribution. Chi-squared and Fischer's exact (for variables with cell counts <5) statistics were used to look for differences between children with and without a chronic illness, and those who indicated 'unknown' with respect to having a chronic illness.

Exploratory Factor Analysis (EFA) was used to examine HR-QoL and group variables into latent factors. EFA is a method of exploring how different items and constructs relate to one and other, providing an opportunity to see empirically which items group together.²⁶⁹ Prior to the EFA, the number of items were reduced from 52 to 39 to achieve an appropriate item to respondent ratio. There are no specific rules on item to respondent ratios, yet it is accepted that a minimum of five respondents to one item is required.²⁶⁹ Item reduction was informed by item correlation and by the qualitative data collected during item creation and professional decision making; the item which was considered to be most representative of the construct was retained.

For the EFA, Principal axis factoring was used for extraction with Promax rotation used to account for correlation among factors. The eigenvalues for each factor were

set as greater than 1.0. Missing data was imputed using Expectation-Maximization Algorithm to preserve relationships between variables. Once the factors were determined, they were reviewed by First Nations health professionals (n = 5) who independently evaluated the relevance and applicability of the factors as domains of child HR-QoL.

Internal consistency was determined using Cronbach's alpha, and Intraclass correlation (ICC) used to assess test-retest reliability. A Cronbach's alpha and ICC of 0.7 or above was considered appropriate. To evaluate convergent and divergent validity, Pearson's correlation was used to examine the correlations between the HR-QoL scale domains and comparison measures; coefficients of 0.7 were considered strong, 0.4-0.6 moderate and ≤ 0.3 weak.

Known-group validity was evaluated between a child's chronic condition status: yes, no, unknown. Purposeful selection of covariates approach was used to produce a multivariable model. An initial multivariable model was created based on bivariate analysis of all variables whose p-value was < 0.2 were entered into the model. Effects not attaining statistical significance ($p < 0.05$) were removed from this initial multivariable model. Excluded variables were added back into the model one at a time, to check if they were significant and/or for confounding effects (changed existing model predictors coefficients by more than 10%). Age of child and if they had a chronic condition were forced into the model. The results of this analysis are not included in the related publication (Chapter 8) as the groupings were considered too broad to be relevant to the psychometric properties of the tool. However, I have included them in Appendix C, and discussed the relevant challenges in section 9.2.4.

3.3.2.6 Ethics

Ethical approval was granted by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/18/QCHQ/44186); Queensland University of Technology's University Human Research Ethics Committee

(1800001262) and the University of Queensland Human Research Ethics Committee (2018002613).

4 RISK FACTORS FOR ORAL HEALTH IN YOUNG, URBAN, ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN.

This chapter reports on the analysis of data collected on the oral health of urban First Nations Australian children enrolled in the Tooth and Lung Health in Murri Kids study.

The following objectives related to Study 1 are addressed in the chapter:

- Determine the prevalence of known risk factors and risk indicators for dental caries in urban First Nations children aged between zero and five years registered with a primary health care practice in Brisbane, Queensland.
- Determine the prevalence of decayed, missing and filled teeth in a population of urban First Nations children aged zero to five years registered with a primary health care practice in Brisbane, Queensland.
- Determine what socio-cultural, environmental and physiological factors were associated with dental caries.

It comprises the following published paper: Butten K, Johnson NW, Hall KK, Anderson J, Toombs M, King N, O'Grady KAF. Risk factors for oral health in young, urban, Aboriginal and Torres Strait Islander children. Australian Dental Journal. 2019 Mar;64(1):72-81.

STATEMENT OF CONTRIBUTION OF CO-AUTHORS FOR THESIS BY PUBLISHED PAPER

The authors listed below have certified that:

1. they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
2. they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. there are no other authors of the publication according to these criteria;
4. potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit, and
5. they agree to the use of the publication in the student's thesis and its publication on the QUT's ePrints site consistent with any limitations set by publisher requirements

In the case of this chapter:

Chapter 4 (Study 1): Butten K, Johnson NW, Hall KK, Anderson J, Toombs M, King N, O'Grady KAF. Risk factors for oral health in young, urban, Aboriginal and Torres Strait Islander children. Australian Dental Journal. 2019 Mar;64(1):72-81.

Author	Statement of contribution
Kaley Butten QUT Verified Signature _____ Signature Date 15/05/20	Organised and completed the data cleaning process. Conducted all statistical analyses of the data. Interpreted the findings. Designed and created tables and figures. Produced the first and final drafts of the manuscript, collated and responded to feedback on drafts from co-authors, and prepared the manuscript for submission.
Newell Johnson	Assisted with interpretation of clinical findings. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Kerry Hall	Conceptualised and designed the study and data collection instruments and oversaw study implementation. Approved final version of the manuscript.
Jennie Anderson	Conceptualised and oversaw study implementation. Approved final version of the manuscript.
Maree Toombs	Provided input into study implementation. Provided cultural guidance on study. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Neil King	Provided critical review of manuscript drafts. Approved final version of the manuscript.

Kerry-Ann O'Grady	Conceptualised and designed the study and data collection instruments. Assisted with planning of statistical analyses and interpretation of findings. Oversaw study implementation. Provided critical review of manuscript drafts. Approved final version of the manuscript.

Principal Supervisor Confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship. (If the Co-authors are not able to sign the form please forward their email or other correspondence confirming the certifying authorship to the RSC).

A/Prof Kerry-Ann O'Grady	QUT Verified Signature	15/05/2020
_____ Name	_____ Signature	_____ Date:

4.1 ABSTRACT

Background: The caries process follows a strong social gradient which can commence in the first years of life. Yet data on young children remain limited. This study reports the potential risk factors and indicators in urban, Aboriginal and Torres Strait Islander children aged less than 5 years and estimates the prevalence of caries.

Methods: Demographic and risk factor and risk indicator data were collected at baseline in a cohort study of children attending a health clinic in north Brisbane. Dentulous children received a basic oral examination to explore the presence of decayed, missing and filled teeth (dmft). Descriptive analyses were performed. A backwards stepwise logistic regression model was performed to identify potential associations with dmft status.

Results: 180 children enrolled: 111 children received the oral examination, of whom 14 (12.6%) (mean age 35 months) were estimated to have dmft >0. There was a high prevalence of socio-economic, dietary and behavioural risk factors/indicators present for children. Due to the small sample size, planned regression was not performed.

Conclusions: Overall, the prevalence of risk factors and risk indicators for caries in the study population is high. More culturally appropriate resources that support preventative care need to be invested before children are school-aged.

4.2 BACKGROUND

Within Australia, dental caries is the most common chronic disease of childhood¹¹⁵ and Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) children experience a disproportionate amount of that burden.⁴ Despite being acknowledged as a priority population by the Australian Government's National Oral Health Plan¹¹⁵ since 2004, data on the oral health of Indigenous peoples are lacking, particularly for those living in urban areas and young children. Indeed, there is a lack of data nationally on the oral health of children aged less than 5 years.⁷

It is important to address this gap as recent research suggests that a cariogenic environment may be established early on and preventative measures should take place in the first year of life before deciduous dentition commences.⁷ Caries are associated with a number of different risk factors and risk indicators. In this paper, we define a risk factor as an attribute in the direct causal chain of the disease (such as poor oral hygiene and high sugar diet), and a risk indicator as an attribute which is not of itself causal, but which has an indirect influence on the outcome, (e.g. parenting practices) by influencing exposure to real risk.^{29, 270} Individual factors attributed to the increased risk of early childhood caries include: going to sleep with a bottle, regular exposure to sugar through food or drink, not visiting a dentist, and lack of preventative care i.e. brushing and fluoride exposure.^{8, 271} Socio-demographic factors including low-income, being a single-parent, and low levels of parent education are also well established risk indicators for caries.²⁷² Further it is hypothesised that cultural factors such as the impact of colonisation and the transgenerational experience of dispossession may also be associated with caries risk within Indigenous populations.⁶⁵ Historically, the oral health of Indigenous peoples was considered good, if not superior to non-Indigenous peoples.⁴ However, it is well known that colonisation and transgenerational inequities have negatively impacted the overall health of Indigenous people.⁶⁵ Cultural factors such as family history (e.g. Stolen Generation), community involvement, connection to country

and partaking in traditional cultural practises have not been studied in relation to oral health.

National data collections currently do not adequately capture Indigenous people and research has mostly taken place in rural and remote communities.⁶⁵ Risk factors and indicators for different populations may vary, particularly between urban, rural and remote populations. Thus, we aimed to determine the prevalence of known risk factors and risk indicators for caries in Indigenous children aged less than 5 years in an urban population and identify the characteristics of a child at risk for caries inclusive of demographic, behavioural, physiological and cultural factors.

4.3 METHODS

The study was approved by the ethics committees of the Queensland Children's Health Services (HREC/12/QRCH/169), University of Queensland (2012001395) and Queensland University of Technology (13000000741). The study was registered with the Australia New Zealand Clinical Trials Registry (ACTRN 12614001214628). Cultural oversight was provided by an Indigenous Research Reference Group.

This paper reports on results from an opportunistic oral health investigation conducted during a prospective cohort study investigating acute respiratory illness in children aged less than five years. The full study protocol has been published.²³³

Recruitment and data collection was opportunistic and was conducted through an Aboriginal owned and operated primary health care clinic in Caboolture, a northern suburb of Brisbane, Queensland, between February 2013 and October 2015. Clients with children were approached in the waiting room by an Aboriginal research officer. Children were eligible for the study if they were aged less than five years, registered as a patient of the clinic, and the parent/carer was willing and able to

consent and complete the study requirements. Children were excluded if the family was planning to move in the following 12 months. The study protocol was explained verbally, and a plain language written statement was provided to potential participants. Signed consent was obtained.

A parent/carer questionnaire was used to collect data at enrolment. Information collected included demographic, cultural, economic and clinical factors. Factors cited in the literature as established or potential risk factors and risk indicators of dental disease were also collected. These included both dietary and oral health behaviours of parent and child.

The oral examination was basic, limited by the child's age and acceptance of the examination to be conducted, and by the staffing and facilities of the organisation. Infants and younger children were held in their parent's arms with their head tilted back. Older children sat in a chair independently. A dental hygienist or the researcher who had been trained by the hygienist visually inspected the mouth and used a gloved hand and mirror when possible (younger children sometimes did not accept the use of the mirror) to look and feel for the number of teeth present and/or erupting and whether teeth had cavities present, were filled or were missing as a result of decay. Teeth were considered present if they had erupted through the gum and could be exposed to saliva, food and microflora. Teeth were marked as having decay if cavitation to the dentine was visible to the naked eye. Plaque levels and non-cavitated lesions were not counted. As there were only two examiners and the one taught the other, they were not calibrated. Decayed, missing and filled deciduous teeth (dmft) were noted on a data collection sheet based on the 'dmft index' criteria proposed by the World Health Organization.²³⁴

Descriptive analyses were performed for all children with proportions presented by children with and without deciduous teeth present. Further analyses were

performed on data from children who had deciduous teeth present and had undergone a dental screen. Due to the small sample size, whether children with deciduous teeth present had any evidence of decayed, missing or filled teeth (dmft) was dichotomised as either 'yes' having dmft or 'no' not having any dmft; proportions were presented by dmft status, 'dmft-yes' or 'dmft-no'. Chi-squared and Fischer's exact (for variables with cell counts <5) statistics were used to look for differences in both the teeth present and not yet present groups and dmft 'yes' or 'no' groups. In the dmft status group (i.e. the 111 children who had teeth present and had a dental screen to determine if they had any dmft, we planned to enter factors that had a *P* value less of <0.2 into a backwards stepwise logistic regression model to identify potential associations with dmft status. All analyses were conducted using Stata 13.1 software (Stata Corp, College Station, TX, USA).

4.4 RESULTS

403 children were screened, and 200 children enrolled. Of those not enrolled, 72 (35.4%) refused, 43 (21.6%) were ineligible, and 88 (43.3%) were not enrolled for other reasons, such as homelessness or because the child was not with a primary carer or legal guardian at the time. Of those enrolled, 180 identified as Indigenous and were eligible for this analysis. The median age was 18.4 months (interquartile range 7.7-34.3); 51% were male. The majority of children 138 (76.6%) had deciduous teeth present and of the 138, 111 received a dental examination. The characteristics of study children by deciduous teeth present or not present are described in Table 6.

Demographic characteristics (Table 6) were similarly distributed between those children with and without deciduous teeth present and a number of demographic associated risk indicators for caries were present: 76.6% of families had an annual household income of <\$52,000, 51.6% of mothers were aged less than 25 years at

the time of their child's birth, 37.7% of mothers and 45.0% of fathers had not completed high school (Table 6).

Of the household and cultural factors assessed, (Table 6) 45.5% carers reported having family from the Stolen Generation, 31.1% did not know and 23.3% reported that they did not. The majority, 76.1% said that they identified with an Indigenous community, 43.3% had a connection with their traditional homeland and 61.1% maintained cultural connections at home (Table 6).

Table 6. Child demographic and cultural characteristics

		All Children N=180 (%)	Deciduous Teeth Not Present N=42 (%)	Deciduous Teeth Present N=138 (%)	P Value*
* Chi2 test for trend, Fischer's exact if cell size <5					
Gender	Female	88 (48.9)	21 (50.0)	67 (48.5)	0.86
	Male	92 (51.1)	21 (50.0)	71 (51.4)	
Age group	<12 months	59 (32.7)	42 (100.0)	17 (12.3)	<0.01
	12 - <24months	48 (26.6)	0 (0.0)	48 (34.7)	
	24 - <36 months	29 (16.1)	0 (0.0)	29 (21.0)	
	36 - <48 months	22 (12.2)	0 (0.0)	22 (15.9)	
	>= 48months	22 (12.2)	0 (0.0)	22 (15.9)	
Birth age	<37 weeks	34 (18.8)	9 (21.4)	25 (18.3)	0.66
	>37 weeks	144 (80.0)	33 (78.5)	111 (81.6)	
	Missing	2 (1.1)	0 (0.0)	2 (1.4)	
Birth weight	<=2500grams	31 (17.2)	8 (19.0)	23 (16.6)	0.72
	>2500grams	149 (82.7)	34 (80.9)	115 (83.3)	
Child has a chronic illness	No	162 (90.0)	39 (92.8)	123 (89.1)	0.57
	Yes	18 (10.0)	3 (7.1)	15 (10.8)	
Diagnosed respiratory illness in past 12 months	No	118 (65.5)	38 (90.4)	80 (57.9)	0.00
	Yes	61 (33.8)	4 (9.5)	57 (41.3)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Toothache in past 7 days	No	177 (98.3)	42 (100.0)	135 (97.8)	1.00
	Yes	3 (1.6)	0 (0.0)	3 (2.1)	
Mother smoked during pregnancy	No	90 (50.0)	23 (54.7)	67 (48.5)	0.50
	Yes	89 (49.4)	19 (45.2)	70 (50.7)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Mother consumed alcohol during pregnancy	No	147 (81.6)	33 (78.5)	114 (82.6)	0.49
	Yes	32 (17.7)	9 (21.4)	23 (16.6)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Child was breastfed ever	No	49 (27.3)	11 (26.1)	38 (27.7)	0.84
	Yes	130 (72.1)	31 (73.8)	99 (72.2)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Maternal age at birth	<25 years	93 (51.6)	19 (45.2)	74 (53.6)	0.15
	25-30 years	37 (20.5)	7 (16.6)	30 (21.7)	
	30+ years	50 (27.7)	16 (38.1)	34 (24.6)	
Paternal age at birth	<25 years	65 (36.1)	11 (26.1)	54 (39.1)	0.01
	25-30 years	47 (26.1)	7 (16.6)	40 (28.9)	
	30+ years	68 (37.7)	24 (57.1)	44 (31.8)	
Mother highest education	Tertiary	3 (1.6)	2 (4.7)	1 (0.7)	0.03
	Certificate/diploma	22 (12.2)	4 (9.5)	18 (13.0)	
	High school	85 (47.2)	26 (61.9)	59 (42.7)	
	Did not complete high school	68 (37.7)	10 (23.8)	58 (42.0)	
	Unknown/missing	2 (1.1)	0 (0.0)	2 (1.4)	
Father highest education	Tertiary	0 (0.0)	0 (0.0)	0 (0.0)	0.10
	Certificate/diploma	22 (12.2)	5 (11.9)	17 (12.3)	
	High school	52 (28.8)	18 (42.8)	34 (24.6)	

	Did not complete high school	81 (45.0)	15 (35.7)	66 (47.8)	
	Declined/ unknown/ missing	25 (13.8)	4 (9.5)	21 (15.2)	
Mother's employment	Employed	25 (85.5)	5 (11.9)	20 (14.4)	0.66
	Unemployed	154 (85.5)	37 (88.1)	117 (87.7)	
	Missing	1 (0.5)	0 (0.0)	0 (0.0)	
Father's employment	Employed	77 (42.7)	21 (50.0)	56 (40.5)	0.57
	Unemployed	77 (42.7)	18 (42.8)	59 (42.7)	
	Declined/unknown/ missing	26 (14.4)	0 (0.0)	0 (0.0)	
Annual household income	\$101,000 - \$156,000	5 (2.7)	1 (2.3)	4 (2.9)	0.54
	\$78,000 - \$104,000	12 (6.6)	4 (9.5)	8 (5.8)	
	\$52,000 - \$78,000	25 (13.8)	7 (16.6)	18 (13.0)	
	\$26,000 - \$52,000	69 (38.3)	18 (42.8)	51 (36.9)	
	<\$26,000	69 (38.3)	12 (28.5)	51 (41.3)	
Primary carer on welfare	No	18 (10.0)	5 (11.9)	13 (9.4)	0.63
	Yes	162 (90.0)	37 (88.1)	125 (90.5)	
Private health insurance	No	171 (95.0)	39 (92.8)	132 (95.6)	0.46
	Yes	9 (5.0)	3 (7.1)	6 (4.3)	
Care type at home	Both parents	100 (55.5)	27 (64.2)	73 (52.9)	0.35
	Single parent	69 (38.3)	14 (33.3)	55 (39.8)	
	Other	11 (6.11)	1 (2.3)	10 (7.2)	
Total number of people in	<=2	10 (5.5)	1 (2.3)	9 (6.5)	0.41
	3-4	81 (45.2)	16 (38.1)	65 (47.4)	
	5-6	69 (38.5)	19 (45.2)	50 (36.5)	
	7+	19 (10.6)	6 (14.2)	13 (9.4)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Total number of people in bedroom with child	0	20 (11.1)	1 (2.3)	19 (13.7)	<0.01
	1	80 (44.4)	14 (33.3)	66 (47.8)	
	2	43 (23.8)	11 (26.1)	32 (23.1)	
	3+	36 (20.0)	16 (38.1)	20 (14.4)	
	Missing	1 (0.5)	0 (0.0)	1 (0.7)	
Indigenous status of father	Indigenous	118 (65.5)	24 (57.1)	94 (68.1)	0.30
	Non-Indigenous	59 (32.7)	17 (40.4)	42 (30.4)	
	Unknown/missing	3 (1.6)	1 (2.3)	2 (1.4)	
Indigenous status of mother	Indigenous	121 (67.2)	28 (66.6)	93 (67.3)	0.93
	Non-Indigenous	59 (32.7)	14 (33.3)	45 (32.6)	
Connection to homeland	No	93 (51.6)	21 (50.0)	72 (52.1)	0.94
	Yes	78 (43.3)	19 (45.2)	59 (42.7)	
	Unknown	9 (5.0)	2 (4.7)	7 (5.0)	
Maintain cultural connections at home	No	68 (37.7)	14 (33.3)	54 (39.1)	0.45
	Yes	110 (61.1)	28 (66.6)	82 (59.4)	
	Unknown	2 (1.1)	0 (0.0)	2 (1.4)	
Connection to community	No	39 (21.6)	8 (19.0)	31 (22.4)	0.92
	Yes	137 (76.1)	33 (78.5)	104 (75.3)	
	Unknown	4 (2.2)	1 (2.3)	3 (2.1)	
Family from stolen generation	No	42 (23.3)	9 (21.4)	33 (23.9)	0.72
	Yes	82 (45.5)	19 (45.2)	63 (45.6)	
	Unknown	56 (31.1)	14 (33.3)	42 (30.4)	

Oral health behaviours for the child and carer are presented in Table 7 and indicate that, of the children that had deciduous teeth present, 81.1% of children had their teeth brushed daily, 89.8% of children had their own toothbrush and 86.6% of children used toothpaste (Table 7). Whether or not the toothpaste contained fluoride was not recorded, but in the geographical area, the vast majority of toothpaste purchased is fluoridated, as is the council water supply since 2010. The majority (75.5%) of carers had self-reported decayed, missed or filled teeth at the time of the study and 48.0% indicated that it had been years since they had been to a dentist (Table 7).

Table 7. Oral health behaviours of child and carer

* Chi2 test for trend excluding unknown/missing, Fischer's exact if cell size <5 † Not Applicable		All Children N=180 (%)	Deciduous Teeth Not Present N=42 (%)	Deciduous Teeth Present N=138 (%)	P Value*
Exclusively breastfed	No	154 (86.0)	22 (52.3)	132 (96.3)	0.86
	Yes	24 (13.4)	20 (47.6)	4 (2.9)	
	Unknown/missing	2 (1.4)	0 (0.0)	2 (1.4)	
Child had bottle at bedtime ever	No	89 (49.4)	32 (76.1)	57 (41.3)	<0.01
	Yes	82 (45.5)	7 (16.6)	75 (54.3)	
	Unknown/missing	9 (5.0)	3 (7.1)	6 (4.3)	
Child sucked thumb ever	No	154 (85.5)	35 (83.3)	119 (86.2)	1.00
	Yes	18 (10.0)	4 (9.5)	14 (10.1)	
	Unknown/missing	8 (4.4)	3 (7.1)	5 (3.6)	
Child used pacifier ever	No	93 (54.6)	23 (54.7)	70 (50.7)	0.46
	Yes	78 (43.3)	15 (35.7)	63 (45.6)	
	Unknown/missing	9 (5.0)	4 (9.5)	5 (3.6)	
Pacifier cleaned in carer mouth ever	No	141 (78.3)	30 (71.4)	111 (80.4)	0.46
	Yes	29 (16.1)	8 (19.0)	21 (15.2)	
	Unknown/missing/NA [†]	10 (5.5)	4 (9.5)	6 (4.3)	
Pacifier dipped in sweet ever	No	155 (86.1)	36 (85.7)	119 (96.2)	0.73
	Yes	14 (7.7)	2 (4.7)	12 (8.7)	
	Unknown/missing/NA	11 (6.1)	4 (9.5)	7 (5.0)	
Are child's teeth brushed	No	7 (3.8)	1 (2.3)	6 (4.3)	<0.01
	Yes	127 (70.5)	2 (4.7)	125 (90.5)	
	Not applicable	39 (21.6)	37 (88.1)	2 (1.4)	
	Unknown/missing	7 (3.8)	2 (4.7)	5 (3.5)	
Child uses toothpaste	No	6 (3.3)	3 (7.1)	3 (2.1)	<0.01
	Yes	120 (66.6)	0 (0.0)	120 (86.6)	
	Unknown/missing/NA	54 (29.8)	39 (92.8)	15 (10.8)	

Child has own toothbrush	No	2 (1.1)	1 (2.3)	1 (0.7)	0.04
	Yes	126 (70.0)	2 (4.7)	124 (89.8)	
	Unknown/missing/NA	52 (28.7)	39 (92.8)	13 (9.2)	
Frequency of brushing	> 2 per day	9 (5.0)	0 (0.0)	9 (6.5)	<0.01
	1 to 2 per day	104 (57.7)	1 (2.3)	103 (74.6)	
	<1 per day	7 (3.8)	1 (2.3)	6 (4.3)	
	None	5 (2.7)	3 (7.1)	2 (1.4)	
	Unknown/missing/NA	55 (30.0)	37 (88.0)	18 (13.0)	
Child has been to dentist	No	157 (87.2)	39 (92.8)	118 (85.5)	0.07
	Yes	11 (6.1)	0 (0.0)	11 (7.9)	
	Unknown/missing	12 (6.6)	3 (7.1)	9 (6.5)	
Child likes dentist	No	14 (7.7)	0 (0.0)	14 (10.1)	N/A
	Yes	12 (6.6)	0 (0.0)	12 (8.7)	
	Unknown/missing/NA	154 (85.5)	42 (100.0)	112 (81.1)	
Last dental visit for carer	Months ago	23 (12.8)	5 (11.9)	18 (13.1)	0.57
	Years ago	86 (48.0)	18 (42.8)	68 (49.6)	
	Unknown	47 (26.6)	12 (28.5)	35 (25.5)	
	Never	3 (1.6)	2 (4.7)	1 (0.7)	
	Missing	21 (11.6)	5 (11.9)	16 (11.5)	
Carer likes dentist	No	68 (37.7)	16 (38.1)	52 (37.6)	0.71
	Yes	97 (53.8)	22 (52.3)	75 (54.3)	
	Unknown/missing	12 (8.3)	4 (9.4)	11 (7.9)	
Carer has DMFT	No	36 (20.0)	4 (9.5)	32 (23.1)	0.09
	Yes	136 (75.5)	35 (83.3)	101 (73.1)	
	Unknown/missing	8 (4.4)	3 (7.1)	5 (3.6)	
Carer perception of fluoride	Good	59 (32.7)	14 (33.3)	45 (32.6)	0.37
	Neither good nor bad	63 (35.0)	16 (38.1)	47 (34.0)	
	Bad	17 (9.4)	2 (4.7)	15 (10.8)	
	Don't know what fluoride is/unknown	33 (18.3)	6 (14.2)	27 (19.5)	
Carer has received education on dental health for child	No	95 (52.7)	25 (59.5)	70 (50.7)	0.94
	Yes	68 (37.7)	13 (30.9)	55 (39.8)	
	Unknown/missing	17 (9.4)	4 (9.5)	13 (9.3)	

Dietary factors are displayed in Table 8. Beverages are described on a daily basis via bottle or cup and food products are described on a weekly basis, as labelled in Table 8. Only small numbers of children were having sweetened beverages in their bottles; 5% of all children were having juice in their bottle 1-3 times per day. However, the percentage increased (21.1%) for children having juice via cup. Table 8 also reports on food items consumed per week. The majority of children who had yet to have deciduous teeth erupt were not eating foods included in the study, yet of those that had teeth, 32.6% were having hot chips ('french fries') 1-3 times per week and 25.3% were having confectionary once or more per week.

Table 8. Dietary variables

Beverages in bottle per day	Serving	All Children N=180 (%)	Teeth Not Present N=42 (%)	Teeth Present N=138(%)	P Value*
Cordial 'fruit drink concentrate'	None	166 (92.2)	19 (45.2)	37 (26.8)	0.17
	<1 per day	3 (1.6)	0 (0.0)	3 (2.1)	
	1 to 3 per day	2 (1.1)	0 (0.0)	2 (1.4)	
	>3 per day	2 (1.1)	0 (0.0)	2 (1.4)	
	Unknown/missing	7 (3.8)	2 (4.7)	5 (3.6)	
Carbonated drink	None	171 (95.0)	40 (95.2)	131 (94.9)	0.46
	<1 per day	1 (0.5)	0 (0.0)	1 (0.7)	
	1 to 3 per day	1 (0.5)	0 (0.0)	1 (0.7)	
	>3 per day	0 (0.0)	0 (0.0)	0 (0.0)	
	Unknown/missing	7 (3.8)	2 (4.7)	5 (3.6)	
Flavoured milk	None	168 (93.3)	40 (95.2)	128 (92.7)	0.04
	<1 per day	1 (0.5)	0 (0.0)	1 (0.7)	
	1 to 3 per day	2 (1.1)	0 (0.0)	2 (1.4)	
	>3 per day	1 (0.5)	0 (0.0)	1 (0.7)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	
Fruit juice	None	156 (86.6)	36 (85.7)	120 (86.9)	0.99
	<1 per day	8 (4.4)	2 (4.7)	6 (4.3)	
	1 to 3 per day	9 (5.0)	2 (4.7)	7 (5.0)	
	>3 per day	0 (0.0)	0 (0.0)	0 (0.0)	
	Unknown/missing	7 (3.8)	2 (4.7)	5 (3.6)	
Plain milk	None	111 (61.6)	21 (50.0)	90 (65.2)	0.04
	<1 per day	0 (0.0)	0 (0.0)	0 (0.0)	
	1 to 3 per day	8 (4.4)	0 (0.0)	8 (5.8)	
	>3 per day	54 (30.0)	19 (45.2)	35 (25.3)	
	Unknown/missing	7 (3.8)	2 (4.7)	5 (3.6)	
Water	None	128 (71.1)	25 (59.5)	103 (74.6)	0.02
	<1 per day	0 (0.0)	0 (0.0)	0 (0.0)	
	1 to 3 per day	5 (2.7)	0 (0.0)	5 (3.6)	
	>3 per day	39 (21.6)	15 (35.7)	24 (17.3)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	
Beverages in cup per day	Serving	All Children N=180 (%)	Deciduous Teeth Not Present N=42 (%)	Deciduous Teeth Present N=138 (%)	P Value*
Cordial 'fruit drink concentrate'	None	118 (65.9)	40 (95.2)	78 (56.9)	<0.01
	<1 per day	36 (20.1)	0 (0.0)	36 (26.2)	
	1 to 3 per day	10 (5.5)	0 (0.0)	10 (7.3)	
	>3 per day	7 (3.9)	0 (0.0)	7 (5.1)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	
Carbonated drink	None	120 (66.6)	39 (92.8)	81 (58.7)	<0.01
	<1 per day	40 (22.2)	1 (2.3)	39 (28.2)	
	1 to 3 per day	10 (5.5)	0 (0.0)	10 (5.5)	
	>3 per day	2 (1.1)	0 (0.0)	2 (1.4)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	

Flavoured milk	None	128 (71.1)	40 (95.2)	88 (63.7)	<0.01
	<1 per day	33 (18.3)	0 (0.0)	33 (23.9)	
	1 to 3 per day	9 (5.0)	0 (0.0)	9 (6.5)	
	>3 per day	2 (1.1)	0 (0.0)	2 (1.4)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	
Fruit juice	None	84 (46.6)	37 (88.1)	47 (34.0)	<0.01
	<1 per day	44 (24.4)	2 (4.7)	42 (30.4)	
	1 to 3 per day	38 (21.1)	1 (2.3)	37 (26.8)	
	>3 per day	6 (3.3)	0 (0.0)	6 (4.3)	
	Unknown/ missing	8 (4.4)	2 (4.7)	6 (4.3)	
Plain Milk	None	43 (23.8)	27 (64.2)	16 (11.5)	<0.01
	<1 per day	6 (3.3)	0 (0.0)	6 (4.3)	
	1 to 3 per day	35 (19.4)	1 (2.3)	34 (24.6)	
	>3 per day	87 (48.3)	12 (28.5)	7 (5.0)	
	Unknown	9 (5.0)	2 (4.7)	7 (5.0)	
Water	None	35 (19.4)	27 (64.2)	8 (5.8)	<0.01
	<1 per day	1 (0.5)	1 (2.3)	0 (0.0)	
	1 to 3 per day	23 (12.7)	1 (2.3)	22 (15.9)	
	>3 per day	113 (62.7)	11 (26.1)	102 (73.9)	
	Unknown/missing	8 (4.4)	2 (4.7)	6 (4.3)	
Food items per week	Serving	All Children N=180 (%)	Deciduous Teeth Not Present N=42 (%)	Deciduous Teeth Present N=138 (%)	P Value*
Cereal	None	123 (68.3)	39 (92.8)	84 (60.8)	<0.01
	<1 per week	34 (18.8)	1 (2.3)	33 (23.9)	
	1 to 3 per week	6 (3.3)	0 (0.0)	6 (4.3)	
	>3 per week	7 (3.8)	0 (0.0)	7 (5.0)	
	Unknown/missing	10 (5.5)	2 (4.7)	8 (5.8)	
Chocolate	None	81 (45.0)	38 (90.4)	43 (31.1)	<0.01
	<1 per week	60 (33.3)	2 (4.7)	58 (42.0)	
	1 to 3 per week	18 (10.0)	0 (0.0)	18 (13.0)	
	>3 per week	12 (6.6)	0 (0.0)	2 (8.7)	
	Unknown/missing	9 (5.0)	2 (4.7)	7 (5.0)	
Fresh fruit	None	48 (26.6)	35 (83.3)	13 (9.4)	<0.01
	<1 per week	5 (2.7)	1 (2.3)	4 (2.9)	
	1 to 3 per week	38 (21.1)	4 (9.5)	34 (24.6)	
	>3 per week	80 (44.4)	0 (0.0)	80 (57.9)	
	Unknown/missing	9 (5.0)	2 (4.7)	7 (5.0)	
Honey	None	118 (65.5)	40 (95.2)	78 (56.5)	<0.01
	<1 per week	39 (21.6)	0 (0.0)	39 (28.2)	
	1 to 3 per week	6 (3.3)	0 (0.0)	6 (4.3)	
	>3 per week	7 (3.8)	0 (0.0)	7 (5.0)	
	Unknown/missing	10 (5.5)	2 (4.7)	8 (5.8)	
Hot chips 'french fries'	None	69 (38.3)	38 (90.4)	31 (22.4)	<0.01
	<1 per week	46 (25.5)	1 (2.3)	45 (32.6)	
	1 to 3 per week	46 (25.5)	1 (2.3)	45 (32.6)	
	>3 per week	9 (5.0)	0 (0.0)	9 (6.5)	
	Unknown/missing	10 (5.5)	2 (4.7)	8 (5.8)	

Jam/fruit conserve	None	125 (69.4)	40 (95.2)	85 (61.5)	<0.01
	<1 per week	34 (18.8)	0 (0.0)	34 (24.6)	
	1 to 3 per week	6 (3.3)	0 (0.0)	6 (4.3)	
	>3 per week	5 (2.7)	0 (0.0)	5 (3.6)	
	Unknown/missing	10 (5.5)	2 (4.7)	8 (5.8)	
Confectionary	None	79 (43.8)	38 (90.4)	41 (29.7)	<0.01
	<1 per week	55 (30.5)	2 (4.7)	53 (38.4)	
	1 to 3 per week	22 (12.2)	0 (0.0)	22 (15.9)	
	>3 per week	13 (7.2)	0 (0.0)	13 (9.4)	
	Unknown/missing	11 (6.1)	2 (4.7)	9 (6.5)	
Potato chips 'crisps'	None	93 (51.6)	39 (92.8)	54 (39.1)	<0.01
	<1 per week	49 (27.2)	1 (2.3)	48 (34.7)	
	1 to 3 per week	15 (8.3)	0 (0.0)	15 (10.8)	
	>3 per week	13 (7.2)	0 (0.0)	13 (9.4)	
	Unknown/missing	10 (5.5)	2 (4.7)	8 (5.8)	
Tinned fruit	None	118 (65.5)	38 (90.4)	80 (57.9)	<0.01
	<1 per week	33 (18.3)	1 (2.3)	32 (23.1)	
	1 to 3 per week	14 (7.7)	1 (2.3)	13 (9.4)	
	>3 per week	4 (2.2)	0 (0.0)	4 (2.9)	
	Unknown/missing	11 (6.1)	2 (4.7)	9 (6.5)	
* Chi2 test for trend excluding unknown/missing, Fischer's exact if cell size <5					

Of the 138 children who had deciduous teeth present, 111 children received a dental examination. The majority 97 (87.3%) had no observed dmft as a result of caries, compared with 14 (12.6%) children who did have dmft from caries i.e dmft >0. The mean dmft was 3.0 teeth (Standard Deviation (SD) 1.7). The mean age for children with dmft experience was 35 months. While there were a number of factors that were identified on univariate analysis for inclusion in regression models, the small sample, the small number of children with dmft, missing data for some variables and the small values in some cells, meant that a statistically valid model could not be constructed, particularly when accounting for the effect of age. Factors eligible for inclusion are available for viewing in Appendix D and E.

4.5 DISCUSSION

Understanding the current oral health environment of young, urban Indigenous children is necessary to inform policy and future programs. This study is one of few Australian studies^{52, 273-275} to report the characteristics of young children in relation

their oral health and is believed to be the first in over a decade to report on the prevalence of risk indicators and risk factors for caries in Indigenous children aged less than five years living in urban Australia.⁴

We found that the prevalence of caries (12.6%), as well as the mean dmft (3.0 teeth, SD 1.7) was higher than has been reported in other studies^{52, 274, 275} for other Australian children of a similar age (mean age 35 months in our study). A longitudinal case-control study (2008)²⁷⁵ of caries development from birth to 36 months conducted in a comparable socio-economic area to our study (Logan, south of Brisbane) reported that 9% of the 552 children aged 36 months had caries experience (i.e. cavitated lesions). The mean dmft was 2.3 teeth (SD 1.5).²⁷⁵ It is speculated that the contact by an oral health therapist every 6 months either by telephone or in a home visit to children during the Logan study may have contributed to the lower prevalence of dmft compared to our study population.

Overall, the prevalence of risk factors and risk indicators for caries in the study population is high. Poverty is one of the greatest influencers of oral health¹¹⁵ and the study population is considerably economically disadvantaged; 42.7% of fathers and 85.5% of mothers were unemployed and 76.6% of households had an annual income of <\$52,000. The Australian National Dental Telephone Interview Survey 2010¹¹⁰ reported that cost was a major barrier to people accessing oral health services and those in the lowest income level were the least likely to receive preventative oral health care.¹¹⁰ In this study, 48.0% of carers had reportedly not visited a dentist in 'years' and 26.0% answered 'unknown' when asked when they last saw a dentist. A qualitative study found that apprehension towards dentists by Indigenous Australians was attributed to feeling judged by the dentist and having their health behaviours questioned.¹¹ In our study, 75.5% of parents/carers reported that at the time of the study, they had decayed, missing or filled teeth themselves and 37.7% indicated that they did not like going to the dentist. Fifty-nine of the 75 respondents suggested that they were frightened; others indicated it

was a mixture of fear, shame and/or embarrassment. The need for culturally safe care within the Australian health care system is well established.¹¹ Programs that are culturally safe and support parents to attend the dentist can potentially influence children's attendance; with the relationship between a carer's oral health behaviours and a child's caries risk having been demonstrated previously.¹²⁸

In our study, children's attendance to the dentist was higher (18.1%) than has been found for other Indigenous children of a similar age; 8% of children aged 30 months in Sydney, Australia (between 2005-2007) and 13.3% of children aged less than 36 months in the Queensland Child Oral Health Survey 2010-2011 (QCOHS).²⁷⁶ It was slightly lower compared with non-Indigenous children (20.5%) as reported in the QCOHS.²⁷⁶ Like other studies^{110, 112}, the QCOHS indicated that children with the lowest family income were the least likely to attend the dentist.²⁷⁶ It is possible that the a change to the Child Dental Benefits Schedule in Queensland, which extended the eligibility to children aged two to four years, when previously it provided for school-aged children only, could have improved attendance in our study population.²⁷⁷ However, as this change in policy came half-way through our data collection timeline, we can only speculate the influence. Other studies have reported that cultural connections and a strong Indigenous identity is protective for Indigenous people's health, particularly for Indigenous children.^{278, 279} Despite over half of parents and carers suggesting they had received no education on caring for their child's oral health, 90.5% of children with deciduous teeth present had their teeth brushed, 74.6 % of those children brushing one to two times per day. Three quarters of participants in our study indicated they had a connection to an Indigenous community and 61.1% maintained cultural practices at home. The prevalence of reported cultural connection within our study community could be a protective factor although this would need to be explored further in larger studies.

Dietary habits have considerable influence on the oral health of young children, particularly night-time feeding with bottles and the regular consumption of cariogenic food and beverages.⁷ In our study, it was encouraging to see that nearly half of children never had a bottle at bedtime and very few were having sugar-

sweetened beverages in their bottles on a daily basis. However, there was a marked increase in the consumption of both cariogenic food and beverages once children had one or more deciduous teeth present and were drinking from a cup. This likely reflects the increased age of the child. Yet the consumption of 'discretionary foods' as described by the Australian Dietary Guidelines (ADG)⁷⁶ is not recommended for young children. The ADG advises that discretionary foods are "not an essential or necessary part of healthy dietary patterns" and children aged less than 12 months should not be consuming them at all and older children should have them "only sometimes and in small amounts".⁷⁶ In univariate analyses, a number of foods/drinks were associated with dmft, as reported in other studies.^{7, 76, 107} However, we could not examine them in regression analyses; larger studies are required to investigate these associations further. A qualitative study of parents of young children found that parents were more likely to give sugary beverages to children as they aged to appease children's preference and temperament.²⁸⁰ There was also the notion that it was more acceptable to give older children sugary beverages compared with infants.²⁸⁰ Programs that support parent's self-efficacy to continue with the healthy choices they are making for their infant could potentially be beneficial. As has been shown in our study, parents appear to be supporting positive oral health behaviours, but there is room for improvement, especially as children age.

There are limitations to our study, including the method of oral screening. Due to the age of children and facility resources, only basic visual examinations were conducted and obvious decay recorded. Some argue that cavitated lesions, as documented for the dmft index, should not be the only marker for disease and pre-cavitated lesions should also be recorded as they contribute to disease trajectory. Given the insensitivity of the dmft measurement index, researchers should consider that the burden of disease is likely higher in a study population.⁵² In this study, due to small numbers, we dichotomised the dmft status. The Australian Research Centre for Population Oral Health²⁸¹ posits that by looking at mean dmft scores, and in our case, a yes or no status, we are potentially overlooking the number of children that

are carrying a disproportionate amount of the disease.²⁸¹ Also impacted by the sample size was our ability to achieve a stable regression model. Despite a number of factors approaching or reaching significance in univariate analysis, a sound model could not be completed because of the small sample size, the small proportion with dmft, and some missing data. Other limitations for the study include its cross-sectional nature, the self-reporting of dietary data and that all data were from a single centre.

4.6 CONCLUSION

Our study indicates that parents and carers of young, urban Indigenous children are engaged in supporting their child's oral health at home. However, there is also a high prevalence of several known risk factors and risk indicators for dental disease. Currently, many research studies and preventative programs take place in school-aged children. This study, and the few others investigating oral health of young children, indicate that more resources need to be invested before children are school-aged, particularly culturally appropriate services that will increase healthy lifestyles amongst families, and the uptake of dental care in this population. Such dental care would need to be both affordable and appropriate, and to support parenting as argued recently by Kumar et al²⁷³ and the authors of the La Cascada Declaration.²⁸²

Acknowledgements

The authors thank the following for their support with study implementation and recruitment: Melissa Dunbar and Dan Arnold from QUT; Jacob Anderson, Ryan Anderson, Kim Bullivant, Gavan Bullivant, Megan Anderson, Lauren Doheny, Loretta Anderson and Melissa Bond from Murri Health Group. Funding was provided through a Queensland Children's Medical Research Institute Project Grant, UQ Foundation Research Excellence Award, a Queensland University of Technology Indigenous Health start-up research grant. KB is supported by a supervisor

scholarship at Queensland University of Technology. KO was supported by a NHMRC Career Development Fellowship (1045157) and Queensland Smart Futures Fellowship and is currently supported by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). KH was supported by an Australian Postgraduate Award and the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). MT is supported part-time by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). The views expressed in this publication are those of the authors and do not reflect the views of the NHMRC.

5 IMPACT OF ORAL HEALTH ON AUSTRALIAN URBAN ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES: A QUALITATIVE STUDY

This chapter reports on the analysis of qualitative data collected when investigating the impact of child oral health on urban, First Nations families.

The following objective related to Study 2 is addressed in the chapter:

- Determine the impacts of child oral health on urban First Nations families from the perspective of parents and carers.

It comprises the following published paper: Batten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF. Impact of oral health on Australian urban Aboriginal and Torres Strait Islander families: a qualitative study. *International Journal for Equity in Health*. 2019 Dec 1;18(1):34.

STATEMENT OF CONTRIBUTION OF CO-AUTHORS FOR THESIS BY PUBLISHED PAPER

The authors listed below have certified that:

1. they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
2. they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. there are no other authors of the publication according to these criteria;
4. potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit, and
5. they agree to the use of the publication in the student's thesis and its publication on the QUT's ePrints site consistent with any limitations set by publisher requirements

In the case of this chapter:

Chapter 5 (Study 2): Batten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF.
Impact of oral health on Australian urban Aboriginal and Torres Strait Islander families:
a qualitative study. International Journal for Equity in Health. 2019 Dec 1;18(1):34.

Author	Statement of contribution
Kaley Batten QUT Verified Signature Signature Date 15/05/20	Conceptualised and designed the study and data collection process. Collected, transcribed, cleaned and analysed all data. Interpreted the findings. Produced the first and final drafts of the manuscript, collated and responded to feedback on drafts from co-authors, and prepared the manuscript for submission.
Newell Johnson	Provided critical review of manuscript drafts. Provided feedback on interpretation of findings. Approved final version of the manuscript.
Kerry Hall	Assisted with data collection and transcription. Provided cultural guidance on study. Provided feedback on interpretation of findings. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Maree Toombs	Provided cultural guidance on study. Provided guidance on analysis and interpretation of findings. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Neil King	Provided critical review of manuscript drafts. Approved final version of the manuscript.
Kerry-Ann O'Grady	Provided input into study implementation. Oversaw study implementation. Provided critical review of manuscript drafts. Approved final version of the manuscript.

Principal Supervisor Confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship. (If the Co-authors are not able to sign the form please forward their email or other correspondence confirming the certifying authorship to the RSC).

A/Prof Kerry O'Grady

QUT Verified Signature

15/05/2020

Name

Signature

Date

5.1 ABSTRACT

Background: The oral health of a child not only impacts the physical well-being of the child but can have quality of life implications for parents and families as they endeavour to provide care and support their child's oral health needs. Within Australia, Aboriginal and Torres Strait Islander children are thought to experience a disproportionate burden of poor oral health compared to non-Indigenous children. Despite the prevalence of oral health challenges, there are limited qualitative studies investigating the oral health experiences of families. The objective of the study was to explore 'from the perspective of urban, Aboriginal and Torres Strait Islander parents and carers' the impact child oral health has on families.

Methods: Yarning circles and face-to-face interviews were used to document the experiences of (N=20) parents of urban, Aboriginal and Torres Strait Islander children. Participants were recruited from an Aboriginal-owned and operated primary health clinic in northern Brisbane, Australia and through word of mouth. Information collected was transcribed and analysed thematically. Codes and themes were confirmed by the researcher and two participants.

Results: The findings indicate that oral health is an important issue for urban Indigenous families and maintaining oral health to a desired standard is having emotional, physical and financial impacts. Themes identified were financial concerns, worry about the future and juggling multiple priorities, all of which were inter-related and cyclical.

Conclusions: Families in this study have demonstrated that with the current policy arrangements, oral health is impacting their quality of life, contributing to stress, financial challenges and at times affecting their physical health. To address these challenges, oral health education and promotion needs a multidisciplinary approach that reaches families before children are school-aged.

5.2 BACKGROUND

The physiological impacts of poor oral health on a child are well described.^{159, 283} Oral health is known to influence systemic health over the life course²⁸⁴ and can be associated with significant pain and morbidity.⁶⁶ Less researched is the psychosocial impact the oral health of a child or children can have on parents and families. Psychosocial factors relate to a person's environment and their mental, emotional and social response to their environment and experiences. Parents are typically responsible for their child's oral health, facilitating preventative behaviours, providing care and comfort, and organising and paying for treatment when needed. Providing this support, they and their family's lives can be impacted by a child's oral health needs.^{107, 285-287}

Within Australia, Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) children experience worse oral health than non-Indigenous children.⁴ Indigenous children experience more caries, are twice as likely to be hospitalised for oral health problems and are more likely to require extraction and receive general anaesthetic than non-Indigenous children.¹⁷¹ Despite the prevalence of oral health issues for Indigenous children, there has been scant research that aims to understand how oral health is impacting family life from the perspective of parents and carers.⁹ In other populations, studies have demonstrated that a child's oral health can negatively impact both their own quality of life and that of their parents.¹⁷⁶ Parents have reported feeling 'bad', 'guilty' and 'upset',^{176, 178, 181} and have experienced financial impacts, attributed to decreased working hours while seeking and paying for treatment.^{178, 184}

Understanding how oral health is experienced by families is necessary to inform policies and programs that aim to close the gap in Indigenous oral health. This study aimed to understand, from the perspective of parents and carers of Indigenous children, how child oral health impacts on their families' overall well-being.

5.3 METHODS

Setting and context

This qualitative study was conducted after the completion of a prospective cohort study²⁸⁸ that investigated the respiratory health and oral health of young Indigenous children in Caboolture. Caboolture is a northern suburb of Brisbane, which is the capital city of Queensland, Australia. Between February 2013 and October 2015, the prospective cohort study used a parent/carer questionnaire to collect data on demographic, cultural, economic, and clinical factors relating to respiratory and oral health as well as conduct opportunistic oral health examinations. The full study protocol and results have been published.^{233, 288, 289} Recruitment for this qualitative study commenced in August 2017 within the same Caboolture population. According to the 2016 Australian National Census, 4.8% of Caboolture's population of 67,460 people identified as Indigenous Australians. The Indigenous population being higher than the rest of Queensland (4.0%) and Australia (2.8%).¹⁷ Demographic data collected previously indicates that the study population is considerably economically disadvantaged; 42.7% of fathers and 85.5% of mothers were unemployed and 76.6% of households had an annual income of <\$37,500 (US).²⁸⁹

Within Australia, oral health care is not included under the public health care system, Medicare.¹¹² Although a public dental care system exists, it is stipulated by eligibility criteria which varies by state and territory.¹¹² In Queensland, adults must have a concession card, which is provided on application by a national social services agency such as Centrelink or the Department of Veterans' Affairs.¹¹² For children and adolescents aged two to 17 years, a national program, The Child Dental Benefits Schedule (CDBS) provides a \$1000 voucher per eligible individual every two years (child must be eligible for Medicare and be of a family that receives Family Tax Benefit A) which can be used in state or private dental services. Services are limited and include basic prevention and treatment options including clinical examinations, diagnostic radiography, tooth cleaning and fillings.¹¹³ State provided oral health

services in Queensland for children and adolescents have traditionally been provided through the School Dental Service.⁵⁴ Over time, these services have changed in their regularity and some locations have moved into hospital and/or clinic sites. Currently, the State Health Department advises that services for children/adolescents should be provided at least once every two years,¹¹³ in accordance with Australia's National Oral Health Plan 2015-2024.¹¹⁵ School dental services are delivered to primary schools and only children that have returned a consent form signed by a parent/carer can receive care.¹¹⁰ Indigenous Australians are entitled to use Aboriginal Community Controlled Health Services (ACCHS). However, like the State services, ACCHS operate using the CDBS voucher and have options for private service.¹¹⁰ These services vary by location. It is believed that the public health system only covers treatment for 20% of concession card holders.¹¹⁰ Any care required outside of the CDBS limits (e.g., orthodontics), needs to be undertaken privately.¹¹⁵ Private oral health services can be subsidised at the time of presentation by an individual's private health insurance. However, within the study area, only 5% of families reported having private health insurance.²⁸⁸

Design

This study used a qualitative approach to investigate the impact of child oral health on the well-being of Indigenous families in an urban community north of Brisbane. Parents/carers were eligible if they were or had previously been the carer of an Indigenous child aged five years old or younger. Participants were recruited from a previous oral health study²⁸⁹ and through word-of-mouth at an Aboriginal-owned and operated primary health care clinic. Both an Indigenous and non-Indigenous researcher were involved in the recruitment of participants. Participants were given the option to have both researchers present if they preferred, or if comfortable, could arrange a time with the primary researcher who is a non-Indigenous Canadian/Australian. The study protocol was explained verbally and through a written plain language statement that was provided to potential participants. Signed consent was obtained. Participants were offered the choice to meet at the health clinic or at a location comfortable for both them and the researchers.

Recruitment continued until saturation with respect to information shared in the discussions.

The study followed a social constructionist perspective²⁹⁰, whereby knowledge is socially created by the participants and researcher and yarning methods were used for data collection: sharing information verbally through a relaxed discussion is an accepted method of exchanging knowledge within Aboriginal culture and is commonly described as yarning.²⁹¹ The yarns were led by a non-Indigenous researcher with the assistance of an Indigenous researcher. The researchers shared information about the previous quantitative study^{233, 289} and described the qualitative study as an opportunity to share their perspective as opposed to answering questions on a paper survey. As part of the yarning process, and to establish rapport with participants, the non-Indigenous researcher shared her personal experiences with oral health including her experience as mother to two boys. The yarns began with a starting question such as, “can you tell me about what oral health is like for your family?” and were given the opportunity to follow the narrative of the participant. Semi-structured questions were available if needed, for example, “what are some of the things you find easy or hard when it comes to oral health for your kids?”. All sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea).

Analyses

The information gathered was transcribed by two authors (KB and KH). The data were entered into the software package NVivo 11.4 and coded thematically by the researcher (KB). Codes established from the data were then printed out onto paper. The researcher returned to two participants who had expressed interest in contributing to the study process for their input into coding and theming. All other participants were offered the opportunity to participate, but declined or were unreachable upon 3 contact attempts. This method of analysis was both verbal and tactile. The words/phrases were placed on pieces of paper and the participants and

researcher could move them into groups, as well as add anything they thought was missing. This element of analysis was important to countering the subconscious bias and ethnocentrism that can occur with non-Indigenous participation in research.² It also aimed to honour the collaborative process and the notion that the participants are the experts on their own lives. The final themes were subsequently cross-referenced in NVivo. This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/17/QCRH/94).

5.4 RESULTS

Participants (N=20) were all mothers with the exception of one carer who was an aunt. The predominance of mothers in the sample is likely reflective of both the recruitment process and the natural division of care within the study population. Although fathers and other carers were invited to the study, the majority of participants were recruited from the prior prospective cohort study whereby participants were recruited opportunistically from a health clinic while attending appointments with their children. In this case, mothers were the predominant carer in attendance with their children. There were two group sessions consisting of three and five participants, and 12 individual yarns. Both researchers were present for the group sessions and for three of the interviews. The other nine interviews were conducted by the non-Indigenous researcher independently. No difference in data, in terms of collection or results, was perceived by the non-Indigenous researcher when conducting the interviews. The duration of the yarns ranged between 35 minutes and two hours. Many participants also had experience caring for children other than their own, either through family responsibilities and/or in a professional capacity working in day care or education. When yarning, participants often drew upon these experiences and shared their knowledge and perception of how other Indigenous families were impacted by oral health as well as themselves. Although no specific demographic details were collected in this study, the participants were recruited from a predominantly low socio-economic population; 76.6% of families

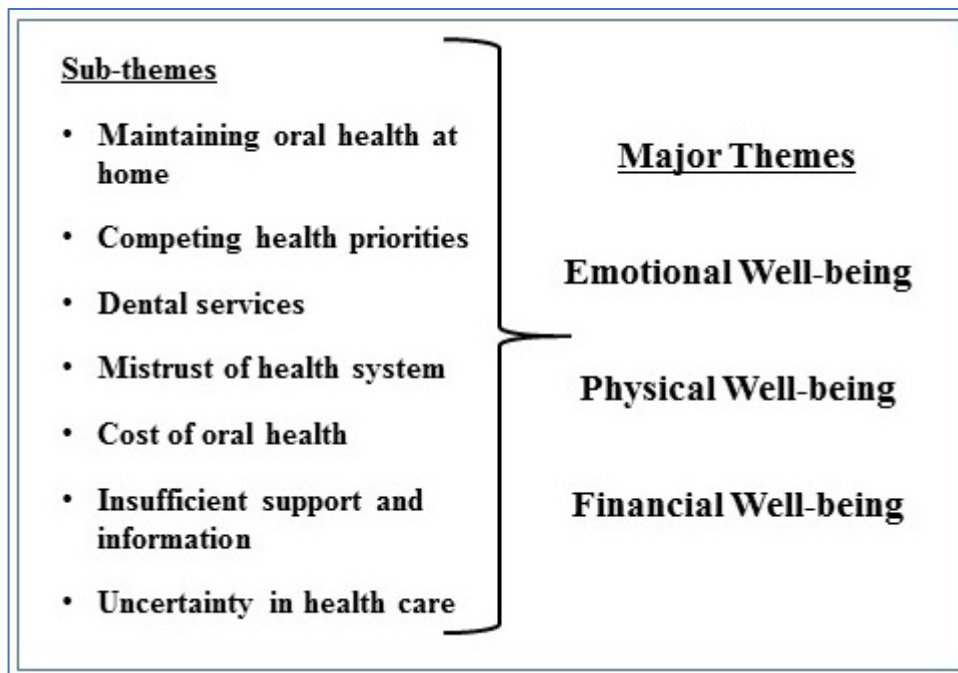
from the same study population had an annual household income of <\$37,500 (US).²⁸⁸

Overall, mothers explained that when their children were very young, they felt efficacious in their approach to oral health and it was something that was at times stressful, but manageable. All mothers were aware that oral health was relevant to their young children and had introduced oral health behaviours such as brushing with toothpaste and limiting sugar. However, as children aged, mothers expressed how oral health had a greater impact on their family lives. Although some mothers accepted caries as a normal part of childhood, prevention and acute issues, such as the need for orthodontic treatment, were taken seriously. The impact of dealing with these issues was multifaceted, experienced both emotionally and physically as well as affecting finances and personal resources.

There were three overarching themes identified: emotional well-being, physical well-being, and financial well-being. These themes overlapped and were interrelated and were present within the sub-themes as shown in Figure 13. In this study, emotional well-being refers to the mental load and emotional and personal resources required to maintain the participants' desired level of oral health for their child. Maintaining oral health at home, engaging health services and competing health priorities all impacted emotional well-being; as did considering whether they were doing enough for their children's health, whether services were available and appropriate, whether they could afford treatment and a concern for their family's future oral health. Physical well-being largely refers to children's experiences as described by their parents; with children experiencing direct physical impacts of oral health problems or indirectly, because of related circumstances. Impacts to financial well-being were experienced at a number of different levels but were most severe when children had oral health needs that required intervention and as children aged. The influence of age and financial challenges permeated the discussion, as many participants related their own oral health experiences as they aged and their

concerns for their growing children. The results have been organised under each sub-theme as the sub-themes often correspond to more than one major theme.

Figure 13. Relationship of themes related to the impact of child oral health on families



Maintaining oral health at home

All mothers were aware of the importance of oral health and strived to have their children brushing at least once a day. Upholding oral health behaviours at home was experienced differently between mothers. Some mothers described their children's relationship to oral health habits as being good and consistent, and felt that they were lucky to have kids that practised desirable oral health behaviours. Other mothers described implementing and upholding oral health habits as far more challenging and contributing to stress for themselves and children.

"It causes a lot of stress in our house. Mainly for the younger two and for my second born son and because he doesn't like doing it or he forgets." (M1 - interview)

Mothers offered different explanations for the challenges. Children's age (younger and older children presented different challenges), and a child's personal perception of oral health and family structure were primarily raised as impediments to oral health routines. There was a sense of exasperation around upholding oral health habits at home.

"I was a single parent right from the time he was born and had that shared care stuff, so that's the difficulty with which I see now so much with the parents that I see, is that your role and parents having such conflict in their homes and then pressure of working and things whatever, so those general routines fall through the cracks or they have a routine but they don't have it in the other home and they have no control of implementing that." (M2 - group)

Competing health priorities

Children's mental and physical health needs were discussed in relation to oral health. Mothers explained how other health needs impacted on their child's oral health habits, particularly where medication was needed. One mother explained how her son's autism was a barrier to his oral health because of his vehement opposition to routine tooth brushing. The mother explained that trying to support him with his oral health on a daily basis was very stressful. Other mothers described how chronic health issues which required medications directly impacted on their child's teeth and the efforts they had to go to support their child's oral health were taxing mentally and physically. Certain medications can increase the risk of caries by lowering the pH of the mouth and/or exposing the teeth to sugars.²⁹² Parents are often advised to either rinse their child's mouth or brush their teeth after each dose.

"Having a health problem changes everything... it impacts on me at midnight and at 4 in the morning because I wanna make sure her teeth are happy and healthy too." (M3 - interview)

Many participants with children with other health needs explained their situation as one in which oral health was just one of the many things that they were juggling. Oral health was not always the top priority. There were also perceptions that when children were young, missing preventative care was not as important as when children were older and had their permanent teeth.

“She’s got lung problems, she’s anorexic, which is also probably destroying her teeth, umm she’s got mental health issues as well. Umm the next child down, they think she has possible EDS (Ehlers Danlos Syndrome) so there’s a whole range of specialists there we need to start seeing, and orthopaedics. Rheumatoid specialists because of the pains she is in. You know there’s just all those sort of things. My youngest has cardiac specialists, she has a hole in her heart and global developmental delay.” (M4 - interview)

Dental services

Few mothers took their preschool children to the dentist, but most participants indicated that school dental vans were well utilised for older children. Mothers considered the school service, coupled with the CDBS ¹¹³, beneficial because it provided an opportunity to see the dentist before there was a problem. Many participants suggested that they themselves would be unlikely to seek preventative treatment, mostly because of the cost.

“At the school they are so wonderful. My kids are scared of dentist and they are wonderful and he wants to go there all the time, every time his teeth hurt he wants to go there, so it’s really good, so we are quite impressed with the way they handle the children there. It’s about the children’s opinion and what they want and they make them feel safe and secure.” (M5 - interview)

Other mothers suggested that the current system had problems and the services available were not to a high standard, not regular enough and not practical for parents.

“When Medicare took over and started issuing those vouchers, parents had to attend the dentists, the school dental van with the children, which a made it really hard, because if they can’t get you in, you have to take time off work. I mean if its big procedure you want to be there, but if it’s their standard check-up it’s no big deal, they are big kids so to speak, but that impacted how often kids were seeing the dentist.” (M6 - interview)

“No, they went once and they just didn’t do a proper job, you know they didn’t clean or do what I know they are supposed to do.” (M4 - interview)

Mistrust of health system

Mistrust and apprehension towards the oral health services provided by the schools was raised, as well as shame and fear regarding the motives of the oral health services. These feelings were transgenerational and based on personal experiences. For example, one participant had grown up in a rural location and one night she tripped and broke her tooth. Her mother brought her to the ‘city’ to have it fixed and the dentist reported her family to social services for suspicions of abuse/neglect which was proven unfounded.

“With some of the Indigenous families, because it was then a government initiative, the dentist was a government initiative but now Medicare required a signature and signing a government form when you don’t know the terms and conditions does bring about a bit of fear like what are you signing, then there’s the other thing, the fear of what my mum went through like when they questioned how I broke my tooth, umm so the shame and the wariness as to what they are going to do, are they going to take their kids away because of bad teeth.” (M6 - interview)

A similar sentiment of mistrust and apprehension was expressed in regards to private dental services, particularly in relation to fees.

With the dental were you go to the hospital and that, they don't offer root canals and things like that, you got the basics. If it can't be filled well then it's pulled out. You don't have a choice when you don't have money to go to the dentist. At the dental hospitals and clinics it's mainly pulled. They don't do a lot. (M12 - group)

"The other option is taking them to a private dentist - well they just take advantage. Unfortunately that's all they do, is do a clean and charge you nearly \$200 and tell you that will need to pay money if you need to get anything else done." (M6 - interview)

Cost of oral health

Some participants felt that current oral health services were insufficient for their child's needs. Those with children that had oral health needs outside the school's dental service capacity explained that their child's oral health requirements exceeded the CDBS. Thus, parents had to go into debt to afford interventions putting costs on credit cards and/or using payment plans. Others offered that to make ends meet, their children had to forgo activities, giving up a sport or an extra-curricular activity.

"It cost us eight grand and we had to go into debt to get that but you do it for your kids there is no reason not to and um but we are slowly getting back on our feet and that type of thing, but you do it for your kids." (M7 - interview)

For some, finances were major impediments and their children missed out on treatment because of the cost. These situations were upsetting to mothers and they expressed their helplessness in not being able to solve their child's health problems despite their engagement with the health system and attention to the problem. There was also an acknowledgment that the overall health and well-being of their

children were being negatively affected by their oral health needs and lack of care by the health system.

“We have always had extra teeth that like grow out of the bottom. I had like two pair that were removed when I was younger because of the overcrowding in the mouth and everything. But my sons are that bad that he actually has to have surgery for his, and it’s more for his jaw than actually his teeth... that’s something I can’t afford unfortunately” (M8 - group)

Insufficient support and information

Participants felt there was a lack of support when it came to referral pathways and options to address orthodontic and acute oral health needs. Mothers whose children required more complex care felt that they were left to navigate private treatments on their own and that there were limited options for those not financially privileged. Others were unsure of who to contact and often didn’t have the time and resources to find other options. One participant in particular described how, coupled with her daughter’s comorbidities, her oral health issues were contributing to her malnourishment. The mother had been in contact with approximately 16 private dentists and the dental universities to try and find an affordable option for her child’s treatment to no avail.

“And like even for some of the dental places, I have called umm, they said they will do a payment plan but they want at least 50% up front and then they’ll do the payment plan and I don’t know if you pay them 50% then they’ll do the braces or take the 50% and then do the payment plan. You know no one has explained even how that works. You know that is going through a private dentist and I think that is \$7500 for just stock standard braces, that is not including any after care, which will be through the roof. And I’ve got two that need braces.” (M9 – interview)

Uncertainty in health care

There was a consensus of concern for the future of their children's oral health amongst participants. Informed by their own experiences, parents were very worried for their children as the children grew up. They felt that along with potential oral health needs, such as braces and wisdom teeth removal, oral health seemed to decline with age. The majority of participants had had their own oral health problems, had experienced tooth loss, and were unable to afford corrective treatment for themselves. A few participants shared that they felt poor oral health was inevitable, irrespective of good oral hygiene. They attributed lifestyle factors such as smoking and other comorbidities such as diabetes to the decline in oral health with age.

"I stress big time about if she will ever need braces. I know it is probably just part of my anxiety, worrying about things that haven't happened yet, but yeah I do worry that I can't afford everything. I get that worried that I start to cry about it. You know, the financial situation. I've been financially strapped for a long time, but I'm used to it, but then I start thinking about all the things they miss out on, instead of it just being me, it's just us." (M10 - interview)

5.5 DISCUSSION

In this study we aimed to understand from the perspective of urban Indigenous parents and carers how child oral health was impacting on their family life. According to national statistics,⁴ Indigenous Australians of all ages experience worse oral health outcomes than non-Indigenous Australians, yet there are few data that explores oral health from an Indigenous Australian personal perspective.⁴ We found that oral health was an important issue for urban Indigenous families and maintaining oral health to a desired standard was impacting mothers and their families. These impacts fell under three major themes: emotional well-being, physical well-being and financial well-being. Sub-themes identified were inter-related and did not necessarily fit under one major theme but were shared across themes. The interconnectedness of the findings suggests that the impact of child

oral health as reported by mothers is complex and is not limited to the individual child or parent but experienced by the whole family as well.

Although oral health research has typically had an individual focus, consideration has also been given to a person's environment, and in child oral health, the relationship dynamic with parents. In our study, mothers had different experiences of maintaining oral health at home, some positive and others stressful. As in other studies²⁹³, mothers in our study reported child un-cooperativeness as a common barrier to maintaining oral health. Research has suggested that parents who have reported positive oral health behaviours for their children have higher levels of oral health knowledge and favourable oral health behaviours themselves.²⁹⁴ Increasing the self-efficacy of parents could potentially ameliorate some of the challenges that parents face when supporting child oral health. However, consideration and support would need to be given to parents, particularly mothers', individual circumstances. As is typical for many families, mothers perform the majority of childcare duties. This study and others²⁹⁵ have found the same is true for Indigenous families. Data from the Longitudinal Study of Indigenous Children indicates that while fathers do participate in supporting oral health, 28% of fathers reportedly helped their child brush their teeth 'most days', fathers are generally less likely to be involved in personal care activities.²⁹⁵ Participants in our study noted the challenges for themselves, but also in the context of shared care and coordinating oral health routines between separated parents. Single-parent families have been found to be an associated risk-indicator for child dental caries⁷¹, which could be indicative of the additional family stress that parents are experiencing, as well as the reduced personal resources related to separation.⁷¹ More research is needed to understand the complexities of the family dynamic on oral health and how parents can be supported in sharing the responsibilities of oral health in all family situations.

The ubiquity of oral health maintenance has potentially contributed to the mindset that achieving 'good oral health' is the same for everyone and simply involves

regular brushing, flossing and limiting sugar. Little thought is given to the competing health priorities of individuals, let alone families. While it was positive to hear that parents are recognising the cariogenic potential of medications, it is important to understand the knock-on effects for families and how they are coping with these additional requirements. Like our study, other studies²⁹⁶ have found that parents of children with additional health needs report increased stress and worry, impacts to sleep, and parent-child conflict. ²⁹⁶ In an oral health context, one way of coping with these additional challenges is the rearranging of health priorities and oral health potentially being overlooked. The perception of oral health as being a non-essential health priority has been reported by researchers in other studies.²⁹⁷ Moreover, the age of the child also seems to affect this perception, with baby-teeth perceived to be less important than permanent teeth. ²⁹⁷ This notion unfortunately can have ramifications for oral health later on and contribute to additional health challenges for children and parents. There has been considerable advocacy for the inclusion of oral health promotion into primary care services to increase parent awareness of oral health requirements related to overall health.²⁹⁸ However, families in our study demonstrate that they are cognisant of oral health, but are struggling regardless. Measures to support families with complex health situations need to be targeted and provide practical strategies that parents can implement.

The cost of oral health care in Australia was a predominant concern for participants. Although the school services and CDBS were generally well-received, they were often insufficient. Families in this study shared the sacrifices they and their children had made to maintain their health. When a monetary sacrifice could not be made, it was a child's health and a parent's well-being that suffered. Participants shared how, in some circumstances, their children had to go without care, all because of the location of their health issue, their mouth. According to an Australian National Health Survey, 10.7% of children aged five to 14 years had avoided or delayed oral health treatment because of the cost; likewise for 44.9% of adults aged 25 to 44 years.²⁹⁹ These sorts of financial/health dilemmas are often not associated with

publicly funded health care and yet, oral health remains a barometer for wealth in many countries including Australia.²⁹⁸

Families indicated that they were aware of these disparities in care and this awareness contributed to anxiety and concern, even before problems or health needs had arisen. Mothers of young children forecast their struggles, anticipating the need for interventions and their potential inability to meet the costs. Tooth loss was a particular concern as it was a common problem for the participants themselves. In Australia, there is a near linear relationship between the number of missing teeth and annual income,²⁹⁹ and the same can be found in other countries.³⁹ The CDBS and school services were reportedly well-used by our study participants, but most indicated that as adults they were unlikely to go to the dentist, citing cost as the primary reason for their avoidance. Others have reported similar findings¹¹ and larger studies have demonstrated that those with lower incomes are the least likely to attend the dentist for preventative care.¹¹² These financial barriers have wider implications than just immediate care. Primary oral health care services provide an opportunity for health promotion, patient education and building on self-efficacy,³⁰⁰ which may support oral health behaviours that reduce the risk for poor oral and general health. Increased self-efficacy has been demonstrated to have positive implications for (oral) health for all individuals regardless of their socio-economic status.³⁰¹

Again, the “siloeing” of oral health from primary care is a likely barrier to education and information for low socio-economic families.³⁰² Parents in our study indicated that there was little guidance when it came to their family’s oral health needs and services. In a similar study, Indigenous mothers and carers from Western Australia expressed their desire for more education and clear, practical reasons and ways to change behaviours in regard to oral health care.⁹ According to a 2014 review³⁰³ of paediatric oral health information within Australia, there are considerable informative resources available. However, the readability of the materials is low and

those that are reader-friendly have little useful information.³⁰³ There also appeared to be very limited culturally relevant material.³⁰³ Effective and respectful communication with Indigenous people is something by which Western health systems are commonly challenged.³⁰⁴ Historical racism and paternalism have fostered transgenerational inequities in care and a mistrust that continues to impact on the health of Indigenous people.¹ As some participants shared, there is a wariness of both the public and private services; and participants do not feel supported throughout their life course. Lack of support and mistrust of health services is commonly reported by Australia's Indigenous population.⁹ These findings are important for oral health professionals who are interested in reducing the disparities in oral health, because although Australia's current oral health policy is focused on children, parents are known to have considerable influence on their child's oral health.¹⁰⁴ More research is needed to understand how best to engage parents within marginalised populations and what information would be most helpful to them and in what format.

As has been highlighted, the impact of oral health on urban Indigenous families can be attributed to a complex interplay of environmental and socio-ecological factors. Emotional, physical and financial well-being do not stand independently of each other but are interconnected and largely co-dependent. At present, the cost of oral health for adults in Australia has arguably influenced the uptake of oral health services for families, which in turn limits the opportunities for support and education across the life course. Families are trying to manage with limited personal and professional resources, which is affecting well-being. Addressing the impact of oral health on families and supporting well-being will require a multi-faceted approach, one that considers both the needs of the child, but also the capacity of the parent and family to support the desired standard of oral health.

Limitations

Our study is not without limitations. Although the sample of this study was small, participants consistently shared similar experiences, suggesting that saturation was met for the overarching themes. However, as the participants were drawn from one location, the findings may not be generalisable to other areas of Australia. Despite an Indigenous researcher being present for many of the yarnings, the primary researcher is a non-Indigenous Australian. This may have influenced the comfortability of the participants in sharing. However, the enthusiasm and length of the yarns suggest that participants felt at ease with both of the researchers.

5.6 CONCLUSION

Families in this study have demonstrated that with the current policy arrangements, oral health is affecting their well-being, contributing to stress, financial challenges and at times affecting their physical health. To address these challenges, we recommend a multi-level and multidisciplinary approach to oral health promotion and education. Oral health promotion can no longer only be the domain of dentists but must be embedded into the routine practices of those that work closely with urban Indigenous families on a more regular basis. The inclusion of oral health education in midwifery, nursing and medicine programs would be a good a start. Health professionals need to feel confident in oral health and in providing patients with information and pathways to support their oral health as they would any other health issue. While school dental programs are well utilised, they are potentially too late for parents who need support in fostering desirable oral health behaviours for their children when dentition commences. We recommend that oral health information and support gets to parents earlier. The inclusion of oral health promotion and screening during pregnancy is certainly beneficial, but it must be acknowledged that this approach often singles out mothers and a whole of family approach is needed. By sharing the responsibility of oral health advocacy across health disciplines, a dialogue can open up and potentially breach some of the barriers expressed by participants in our study and others.

Declarations

Acknowledgements

The authors would like to thank all of the families who participated and shared their stories. As well as thank, Dr Jeanie Scheffield for her feedback on presenting the data.

Authors' Contributions

KB and KH were responsible for data collection and transcription. KB completed analysis and with support from KO and MT. The manuscript was drafted by KB, and KH, NK, NWJ, MT and KO contributed to the content and revision of the manuscript. All authors read and approved the final version.

Funding

Funding was provided through a Queensland Children's Medical Research Institute Project Grant, UQ Foundation Research Excellence Award, a Queensland University of Technology Indigenous Health start-up research grant. KB is supported by a supervisor scholarship at Queensland University of Technology. KO was supported by a NHMRC Career Development Fellowship (1045157) and Queensland Smart Futures Fellowship and is currently supported by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). KH was supported by an Australian Postgraduate Award and the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). MT is supported part-time by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). The views expressed in this publication are those of the authors and do not reflect the views of the NHMRC.

Ethics and consent to participate

This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/17/QCRH/94). All participants provided written informed consent.

Consent for publication

All participants, as part of the consent process, were informed that the study would be published.

Competing interests

The authors declare that they have no competing interests.

6 YARNING ABOUT ORAL HEALTH: PERCEPTIONS OF URBAN AUSTRALIAN ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN

This chapter presents the additional qualitative data that was collected opportunistically during Study 2. Given the topic was important to participants and the amount of data collected, it was decided to publish the data independent of the first objective.

The objective addressed in this chapter was to:

1. Report the perceptions and oral health experiences of urban First Nations women.

It comprises the following published paper: Butten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF. Yarning about oral health: perceptions of urban Australian Aboriginal and Torres Strait Islander women. BMC Oral Health. 2020;20(1):1-12.

STATEMENT OF CONTRIBUTION OF CO-AUTHORS FOR THESIS BY PUBLISHED PAPER

The authors listed below have certified that:

1. they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
2. they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. there are no other authors of the publication according to these criteria;
4. potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit, and
5. they agree to the use of the publication in the student's thesis and its publication on the QUT's ePrints site consistent with any limitations set by publisher requirements

In the case of this chapter:

Chapter 6 (Study 2): Batten K, Johnson NW, Hall KK, Toombs M, King N, O'Grady KAF. Yarning about oral health: perceptions of urban Australian Aboriginal and Torres Strait Islander women. BMC Oral Health. 2020;20(1):1-12.

Author	Statement of contribution
Kaley Batten QUT Verified Signature Signature Date 15/05/20	Conceptualised and designed the study and data collection process. Collected, transcribed, cleaned and analysed all data. Interpreted the findings. Produced the first and final drafts of the manuscript, collated and responded to feedback on drafts from co-authors, and prepared the manuscript for submission.
Newell Johnson	Provided critical review of manuscript drafts. Provided feedback on interpretation of findings. Approved final version of the manuscript.
Kerry Hall	Assisted with data collection and transcription. Provided cultural guidance on study. Provided feedback on interpretation of findings. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Maree Toombs	Provided cultural guidance on study. Provided guidance on analysis and interpretation of findings. Provided critical review of manuscript drafts. Approved final version of the manuscript.
Neil King	Provided critical review of manuscript drafts. Approved final version of the manuscript.
Kerry-Ann O'Grady	Provided input into study implementation. Oversaw study implementation. Provided critical review of manuscript drafts. Approved final version of the manuscript.

Principal Supervisor Confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship. (If the Co-authors are not able to sign the form please forward their email or other correspondence confirming the certifying authorship to the RSC).

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15/05/2020

Date

6.1 ABSTRACT

Background: Many factors influence how a person experiences oral health and how such experiences may facilitate supportive oral health behaviours. Women in particular face different challenges due to their environment, responsibilities and physiological differences to men. Within Australia, Aboriginal and Torres Strait Islander women are reported to have poorer oral health and are faced with additional barriers to supporting their oral health compared with non-Indigenous women. The objective of this paper is to report the experiences and perceptions of oral health from the perspective of urban, Aboriginal and Torres Strait Islander women.

Methods: The present data derive from a descriptive study that used yarning circles and face-to-face interviews with women who were mothers/carers of urban, Aboriginal and/or Torres Strait Islander children. This was a qualitative study to investigate the impact of child oral health on families. Participants used the opportunity to share their own personal experiences of oral health as women, thus providing data for the present analyses. Information collected was transcribed and analysed thematically

Results: Twenty women shared their personal narratives on the topic of oral health which were reflective of different time points in their life: growing up, as an adult and as a mother/carer. Although women are trying to support their oral health across their life-course, they face a number of barriers, including a lack of information and the costs of accessing dental care. The teenage years and pregnancy were reported as important time periods for oral health support.

Conclusions: To improve the oral health of Indigenous Australian women, policymakers must consider the barriers reported by women and critically review current oral health information and services. Current oral health services are financially out of reach for Indigenous Australian women and there is not sufficient or appropriate, oral information across the life-course.

6.2 BACKGROUND

Basic requirements for good oral health are, in general, similar across the life span: keep the mouth clean, use fluoride, limit sugar, avoid drugs and alcohol, and visit the dentist regularly.³⁰⁵ Yet, despite the relatively homogenous recommendations for good oral health, many experience oral health differently. Our environment, life experiences, socio-economic status, overall health, age and gender can shape how we experience oral health and practice oral health behaviours.^{38, 62}

Whilst Aboriginal and Torres Strait Islander (hereafter respectfully referred to as Indigenous) Australians are reported to experience worse oral health than non-Indigenous Australians⁴, little has been published in understanding oral health from the personal perspective of Indigenous Australians.⁴ Likewise, little is known about how Indigenous women and mothers experience and perceive oral health, for themselves and for their family.⁹ 'Mothers' specifically represent a sub-population that can have oral health experiences unique to their role.³⁰⁶ Oral health can be influenced by behaviours related to women's traditional gender roles such as being the primary carer of children and responsible for domestic duties which include but are not limited to grocery shopping, cooking meals and facilitating family health care.^{189, 190} The intensity of these roles can be heightened if women are single parents. Within Australia, single mothers represent 82% of single parent families and experience more financial stress than their male counterparts.³⁰⁷ In general, women are more likely to avoid the dentist because of the cost than men.¹⁰⁹ They are also physiologically different to men and can experience numerous hormonal changes during their lifespan which interact with their oral health status. The fluctuation of sex hormones (estrogen and progesterone) change the oral environment and can increase inflammation and bacterial colonisation, putting women at increased risk of caries and periodontitis amongst other conditions.¹⁹³

Understanding how women experience oral health across their life course has important implications, not only for them, but for those they care for as well. Poor

oral health during pregnancy has been linked to low birth weight, preeclampsia and preterm birth⁷¹ and maternal social determinants influence health-literacy, health-seeking behaviours, dietary knowledge and family oral health habits.^{71, 107, 191, 308}

Studies suggest there are a number of barriers to oral health experienced by Indigenous Australians.⁶⁵ These include avoiding preventative care because of the cost and difficulty of attending oral health services because of family responsibilities, distance and waiting times.^{11, 65} Additional challenges include finding services that are family-friendly and culturally safe⁹, and there is a mistrust of the health system and a fear of judgement by health professionals.¹¹

Understanding the personal experiences and perceptions of oral health from urban, Indigenous women is necessary in order to provide services that are accessible, engaging, culturally safe and lead to better health outcomes for themselves and their children. Thus, our primary objective is to honour the voices and describe the experiences of urban Indigenous women while yarning on the topic of oral health.

6.3 METHODS

Methodology

This study was conducted in accordance with the World Medical Association Declaration of Helsinki 2013³⁰⁹ and guided by the principles of Participatory Action Research (PAR). PAR is in contrast to the historical positivism and paternalism of social research and instead endeavours to distribute power and engage participants as researchers themselves.²³⁹ The central tenets of PAR come from a strong background of collaboration and advocacy, whereby research can be used to progress change and support social and community agendas.²⁴²

Setting and Context

This study came about because of a community interest in oral health. The research group had initially proposed investigating respiratory health in collaboration with an Aboriginal owned and operated primary health care clinic in Caboolture, a northern suburb of Brisbane, Australia. Senior members of the community indicated that oral health ought to be researched as well because there were limited data available on the oral health of urban Indigenous families, and the community was unable to effectively advocate for additional oral health resources. In conjunction with the respiratory study, a quantitative oral health study investigating the prevalence of caries and the associated risk factors was undertaken, and the results published.^{233, 288, 289, 310} Additionally, a qualitative study was proposed to provide a voice to the participants and assist in understanding the impact child oral health was having on families.

The primary health clinic where the study took place had an Indigenous client population of approximately 60% and hosted general practitioners, Indigenous health workers and midwives. It was affiliated with a dental clinic within the same building complex. Dental services are not provided for under the Australian public health care funding system, Medicare,⁴² and as such attract an out-of-pocket fee for service. Although a public dental care system exists, it is stipulated by eligibility criteria which varies by Australian state and Territory.⁴² In the state of Queensland, adults must have a concession card, which is provided on application by a national social services agency such as Centrelink or the Department of Veterans' Affairs.⁴² A range of preventative and treatment-based services are available for those eligible. However, the services are associated with considerable waiting times.⁴²

Design

In August 2017, the qualitative study commenced with the aim of investigating the impact of child oral health on urban Indigenous families. The study utilised PAR

principles and in collaboration with the researcher, two participants took part in coding and theming the data to answer the research question. The results were published.³¹⁰ However, in addition to the data relevant to the research question, participants also contributed data which was deemed unrelated (as determined by the participants and researcher) to the initial research question, but valuable to the participants and their narrative. According to the Australian Institute of Aboriginal and Torres Strait Islander Studies,³¹¹ one of the principles of ethical research with Indigenous Australian populations is that the “research outcomes should include specific results that respond to the needs and interests of Indigenous people”.³¹¹ The participants, while providing data related to the initial research question, also provided qualitative data on topics that were of importance to them and their own oral health as women. This paper focuses on reporting those data.

Participants

Women of all ages were eligible for the study if they were or had been the parent or carer of an Indigenous child under the age of five. Purposive sampling was used and participants were recruited from the previous respiratory and oral health studies^{233, 288, 289, 310} and through word-of-mouth at the Aboriginal-owned and operated primary health care clinic. Two researchers undertook recruitment. KH, PhD, is an Aboriginal woman and nurse, who had been the lead investigator in the respiratory study and worked at the clinic as a nurse and Aboriginal Health Worker. KB, BPubHlth, is a non-Indigenous Canadian/Australian woman, who had been working within the study community on a separate research project and was responsible for analysing the quantitative oral health data and facilitating the qualitative oral health study. Participants were given the option to have both researchers present if they preferred, or if comfortable, could arrange a time with the primary researcher (KB). The study protocol was explained verbally and through a written plain language statement. Signed consent was obtained. Participants were offered the choice to meet at the health clinic or at a location comfortable for both them and the researchers. Data collection ceased once no new information

emerged in participants' responses to the initial research question: the impact of child oral health on families.

Data collection

Yarning is an accepted method of sharing information and communicating within Aboriginal culture.²³⁸ Yarning is not unlike a conversation as determined by Western definitions, whereby a story may be used to share information or knowledge. However, it arguably carries more significance within Aboriginal culture, and is considered a cultural practice. This is because, as has been described by Bessarab and Ng'andu²³⁸ oral traditions have historically been the main form of transmitting knowledge and information within many Indigenous cultures, including Australia. Within a research context, yarning aims to mitigate the power imbalance between researcher and participant, which can come with an interview or conversation that has a research motive. Yarning places value on the participants knowledge and expertise and is an open process of sharing between the participant and researcher. This process is supported by the relationship developed between the researcher and participants before the research yarn takes place.²³⁸ Bessarab and Ng'andu explain this as social yarning and involves getting to know a person through discussions unrelated to the research.²³⁸ In this study, the researcher, KH, had already established relationships with the majority of participants from working in the clinic and facilitating the other studies. KH was able to introduce researcher, KB, to many of the study participants and begin establishing a relationship outside of the study. This meant that by the time the researchers and participants had scheduled the research yarn, there was a familiarity between primary researcher and participants. When the yarns took place, to establish rapport and provide additional context for the participants, researcher, KB, shared her own experiences of oral health, both as a young girl and as the mother to two boys. The yarns began with a starting question such as, "can you tell me about what oral health is like for your family?". In this process, participants shared their thoughts related to the initial research question concerning the impact of child oral health on families, as well as their own personal experiences of oral health as individuals; sharing what oral

health was like for them as children and throughout their life as they became mothers. All sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea).

Analyses

The information gathered was transcribed by two authors (KB and KH) and entered into the software package NVivo 11.4 (QSR International Pty Ltd. Version 11.4.1.1064). KB was responsible for facilitating the analysis and KH and MT were available for consultation and guidance. Analysis was guided by Braun and Clarke's '6 Steps',²⁴¹ which does not use a specific lens or theory to guide the analytical process but provides a framework to follow.²⁴¹ This includes becoming familiar with the transcripts, initial coding, searching for themes, reviewing themes, defining the themes and writing them up.²⁴¹ This process was supplemented by participants' contribution to the coding and theming steps. Participant involvement in qualitative analysis is necessary to uphold collaborative research agreements, as well as a method to support the validity of the data.^{242, 243} Upon reviewing the transcripts, the researcher, KB, inductively coded the data and printed the coded transcripts to paper. These codes were informed by personal notes made after the yarning sessions and informal discussions with KH. The transcripts were then brought to two participants on separate occasions who had expressed interest in participating in the analysis process. All other participants were offered the opportunity and either declined or were unreachable upon three contact attempts. The researcher and participants used the transcripts, along with blank pieces of paper ('post-it notes') for any additional information and to place the codes into initial themes. This process was iterative and prompted by a discussion of the yarning sessions and the participant and researcher sharing their ideas about the data that arose and potential themes. For instance, some concepts were not repeated individually within the group sessions, but consensus was given by participants by way of agreement and affirmations. Like codes were grouped together and once established, it was discussed whether the themes were relevant or not in terms of the research question. This was both a tactile and verbal collaboration that aimed

to acknowledge the participants as experts on their own lives and counteract the sub-conscious bias that can occur with non-Indigenous participation in research.² Some themes were leftover in the analysis process and although they did not fit the original research question: 'what is the impact of child oral health on urban Indigenous families?' (results of which have been published separately),³¹⁰ the participants and researchers, KH and KB, agreed that they were representative of the participants' personal stories as women in addition to their experiences with child oral health and should be considered for publication in their own right. These themes were discussed and finalised by KH and KB for publication.

6.4 RESULTS

Twelve individual interviews and two yarning groups with three and five people respectively, were conducted. All participants were mothers with the exception of one aunty. Of the people approached, no one declined participation. The majority of the participants were recruited from the larger study population attending the health clinic. According to previously collected data, the families in the study population had an average annual income of <\$37,000 (US) and 85.5% of mothers were unemployed.²⁸⁹ Both researchers were present for the group sessions and for three of the interviews. The other nine interviews were conducted by the non-Indigenous researcher independently. Yarns took place at a number of different locations including: the clinic, church and school halls, cafes and local parks. The duration of the yarns ranged between 35 minutes and two hours. Along with discussions regarding the impact of child oral health, which have been previously published,³¹⁰ participants shared their personal narratives on the topic of oral health. The additional discourse is reflective of the yarning process and the participant focused approach of the study. Congruence was observed in participant responses, with women sharing similar experiences and perceptions in both the interviews and group yarning sessions. The themes raised were associated with three stages of life: growing up, as an adult and as a mother and are organised under each stage as shown in Table 9.

Table 9. Stages of life and themes raised during yarning

Growing up	As an adult	As a mother
• Teenage perceptions • Fluoride • Traditional approaches • Diet • Negative impacts	• Disease • Traumatic past experience • Cost • Tooth loss and wellbeing	• Pregnancy • Diet • Lack of information • Recommendations for health promotion

Oral health growing up

Childhood experiences of oral health varied for participants. The geographic location of participants when they were growing up, along with their age and resources of their parents all influenced their experiences. Most participants indicated that they have more information now than their parents did; cleaning teeth was an accepted practice, but the regularity and approach varied amongst families. Some families were quite ‘strict’, and parents supervised tooth brushing at least once a day. Others indicated that their parents provided the supplies (toothbrush and toothpaste), but didn’t necessarily monitor their oral hygiene habits. Some participants grew up in regional and remote areas and did not have running water or electric power which acted as a structural barrier to regular oral hygiene habits, even if they did have the personal resources.

We weren’t taught about mouthwash or flossing, we were just taught about brushing, we didn’t know it was about your gums too, I never remember that. But now we learn all that, you know, brush your gums, and clean your whole mouth. Yeah, when I was a teenager, I didn’t give a toss, but then you come to full circle into an adult and you start taking care of it, you remember ‘oh yeah that’s why’, and you start to do things. (Interview – Mum A)

Teenage perceptions

Of those who insisted their parents were 'strict' about oral health and regimented tooth brushing, there was not a consensus on whether this influenced their own approach to oral health care in their youth. Many participants remarked that oral health did not become a priority for them until they themselves were adults and started having problems with their oral health. Many participants acknowledged that they did not practice regular oral hygiene habits as teenagers and remember actively disliking having to maintain their oral health. However, most did participate in school dental service visits, which in Queensland are designed to screen all children and render all dentally fit: this was their primary source of professional dental education.

I hated it. There was a period of time where I never used a tooth-brush at all, I just used a towel or whatever I had and went like this (action of rubbing towel across teeth with fingers), but now I brush all the time because I don't want false teeth. (Group 1 – Mum 1)

Fluoride

Many participants remembered attending school dental services regularly and the use of fluoride tablets administered by the school or their parents. The use of fluoride was generally accepted as a good thing and participants recalled fluoride either being in the water naturally, being added or receiving tablets. Fluoride tablets, along with disclosing tablets (chewable tablets with a vegetable-based dye that colours dental plaque) seemed to evoke a lot of detailed memories for participants and they shared stories of learning about plaque and the tablets they were given to demonstrate how to brush effectively. These tablets caused some embarrassment but were indelible in participant's memories as a kind of 'rite of passage' during childhood.

I remember one time because my front tooth crossed over the other, it would be really dark and I hated it and we would have to take them home and we would have a pink one at home and you would have to chew on it before you brushed

your teeth and it would show (the plaque) then you would brush your teeth to see if you were getting it. (Group 1 – Mum 2)

Traditional approaches

Traditional approaches to oral health such as the use of charcoal for cleaning teeth was discussed by a number of older participants; younger participants also indicated that they remembered their parents sharing traditional teeth cleaning methods with them and had an interest in reviving traditional methods for themselves. One participant had acknowledged how oral health had come ‘full circle’ with the availability of charcoal toothpastes in conventional stores. Participants remembered fondly that in addition to teeth cleaning, their parents and elders had used charcoal in a number of household products. This was attributed to cultural practices, but participants also acknowledged that cost was a factor in utilising alternative methods; often conventional items were more costly than home remedies.

They cooked in the charcoal, and they didn’t shake it off, they just ate it. I can remember going fishing they chucked the fish on the coals. I can remember sitting there spitting out charcoal, you know what I mean about the crunchy gritty bits, but that’s how they lived off the land. (Group 2 – Mum 3)

Diet

Along with more culturally specific practices such as the use of charcoal, participants reminisced about the difference in their diets when they were young. Acknowledging that foods were less processed in their childhood and they had less exposure to sugars.

Fluoride was in the water, so we had the healthiest teeth in the cemetery. But being a child back in my day, my folks and I didn’t have a lot of money, so we ate a lot of fruit and mum killed her own cows and stuff, and we did all that. We never went to the shops to buy anything, because mum milked the cows, the

goats. We used to eat chook eggs, the duck eggs, you know. (Interview – Mum B)

Negatives impacts to oral health

Not all past practices were as well regarded as the use of charcoal and home-cooking. Participants shared that they felt that the past social acceptance of smoking likely contributed negatively to their oral health as an adult. As did a lack of preventative dentistry and some dietary habits, such as having baby bottles containing tea or a carbonated, high sugar, beverage. Participants were cognisant of the yellowing of their teeth from a young age and this was seen as undesirable, even when they were young.

You know one thing I feel really strongly about now that I know, is we were brought up with mum and dad smoking in the house. Mum and dad smoking in the car. Mum and dad smoking around children. You know what I mean, and then I look at my teeth and think to myself how yellow they are. And when I go to the dentist, they ask how long have you been smoking: I have never smoked in my life. You know what I mean and then I look back at it and think to myself, like for them to say smoking causes yellowness, and you have that yellow look on your teeth. (Group 2 – Mum 3)

Oral health as an adult

Despite the varied experiences of participants as children, whether they had practiced regular preventative oral health habits or had less structured habits, most indicated that as adults they had experienced poor oral health. Some participants acknowledged that their experience was likely a result of their poor oral health as teenagers. Whereas others felt that they had poor oral health despite the efforts they made to support good oral health. Disease, traumatic past dental experiences and cost were raised as impediments to their current oral health, with tooth loss and its effect on well-being also a commonly shared concern.

Disease

A number of participants explained that good oral health was taken away from them by another health condition. Conditions discussed included diabetes, cancer and hypothyroidism. There was a sense in the discussion that they had no agency over their oral health because of their systemic disease. A shared sentiment was that their poor oral health was 'coming from the inside' and that externally it didn't matter what they tried, their oral health seemed to be out of their hands.

For me I had the perfect teeth, you know, and it wasn't until I got diabetes and I'm fanatical with brushing teeth and mouthwash and flossing, you know, but because of diabetes and stuff like that - I mean don't believe everything you hear about: 'if you don't do this and you don't do that, this is what's going to happen'. You can do all the right things and still end up with no teeth. Like I've got no teeth because I got really bad infections from my wisdom teeth. I've got no molars and I had root canal here, so you can be fanatical as you want. (Group 2 – Mum 2)

Traumatic past dental experiences

A number of participants shared 'dental horror stories', where their oral health and well-being was negatively impacted during dental visits and this made them reluctant to ever attend the dentist again. Some participants readily articulated that they had a dental phobia, whereas others reflected that the fear of pain and their childhood memories of the dentist put them off attending.

And then I got wisdom teeth down and the dentist lady used my good tooth to anchor off and she shattered it. So I still have bits of jaw bone come through, yeah so I'm picking bone out every now and then. I'm picking bone out going, where did this come from? (Interview – Mum B)

Cost

There was a consensus amongst participants that the cost of dental care for adults was prohibitive. Many shared anecdotes of the dental restorative work they required but had put off indefinitely because they could not afford it. Participants agreed that they would just wait until there was an issue of pain or loss of function and going to the dentist was no longer optional. For some participants, there was the notion that the dentist was not a welcome place unless you had the work done that was recommended, so why bother going for prevention. One participant shared how she was saving up to go overseas for dental care, hoping to have dentures made as the cost of keeping her teeth in Australia was too much.

I've got extras health insurance and I still don't go unless I have to and there is something going on. I'm supposed to have a plate to wear when I am sleeping but that thing costs like \$400-\$500 dollars. (Group 2 – Mum 1)

Tooth loss

Tooth loss was a commonly shared concern amongst participants. As was the impact on well-being and confidence when teeth were removed or damaged. Participants explained that tooth loss influenced the way they ate, drank, spoke, smiled and laughed. One participant shared how it had affected her ability to find work because of judgement from potential employers.

Your face changes, even the way you talk, even just rinsing your mouth after you brush your teeth, you know water spurts out. You have to be careful when you are out drinking or eating. I work in a high school and I don't even laugh anymore because of it. (Group 1 – Mum 3)

Few reasons for tooth loss were discussed specifically. As mentioned previously, some participants shared that their overall health contributed to their poor oral health and others also shared how pregnancy contributed to tooth loss. However, some participants indicated that tooth loss was a result of their limited choices in

dental care. Suggesting that given more options for oral health services, they could have kept their teeth.

Going to the dentist nowadays it is cheaper to get a tooth taken out than filled most of the time. (Group 1 – Mum 2)

Oral health as a mother

All participants indicated that their oral health changed when they became a mother. Most insisted there were noticeable physiological changes. Others suggested that the change came from the deficit in time and energy associated with becoming a mother: their focus was moved to their children. As has been reported previously¹¹, supporting children's oral health can be stressful and mothers have multiple priorities to juggle including the oral health of their child.

Pregnancy

Participants had a lot to share on the topic of pregnancy and oral health. It seemed accepted and commonplace that a woman's oral health would be impacted with pregnancy. A couple of participants shared some interpretation of the proverb: 'gain a child, lose a tooth'. There wasn't a lot of negativity in the yarning, it was just accepted as a fact of motherhood that with children, came poor oral health and even tooth loss. Participants described being drained of nutrients and their bodies giving everything to the baby. No comments were made regarding maternal oral health education or information and so it is difficult to comment whether participants felt that they should have had been provided with more information during their prenatal period.

I think all of it too is having kids, they are just drawing everything out. They just suck the life out of you. They do, because it is all nutrients, the baby is taking everything, you know everything in your gums. That's when I first started having trouble with my teeth. (Interview – Mum C)

I actually had pretty good teeth up until 19 years ago. And yeah it was true, the minute I fell pregnant I started having issues with my teeth. I was 18 and yeah that's when I first started having problems. I mean I had fillings all though school, but that's when they really started deteriorating and the first pulled. (Interview – Mum D)

Diet

All participants were aware of the damage that sugar could cause to teeth and shared their approaches to finding balance with their child's sugar consumption. Many participants shared how it had been an ongoing education for them learning about the effects of sugar on teeth. One participant acknowledged that it had become easier since the obesity epidemic to understand the negative impact of sugar, but still felt there were a lot of mixed messages in society.

The biggest thing for me, I mean my kids still have sugar, they still have soft drink, they still have lollies, chips, ice-blocks. I think it's all about kind of balancing. You know we might have a treat day, and then the next day we will cut back a little bit, but I'm not so concerned about that. Or that's not my main concern. But I'm not going to put her to bed with a coke, you know, she is still being breastfed, she's not having a lot of that food, so I'm not too worried. (Interview - Mum E)

It comes down to your dietary intake, eating your fruit and vegies, if they don't like what they see in solid, I will blend it and put it on pizza bases or in spaghetti bolognese. They are going to get it one way or another. (Interview – Mum F)

Lack of information

A number of participants explained that they either 'learned the hard way' or had to go out and get information for themselves because of a lack of oral health

information, specifically regarding child oral health. One participant in a group yarn shared that she felt that many people in her community did not have enough information and she had never seen any culturally specific information, the group agreed there was nothing available. This sentiment was also shared in other individual yarns with participants commenting on how they perceived the lack of information for their community.

You still see it now when you're out walking, kids with parents, the kids are just handed a bottle of coke. (Interview – Mum A)

A few participants shared that they had 'done the wrong thing' and gave their children milk or juice in bottles or sippy cups as they got older, believing that milk and juice were healthy.

I had to go research it myself, there's not a lot of parents that get to have the internet and stuff. Like I can't get on the internet. It's not like old-school where you can go to an encyclopaedia. Yeah maybe through the school, there is not enough in the school. (Interview – Mum B)

Recommendations for health promotion

There were mixed feelings about oral health promotion. Most participants agreed that they had more information than their parents, but they also felt that that in some instances some of the approaches that were used when they were children were more beneficial and got a stronger message across than what was available now. For instance, the use of the tablets to colour plaque, school-based interventions and commercials on television. A number of participants lamented that Australian children no longer had a 'Mrs Marsh' to learn from. During the '70s and '80s, television commercials featuring 'Mrs Marsh' were aired in Australia, promoting oral health behaviours. A shared sentiment was that more information was needed in schools and parents needed more clear information when children were very young. A few participants shared that it would be good if oral health was

addressed when child health nurses came for infant checks or when they had health checks done. Further integration of both primary health care and dental services was raised specifically by one interview participant.

I think it (dental) could be more into the medical side of things, like medical centres as well because you know it seems so separate. You know you got the dental side and the medical side, and I think they really need to push it, you know when they do the health checks, they really don't check too much about the dental. (Interview – Mum E)

I think to educate kids, especially little, because that is where it starts. You need to start these little jingles up again about brushing your teeth. We do it with hand washing, do it with teeth, you know. Take this jingle back home to mum, like "slip slop slap". And then maybe with the preppies to year 3, create a person that will come in and dress up as a tooth and show them how to brush their teeth, you know. (Group 2 – Mum 3)

I also think there does need to be more education for the parent, particularly in those early years. If they don't have good dental hygiene, they are not going to be able to teach the kids well and for them just waiting until school age, there needs to be something out there for the parents. (Group 2 – Mum 1)

In addition to information, some participants acknowledged that limited oral health resources were a problem for families.

Your mouth is, you know talking, eating, and drinking. There is just so much involved around it. I used to do Indigenous support in high schools and we used to have a program focusing on general well-being and puberty and body image, and it was focused on your hygiene and we would sit down and talk to the kids as something as simple as: 'it was important to brush your teeth twice

day'. I mean some of these kids didn't even have a toothbrush. Well this is when I was working in Toowoomba and we would have to fund it ourselves. We would have to outsource toothbrushes and toothpastes and you know little deodorants and soaps and you would be surprised how many Indigenous kids did not have the equipment, the means to get that and it was really sad.
(Interview – Mum E)

6.5 DISCUSSION

Our study contributes to a growing body of research reporting the experiences and perceptions of Indigenous Australian women on the topic of oral health. Our previous publication³¹⁰ from this dataset reported the impact of child oral health on families from the perspective of mothers. The focus of this paper was to present the voice of the mother speaking for herself as a woman and individual, not limited to the motherhood aspect of her identity or spokesperson for her family. Adding a generational context to our previous publication, this paper sheds light on how Indigenous Australian women experience oral health during different stages of their life: growing up, as an adult and as a mother.

The present findings from Queensland align with other research^{9, 11, 187} which has qualitatively investigated oral health experiences of Indigenous Australian women in Western Australia and South Australia. The research suggests that current oral health policies are insufficient in supporting Indigenous Australian women across their life course. Indigenous Australian women care about their oral health and they would like more consistent and culturally appropriate information to support their oral health behaviours from birth into adulthood, as well as more options to access and pay for professional oral health care should they need it as adults.^{9, 11, 187}

Oral health policy and health promotion in Australia has historically been inconsistent. Unlike the public medical care funding system, Medicare, there has

been no sustained, publicly funded, oral health program that provides subsidised dental care for all ages. Past and present government subsidised dental services have largely been targeted at school-aged children and, as our participants have shared, the effect of these programs is not necessarily long-lasting. There needs to be more consistent opportunities for information throughout the lifespan, so information can be passed down generationally and supportive oral health habits perpetuated.

Similarly, consideration must be given to the wider social contexts in which Indigenous Australians are trying to maintain their oral health. The effects of colonization have contributed to widespread disadvantage and present policies do not consider these 'structural barriers' to oral health.⁶⁵ The cost of oral health is not limited to services, but to the environment in which oral health behaviours occur, including factors such as the cost of a healthy diet, supporting overall health and accessing education which supports health literacy.^{11, 65, 192} Using hindsight, participants in this study have highlighted some of the challenges in supporting oral health within their own environments; providing insight into the gaps in service provision and missed opportunities for health information and promotion.

According to our findings, previous policies have fallen short in supporting older teenagers. Participants indicated feelings of apathy during their teenage years toward their oral health, which did not resolve until they reached adulthood and began having problems with their teeth. The School Dental Service, the first federally funded program for school children founded in 1973 provided for children aged five to 15 years. Providing Australian children regular opportunities for professional screening and care, the program was devolved to State and Territory government responsibility in the 1980s and is presently only active in select schools.³¹² The percentage of children attending school dental services dropped considerably (54% to 21%) during the period of 1994 to 2013.⁴² Likewise, subsequent federal programs such as the Teen Dental Program (2007)³¹² and the

current Child Dental Benefits Scheme (CDBS), are not available in all schools, but can be utilised during public and/or private dental consultations. The CDBS provides all eligible Australian children aged two to 17 years with \$1000 every two years towards their oral health.⁴² Whilst it provides financial support for families, it is dependent on parent/carer engagement with a dental practice if one is not available at their child's school. We are unable to comment on how our participants have received the new policy as it was only newly introduced when the study was conducted. Yet, it was clear that more information and interventions from schools would be welcome. An evaluation of the uptake of CDBS by all children and teenagers is required to determine whether Indigenous Australians are accessing the service given the inconsistency in service provision and adult attendance to dental services.

Participants in this study had strong memories of using disclosing tablets to demonstrate plaque as children and Joanne Kerr advocates that this approach could be used with teenagers again.³¹³ Kerr points out that while disclosing tablets may be unsophisticated and typically used with primary school children,³¹³ our study suggests they are readily recalled and considered useful. Research suggests that aesthetics is a key motivator for teens in terms of oral health,^{314, 315} with teens caring more about the appearance and smell of their mouth than the actual health status.³¹⁵ We were unable to find any studies that had investigated the efficacy of disclosing tablets with teenagers specifically, and studies examining their effectiveness in this population are warranted.

Women in our study reported that their oral health declined not only with their age, but with their transition to motherhood; suggesting that their pregnancies had physiological effects on their oral health. Pregnancy can affect oral health.¹⁹⁴ However, the notion that pregnancy is threatening to oral health, while not unfounded,¹⁹⁴ is perhaps misleading. The misconception that poor oral health is inevitable when you have children is not uncommon,¹⁹⁶ but it is indicative that oral

health information is not reaching Indigenous Australian women. Antenatal care represents an opportunity to commence a generational cycle of oral health education. There was a consensus, that women are not attending the dentist themselves regularly and feel like there is little information coming to them from other sources. Our findings support other studies^{306, 316, 317} which suggest that oral health care needs to be embedded into antenatal care. However, there remains considerable barriers within the current Australian policy landscape for this to happen. Although pilot projects^{306, 316, 318} have demonstrated that midwives are cognisant of the importance of oral health for their patients, they feel they do not have the time or skills to provide adequate care. At present, to our knowledge there is only one midwifery course in Australia offering formal oral health education to students.³¹⁹ While it shows promise in increasing the oral health promotion skills of midwives, it is limited in its ability to support the 'next step' in the care process.³¹⁹ Midwives indicated that with education they feel confident in making referrals to dentists, but it means little when women are not able to access those services.³¹⁹ Like our participants, midwives report that cost is a major barrier to accessing dental services. Free dental clinics for pregnant women and an online referral system have been proposed by midwives to overcome these barriers³¹⁹ and our findings indicate that these services would be well-received.

Unfortunately, subsidised oral health services remain limited for adults in Australia, including pregnant women. Within Queensland, public oral health services are only available for concession card holders and are associated with significant waiting periods.⁴² While we did not determine whether all of our participants were aware of the services available to them, it was clear that they felt they had limited options and agency over their oral health. At present, as an adult in Australia if you are unable to afford a private dentist, there are few opportunities to receive oral health information or advice. Many Indigenous Australians participate in general health checks, dubbed '715s' as per the Medicare Benefits Schedule billing code.³²⁰ These health checks are specifically for Indigenous Australians and meant to evaluate and support all aspects of health, including oral health. According to the '715' criteria,

patients are to receive an oral examination and a referral to a dental professional if further investigations or treatment is needed. Our study and others^{321, 322} suggest that the oral health criteria are not routinely being met. Bailie et al³²¹ posits that services, such as oral health examinations, that do not have clear referral pathways are less likely to take place during health checks.³²¹

In the absence of referral options, discussion and education regarding oral health should be prioritised. The common-risk factor approach has been proposed as a way of improving the oral health of Indigenous Australians.³²³ Given many health conditions share a common set of risk-factors to oral health, education could be bundled, and advice given holistically.³²³ Yet this approach is unlikely to be achieved while treatment is prioritised before prevention. Our study lends weight to the growing call for radical reforms to the current model of oral health.^{282, 324} Watt et al and Cohen et al have indicated that the present treatment focus on individuals is harming those that are most vulnerable and unable to afford care.^{282, 324} Indeed, all our participants reported poor oral health as adults and within the wider study population, 75.5% of participants had self-reported decayed, missing or filled teeth.²⁸⁹ In other studies, Indigenous adults have reported considerable negative oral health issues including high levels of caries, tooth loss and pain⁴; this is supported by national data that demonstrates a disparity in oral health between Indigenous and non-Indigenous people.⁴² Watt et al and Cohen et al argue that within dentistry, prevention should be prioritised, and the responsibility of oral health disseminated amongst a primary care team.^{282, 324} In addition to increasing the accessibility of oral health services, this approach would likely improve the regularity at which Indigenous Australian women received oral health information and education. As shared previously, oral health information is not getting to Indigenous Australian women and they feel that society would benefit from a greater diversity of oral health promotion, perhaps even reviving Mrs Marsh. Recent analysis of oral health messages in Australia mass media shares their sentiment and researchers suggest that there is a 'contemporary crisis in population level oral health promotion',³²⁵ with oral health promotion severely lacking social context and

usable content. These insights are valuable for finding a way forward in terms of health promotion and suggest there is an audience for culturally appropriate and potentially co-designed health promotion materials.

Limitations

As the findings described in this paper are opportunistic, it is possible that they do not adequately reflect the breadth of data that could have been reported had there been a targeted research question that queried women's experiences across the life course. Further, determining if women's perceptions changed with age would have been valuable. However, the extent of the data collected and the commonality in the data between participants of different ages suggest that the themes raised are topics of importance to the participants and as such should be considered nonetheless. Another potential limitation to the findings is the participation of a non-Indigenous Australian as the primary researcher. Although there appeared to be no difference in the topics raised between yarnings, this is only the perception of the researcher and participation of a non-Indigenous Australian may have influenced the comfortability of the participants.

6.6 CONCLUSION

There are limited qualitative data^{9, 11, 187} reporting the oral health experiences and perspectives of Indigenous Australian women. This study highlights that Indigenous Australian women are experiencing similar challenges to their counterparts in Western Australian and South Australia. The research demonstrates that both past and present oral health policies have been insufficient in adequately supporting the oral health of Indigenous Australian women. Current policies are short-sighted and do not consider the economic barriers to good oral health within a treatment-focused oral health system. Nor do they provide enough opportunities for oral health education across the life course. Indigenous Australian women have their own views of what they would like to see in terms of information and services, and

policy-makers are urged to consider the available evidence to develop and facilitate future oral health care programs.

Declarations

Ethics approval and consent to participate

This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/17/QCRH/94). The study protocol was explained verbally and through a written plain language statement and signed consent was obtained from all participants.

Consent for publication

Not applicable

Availability of data and material

Study data and materials may be made available on request with the appropriate human research ethics committee approval and with the consent of the participating community as required by Australian criteria for research within Indigenous communities.

Competing interests

The authors declare that they have no competing interests

Funding

Funding was provided through a Queensland Children's Medical Research Institute Project Grant, UQ Foundation Research Excellence Award, a Queensland University of Technology Indigenous Health start-up research grant. KB is supported by a

supervisor scholarship at Queensland University of Technology. KO was supported by a NHMRC Career Development Fellowship (1045157) and Queensland Smart Futures Fellowship and is currently supported by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). KH was supported by an Australian Postgraduate Award and the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). MT is supported part-time by the NHMRC Centre for Research Excellence in Lung Health for Indigenous children (1040830). The views expressed in this publication are those of the authors and do not reflect the views of the NHMRC.

Authors' contributions

KB was the primary author of the manuscript with substantial contribution from KOG and NWJ. MT and NK provided guidance in drafting the manuscript. KH contributed to the study protocol, recruited participants and transcribed data. All authors reviewed and approved the draft manuscript.

Acknowledgements

The authors would like to thank the study participants for sharing their time and experiences so generously.

7 CONCEPTS OF HEALTH-RELATED QUALITY OF LIFE OF AUSTRALIAN ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN: PARENT PERCEPTIONS

This chapter presents the first steps taken in developing the HR-QoL tool, the collection and analysis of qualitative data related to HR-QoL.

The chapter addresses the following research question:

- According to First Nations Australian parents and carers of children aged less than 18 years with a chronic illness, what concepts are representative of HR-QoL for First Nations Australian children?

It comprises the following published paper: Batten K, Newcombe PA, Chang AB, Sheffield JK, O'Grady KA, Johnson NW, King N, Toombs M. Concepts of Health-Related Quality of Life of Australian Aboriginal and Torres Strait Islander Children: Parent Perceptions. *Applied Research in Quality of Life*. 2020 May 6; 1-19.

STATEMENT OF CONTRIBUTION OF CO-AUTHORS FOR THESIS BY PUBLISHED PAPER

The authors listed below have certified that:

1. they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
2. they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. there are no other authors of the publication according to these criteria;
4. potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit, and
5. they agree to the use of the publication in the student's thesis and its publication on the QUT's ePrints site consistent with any limitations set by publisher requirements

In the case of this chapter:

Chapter 7 (Study 3): Batten K, Newcombe PA, Chang AB, Sheffield JK, O'Grady KA, Johnson NW, King N, Toombs M. Concepts of Health-Related Quality of Life of Australian Aboriginal and Torres Strait Islander Children: Parent Perceptions. Applied Research in Quality of Life. 2020 May 6; 1-19.

Author	Statement of contribution
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Principal Supervisor Confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship. (If the Co-authors are not able to sign the form please forward their email or other correspondence confirming the certifying authorship to the RSC).

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7.1 ABSTRACT

Objectives: Health-related quality of life (HR-QoL) is a valued patient-related outcome measure. HR-QoL is typically measured using a psychometric tool. Although there are a number of general and illness-specific HR-QoL measurement tools available globally, no tool has been validated for Australian Aboriginal and/or Torres Strait Islander children. The purpose of this study was to gather Australian Aboriginal and Torres Strait Islander parent/carer perspectives of HR-QoL in children in order to inform the development of a culturally appropriate tool.

Design: Yarning circles and face to face interviews were used to document the experiences of parents and carers of Aboriginal and Torres Strait Islander children who had experienced a chronic illness. Participants were recruited through word of mouth and via established social and professional networks in Queensland and the Northern Territory of Australia. Information collected was transcribed and analysed thematically and placed into a concept map.

Results: HR-QoL was defined as more than just physical, social and psychological wellbeing. Family and social support were valued aspects of HR-QoL, as was knowledge, communication and the relationship with the health system. Participants described the importance of being heard; their voice trusted and valued by health practitioners. Racism and prejudicial behaviour had negative impacts on HR-QoL.

Conclusions: The concepts of HR-QoL identified in this study are not included in conventional HR-QoL measurement tools. Consideration should be given to concepts proposed by Australian Aboriginal and Torres Strait Islander populations in order to adequately capture perceived HR-QoL.

7.2 BACKGROUND

Health-related quality of life (HR-QoL) is an important patient-related outcome, now commonly used for evaluation in contemporary health settings. HR-QoL provides a valuable patient-centred metric in addition to traditional physiological diagnostics.²⁰⁷ Many HR-QoL measurement tools are available but the homogeneity of these tools have been criticised in the context of the subjective nature of HR-QoL and the diversity of populations globally.³²⁶ A concern is that many tools are ‘expert-driven’, having been designed by clinicians, and have failed to adequately consult and incorporate the perceptions of the populations to which they are intended to be applied, particularly ethnic minority populations.^{230, 326} Within Australia, there may be cultural differences in defining HR-QoL, which make available tools inadequate for measuring the HR-QoL of Aboriginal and Torres Strait Islander Australians.^{14, 327} These citizens are hereafter respectfully referred to as Indigenous Australians.

In addition, current HR-QoL measurement tools typically reflect Western definitions of health, which focus on the physical, mental and emotional health of an individual.²⁰⁷ Indigenous Australian concepts of health are different as they are defined more broadly and include not only the health of the individual but also the health of the family and community.²³¹ Although little research has investigated the perceptions of ‘HR-QoL’ of Indigenous Australians specifically, there has been considerable work defining ‘health and wellbeing’ and ‘quality of life’ in general.¹⁶ Few studies have tried to adapt and/or validate existing HR-QoL measures for Indigenous Australians.¹⁴ Several studies^{14, 16, 215} indicate that further consultation with Indigenous Australian people is needed to properly define HR-QoL and create a measurement tool that is inclusive of culturally relevant domains and indicators.

Childhood has been targeted as a key area for health interventions and evaluation because of the understanding that many chronic conditions have their origins in childhood due to both physical and environmental factors.³²⁸ While it is preferable

that children self-report their HR-QoL, there are instances when this cannot occur due to age and/or illness. If children are unable to report their HR-QoL, a parent-proxy report can be used.¹⁷⁰ Despite documented discrepancies between child and proxy reports, a parent-proxy report is preferred to no evaluation and, although not interchangeable, they provide valuable insight into health care utilisation and family values regarding potential treatment options.¹⁷⁰

In the absence of a validated HR-QoL tool for Indigenous children, we undertook this study to identify key concepts that Indigenous parents and carers consider fundamental to HR-QoL in their young children with a chronic illness. These data will be used to inform the development of a valid culturally-specific parent-proxy HR-QoL measurement tool for Australian Indigenous children.

7.3 METHODS

Design

We used a qualitative phenomenological approach to explore parents' and carers' perceptions of HR-QoL of Indigenous children with a chronic illness. Phenomenology refers to understanding a person's experience through their eyes and understanding how they experience a phenomenon - in this case, HR-QoL.²⁴⁴ We used this approach as it is important for data collection and for decolonising the research process. Historically, research with Indigenous Australians has been paternalistic and failed to privilege Indigenous ways of knowing.³²⁹ A phenomenological approach is flexible and is able to incorporate Indigenous research methods such as yarning.³³⁰ Yarning is a traditional method of communication within Indigenous Australian culture, involving the sharing of stories and knowledge in a mutually respectful way.²³⁷ Yarning has become an accepted method of qualitative enquiry within Australia and has also been used in community-based epidemiology studies.³³¹ The yarning process aims to step away from the one-sided, research-led approach of data collection and instead places

value on symbiotic dialogue between the researcher and participant.²³⁷ The oral traditions of yarning and story-telling therefore provide an appropriate phenomenological platform because the knowledge is constructed by the participant and is privileging their voice. Yarning methods were used to conduct individual and group discussions during the data collection process.

Setting and participants

Parents and carers were eligible if they identified as being of Aboriginal and/or Torres Strait Islander descent and were, or had been, the carer of an Indigenous child aged <18 years with a chronic illness (defined as any condition which affected the child's daily life and required them to attend the doctor and/or hospital regularly).²⁵³

Convenience sampling was used; participants were recruited through word of mouth and via established social and professional networks in Queensland and the Northern Territory of Australia. The study protocol was explained verbally and through a written plain language statement that was provided to potential participants. Signed consent was obtained. Two researchers, an Indigenous Australian (MT) and non-Indigenous Australian (KB), recruited and interviewed participants using the yarning method described below. Yarnings (individual or group sessions) were held at times and places that were convenient for the participants.

Data collection

Yarning requires a rapport to be developed between the researcher and participants.²³⁷ In this study, time was spent with participants getting to know each other over morning or afternoon tea before commencing data-collection. This involved the researchers sharing information about themselves, including personal information in the context of the research question and discussing why they were

conducting the research and how they related as mothers in caring roles. This balance of sharing continued throughout the yarning sessions, as both researchers and participants contributed to the yarn, sharing information and asking questions of each other.

As HR-QoL was not a concept or phrase that everyone was familiar with, the researchers utilised questions to prompt discussion around 'health and wellbeing'. For example, asking 'how can you tell when your child is sick or unwell' prompted discussion around some of the attributes of wellness as perceived by parents and carers. Likewise, asking 'what are some ways you know your child is feeling good and you know their quality of life is good?' provided talking points that the researchers could explore further with participants. A more detailed question list is provided in Appendix F. All yarning sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea).

Analyses

The recordings were transcribed by a transcribing service (Smart Docs., Lexical Ventures, Brisbane, Australia). The data were entered into the software package NVivo 11.4 (QSR International Pty Ltd. Version 11.4.1.1064). and coded by one researcher (KB). Definitions of health and wellbeing as described by participants were coded first, with like codes grouped together and then further refined into specific concepts which were illustrated on a concept map (Figure 14). Remaining data were coded and organised thematically before being refined into more specific concepts to be placed on a concept map. All data were included on the concept map regardless of volume or repetition by participants. Codes were cross-checked by a second researcher (MT) for interpretation and accuracy. These concepts were discussed between both researchers before finalisation of the concept map.

Ethical statement

This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/16/QRCH/281) and Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (HREC 2017-2866).

7.4 RESULTS

Twenty-six participants were screened and recruited: none declined (Table 10). The majority of participants (18 females and eight males) were the biological parents of children with a chronic illness. Although specific demographics were not collected from participants, the majority were parents/carers to children aged less than 13 years, the others to adolescents aged 13 years and over. The illnesses and chronic conditions experienced by children of participants varied in severity and included, but were not limited to: asthma, chronic ear problems, developmental delay, rheumatic fever, bronchiectasis, osteomyelitis, and chronic liver and heart disease.

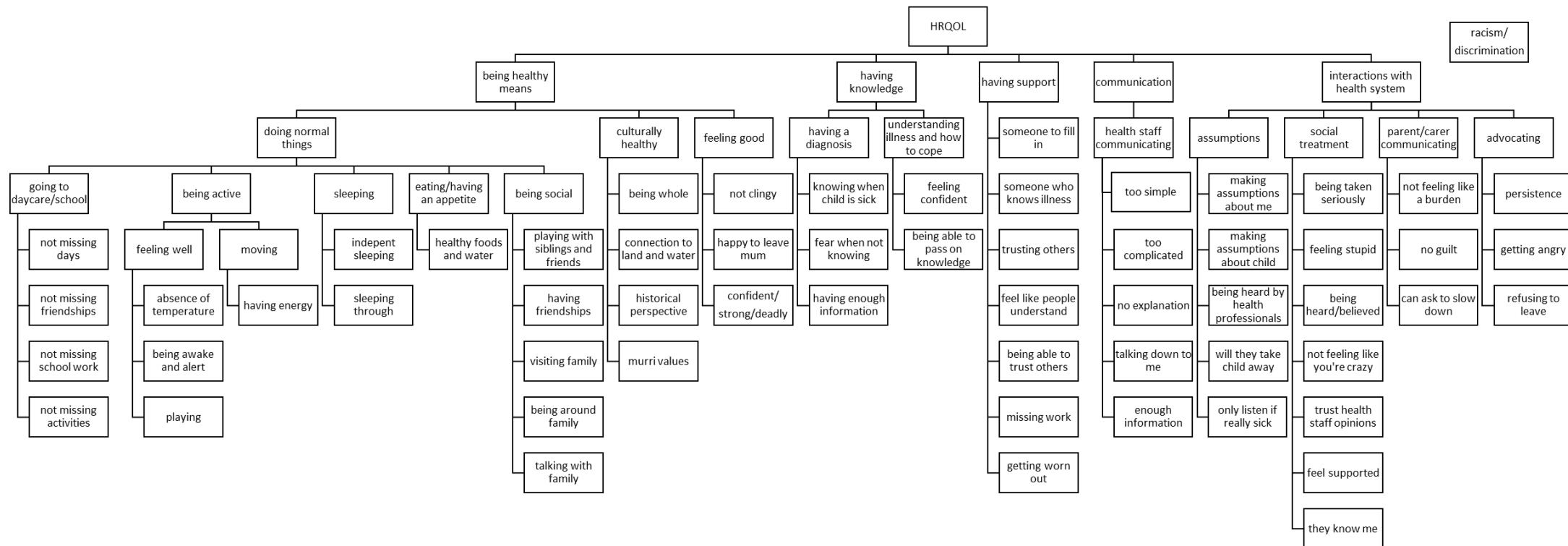
Participants defined their child's HR-QoL as being multi-faceted. Physical, social, emotional and cultural health were described as important components. Other components of child HR-QoL described were concepts such as: having knowledge, having support, ease and effectiveness of communication between parties and the nature of interactions with the health system. The 'health system' in this context pertained not only to clinicians, but to the many stakeholders within a health system, including allied health, Indigenous Health Workers and administrative staff. These concepts were complex, inter-related and described in relation to both the child and their primary carer (see Figure 14). In addition, although not raised with each concept, there were undertones of perceived racism and discrimination in many topics discussed. Parents and carers explained what they valued in relation to HR-QoL, and this was often the absence of prejudicial behaviour from health

services, be it overt or sub-conscious. As systemic racism and discrimination can be facilitated in many different ways it is acknowledged as a floating concept within the map (Figure 14) and is apparent in a number of the concepts raised.

Table 10. Description of the yarning sessions

Yarning	Participants (N=26)	Location	Researchers present
Group 1	8 participants, 4 males, 4 females	Toowoomba, QLD	Indigenous researcher
Group 2	3 participants, all female	Toowoomba, QLD	Indigenous researcher
Group 3	3 participants, all female	Darwin, NT	Both researchers
Interview 1	Female	Darwin, NT	Both researchers
Interview 2	Female	Darwin, NT	Both researchers
Interview 3	Male	Darwin, NT	Both researchers
Interview 4	Male	Darwin, NT	Both researchers
Interview 5	Male	Darwin, NT	Both researchers
Interview 6	Male	Toowoomba, QLD	Both researchers
Interview 7	Female	Toowoomba, QLD	Both researchers
Interview 8	Female	Darwin, NT	Non-Indigenous researcher
Interview 9	Female	Brisbane, QLD	Non-Indigenous researcher
Interview 10	Female	Brisbane, QLD	Non-Indigenous researcher
Interview 11	Female	Caboolture, QLD	Non-Indigenous researcher
Interview 12	Female	Caboolture, QLD	Non-Indigenous researcher

Figure 14. Concept map of Australian First Nations perceptions of HR-QoL



What does being healthy mean?

The notion of being healthy was attributed to more than just physical health. While participants indicated that being healthy meant their child being able to do normal things in life, such as go to school, be active, sleep, eat and be social, being culturally healthy and feeling good mentally and emotionally was also part of health. Social wellness contributed to HR-QoL for their children and being away from school or day-care because of illness had social implications as well as developmental and academic consequences.

Yes, because the ongoing effect of them not being at school and not participating and thinking 'why is it always me', they start to internalise and think there's something wrong with them. 'What did I do? What do I do differently? Why can't I do this? I missed out on this. Everyone else went to camp and they all bonded and I missed out. I can't go to sports day because I'll never make it around that track like everybody else'. Absolutely, it's not just a physical thing, yeah. (Female, Interview 9, Brisbane)

As well as friends and social interactions, being able to spend time with family and stay connected to cultural traditions was important for child HR-QoL. Parents explained that visiting family regularly, as well as regularly visiting traditional environments such as family land or wherever the family felt culturally connected, such as the beach or bush (countryside), was important for child HR-QoL. Participants shared the heartache of being absent from family during hospital stays or having to leave their home or land for long term treatment. Family was described as having a 'strengthening' capacity for individual health and children, parents and carers described feeling bolstered to conquer anything if they had their family near. The absence of family was seen as detrimental to child wellbeing and HR-QoL.

I think that's something - people often think that health is just all about the person and they don't think about the bigger picture, that you need some people around you as well. (Female, Interview 7, Toowoomba)

Also raised was the notion of 'feeling whole'. This was a challenging concept to articulate, as it was something that was more felt and understood, than could be defined. Yet participants shared that 'feeling whole' was associated with having traditional values specific to being Indigenous, as well as an awareness of the past (in the context of colonisation). It was related to identity and having an understanding of who and where you came from.

Each different culture, has got their own beliefs and your link to the land and the water and everything else is all different for each individual group sort of thing. (Male 2, Group, Toowoomba)

'Feeling good' was an important aspect of HR-QoL and parents explained that this could be expressed by a child's temperament and how clingy they were to their main parent/carer. Children who have good HR-QoL were reportedly more confident to be independent, requiring less reassurance or cuddles. Feeling good was not age specific, as parents indicated that even older children would express more neediness when they were unwell, not wanting to be alone and having their parents/carers close by. A child's energy levels and whether they were eating and sleeping as normal were also indicators for HR-QoL. Lethargy was associated with poor HR-QoL, even for older children. Many parents and carers explained that for older children (who may have an interest in technology for recreation), wanting to go out, and being able to go out and be outside, was a good indicator of the child's HR-QoL.

She is a bit more like happy and really energetic – like, do things, go to school and get up in the morning. Not like before, she was a bit lazy – not lazy, but weak, tired all the time, and not getting up in the morning. (Male, Interview 3, Darwin)

Having knowledge

Knowledge and self-efficacy were described by participants as aspects of child HR-QoL. The health-related circumstance of the child and carer determined what knowledge and level of self-efficacy was needed to improve HR-QoL. For instance, participants described the importance of having a diagnosis for child HR-QoL. Without a diagnosis, parents and carers felt unable to navigate their child's illness effectively and properly support them. It also contributed to fear and stress for both child and parent/carer, as they felt ignorant.

It was just getting that diagnosis and knowing that I wasn't going crazy. Because it lifted a lot of weight off my shoulders. Yeah, it just – I was crying a lot too, because I knew that there was something not right, but then not being heard is like – yeah, it's not the nicest thing. (Female, Interview 3, Darwin)

Adequate knowledge was judged by feeling confident in how to help their child cope and being able to teach their child and help them feel confident as well.

He knows what his body's doing, so he knows when to take his medications, if he's got to take the medications; if he doesn't need it then he'll go 'I don't need it'. So they, themselves, knowing what their own body's doing is good - yeah. (Female A, Group 1, Toowoomba)

Teaching family about the child's health situation was also valued, because without this, children could become isolated from their family. For children who were school-aged or attended day-care, the ability to pass on knowledge to the child's school was important to HR-QoL. Teaching and sharing knowledge was explained as an important cultural practice; passing on information to the younger generation was valued and contributed to the HR-QoL of both the individual receiving the information and the person delivering it.

We got to teach our generation that to come to terms with an illness, they need to understand what it's all about and they can actually live a normal life without thinking what's coming in front of them. (Female B, Group 2, Toowoomba)

Having support

A lack of social support for parents and carers was explained as having both direct and indirect effects on child HR-QoL. For example, emotionally fatigued parents acknowledged that their moods affected their children's moods. Parents described the importance of having someone to provide emotional and physical respite if they needed it, as well as allowing them to participate in paid work if they had to take time off to be a carer. In both group discussion and interview, participants shared how there was a ripple effect when support was not available, which affects emotional wellbeing immediately and extends to resources and opportunities, which again compounds wellbeing issues. For instance, not being able to have a break from routine and both child and family becoming isolated because of decreased earning capacity of the parent/carer. However, having a good support system was described as having more than just someone to call on to provide respite. Parents and carers expressed their reluctance to leave their children with anyone including family who did not have the capacity to provide for their child's health needs.

I don't trust her with anyone else, because I'm frightened if she has an asthma attack, they're not going to do what I do. You're wrapping them up in cotton wool, because you can't trust anyone else to give you a break. (Female B, Group 2, Toowoomba)

In addition to practical support, parents and carers explained that an emotionally supportive environment also contributed to child HR-QoL. Parents and carers explained that at times, family, community and schools would question or make

judgements about their child and their illness; either not understanding the severity of their child's illness, or in contrast, feeling threatened by their child's illness. This type of thinking increased isolation for children and carers and affected their social and emotional wellbeing.

You wish a friend would turn up or give you a call but no one does. So, yeah, unless you're one of those people that you're always making the phone calls, you don't get it back. Or if people know that you're sick, they don't want to come near you anyway. And once again, you just go, "Well, just suck it up and just do it," yeah, but it does drive you nuts, wears you out. (Female, Interview 11, Caboolture)

Communication

Strong and respectful communication between the health system and families was essential for child HR-QoL according to parents and carers. They described how appropriate communication allowed them to navigate the health system in a meaningful and effective way, ensuring their child received the best care possible. When communication was perceived as being insufficient, too complex or disrespectful, families were left feeling disenfranchised from the health system and its stakeholders. A breakdown in communication had ramifications at home as well. Parents and carers described the challenges and frustrations of not having enough information or resources communicated to them so that they could confidently manage their child's care at home.

Communication and listening has got a lot to do with it as well, because like us, we're Indigenous, the three of us, but we can speak up and we know - like, where if you get some of our mob from communities, and even family mob in town they're like, come to the doctor with me and that's why liaison officers, they're okay, but the majority of the time we know what we're talking about more than them. They don't listen. They just think they can send you home, or you don't know what you're talking about; you're not a doctor. (Female A, Group 3, Darwin)

They need to explain more because for me, sometimes I don't understand what my son's condition is. I know he has a problem with his lung but it's a hard word that I don't understand what it's really called. (Female, Interview 2, Darwin)

Interactions with the health system

Parents and carers shared the multiple ways they had experienced judgement from the health system and the ramifications these experiences had on child HR-QoL. Negative assumptions about parents and carers were described as commonplace and related to their capacity as a parent and/or their Indigenous identity. Issues raised included: health professionals making negative assumptions about children and their families; not believing or trusting parents/carers; and unwelcoming environments where parents/carers felt judged and unable ask questions or engage with health professionals confidently.

I didn't trust the welfare and all that sort of stuff, because when my daughter was born, this lovely social worker thought that I shouldn't have her, because I was only 21. She had spina bifida, my husband was an interstate truck driver, so I have a trust issue because they were trying to take her off me. So, that in turn, took away a lot of me wanting to get any help. So, that was 27 years ago. It's a big difference, but what it has also done, by not getting the help, you lose it, so then your whole family becomes unravelled. (Female A, Group 2, Toowoomba)

From their experiences, participants shared the additional advocacy they had to undertake. A common theme raised by participants was that they had to invoke negative stereotypes, such as 'the angry black woman' in order to get what they needed from the health system, be that attention, information, or physical care for their child. The additional stress and energy from having to advocate at such a high level had detrimental effects on families and, as participants explained, it

perpetuated the judgement cycle. However participants, particularly mothers, felt like they did not have any other options except to speak loudly and get angry.

Racism

While participants describe situations of feeling judged in general, they also reported being treated differently because of their Indigenous identity and were victim to negative stereo-typing, particularly with respect to their capacity to care for their child.

The problem is, they see you come in and they think because we're Indigenous, we don't know, and they automatically put us in that box. (Female B, Group 3 Darwin)

Yeah, he bruises really easily. I actually had a coronary one day, because he came home and he's had these bruises on him; I said 'where did you get them from mate?' and he said 'I've just bumped my shins on the thing'. So he could bump himself and within an hour or so he'd have a bruise, and you go 'oh God, hope they don't get a hold of me' [laughs]. Because that's the biggest fear; because he bruises so easily it's just constant bruising all the time, but if he breaks a bone the blood can bleed into the bone, and that causes major infection and that sort of stuff... it's a big concern that I had when he was younger, but because it's been documented in his medical journal/papers (I call it) I can actually say 'look, this is what it is, it's not me bashing him, it's actually his medical condition'. (Female B, Group 1, Toowoomba)

7.5 DISCUSSION

In recent years there has been increasing awareness of the potential lack of suitability of available health psychometrics for Indigenous Australians. Developed from Anglo-centric and biomedical notions of health and wellbeing, available tools

are reported to lack the relevant concepts needed to reflect Indigenous Australians perceptions of health and wellbeing.^{14, 16, 215} The findings of our study support this viewpoint, demonstrating that other concepts are important from the perspective of parents and carers of Indigenous Australian children.

What being healthy means

When considering health and wellbeing, our participants described the importance of children being able to participate in day-to-day life and feel well while doing so. Everyday physical, emotional and social functioning is often reflected in established HR-QoL measures.²¹¹ However, participants also emphasised the importance of family and engaging with family regularly for health and wellbeing. The significance of family to Indigenous Australian notions of health and wellbeing is well reported,¹⁶ yet few studies have specified whether these concepts are representative of all age groups within the Indigenous Australian population. Our findings contribute a parent-proxy perspective to this growing understanding of family and health and align with Priest et al.'s (2017) research with urban Indigenous children. Yarning with children aged eight to 12 years, Priest et al. (2017) reflected that, like the broader population, children view family as central to their health and wellbeing, and the same is found for other Indigenous children globally.²³⁰

Cultural health was also raised as an attribute of overall health and wellbeing. A multi-dimensional concept, as our participants explained, culture can transcend practice and ceremony and also be about identity and your place in the world.³³² Some participants used the term 'feeling whole' to describe cultural health. This notion of wholeness was indicative of the level of importance of culture to health - without it, one does not feel complete. Other parents and carers have shared similar thoughts on culture during the Longitudinal Study of Indigenous Children (LSIC), stating that a strong sense of culture and identity are key components of Indigenous Australian children's strength and wellbeing as they grow.³³²

Emotional domains are common within HR-QoL measures and typical proxy indicators require the subjective assessment of feelings such as being sad, angry or afraid.³³³ In contrast to this normative approach, our participants suggested some practical ways of assessing whether or not their children were ‘feeling good’, using physical cues such as their child’s level of clinginess or fatigue. These insights were useful, as there is considerable evidence that proxy measures of less observable domains, such as emotions, are less reliable.^{259, 334, 335} Likewise, the language our participants used in describing emotional states, such as feeling good, has important implications for future tools. Examination of culturally specific sub-populations have shown that some indicators of wellbeing are ‘lost in translation’, skewing results.³³⁶ Utilising the suggested cues, as well as the language of parents and carers, could assist in overcoming these issues of reliability and interpretation.

Having knowledge

In conceptualising what factors contributed to HR-QoL, having health knowledge and information were raised as key factors by participants. Studies of both Indigenous and non-Indigenous populations have demonstrated that when you are unwell, having ample information and knowledge about your situation is important for patient wellbeing and satisfaction,³³⁷⁻³⁴⁰ and the same has been found for parents/carers of chronically ill children.³⁴¹ Research into cancer care and survivorship of Indigenous Australians has demonstrated that patients having enough information and knowledge about their health condition not only contributes to their wellbeing, but can increase their chance of survival.³⁴²⁻³⁴⁴ This is because, as our participants elucidated, information is not just about peace of mind, but navigating a health journey and the practicalities of daily life with a health condition. Similar sentiments have been raised with respect to Indigenous Australian children with chronic wet cough.³⁴⁵ In gathering parent/carer perspectives, D’Sylva et al. reported having usable information was not only highly valued by participants, but was a key indicator of whether they sought and/or received appropriate care for their child.³⁴⁵ Although knowledge and information

are more typically utilised as indicators in patient care experience measures,³⁴⁶ our findings suggest that they should be considered in a HR-QoL context as well.

Having support

Participants in our study were adamant that parental/carer social support had implications for child HR-QoL, and their assumptions are supported empirically.³⁴⁷ Newland (2015) advocates that a child's wellbeing stems from family wellbeing and when 'families are struggling, a child's wellbeing suffers'.³⁴⁷ Parents/carers supporting chronically ill children experience greater emotional and financial adversity and are at risk for worse HR-QoL themselves than parents/carers of children with no health issues.^{348, 349} Support, connection and social capital have been found to be protective factors for both children and parents/carers when dealing with chronic illness^{341, 348} and as our participants have indicated, they reflect potential indicators of HR-QoL. The inclusion of parent-proxy measures in tandem with child measures in child HR-QoL tools to capture additional indicators is supported by Varni, Limbers, and Burwinkle, who attributed the need for greater consideration of parent indicators to the expanding role parents/carers have in managing their child's conditions.²⁵⁹

Communication

The findings of this study are consistent with other research that has investigated the effect of health service communication on patient health outcomes. Doctor-patient communication can affect both patient satisfaction and physical health outcomes.^{350, 351} As participants in our study conveyed, appropriate communication is more than just positive interactions with health services, it is a pathway for care and knowledge, which ultimately affects other aspects of health and wellbeing. A systematic review which included 65 papers on Indigenous narratives of culturally safe healthcare communication in Australia reported 'talk' as central to the experience of healthcare for Indigenous Australians.³³⁹ Talk and/or communication

was found to influence patients' physical health and feelings of wellbeing.³³⁹ The nexus between communication and health within an Indigenous Australian context is likely so highly regarded because of the continued communication gap within Indigenous Australian health settings.³²⁹ There is considerable evidence to suggest that health communication continues to be problematic and impact on concepts related to Indigenous Australian HR-QoL,³⁵² yet there are limited methods of understanding or measuring the effect.

Interactions with the health system and racism

As previously discussed, our findings are in accordance with current evidence that suggests that there remain inequities in the delivery of health care for Indigenous Australians.³³⁹ Participants in our study viewed their interaction with the health system as contributing to their child's HR-QoL status. The causal pathway is complex and related to the aforementioned concepts of communication and information/knowledge, as well as the more nuanced interactions which concern how the health system views Indigenous Australians and how Indigenous Australians feel they have to respond to the treatment they receive. Jennings, Bond, and Hill highlighted the power differentials experienced by Indigenous Australians and the negative effects they have on their health and wellbeing.³³⁹ As our participants shared, other Indigenous Australians report that their interactions with the health system influence the accessibility of care and their emotional wellbeing.³³⁹ Although there appears to be no research that examines these experiences in a HR-QoL context, there is evidence to suggest that these experiences do undermine aspects central to wellbeing. Autonomy, empowerment and recognition have been found to be profoundly relevant to Indigenous Australians notions of wellbeing and these qualities are eroded when people are unable to experience equitable health care and experience both subtle and overt racism.¹⁶ These experiences have an historical context that is specific to Australia and the transgenerational prejudice that Indigenous Australians have dealt with because of colonisation. This prejudice is based not only 'othering' with respect to

a person's race, but on inequities that have manifested in social determinants, such as employment, education and health.³⁵³

As depicted in Figure 14, there are multiple concepts to be considered in relation to HR-QoL. Due to space limitations, we have only touched on the main branches of the map in an aim to highlight the core concepts raised. However, many of the concepts are interrelated and could be interpreted with greater detail in their own right. The findings provide a platform for investigating whether additional indicators should be included in future culturally-specific HR-QoL tools.

Limitations

In our findings, many questions related back to the parent and family. This is potentially a bias of the parent-proxy approach but is also likely connected to the cultural perceptions of health; the emphasis on the collective as opposed to the individual. Due to the small sample size, these findings are limited, and more research is needed to understand whether the concepts raised are reflective of broader populations, including both geographically and linguistically diverse populations. The majority of the participants were from urban or regional areas or had been living in urban areas due to their child's illness and all spoke English. It is possible that perceptions of HR-QoL could be different or 'lost in translation' for those who speak English as their second, third or fourth language and/or live in rural and remote locations. Another limitation is the participation of a non-Indigenous researcher. This may have affected the comfortability of participants in sharing their perceptions, as well as biased the interpretation of the data. Although data collection was performed and final concepts confirmed in partnership with an Indigenous Australian researcher, the concepts were not reviewed or confirmed by participants for accuracy.

7.6 CONCLUSION

Given the growing demand for patient reported metrics to inform health care services and improve health and wellbeing, accurate representation of HR-QoL is needed. The concepts of HR-QoL identified in this study are not included in conventional HR-QoL measurement tools. Consideration should be given to concepts proposed by Australian Aboriginal and Torres Strait Islander populations in order to adequately capture perceived HR-QoL.

Data availability

Study data may be made available on request with the appropriate human research ethics committee approval and with the consent of the participating community as required by Australian criteria for research within Indigenous communities.

Acknowledgments

We would like to thank the families who generously shared their time, thoughts and experiences for this study. We thank, Lesley Versteegh, for her kindness, time and energy in connecting us with families in Darwin. This work was supported by the Queensland Children's Hospital Foundation under Grant no. 50227. ABC is supported by Australia's National Health and Medical Research Council (NHMRC) Practitioner Fellowship (1058213) and a Children's Hospital Foundation Queensland (50286) top-up fellowship.

Author Contributions:

AC, MT, PN, JS, KOG and KB all contributed to the study conception and design. KB and MT were responsible for data collection, analysis and concept map. The manuscript was drafted by KB and KOG, and AC, MT, PN, JS, NWJ, and NK contributed to the content and revision of the manuscript. All authors read and approved the final version.

8 DEVELOPMENT AND VALIDATION OF A PARENT-PROXY HEALTH-RELATED QUALITY OF LIFE SURVEY FOR AUSTRALIAN FIRST NATIONS CHILDREN.

This chapter reports on the development and validation process undertaken during Study 3 to develop a culturally specific psychometric tool.

The objectives addressed in the chapter include:

- Create a usable survey to be tested with the study population: First Nations Australian parents and carers of children aged zero to 12 years.
- Evaluate whether the survey (including instructions and response options) and item wording are culturally sensitive and appropriate, clear, relevant and not too time-consuming to complete, as determined by First Nations Australian parents and carers of children aged zero to 12 years.
- Evaluate the survey for statistical sensitivity within the study population.

It comprises the following manuscript which has been submitted for publication on April 18th, 2020 and is under peer-review: Butten K, Jones L, Newcombe P, Chang AB, Sheffield JK, O’Grady KAF, Johnson NW, Bell AM, Ross G & Toombs M. Development and validation of a Parent Proxy Health-Related Quality of Life survey for Australian First Nations Children. Submitted to Quality of Life Research.

STATEMENT OF CONTRIBUTION OF CO-AUTHORS FOR THESIS BY PUBLISHED PAPER

The authors listed below have certified that:

1. they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;
2. they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. there are no other authors of the publication according to these criteria;
4. potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit, and
5. they agree to the use of the publication in the student's thesis and its publication on the QUT's ePrints site consistent with any limitations set by publisher requirements

In the case of this chapter:

Chapter 8 (Study 3): Butten K, Jones L, Newcombe P, Chang AB, Sheffield JK, O'Grady KAF, Johnson NW, Bell AM, Ross G & Toombs M. Development and validation of a Parent Proxy Health-Related Quality of Life survey for Australian First Nations Children. Submitted to Quality of Life Research.

Author	Statement of contribution
Kaley Butten QUT Verified Signature Signature Date 15/05/20	Responsible for establishing and facilitating the study. Designed the study materials, collected, and cleaned all data. Performed basic analysis of descriptive data. Interpreted the findings. Produced the first and final drafts of the manuscript, collated and responded to feedback on drafts from co-authors, and prepared the manuscript for submission.
Lee Jones	Performed complex statistical analysis of data and assisted in the interpretation of the findings. Provided critical review of manuscript drafts.
Peter Newcombe	Contributed to the conception and facilitation of the study. Oversaw study implementation. Provided critical review of manuscript drafts.
Anne Chang	Contributed to the conception and facilitation of the study. Oversaw study implementation. Provided critical review of manuscript drafts.
Jeanie Sheffield	Contributed to the conception and facilitation of the study. Oversaw study implementation. Provided critical review of manuscript drafts.
Kerry-Ann O'Grady	Contributed to the conception and facilitation of the study. Oversaw study implementation. Provided critical review of manuscript drafts.
Newell Johnson	Provided critical review of manuscript drafts.
Anna Bell	Provided critical review of manuscript drafts.

Greggory Ross	Provided critical review of manuscript drafts.
Maree Toombs	Contributed to the conception and facilitation of the study. Oversaw study implementation and collected data. Provided cultural guidance on study. Provided critical review of manuscript drafts.

Principal Supervisor Confirmation

I have sighted email or other correspondence from all Co-authors confirming their certifying authorship. (If the Co-authors are not able to sign the form please forward their email or other correspondence confirming the certifying authorship to the RSC).

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15/05/2015

Name

Signature

Date

8.1 ABSTRACT

Purpose: Within Australia, Aboriginal and Torres Strait Islander (First Nations) populations perceive health and wellbeing differently to non-Indigenous Australians. Existing health-related quality of life (HR-QoL) measurement tools do not account for these differences and to date, no validated HR-QoL for First Nations children exists. The objective of this study was to develop and validate a culturally-specific parent-proxy HR-QoL measurement tool for Aboriginal and Torres Strait Islander children.

Methods: Scale development was informed by parents/carers of children with a chronic illness and an expert panel. The preliminary 39 item survey was piloted (n=12) and tested (n=163) with parents/carers of First Nations children aged zero to 12 years at baseline with comparative scales: the Kessler Psychological Distress Scale, generic HR-QoL (PedsQL4.0) and Spence Children's Anxiety Scale, and repeated (n=46) four weeks later. Exploratory Factor Analysis was used for scale reduction. Reliability and validity were assessed by internal consistency, test-retest, known-group validity and correlations with comparison scales.

Results: Items within our FirstNations-Child Quality of Life (FirstNations-CQoL) measure were internally consistent with Cronbach alpha coefficients of ≥ 0.7 (Quality of Life, 0.808; Patient Experience, 0.880; Patient Support, 0.768) and overall test-retest reliability was good ($r=0.75$; 95% confidence interval (CI)=0.593-0.856). Convergent reliability was observed with the PedsQL^{4.0} with Pearson's coefficients of $r=.681$ (ages two to four years); $r=0.651$ (ages five to 12 years) and with the Kessler Psychological Distress scale ($r=-0.513$). Divergent validity against the Spence Anxiety Scale and known-group validity between children with/without a chronic condition was not demonstrated.

Conclusion: The FirstNations-CQoL scale was accepted by participants, reliable and demonstrated convergent validity with comparison measures. This tool requires further evaluation to determine responsiveness, its minimal important difference and clinical utility.

8.2 BACKGROUND

Health-related quality of life (HR-QoL) is informed by an individual's culture and value systems.²¹⁰ Within Australia, the way Aboriginal and Torres Strait Islander (hereafter respectfully referred to as First Nations) populations perceive health and wellbeing is different to other Australians.^{14, 16} Unlike Anglo-centric notions of health, the wellbeing of First Nations Australians is not an individual concept, but can be better understood in how the individual is connected to their identity, culture, spirituality, family, community and country.²²³ Social and historical determinants such as colonisation also play a role in how health and wellbeing is perceived. The colonial process has undermined the autonomy, empowerment and recognition of First Nations people and as such, experiences of health and health care are valued differently to those that have not experienced the same marginalisation.^{14, 16}

Angell and colleagues' review of available HR-QoL measures for Indigenous populations globally concluded that available tools are primarily built using Anglo-centric notions of health. As these do not adequately capture the subjective HR-QoL of Indigenous populations (including First Nations Australians¹⁴), psychometric tools should be developed in cooperation with First Nations Australians in order to accurately reflect their values.^{14, 16, 215, 223, 354} To the best of our knowledge, there are no tools that have been developed or validated specifically to measure the HR-QoL of Australian First Nations adults or children.¹⁴

Given the understanding that many chronic conditions have their origins in childhood, health interventions in children have been targeted as a key area.³²⁸ Older children are able to report their own HR-QoL but a parent-proxy report is required for young or unwell children who are unable to report for themselves.¹⁷⁰ Understanding the parent or carer's perspectives can also provide insight into health care utilisation and family values regarding potential treatment options.¹⁷⁰

In the absence of a validated HR-QoL tool for First Nations children, we developed and validated a culturally-specific parent-proxy HR-QoL measurement tool for First Nations children. The FirstNations-CQoL aims to reflect the values associated with the HR-QoL of First Nations Australian children from the perspective of their parents and carers. Here we describe the procedure we used to identify items, draft the tool and test its validity.

8.3 METHOD

Study design

This study was informed by a prior qualitative investigation which aimed to understand the meaning of HR-QoL to parents and carers of Australian First Nations children with a chronic illness. The qualitative findings have been published.³⁵⁵ Development of our measurement tool, the FirstNations-Child Quality of Life (First Nations-CQoL), consisted of three stages: (A) development of a draft tool based on the findings of the qualitative study,³⁵⁵ (B) piloting the tool and (C) validation of the tool using statistical techniques and comparative measures.

Setting and participants

The primary recruitment location was the Queensland Children's Hospital in Brisbane, Australia, the State's only tertiary paediatric facility. Recruitment took place across the hospital, on patient wards and in outpatient clinics. Additional recruitment took place in regional areas outside of Brisbane at primary health care clinics located in Toowoomba and Warwick; these centres are approximately two hour's drive west of Brisbane.

Parents and carers of First Nations children aged zero to 12 years inclusive were eligible to participate. Stage B (piloting) included only parents and carers of children with a chronic health condition and recruitment was ceased for this stage once no further new feedback was obtained. Stage C (validation) included parents and carers

of children with and without chronic conditions. Children were excluded if they were in the care of State services.

Screening of potential participants for Stages B and C was supported by two hospital Indigenous Liaison officers who provided daily guidance on which families were available to approach for recruitment. The primary researcher (KB) and another research assistant approached potential participants in person in the hospital clinic waiting rooms and on the hospital wards. Participants in Toowoomba and Warwick were recruited from the clinic waiting room. The study protocol was explained verbally and through a written plain language statement and signed consent was obtained from all potential participants.

During Stage B, potential participants were invited to complete the draft paper-based survey which included demographic and health-related questions about themselves and their children, as well as the associated comparison measures. The survey had additional blank space for written feedback.

For Stage C, participants had the option of completing the finalised paper-based survey or a de-identified online survey (via [surveymonkey.com.au](https://www.surveymonkey.com.au)). For the paper-based survey, participants were required to consent at the time of recruitment as to whether they would agree to being contacted four weeks later to complete the scales again. For the online survey, participants were able to indicate after completing the survey online whether they consented to the follow up survey being sent four weeks later.

Stage A: Development of draft First Nations-CQoL

Item development

Fifty-two items for the FirstNations-CQoL were obtained from our prior qualitative study that involved yarning sessions with 26 First Nations parents and carers of children aged less than 18 years who experienced a chronic condition.³⁵⁵ An 'item' refers to the concept that is used to represent the different facets of HR-QoL in the form of a question when placed into survey format.

Item reduction

The 52 items above were formatted in a document with a ranking scale to determine an item validity content index (I-CVI) by an expert panel. We used Polit and Beck's method²⁵⁴ where each item could be ranked from 1 (Do not use) to 4 (Definitely Keep). Six experts ranked these items in accordance with Polit and Beck's method.²⁵⁴ These included First Nations academics, First Nations Health Workers and clinicians who work closely with First Nations Australian paediatric and adult populations. The I-CVI score was determined by summing the percentage of agreement between the panel: items were included upon greater than 79% agreement and removed if less than 69% agreement, those in-between were iteratively reviewed until a resolution was achieved.²⁵⁴ The ranking process effectively reduced the number of items from 52 to 39 items and these were formatted into questions in a paper-based survey format with a 5-point Likert-style scale for answers (Never, Almost Never, Sometimes, Often, Always).

Materials

The 39-item FirstNations-CQoL was then formatted and collated with the following questionnaires (the comparative scales) for stage (B), before being finalised and formatted into an additional online version for stage (C).

- a) Single item HR-QoL. Participants were invited to indicate on a numerical scale from 1 (terrible) to 10 (excellent), how they would rate their child's HR-QoL.
- b) The Kessler Psychological Distress Scale (KPDS).²⁶⁷ This is a validated 10-item scale investigating whether a person has been experiencing anxiety or depression in the past four weeks. The tool has been used with general Australian adults previously, and adapted versions of the scale (the Kessler 5 & 6) validated with Australian First Nations adults ²¹⁵. Participants were invited to complete the Kessler 10 based on their own experiences.
- c) The Paediatric QoL Inventory 4.0 (PedsQL).²⁵⁹ This is a validated 23-item parent-proxy measure of child HR-QoL. It has a 5-point Likert-style scale (0 = never a problem to 4 = almost always a problem). The PedsQL^{4.0} inventory has demonstrated reliability and validity and is reported to be applicable across a variety of settings, including clinical trials and research ²⁵⁹. The inventory caters to four age groups (2-4, 5-7, 8-12, and 13-18 years). Depending on the age of their child, parents of children aged 2 to 12 were invited to complete the respective measure.
- d) The Spence Children's Anxiety Scale (SCAS-P), parent-version.²⁶⁵ This is a scale designed to measure anxiety in children. There are two versions of the scale, one for preschool children and one for school-aged children. The preschool scale consists of 28 items that ask parents to report on the frequency of which an item is true for their child. Each item is rated on a 5-point scale from 0 'not at all' to 4 'very often true'. The scale has been validated for Australian children aged 2.5 to 6 years.²⁶⁶ The school aged version consists of 44 items and has been validated for Australian children aged six to 18 years. The parent rates on a 4-point scale (never, sometimes, often or always) how often each of the items happens to their child.²⁶⁵

In addition to the above, socio-demographic, cultural, health and wellbeing information were collected by self-report.

Stage B: Piloting the FirstNations-CQoL

The draft 39-item FirstNations-CQoL and related materials were disseminated to 12 participants (participants included mothers who identified as First Nations women and whose children had a chronic illness) to test for appropriateness and acceptability. Participants were encouraged to provide both verbal and written feedback on the usability and applicability of the tool to Australian First Nations HR-QoL values. Feedback on the item content specifically was encouraged, including whether items should be deleted, created, or refined. As well, feedback on the entirety of the research materials was sought.

All 12 participants who undertook the pilot study indicated that the FirstNations-CQoL was both acceptable and appropriate for use with First Nations families. While we received feedback to shorten the tool if possible, the participants indicated that this was not a priority for stage (C) validation as all the content was relevant and no items were deemed inappropriate or unacceptable. We thus retained all 39 items chosen from the item reduction process.

Stage C: Statistical validation of FirstNations-CQoL

Stage C comprised the dissemination of the tool along with the comparison measures above to participants recruited through the Queensland Children's Hospital and community clinics as described above.

Sample Size

Guidelines for establishing the respondent-to-item ratio vary, 5:1 (participants: question) is suggested as the minimum.³⁵⁶ We aimed for a ratio of 6:1. We had initially anticipated no more than 21 questions to be included on the FirstNations-CQoL and as such aimed to recruit 160 participants (allowing for 20% attrition over a 4-week test-retest period) with respect to our timelines.

Identification of domains

Participant feedback and prior research²⁶¹ have indicated a preference for measures that are shorter and quicker to complete. In this instance there was also an insufficient participant to item ratio to complete an Exploratory Factor Analysis (EFA) with all 39 items. An EFA is a statistical technique that is used to summarise variables that have patterned correlations, known as latent factors.²⁶⁹ For HR-QoL scales, this means evaluating whether the themes that have been identified as relating to HR-QoL conceptually, also correlate together statistically into factors or what is commonly termed 'domains'. This technique is best performed with a large respondent-to-item ratio.²⁶⁹ Thus, it was decided to reduce items prior to conducting the EFA. Item reduction was informed by item correlation and by the qualitative data collected during item creation. According to the lead investigator and the statistician, the items which were considered to be most representative of the concept were retained. To facilitate the EFA, principal axis factoring was used for extraction with Promax rotation used to account for correlation among factors.³⁵⁷ The number of factors included were chosen with consideration of the proportion of variance explained by each factor, viz: number of eigenvalues greater than one and clinical interpretation of factors. Once the factors were determined, they were reviewed by First Nations health professionals (n = 5) who independently evaluated the relevance and applicability of the factors as domains of child HR-QoL.

Reliability and Validity

Cronbach's alpha was used to examine internal consistency³⁵⁶ and intraclass correlation (ICC) was used to assess test-retest reliability when the survey was repeated by participants four weeks later. Internal scale reliability refers to the correlation of the items within the scale.³⁵⁶

To evaluate construct validity, Pearson's correlation was used to examine the correlations between the FirstNations-CQoL domains and comparative measures. Construct validity refers to how a survey correlates to other surveys with similar (convergent) and dissimilar (divergent) constructs.³⁵⁶ For instance, we would expect the FirstNations-CQoL to be moderately correlated to the established PedsQL^{4.0} and weakly correlated to the Spence Anxiety scale. Pearson coefficients of 0.7 were considered strong, 0.4-0.6 moderate and ≤ 0.3 weak.³⁵⁸ Data were analysed using SPSS (SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp) and R (R Core Team, Version 3.6.3, www.r-project.org).

Descriptive statistics were produced for all demographic characteristics and are presented using means and standard deviations (SD) for data that were normally distributed and medians and interquartile range (IQR) for non-parametric data. Missing data in the scales were imputed using the Expectation-Maximization Algorithm to preserve relationships between variables.³⁵⁹

8.4 RESULTS

Baseline characteristics

Of the 335 potential participants screened, 263 were enrolled. Of these three withdrew (due to other commitments) and 97 did not return the survey (lost to follow up), leaving 163 who completed the baseline survey. Of the 163, 46 repeated the survey four weeks later. The demographic characteristics of the parent/carer and child are presented in Table 11. The majority (87.1%) of participants were female and mothers (79.7%) to the child for whom they were completing the survey; the median age of the children was 5.7 years, IQR 6.9.

Table 11. Baseline characteristics of parents/carers and children in HR-QoL study

Characteristics		N=163 (%)
Gender of children	Male	101 (61.9)
	Female	61 (37.4)
	Missing	1 (0.6)
Age range of children	Less than 24 months	34 (21.1)
	2-4 years	38 (23.6)
	5-7 years	32 (19.8)
	8-12 years	57 (35.4)
	Missing	2 (1.2)
Gender of parents/carers	Male	21 (12.8)
	Female	142 (87.1)
Age range of parents/carers	18-25 years	23 (14.1)
	26-35 years	66 (40.4)
	36-45 years	46 (28.2)
	46 + years	24 (14.7)
	Missing	4 (2.4)
Relationship to child	Father	17 (10.4)
	Mother	130 (79.7)
	Relative/Carer	16 (9.8)
Care type at home	Both parents	87 (53.3)
	Single parent	46 (28.2)
	Shared care/Relative/Carer	18 (11.0)
	Missing	12 (7.3)
Employment status	Full time	41 (25.1)
	Part time	25 (15.3)
	Casual	11 (6.7)
	Not in paid employment	84 (51.5)
	Missing	2 (1.2)
Home location	Major city	108 (66.2)
	Inner regional	36 (22.0)
	Outer Regional/Rural/Remote	17 (10.4)
	Missing	2 (1.2)
Indigenous status of parent/carer	Aboriginal	83 (50.9)
	Torres Strait Islander	8 (4.9)
	Both	9 (5.5)
	Non-Indigenous	53 (32.5)
	Declined	7 (4.2)
	Missing	3 (1.8)

Identification of domains

Twenty-one items were subjected to EFA resulting in five factors with eigenvalues greater than one explaining 63% of the total variance. However, models containing the four and five factor solutions did not converge, indicating a simpler three factor model was more appropriate, explaining 52% of the variation. The three latent factors reflected themes raised during item creation: Quality of life, Patient Experience and Patient Support (Table 12). The subscale correlations were weak to moderate: Quality of Life and Patient Experience ($r=0.359$, $p<0.001$); Quality of Life and Patient Support ($r=0.406$, $p<0.001$) and Patient Support and Patient Experience ($r=0.433$, $p<0.001$), indicating low overlap between factors. There was a consensus from the panel of First Nations health professionals that these domains were representative of child HR-QoL.

Table 12. Results of exploratory factor analysis: item means with standard deviations and factor loadings

Items - 152	Mean (SD)	Patient Experience	QOL	Patient Support
Felt respected by medical staff	3.08 (0.87)	0.811	-0.134	0.000
Felt like you had enough information	2.97 (0.95)	0.774	0.093	-0.083
Felt like your child's health situations were well explained	3.14 (0.90)	0.771	-0.020	0.045
The medical staff listen to you	2.94 (0.91)	0.749	0.064	-0.086
Felt like medical staff are there to help you	3.12 (0.88)	0.673	-0.116	0.193
The medical staff don't believe you	2.96 (1.05)	0.656	0.028	-0.019
Felt frustrated	2.02 (1.06)	0.567	0.197	-0.240
You could ask medical staff questions if you needed to	3.45 (0.81)	0.547	-0.031	0.197
You could teach your family about your child's health needs	3.41 (0.85)	0.446	0.044	0.219
You have enough knowledge to care for your child when they are sick	3.51 (0.76)	0.352	-0.007	0.076
Spend time with family as usual	3.20 (0.97)	0.018	0.838	-0.048
Do activities they enjoy	3.03 (0.95)	0.052	0.765	-0.024
Felt strong/good/deadly	2.89 (1.00)	-0.043	0.687	0.208
Go to school/day care	2.89 (1.27)	0.013	0.579	-0.089
Had very little energy	2.49 (1.19)	0.087	0.535	-0.141
Slept through the night	2.76 (1.32)	-0.089	0.485	0.231
Eating as normal	2.86 (1.16)	-0.108	0.459	0.196
Been extra clingy	1.99 (1.12)	0.058	0.329	0.007
There is someone you can trust to provide childcare if you are away	3.00 (1.18)	0.026	-0.043	0.763
Your family could manage your child's health if they needed to	2.84 (1.14)	-0.046	0.060	0.716
You could call someone if you are struggling	3.24 (1.00)	0.189	0.042	0.592

Extraction Method: Principal Axis Factoring. Rotation Method: Promax with Kaiser Normalization. Rotation converged in 5 iterations. SD: Standard Deviation, QOL: Quality of Life

Reliability

The novel HR-QoL tool demonstrated good internal consistency, with Cronbach alpha coefficients of ≥ 0.7 (Cronbach alpha for Quality of Life=0.808; Patient Experience=0.880; Patient Support=0.768). Test-retest reliability was conducted with 45 participants. Good reliability was observed for the overall scale (ICC $r=0.753$; 95%CI:0.593-0.856) and subscale reliability varied: Quality of Life (ICC $r=0.663$; 95%CI:0.462-0.799), Patient Experience (ICC $r=0.744$, 95%CI:0.579-0.850) and Patient Support (ICC $r=0.794$; 95%CI:0.655-0.881) are displayed in Table 13.

Table 13. Internal reliability and test-retest reliability of FirstNations-CQoL scale and scale domains against comparison measures: single-item HR-QoL, KPDS, PedsQL4.0 and SCAS-P

Measures	Baseline scores				Four-week follow-up				Test-retest
	N	Mean	SD	Cronbach's alpha	N	Mean	SD	Cronbach's alpha	ICC~
FirstNations-CQoL Total (21-items)	152	61.81	11.72	0.880	45	64.49	11.39	0.876	0.753
Quality of Life	152	22.12	5.91	0.808	45	23.39	5.60	0.818	0.663
Patient Experience	152	30.61	6.31	0.880	45	31.68	6.68	0.873	0.744
Patient Support	152	9.08	2.75	0.768	45	9.42	2.52	0.766	0.794
Single item HR-QoL*	157	7.61	2.13	NA	45	8.13	1.89	NA	0.545
Kessler Scale	161	19.86	8.09	0.937	45	19.11	7.40	0.929	0.812
PedsQL aged 5-12 years	83	57.74	20.15	0.931	23	62.15	16.43	0.899	0.798
PedsQL aged 2-4 years	36	75.33	18.12	0.919	23	76.06	16.57	0.897	0.938
Spence Preschool	36	20.96	12.74	0.845	11	18.82	14.09	0.881	0.897
Spence School-aged	74	25.18	18.24	0.947	23	23.33	13.99	0.908	0.806

*Parent rating of child HR-QoL using single numerical scale, ~Intra-class correlation

Validity

The FirstNations-CQoL was moderately to strongly correlated to the PedsQL^{4.0}, with Pearson's coefficients of $r=0.681$ for ages two to four years and $r=0.651$ for ages five to 12 years. Likewise, the Kessler Psychological Distress Scale ($r=-0.513$) and independent assessment of HR-QoL (single item scale) by parents was moderately correlated ($r=0.480$) to the FirstNations-CQoL, suggesting acceptable convergent validity across the relative comparison measures. Divergent validity was not demonstrated against the Spence Anxiety Scales, the FirstNations-CQoL being moderately correlated to both the preschool ($r=-0.466$) and school age ($r=-0.535$) scales, presented in Table 14.

Table 14. Construct validity of FirstNations-CQoL against comparison measures: single-item HR-QoL, PedsQL4.0 ages 2-4 years, PedsQL4.0 ages 5-12 years, KPDS and SCAS-P

Pearson's Correlation	FirstNations-CQoL Total	Single-item HR-QoL	PedsQL aged 5-12 years	PedsQL aged 2-4 years	Kessler Scale	Spence School-aged	Spence Preschool
FirstNations-CQoL	1	0.480**	0.651**	0.681**	-0.513**	-0.535**	-0.466**
Single-item HR-QoL	0.480**	1	0.392**	0.518**	-0.389**	-0.304**	-0.264
PedsQL aged 5-12 years	0.651**	0.392**	1	.b	-0.498**	-.707**	.b
PedsQL aged 2-4 years	0.681**	0.518**	.b	1	-0.385*	.b	-0.548**
Kessler Scale	-0.513**	-0.389**	-0.498**	-0.385*	1	0.492**	0.275
Spence Preschool	-0.466**	-.264	.b	-0.548**	0.275	.b	1
Spence School-age	-0.535**	-0.304**	-0.707**	.b	0.492**	1	.b

**Correlation is significant at the 0.01 level (2-tailed), * Correlation is significant at the 0.05 level (2-tailed).

b. Cannot be computed because at least one of the variables is constant.

8.5 DISCUSSION

As far as we are aware, we have developed the first parent-proxy HR-QoL tool applicable to Australian First Nations children for use in clinical and research settings. In testing with 163 parents/carers of First Nations children in South-East Queensland, the tool demonstrated reliability (internal consistency, test-retest) and validity (convergent, divergent) for use with parents of First Nations children demographically similar to our study population.

We identified three domains and 21 questions (items) that reflected concepts of Quality of Life, Patient Experience and Patient Support. These domains were determined by evaluating which items correlated together via EFA and whether these groupings were logical and appropriate in terms of content from the perspective of First Nations health professionals. The domains of the FirstNations-CQoL are not typical domains of current Western-based HR-QoL, such as found in well-established proxy measures: PedsQL^{4.0},²⁵⁹ KINDL^R,³⁶⁰ and the Child Health Questionnaire.³⁶¹ In these established HR-QoL measures, the domains reflect individual functioning as it relates to physical, mental and social wellbeing.^{362, 363} For example, the widely used PedsQL^{4.0} has four domains: 1) Physical Functioning, 2) Emotional Functioning, 3) Social Functioning and 4) School Functioning. The items included in these domains query the functioning of the individual i.e. 'In the past month, how much of a problem has your child had bathing'.²⁵⁹ The FirstNations-CQoL also includes items related to individual functioning in the Quality of Life domain, however it differs to the PedsQL^{4.0} and others mentioned, in that it also considers the wider health environment that influences and can facilitate human function, such as a person's interactions with the health system (Patient Experience domain) and/or whether they have support (Patient Support domain).

In the Patient Experience domain, the questions relate to the respondent's perceptions of health information, the delivery of that information and whether respondents feel they have adequate information. Although feeling informed and

knowledgeable about one's health is valued generally, it is perhaps more important for First Nations people in terms of HR-QoL.³⁴² This is because the colonial process has undermined First Nations people's autonomy and access to culturally relevant and safe health care.¹⁶ Qualitative studies^{9, 279, 310, 345, 355, 364} demonstrate that First Nation's parents and carers experience considerable barriers to health-literacy and self-efficacy in engaging with the health system to manage child illness which has implications for healthcare utilisation and parent and child wellbeing. Baba et al's³⁶⁵ work with Aboriginal Medical Services highlights how insufficient information and inadequate support from mainstream health services can leave First Nations patients feeling scared, confused and alone. These experiences are likely to inform child HR-QoL as parents act on their behalf in navigating the health system.

Similarly, in the Patient Support domain, the questions relate to whether the respondent feels supported in their home environment. It is well-established that family and community play a central role in how First Nations people define health and wellbeing.¹⁶ Yet many social factors can affect the capacity of traditional family support networks,¹ which in turn affects how families are able to cope with child health challenges.³⁴⁸ The relevance of these domains with respect to HR-QoL has been identified, both in our own qualitative investigations,³⁵⁵ and prior studies investigating how Australian First Nations people perceive health and wellbeing.^{16, 215, 342} Moreover, 'having a support network' and 'experience of health services' are recognised components of Quality of Life as determined by the World Health Organization's Quality of Life Instrument (WHO-QOL) manual.³⁶⁶ A content evaluation³⁶³ of available HR-QoL measures against the WHO-QOL criteria suggests that many tools were created prior to establishing the differences between individual function and HR-QoL and as such do not adequately reflect HR-QoL in its holistic definition. Acceptance of the First Nations-CQoL at face value by parents and health professionals, and demonstrated convergent validity with the comparison measures, suggest that the incorporation of these domains into future culturally-specific HR-QoL measures is important and worthwhile.

This study provides insight into culturally specific psychometrics for First Nations Australians. A strength of the study has been the consultative approach taken to develop the tool; item development was informed by First Nations Australian conceptualisations of HR-QoL and subsequently checked for acceptability by a wider population. The findings contribute to the growing understanding of what Australian First Nations families value in terms of HR-QoL and how those values can be evaluated in a health setting. Yet, the project is not without limitations. Firstly, in removing excess items prior to the EFA, it is possible that the results are biased to the researchers. However, the alignment of the resulting domains with the preceding qualitative investigation suggest that the relevant constructs have been adequately represented. Secondly, given there are no age-appropriate comparison scales for infants age zero to two years, we combined the infants with children aged two to four for comparison to the other measures. While this approach has shown sound psychometric properties in our study, we are unable to distinguish the sensitivity for babies in particular. Likewise, we have been unable to demonstrate divergent validity to the Spence Anxiety Scale. This is likely because several items within the FirstNations-CQoL relate to anxiety. Future research should consider other comparison measures. However, cultural and age appropriate proxy measures for comparison remain limited and there is a dearth of psychometric tools validated for First Nations Australians generally.^{215, 354} A focus of future research should be to evaluate the psychometric properties of the tool with specific disease groups and disease specific items.

8.6 CONCLUSION

There is evidence to suggest that the values of Australian First Nations people are not being adequately represented in available HR-QoL measures.¹⁴ We have developed a culturally-specific HR-QoL measure which has been conceptualised using Australian First Nations values of HR-QoL, which is acceptable for use and relative to other HR-QoL measures. Future research should expand on the further evaluation of the novel measure with larger and disease-specific populations, as well as evaluate its sensitivity when used to evaluate treatment.

Declarations**Funding**

This work was supported by the Queensland Children's Hospital Foundation under Grant no. 50227. ABC is supported by Australia's National Health and Medical Research Council (NHMRC) Practitioner Fellowship (1058213) and a Children's Hospital Foundation Queensland (50286) top-up fellowship.

Conflict of Interest

The authors declare that they have no conflict of interest.

Ethics approval

Ethical approval was granted by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/18/QCHQ/44186); Queensland University of Technology's University Human Research Ethics Committee (1800001262) and the University of Queensland Human Research Ethics Committee (2018002613).

Consent to participate

Signed consent was obtained from all potential participants.

Consent for publication

Not applicable

Availability of data and material

Study data may be made available on request with the appropriate human research ethics committee approval and with the consent of the participating community as required by Australian criteria for research within First Nations communities.

Code availability

Not applicable

Author Contributions

PN, ABC, JS, KOG, MT and KB all contributed to the study conception and design. KB, AMB and GR were responsible for data collection and KB and LJ undertook the analysis. The manuscript was drafted by KB and KOG, and ABC, JS, NWJ, MT and LJ contributed to the content and revision of the manuscript. All authors read and approved the final version.

Acknowledgements

We would like to thank the many families and health professionals who generously provided their time and feedback on this study

9 DISCUSSION

9.1 INTRODUCTION

The health challenges experienced by many First Nations Australians are well documented.¹¹⁶ Yet there remain considerable gaps in knowledge and services to support and progress the health and wellbeing of First Nations Australians, particularly in the area of oral health and health metrics, such as oral health quality of life measurement tools and other wellbeing tools.^{4, 9, 14} The aim of this thesis was to address some of the gaps in oral health knowledge and establish a generic HR-QoL measurement tool that would be appropriate and acceptable for use with First Nations Australian children, creating a foundation for future, culturally specific tools. Three studies were used to facilitate this aim. These studies were guided by specific research questions that were outlined in Chapter 3. Chapters 4 to 8 have described the study topics and the findings of the studies as they have been prepared for publication and peer review. This final chapter summarises the findings of the three studies as they relate to each specific research question, discussing the implications of the findings in the context of other research and recommendations for future research. The strength and limitations of each study are also described and discussed in the context of the overall thesis.

9.2 SUMMARY OF FINDINGS, IMPLICATIONS AND FUTURE RESEARCH

9.2.1 STUDY 1

This study aimed to address the lack of contemporary data on the prevalence of dental caries experienced by First Nations Australian children aged less than five years, as well as explore what risk factors and indicators were prevalent for children living in an urban location. The study included 180 First Nations Australian children aged zero to five years with a mean age of 18.4 months. Of those children, 111 children received a dental examination and were evaluated for the presence of decayed, missing and filled teeth (dmft).

Research question: *Among First Nations Australian children aged less than five years living in an urban area in Australia:*

- a) *What is the prevalence of decayed, missing and filled teeth (dmft) due to dental caries?*

The 111 children evaluated for caries had a mean age of 35 months and 12.6% of children had dmft experience. The mean dmft = 3.0 teeth (standard deviation (SD) 1.7).

The prevalence of caries experienced by children in this study was considerably lower than has been previously reported for First Nations Australian preschool aged children living in a similar geographic area as our study. Prior to our study, the only available dental caries data on young, First Nations Australian children living in urban Queensland were from 1996 and indicated that 78% of preschool aged children living in Brisbane had decay experience and a mean dmft of 3.8 (SD, 3.7).³⁶⁷ Since our findings were published, there have been data published on First Nations Australian children of a similar age in other areas of Australia: in 2011 in South Australia, 22% of First Nations Australian children aged two years had caries experience and experienced a mean of 0.75 decayed teeth.⁶⁰ The overall prevalence increased when the same children were screened for caries at three years of age. However, the prevalence of caries (29.7%) was lower in the cohort of children that received an early intervention as part of the study, compared with children who received a delayed intervention (37.7%).⁶⁰ The prevalence was also slightly lower for those children living in metropolitan areas of South Australia compared to non-metropolitan areas (19% vs 20% respectively).⁶⁰ Indeed, other studies report a higher prevalence of caries in non-urban areas generally.⁴ Most recently, in the Northern Territory 43% of First Nations Australian children aged one to three years had caries experience in 2017; a reduction of 30% since 2009 which was attributed to a targeted federal government oral health initiative.⁵⁵ The program focused on providing ancillary funding to the state-based oral health program and provided

both preventative (application of full-mouth fluoride varnish and fissure sealants) and clinical (tooth extractions, diagnostics, restorations and examinations) services.⁵⁵ The initiative has not been made available in Queensland.

While our study indicates that the prevalence of dental caries is lower compared to other First Nations Australian children, compared to Australian children overall, the prevalence was slightly higher. In 2008 in a comparable socio-economic area, Logan, south of Brisbane, 9% of Australian children aged zero to 36 months had caries (mean dmft 2.3, SD 1.5).²⁷⁵ This population did receive contact from an oral health therapist every six months as part of the study which may have influenced the oral health behaviours of the parents and children and contributed to the lower prevalence of caries.

It is important to consider the factors that may influence how the prevalence of caries is reported. Although the prevalence of caries in our study was relatively low compared to past evaluations, it may have been higher with a more sensitive measure which considers all carious lesions as well as decay. The mean dmft was higher than what has been found for other Australian children of a similar age which suggests that the caries in our population is more severe than other Australian populations.^{52, 275, 368} Previous national data⁴² indicated that First Nations Australian children remain disproportionately burdened compared to their non-Indigenous counterparts when it comes to their oral health and our findings demonstrate that this remains the case.

The new data from our study have important implications in terms of planning for health services, health promotion and health education at both a state and national level. This is because there remains limited data on preschool aged children and there appears to be no plan to collect data at a state or national level.⁴² In their latest report on the health of Australian children, the Australian Institute of Health

and Welfare acknowledged that there have been no new nationally representative data since the completion of the Child Dental Health Surveys in 2012–2014 and thus it is not possible to monitor changes in the oral health of Australian children at present.⁴² At the time of writing, our data are the only current insight we have into how preschool aged children in urban Queensland are faring in terms of their oral health. Although, data from the National Child Oral Health Study 2012–14 suggested that the overall oral health of Australian children had been improving from a decline in the early 2000s, hospitalisation data³⁶⁹ and smaller oral health investigations,¹¹⁴ including the study completed as part of this thesis, illustrate that Australian children continue to be affected by this avoidable disease.

Future research should be directed at understanding whether the prevalence of this disease in the preschool aged population is increasing and whether our findings are representative of other urban First Nations Australian populations. In addition to the prevalence of caries, it would be useful to understand which children are experiencing the greatest burden of caries and what factors are attributed to that severity. This would require a more comprehensive clinical examination which was outside the scope of this study. The limitations of this study and other small-scale studies highlight the need for a uniform clinical data collection process for young children in both public and private services.³⁷⁰ In progressing child oral health outcomes, it is recommended that policy-makers consider other avenues for standardised data collection. These could include options such as mHealth technologies,³⁷⁰ whereby dmft and other clinical data could be collected via smart phone and/or mobile application (apps) in a standardised fashion. Collection of oral health data via smart phone application has been successfully trialled in Denmark,³⁷⁰ where both dentists and patients indicated that the methodology was user-friendly. Other studies³⁷¹ indicate that there is even scope for clinical data to be collected remotely, with apps being developed to detect caries using mobile devices. This progress and innovation in population oral health is promising and should be trialled in Australia.

Research question: *Among First Nations Australian children aged less than five years living in an urban area in Australia:*

b) *What known risk factors and risk indicators are prevalent?*

As reported in section 2.3, there are number of risk factors and risk indicators for caries and poor oral health in general. Our study investigated a wide range of potential factors which could contribute to poor oral health and caries. In addition to the population being significantly economically disadvantaged, we found that there were several risk indicators. These included low levels of formal education for parents, low levels of dental attendance for families, and high levels of self-reported dmft for parents. The risk factors and indicators are reported in detail in Chapter 4.

In summation of the study overall, we found that parents and carers value oral health, but there is room for improvement in terms of education, dental behaviours for older children and accessing services. The findings indicate that parents and carers are practising regular personal oral health behaviours such as brushing with toothpaste and avoiding sugary foods during infancy. However, dental attendance for the population was not optimum and over half of our parents indicated they had not received education on child oral health. Lower levels of oral health education may be responsible for the unfavourable dietary patterns as children aged, given parents and carers seem to be aware that discretionary foods are not ideal for infants.

These findings provide valuable insight into what areas of oral health need further promotion and focus from a research perspective. At present, the current model of care (predominantly private, fee for service) does not appear to be sufficiently engaging families in our study area to access preventative dental services themselves, thus limiting opportunities for ongoing oral health education. According to the national oral health plan¹¹⁵ and the 2019 Australian Medical

Association (AMA) 'report card' on First Nations Australian oral health,³⁷² insufficient data on the services and programs we have remains one of the largest barriers to achieving equitable oral health outcomes for First Nations Australians.

Our first study did not aim to understand why participants were not attending dental services. However, our findings in Study 2 provided some indication that cost is a core issue for our participants. While cost is a notable barrier, there are service options for First Nations Australian people in addition to costly private services, and a priority of future research needs to be in understanding how these services are being utilised. In addition to public and private health services, Aboriginal Community Controlled Health Services (ACCHS) provide dental services in primary health care settings.³⁷² However, these services are not standardised (i.e. not all sites provide the same services or have the same capacity) and there is inadequate evaluation of the services in South East Queensland to report whether or not they are effective in supporting their respective service area.³⁷²

An evaluation conducted in New South Wales of oral health services provided by ACCHS found that although these services are well-received and well-attended, the services are overburdened, with a backlog of cases and insufficient funding to appropriately support patients in a timely manner.¹⁸⁶ The sentiment is shared in Western Australia. An investigation into First Nations Australian perspectives of oral health services found that participants felt there were not enough services to meet demand.⁶⁵ Moving forward we need to understand whether these experiences are mirrored in South East Queensland generally and, specifically, what aspects of the services need to be adjusted or developed to improve attendance and engagement. This should include establishing the number of services within the geographic area of South East Queensland, the service capacity with respect to the corresponding population, the distance between service providers, the number of patrons, and types of services that are being engaged. Once a comprehensive service evaluation

is conducted, we would be in a better position to make more tailored recommendations for each community and/or geographic area.

In addition to dental services, another avenue for oral health education is via health promotion in the wider lived environment. An evaluation of Australia's oral health promotion has demonstrated that there is limited promotion of oral health messages across all mediums (television, magazines, and other media),³²⁵ leaving families to work out for themselves what is appropriate. Parents in our study seemed to be cognisant of which foods were unfavourable from a nutritional standpoint for their infants, avoiding SSB and discretionary foods for children that had not started teething, but consumption increased in those children with teeth and who were drinking from a cup. As outlined in section 2.3, a person's diet, particularly the regular consumption of discretionary foods that are high in sugar and fermentable carbohydrates, can contribute to the development and progress of caries, yet these foods are regularly advertised to children in targeted media campaigns. Although there are some restrictions in advertising as a result of concerns regarding obesity,³⁷³ our study suggests that the effect of diet on oral health is flying under the radar. Studies³⁷³ that evaluate parent and child media literacy demonstrate that many families are unaware of the messaging they are exposed to and unable to critically analyse how the messaging may be informing their behaviours. Research^{169, 280, 374} suggests that there is still misunderstanding regarding the cariogenic potential of fruit juice and parents report that there continues to be mixed messages from the media and health professionals about what is healthy and what is not for their child.^{169, 280, 374} Indeed, in Study 2 participants indicated that child oral health information was insufficient and confusing, and it was often up to the parents to find information themselves.

Broadly, policymakers should focus on further refining food advertising to children, as well as include oral health more liberally in available nutrition messaging. Research is needed to better understand how this might be done in a culturally

relevant and appropriate manner that reaches urban First Nations families. Australia's leading health organisations⁸⁹ such as the Australian Medical Association, Australian Dental Association and Cancer Council, have argued that a sugar tax would be the most effective way of addressing SSB consumption population wide.⁸⁹ Another option is increased utilisation of 'drinking water' promotion programs. Programs that encourage children to drink more water have been trialled in education settings with school aged children and have been shown to be effective in reducing SSB consumption.^{375, 376} However, there is a dearth of evidence for programs for preschool aged children, and programs outside of an education setting for the preschool age-group.^{375, 377} Nonetheless, targeted messaging is recommended with respect to SSB and should prioritise the consumption of fluoridated water as the drink of choice for young children.³⁷⁷

Research question: Among First Nations Australian children aged less than five years living in an urban area in Australia:

- c) *What socio-cultural, environmental and physiological risk factors and risk indicators are associated with having dmft?*

Unfortunately, we were unable answer this question. Due to the small sample size of our study, we were not able to facilitate a stable regression model. Exploring the potential factors associated with dmft in a young, urban First Nations Australian population needs to be a priority. In addition to the insufficient data available for young, urban children, other researchers⁴ have acknowledged that future research must go beyond reporting the prevalence of caries, and look to find potential relationships between caries and the environment and possible solutions for oral disease within the population. Colonisation and transgenerational inequities have negatively impacted the overall health of First Nations people and these cultural factors have yet to be explored in an oral health context. Future research in this population should prioritise a larger sample size and a comprehensive investigation

of potential factors, including socio-cultural, environmental and physiological factors.

9.2.2 STUDY 2

This study aimed to understand, from the perspective of parents and carers of urban First Nations children, how child oral health was impacting on families. Prior to starting this study there was concern in the community about poor child oral health. However, Study 1 did not provide the opportunity to hear from parents and carers in their own voice. Using narrative enquiry this study engaged parents and carers to share their thoughts and experiences related to child oral health.

Research question:

- a) *According to parents and carers that have cared for First Nations Australian children aged less than five years living in an urban area of Australia, what are the impacts of child oral health on families?*

The impacts of child oral health on families were complex and related to their emotional wellbeing, physical wellbeing and financial wellbeing. The major findings of this study were the ways in which oral health affects families and an understanding of the environment in which families are trying to support child oral health.

Like other studies,^{374, 378} our findings suggest that parents care about their child's oral health, but for some families supporting children's oral health can be stressful, challenging and costly. Within the home, children can be reluctant to participate in desired oral health behaviours such as regular brushing and the conflict can lead to stress and/or apathy during oral health routines. These experiences can be further

complicated by the family dynamic (i.e. whether the child has shared care) and/or whether the child has an illness or behavioural condition which requires additional effort from the parents to facilitate healthy oral habits. Mothers are overwhelmed by competing priorities and child oral health is one of many aspects of family life they are trying to juggle.

There is also the notion that the deciduous dentition of children is less of a priority than their permanent dentition, which means that oral health for preschool aged children can sometimes be overlooked. These findings align with other qualitative studies which investigate parent experiences of oral health in other populations including in Australia.^{374, 378, 379} As has been suggested with respect to Study 1, our focus moving forward needs to be on, not only targeting young children, but the family holistically. The relationship between parent and child oral health is well documented¹⁰⁷ and those parents with lower levels of oral health knowledge and self-efficacy are more likely to have children with higher levels of caries.^{301, 380} Our focus needs to be in finding ways to address the social and economic inequities experienced by many First Nations Australian families. Within an oral health context, this should begin with finding a way to bridge oral health into primary care services. Preventative steps such as education, screening and fluoride application can all be delivered within a primary care service, but for that to happen, changes need to be made at a policy level.^{40, 324} Creating a primary care environment that embraces oral health as any other health condition and engaging specialised care when required.

Outside of the home, our study found that there were mixed feelings regarding dental services for children. Although many parents indicated that they utilised, and were happy with, the school dental service and the child dental benefits scheme (a government dental subsidy),²⁷⁷ some felt that the services were insufficient for their needs. This was highlighted if their child needed additional oral health attention outside the coverage of the school and subsidised services which only cover limited

services, such as cleaning and radiography.²⁷⁷ In Queensland, if children require orthodontics or other specialised oral health care, parents can either pay for private services, or if eligible, navigate the public specialist dental services.²⁷⁷ According to the waitlist data for January 2020³⁸¹ for the nearest specialist oral health service to the study location, Caboolture, only 33% of patients with a 'Priority 1' condition were seen within the recommended waiting time. A 'Priority 1' condition is defined as an oral health issue that has the *'potential to deteriorate quickly to the point that it may become a medical emergency, or failure to provide dental care would delay the commencement or progress of urgent medical treatment.'*³⁸² Although the recommended treatment time is within one month, according to the waitlist, 15 people as at January 2020 had been waiting for four to five months. Moreover, for less 'serious' conditions, which are likely to include aesthetic measures such as braces, the wait times were considerably longer. 'Priority 3' conditions had a recommended treatment window of 12 months and yet there were 234 people that had been waiting for 25 to 30 months. Only 49% of people had been seen within the recommended time.³⁸¹

These figures provide context to the feelings of stress and anxiety that were expressed by our participants related to their child's oral health and available services. Unable to pay for private services to expedite their child's treatment needs, urban First Nations families are facing the consequences of the current policy structure. Children missing out on health care and a sense of helplessness from parents is not something that is typically associated with a wealthy nation such as Australia and yet this study and others^{9, 11, 187} indicate that oral health has consequences for both child and parent quality of life. At present, there are no culturally validated psychometric tools that are available to measure the impacts of oral health on First Nations Australians and as such the findings of this study provide valuable insight on the topic of oral HR-QoL.

Understanding how child oral health is experienced by families is important, not only for dental practitioners, but also for wider primary care professionals. Clinicians and health workers involved in family care need to know where to focus their efforts in supporting families with their oral health care. Prior research has suggested that First Nations Health Workers are prime candidates for delivering oral health education and dental screening.¹⁸⁶ However, there is the need for more oral health support at an organisation level, as well as culturally specific screening tools to support health workers in evaluating potential patients.¹⁸⁶ It is remiss to think that the circumstances of our participants are unique. There are potentially numerous children in South East Queensland missing out on essential oral health interventions and yet we are challenged in identifying who those children might be without appropriate screening tools. The findings of this study provide a greater understanding of some of the issues that need to be addressed in service provision as well as potential concepts to be included in future health metrics and screening tools.

An unexpected outcome of engaging mothers to discuss their child's oral health was the sharing of personal experiences unrelated to their child, but to the participants themselves. The flexible qualitative approach utilised in Study 2 allowed for the data collection process to be intuitive and follow the participants' narrative. This resulted in ample discussion of child oral health which were current issues for families, and in participants reflecting on their own upbringing in relation to oral health and how they had experienced oral health and disease as women. The study found that oral health was a problem for women as they aged, regardless of their prior environment and oral health experiences. Pregnancy, in particular caused a lot of issues around oral health and like other studies,³⁸³ women in our study accepted that this was normal and inevitable. While oral health can be affected by pregnancy due to physiological changes, women's oral health does not need to suffer.³⁸⁴ The importance of oral health in maternal care is beginning to gain traction³⁸⁴ and this study provides further evidence that the inclusion of oral health education and services to urban First Nations mothers would likely be well-received.

The participants also shared valuable insight into where oral health promotion could best be utilised. As other studies⁶³ have demonstrated, the teenage years are particularly challenging for upholding oral health behaviours and participants shared that they felt that they were largely apathetic to their oral health in their teenage years. They felt that more of the oral health promotion they experienced in their early childhood would be of benefit today. These findings are important for informing future health promotion campaigns. As mentioned previously, there is evidence that oral health campaigns have decreased substantially³⁰³ and our study suggests health consumers have noticed the decline and are advocating more widespread education in the media.

Too often the disparity between First Nations and non-Indigenous Australians is reported without context and First Nations Australians are unable to share their side of the story. The findings of this study demonstrate that while there are multiple barriers to be addressed, First Nations Australian women have clear ideas about what their challenges are and how they could potentially be addressed. As has been evidenced previously in other areas of health, programs and interventions that are developed and facilitated in collaboration with First Nations Australians are the most effective.³⁸⁵ A direction for future research would be to work with First Nations Australian families to further define the problems they are facing in relation to oral health for themselves and their children and engage their expertise in finding potential solutions.

9.2.3 Study 3 – Phase 1

The first phase of Study 3 was concerned with establishing the concepts that should be included in a culturally specific parent-proxy HR-QoL tool. Qualitative methods were used to document the perceptions of 26 First Nations parents and carers of children aged zero to 18 years with a chronic condition.

Research question:

- a) *According to First Nations Australian parents and carers of children aged less than 18 years with a chronic illness, what concepts are representative of HR-QoL for First Nations Australian children?*

According to First Nations Australian parents and carers, their child's HR-QoL is multifaceted. It includes not only physical, social and emotional components, but factors that are culturally specific as well. Our study found that in addition to classic concepts which denote health (such as being able to go to school, be active, sleep, eat and be social), being able to be connected to family and culture was also highly valued in the same context. Family and culture are well established in the literature describing how First Nations Australian health is defined.¹⁶ In addition to defining health specifically, a number of other concepts were raised in relation to HR-QoL. These included having knowledge, having support and communication and interaction with the health system.

Having knowledge was explained in terms of having information and feelings of self-efficacy. Parents explained the importance of knowing what was going on with their child's health status and how to manage their health issues. The ability to pass this information on to their child, family and community was also valued. The absence of these abilities had consequences for HR-QoL, in that it contributed to stress and could keep children isolated from partaking in their everyday activities. Autonomy and empowerment have previously been described as domains of First Nations Australians' wellbeing and our findings further support the importance of these concepts.¹⁶

Having support was also found to be a key component of HR-QoL. Support relates to both the emotional and practical support of the child and parent. Support is

necessary not only for emotional wellbeing, but to facilitate a balanced and engaged life outside of illness. Parents described the importance of having a reprieve from caring duties so that they could participate in paid work and provide opportunities for their child which affected their HR-QoL both directly and indirectly. Likewise, support for children from friends, family and community had implications for HR-QoL, as it pertained to the child's social capital and levels of connection with the outside world. Like our study, other studies^{341, 348} have found support to be a protective factor for children and parents when dealing with chronic illness.

Communication was described with respect to the health system. Being heard, being believed and being taken seriously by health professionals had implications for the child's health outcomes, as well as parent and child emotional wellbeing. Prior research³³⁹ has found that communication is a central to the healthcare experiences of First Nations Australians. Like our study found, this is because First Nations Australians report a continued communication gap with health services.³⁵²

In addition to the aforementioned concepts, a major finding of this study is the emphasis on the health system as a key contributor to the HR-QoL of children. Given the historical challenges and present prejudice experienced by families, participants described that child HR-QoL was influenced by their health care experiences and as such, an essential component when defining HR-QoL. Parents explained how they felt that health professionals could have pre-conceived notions related to their First Nations identity and this could affect their timely and equitable health care. These findings are in accordance with other studies which suggest that there remain inequities in the delivery of health care for First Nations Australians.^{339, 352}

The concepts uncovered in this study have been documented in other studies collated in a systematic review published in 2019¹⁶ which investigate the domains of health and wellbeing for First Nations Australians. However, few of these studies

delineate whether these concepts are relevant to children or are reflective of HR-QoL specifically. Our study builds on this previous research, providing a parent-proxy and HR-QoL perspective. The findings of our study contribute useful data to this growing field and can assist clinicians and other health stakeholders in understanding what is important to First Nations Australians in terms of their HR-QoL. It will also inform future development of psychometric health and wellbeing tools. The perceptions of First Nations Australian children will need to be prioritised in order to fully conceptualise HR-QoL for children. Yet, our study provides a useful starting point. As has been mentioned previously, there are occasions when children are either too young or unwell to participate in HR-QoL measures and proxy measures serve a purpose.²⁵⁹ Likewise, the concepts for HR-QoL in this study are likely not reflective of all First Nations Australians. A direction for future research would be to establish if perceptions differ between urban, rural and remote populations and different language groups.

Research question:

- b) According to professionals in the field of First Nations Australian child health, what concepts are representative of HR-QoL for First Nations Australian children for inclusion in a draft survey tool on HR-QoL?*

Upon establishing the concepts for HR-QoL, questions reflective of the concepts were placed in a draft tool. This tool was then reviewed by professionals for their opinion. This process found that conceptually the professionals were in agreement with the concepts put forward. Evaluation and discrimination of the draft questions was primarily based on wording of questions to represent each concept. The ranking process effectively reduced the number of questions from 52 to 39.

Research question:

- c) *According to First Nations Australian parents and carers of children aged <13 years, is the formulation of a draft survey tool on HR-QoL applicable and appropriate to be used with a wider population?*

Using the data collected from the qualitative investigation and expert panel, a novel HR-QoL tool was created and prepared for pilot testing with 12 First Nations Australians parents/carers of children with a chronic condition. The tool was found to be both acceptable and appropriate, with only minor formatting changes recommended prior to validation.

9.2.4 STUDY 3 – PHASE 2

The psychometric properties addressed in the following questions are used to establish the reliability and validity of the novel tool. As discussed in section 2.5.2, these principles are addressed by determining a) whether the items we have developed group together into factors reflective of HR-QoL domains, b & c) by examining whether all of the items we chose measure the same construct and do so consistently, d) whether the tool can distinguish a difference between groups, e) whether the tool is relatable to other similar measures and f) whether it is sufficiently different from measures that are unrelated.³⁵⁶

Research question: *In a population of parents and carers of First Nations Australian children aged <13 years:*

- a) *What are the latent factors of a draft HR-QoL survey tool?*

Three latent factors were revealed which reflected themes raised during item creation: Quality of life (QOL), Patient Experience (PE) and Patient Support (PS). The

subscale correlations were weak to moderate QoL and PE ($r=0.359$, $p<0.001$), QoL and PS ($r=0.406$, $p<0.001$) and PS and PE ($r=0.433$, $p<0.001$), indicating low overlap between factors.

Research question:

b) Does the draft HR-QoL survey tool demonstrate internal consistency?

Yes. The novel HR-QoL tool demonstrated good internal scale reliability, with Cronbach alpha coefficients of >0.7 (QOL, 0.808; PE, 0.880; PS, 0.768).

Research question:

c) Does the draft HR-QoL survey tool demonstrate test-retest reliability?

Yes. Good reliability was observed for the overall scale ($r=0.753$; 95%CI: 0.593-0.856). However, subscale reliability varied: QOL ($r=0.663$; 95%CI:0.462-0.799), PE ($r=0.744$, 95%CI:0.579) and PS (0.794; 95%CI:0.655-0.881). The QOL domain did not show the desired $r\geq 0.7$. We hypothesise that the scope of health conditions and health circumstances in the whole-of-hospital setting likely influenced our findings. For example, one child may test at baseline with a broken leg and four weeks later, their HR-QoL may have drastically improved because they have had treatment. Similarly, a child may test positively at baseline, but then have a diagnosis four weeks later that changes their proxy perceptions. The tool will need to be evaluated within a hospital sub-setting, such as a specific clinic or disease group.

Research question:

d) Does the draft HR-QoL survey tool demonstrate known-group validity?

No. The scale was not able to demonstrate a statistical difference between children with and without a chronic health condition but could discriminate between those that did not have a condition and those who did not know if they had one or not. As we found with the test-retest reliability, we suspect that the diversity of participants with respect to their child's health status and/or chronic condition may have affected these results. This is because there is so much variation in the conditions when participants are recruited from the hospital generally. For example, we did not determine the type or severity of the child's condition, only if they had one or not. Children were recruited from a variety of clinics and hospital wards and as such would have been experiencing different impacts to their HR-QoL whether or not they had a chronic condition. Evaluation of the questionnaire will need to be conducted with a more homogenous and disease specific sample. This would also allow for the collection of a Minimally Important Difference (MID) score. MID refers to the change in the survey score which is important to either the patient or clinician and could indicate a change in the patient's care based on the score.³⁸⁶ The results of the bivariate and multivariable regression models for total FirstNations-CQoL can be viewed in Appendix C.

Research question:

e) Does the draft HR-QoL survey tool demonstrate convergent validity?

Yes. The novel HR-QoL was moderately to strongly correlated to the PedsQL, with Pearson's coefficients of $r=0.681$ for ages two to four years and $r=0.651$ for ages five to 12 years. Likewise, the Kessler Psychological Distress scale ($r=-.513$) and independent assessment of HR-QoL by parents was moderately correlated ($r=.480$) to the novel HR-QoL tool, suggesting acceptable convergent validity across the established HR-QoL and relative comparison measures.

Research question:

f) Does the draft HR-QoL survey tool demonstrate divergent validity?

No. Divergent validity was not demonstrated against the Spence Anxiety Scales, the novel HR-QoL tool being moderately correlated to both the preschool ($r=-.466$) and school age ($r=-.535$) scales. As has been discussed in Chapter 8, section 8.5, the PE and PS domains of the novel tool likely include too many similar concepts to the anxiety measure. The domains focus on values of information, support and service; and anxiety is a potential outcome if these values are not met. Future research should consider other comparison measures. However, cultural and age appropriate proxy measures for comparison remain limited and there is a dearth of psychometric tools validated for First Nations Australians generally.³⁸⁷

Additional comments:

In answering these questions, we have been able to determine that the draft tool we have created is psychometrically sound for further evaluation. During both the pilot and validation process, the tool was well-received by participants and the psychometric results indicate that the tool is comparable to established HR-QoL measures. The next steps will be to evaluate the tool within a larger, disease specific sample.

Further, in conducting future HR-QoL research, the importance of this study extends past the psychometrics and we can take much from the process itself. Upon reflection of this study, I believe it is important to recognise some of the more nuanced findings that are specific to the research process I experienced. These thoughts are my own and are not necessarily relative to any empirical evidence, but I believe useful, nonetheless.

- a) Psychometrics are not necessarily 'in demand' from the First Nations people that I engaged with. As in, there was some perplexity at why we needed to create a survey to measure HR-QoL. Yet, while the concept of psychometric measurement was not well-received or necessarily understood by everyone, there seemed to be a consensus that providing feedback to the health system was a good thing, particularly on the topic of services and experiences. Providing additional space for participants to contribute their thoughts should be considered.
- b) Those in critical care situations are likely over researched and/or over-engaged (given the numerous health specialists required on cases) and conducting an independent validation study amongst other studies happening is potentially too much for families to cope with. Future research should consider 'piggy-backing' onto other studies already happening, or reconsider whether the population group is necessary for recruitment.
- c) By that same token, future research should consider the length of the surveys being delivered and critically assess what data are necessary for collection. Many participants were put off by the length of the survey and the associated comparison measures. Trimming of the whole survey package should be a priority during further development stages.
- d) In our study sample, there was a preference for an online survey option compared to paper-based forms. Consideration should be given to how surveys can be placed online and formatted for mobile phones. Participants responded well to personalised text messaging from a mobile phone and the ability to click on a survey link within the text.

- e) The use of a participant ID to conduct anonymous surveys was also well accepted and future research should think critically about whether the survey could be responded to anonymously. This is because 'e-consent' or consent given by the act of participating was desired. Many participants would have liked to share the survey with friends and/or family, but this was hampered by the need for a physical signature. The process of getting the paper to the potential participant and them sending via scanning or post, significantly limited this engagement.
- f) There was also a preference for conducting the survey package at home. This was likely because of the length of the survey (and challenges in completing while also supervising a child) but may also have to do with the content. Although I was not part of the health or treatment staff, I was cognisant that participants may have felt uncomfortable answering questions about HR-QoL in person. Although no evaluation was undertaken to determine if there was difference in answers between those who completed the survey at home compared to those in person, it was noted that there were very little missing data generally. I believe this is possibly due to the high proportion of participants who completed online surveys.

9.2.5 DISSEMINATION

The findings of these studies continue to be shared both formally and informally. For Study 1 and 2, participants were made aware of the published findings through their best contact details. Since publication, findings from Study 1 and 2 have been utilised to inform policy documents by the Queensland Aboriginal and Islander Health Council (submission to Queensland Health - Aboriginal and Torres Strait Islander Oral Health Care in Queensland, 2020) and the Australian Medical Association (2019 Report Card on Indigenous Health). The Findings of Study 3 are still with publishers and will be made available to the Queensland Children's

Hospital for dissemination to families and clinicians. A list of formal presentations regarding all studies can be viewed on page xvi.

9.3 STRENGTHS AND LIMITATIONS

The strengths and limitations specific to each study are raised in the respective chapters. However, there remain several strengths and limitations that relate to the thesis project more broadly, as well as limitations that could not be expanded on because of word limitations within publications.

An overall strength of this thesis project is the focus on urban First Nations Australians. Despite the majority of First Nations Australians living in urban areas, much of the health research, particularly oral health research, is undertaken in rural and remote areas.^{3,4} This project has also had a high level of engagement from First Nations Australian colleagues and participants. For each study conducted, First Nations Australian stakeholders have provided input into the study protocol and provided cultural governance during facilitation. This type of cultural engagement and governance is an essential component of conducting respectful research within a First Nations Australian health setting.³⁸⁸

Likewise, the mixed-methods approach to the overall thesis project allowed for greater incorporation of First Nations knowledge and perspectives. For example, in facilitating Study 2, Dr Kerry Hall had established relationships with many of the participants from a prior study and so there was a familiarity amongst the cohort. Using yarning sessions for data collection provided the opportunity for informal discourse and topics were able to be guided by participants without the pressure of a formal interview dynamic. This collaboration was carried on into the analysis where input into interpretation of the data was received from two participants. This step is important for the rigour of qualitative data³⁸⁹, but also for addressing the participation of a non-Indigenous researcher in the project.²³⁷

In Study 3 we were able to engage with participants from a number of different locations, gaining different environmental and health perspectives. We had representation from parents/carers who were from urban, rural and remote areas. The participants also had children who had a range of chronic conditions, with varying degrees of severity. This diversity extends to the second phase of the study. Recruiting from a large tertiary hospital in the capital of Queensland, participants were from areas all around Brisbane, northern New South Wales and regional Queensland. Likewise, the children of participants were attending hospital for varying reasons and were relatively even in their age ranges, which ranged zero to 12 years. Engaging with such a varied group of participants was made possible by the continued support of the study by First Nations Australian stakeholders, such as the First Nations Liaison Officers, who are the main social support for families in the Queensland Children's Hospital.

Limitations

While I sought and received cultural guidance over the duration of this thesis project and aimed to take a strengths-based approach, I feel it is important to recognise the limitations I have as a white researcher with a colonial heritage in a First Nations Australian health space. These limitations extend past practical limitations of not being a part of the community I am researching, to the effect my participation has on data collection and data interpretation. My participation may have influenced the comfort of the participants I screened and recruited, affecting the data they contributed. Further, the way their data was interpreted may have been affected by my own unconscious bias and/or Western ways of knowing.¹⁰

Another overall limitation is the small sample size across all three studies. In the first study, we were unable to process a sound logistical model because of our limited sample and this meant that we could not examine any correlations of the data

collected as planned. Given the data were analysed retrospectively, there was also no opportunity to add to our sample. Qualitative studies typically have smaller sample sizes.³⁹⁰ However, outside the time constraints of a PhD it would have been preferable to engage with additional participants, particularly from other geographical areas which may have brought different perspectives. The qualitative investigation in Study 3 did include participants from urban, rural and remote locations, but these were not evenly distributed, nor were we able to recruit from other language groups. The validation component of Study 3 would have also benefitted from a larger sample. While there are no established guidelines for testing validity and sample sizes, there are general recommendations and precedence from other studies.³⁹¹ Based on other validation procedures, it is recommended that there be a minimum of five participants per question.³⁹¹ Given we planned on recruiting children with and without a chronic illness, we proposed a ratio of six participants to one question. We had anticipated that our survey would include no more than 21 questions which would set our sample at 126, and our target sample at 163 (allowing for 20% attrition). However, the item creation process and subsequent screening process by experts and participants (in the pilot phase) resulted in the survey having 39 questions. This was an unexpected outcome, but rather than reducing the questions at the outset to match the sample, we made the decision to reduce the questions at the completion of the study; recruiting as many participants as possible in the time available and thus having a better understanding of which questions in the draft survey were most appropriate with the wider population. In the end, we were able to recruit 163 participants which increased our ratio to over 7:1, having reduced our survey questions after the data were collected and correlations considered.

The limitations of Study 1 included the reliance on self-reported data, much of which was retrospective. A number of biases can result from this approach.³⁹² Recall bias is a notorious challenge for dietary data in particular and one method of reducing this is to have shorter recall periods.³⁹² In this study, participants were not asked to recall what their child's past food and drink consumption was, but to make

a judgement about how frequently on a daily or weekly basis their child would consume a particular food/drink item. It is possible that participants may have over or under-estimated their child's consumption. With respect to the oral health behaviour questions, a limitation of our study was the description of tooth-brushing. Although the recommendations for tooth-brushing is twice a day,¹⁶⁰ we were unable to distinguish if participants were brushing once or twice a day because of the way the question was framed. In future, it is recommended that participants have the option to indicate the number of times they are brushing per day.

Another limitation of Study 1 was that the study population were predominantly recruited from the one site which may have narrowed the generalisability of the sample to other populations. Likewise, given the participants were attending a primary health care clinic and engaged with health services, the findings may not be reflective of populations in other areas and/or those not attending culturally specific health care. The same limitation extends to Study 2; many of the participants were recruited from the primary health care clinic and had participated in health research previously. The data collection methods of Study 2 are particularly vulnerable to social desirability bias as participants identities are not hidden from the researcher or other participants. Social desirability bias refers to the way data may be affected given participants interest in approval or being socially desirable.³⁹² While we felt that being somewhat familiar with the participants was to the benefit of the study, there is the potential that participants may have felt less willing to share or judged because we were familiar to them.

The scope of Study 3 predisposes it to considerable limitations along the way. In phase 1, as previously mentioned we were limited by our sample size and uneven distribution between geographic locations. We were also limited by the fact that our sample was adults only. We were unable to gather perceptions of children within the timeframes of this thesis project and so decided to first start with a proxy tool. From age six, children have been shown to be able to report for themselves.²⁵⁹

Yet proxy measures are still considered useful. Additional investigations with children will be needed to develop age-specific tools. Likewise, the perceptions of HR-QoL collected in this study are likely not representative of all First Nations Australians and as such further research will be needed to evaluate the applicability of the survey with other populations and conduct further qualitative investigations where necessary.

Limitations of the validation process included the overall length of the draft survey and comparison measures. Although 61.9% of parents/carers who had been invited to participate did go onto complete the survey, the time and personal resources required to complete the survey may have discouraged some potential participants. For those that chose to do the paper version, although a replied envelope was provided, finding the time to complete the survey and get to a post box can be challenging. Likewise, those completing the online survey would have had to have access to the internet and a computer, or if on their phone, enough internet data to complete the survey.

Another issue with the survey is the use of comparison measures that have not been validated with First Nations Australians. This was unavoidable,¹⁴ but should be considered nonetheless. Further, given the presence of so many questions in the draft survey that were reflective of anxiety, the Spence Anxiety Scale was not an ideal choice as a discretionary measure to evaluate divergent validity. However, we were challenged to find a suitable parent-proxy measure that was both age appropriate and culturally sensitive. When considering the test-retest reliability and known-group validity, this study was limited by the diversity of the participants. This is because there was so much variation in the health conditions of the children when collected from the hospital generally.

9.4 CONCLUSION

The focus of this thesis was to address the gaps in knowledge we have for the oral health of preschool aged First Nations Australian children and their families. The research has been timely as the last indication of how the population was faring in Queensland was from over 20 years ago. Our findings are reflective of the growing concern that oral health continues to be a challenge for families in Queensland. Despite dental caries being a preventable disease, preschool aged children continue to be affected and families have limited opportunities for oral health education or intervention before children are school-aged. Continued efforts are needed to understand how best to support parents of young children as parents indicate that child oral health is affecting both their own, and their child's quality of life. To better understand the impacts of oral health on First Nations Australians, health metrics need to be validated with the population. This thesis project has brought health professionals a step closer to a culturally specific and appropriate health metric by establishing a general HR-QoL tool with First Nations Australian parents/carers. However, more work will need to be done to establish an oral health and age specific metric. Given First Nations Australians continue to experience a disproportionate burden of ill health, including oral health, culturally relevant health care should be prioritised.

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11 APPENDICES

Appendix A: Ranking documents for expert panel

INFORMATION FOR RANKING

Thank you for agreeing to provide feedback. We really value your time and expertise 😊

The questions we would like your feedback on have come from qualitative research conducted with parents/carers of Aboriginal and Torres Strait Islander children with a chronic illness in and around Brisbane, Toowoomba and Darwin.

We spoke with parents/carers and asked them what health-related quality of life meant to them and their children. As it is quite an abstract and subjective concept, we asked questions like: 'how can you tell when your child is not well?' and 'how can you tell when your child is well?' and 'what things impact your child's quality of life?'

We transcribed all of our conversations and analysed them to develop questions we thought reflected the parents/carers beliefs about health-related quality of life for their children.

We are asking you and others to provide feedback on these questions because we believe you have experience within the context of health-related quality of life of Aboriginal and Torres Strait Islander children. We would like you to help decide which questions would best reflect health-related quality of life of Aboriginal and Torres Strait Islander children.

Enclosed is a form that lists all the identified questions and a section to rank each question on their appropriateness out of 4. In your opinion we would like to know which questions to use, which to discard and perhaps which questions we have not yet identified. We have also included space in the document so that you can provide written feedback. For example, if you think the question could be worded differently or if you have any other comments/questions.

Once your review is complete, we will consider everyone's feedback and look to find a consensus. If there is not a consensus, we may ask you again for your opinion.

When we have a final list of questions, we will then take the questionnaire to a group of parents/carers to gather their feedback on the questionnaire and implement their suggestions.

If you are interested, we will provide you with the outcome of the questionnaire.

If you have any questions during the process, please feel welcome to contact Kaley Batten on

0448 949 735/3069 7572 or kaley.batten@hdr.qut.edu.au

Thank you!

Ranking Comments

Parents/carers of Aboriginal and Torres Strait Islander children under the age of 12 will be asked the following questions on behalf of their child.

In your opinion, please rank the questions from 1 to 4 ('do not use' to 'definitely use').

If you have comments, please use the sections below the topic to write. We welcome your feedback related to the question: wording, content, clarity, relevance etc. As well, if you think there is a question that we have not included, please make a suggestion.

For clarity, if referring to a question, you can use the letter(s) in the left hand column to identify the question. For example 'FF: needs rewording, such as ...'

The answering scale we are proposing is either:

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

OR

Definitely True	Mostly True	Don't Know	Mostly False	Definitely False

If you have any thoughts on the scale, please feel welcome to share.

Physical wellbeing In the past month...		Do not use	Probably Not	Probably Keep	Definitely Keep
A	My child has been sleeping through the night	1	2	3	4
B	My child has been ok to sleep alone	1	2	3	4
C	My child has been awake and alert	1	2	3	4
D	My child has had very little energy	1	2	3	4
E	My child has been eating as usual	1	2	3	4
F	My child has wanted to do their usual favourite activities (play with toys, play on iPad, watch TV etc.)	1	2	3	4
G	My child has been able to go outside and do activities when they want to	1	2	3	4
H	My child has been able to be as active as usual	1	2	3	4
I	My child has been able to do the things they enjoy	1	2	3	4

Please return to kaley.budden@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Ranking Comments

Comments:					
Social wellbeing In the past month...					
J	My child has been able to do things with playmates/friends as usual	1	2	3	4
K	My child has been able to have yarns with family as usual	1	2	3	4
L	My child has been able to spend time with family as usual	1	2	3	4
M	My child has felt left out from usual activities	1	2	3	4
Comments:					
Emotional wellbeing In the past month...					
N	My child has felt ok to leave my side	1	2	3	4
O	My child has needed more comforting than usual	1	2	3	4
P	My child has felt strong/good/deadly	1	2	3	4
Q	My child has felt connected to their culture	1	2	3	4
Comments:					

Please return to kaley.budden@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Ranking Comments

School In the past month...					
R	My child has been missing school/day care	1	2	3	4
S	My child has been missing home-work	1	2	3	4
T	My child has been missing organised activities (lessons, sports)	1	2	3	4
Comments:					
Parent knowledge In the past month...					
U	I feel like I have enough knowledge to care for my child when they are sick	1	2	3	4
V	I know how to manage when my child is sick	1	2	3	4
W	I can teach my child about their health	1	2	3	4
X	I can teach my family about my child's health needs	1	2	3	4
Comments:					

Please return to kaley.budden@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Ranking Comments

Parent capacity In the past month...					
Y	I feel like I can manage when my child is sick	1	2	3	4
Z	I feel confident about the care I can provide my child	1	2	3	4
AA	I feel comfortable providing health care to my child	1	2	3	4
BB	I know what to do if my child has a health emergency	1	2	3	4
CC	I often worry about my child's health	1	2	3	4
Comments:					
Support for parent In the past month...					
DD	My family know how to take care of my child's health	1	2	3	4
EE	There is someone I can trust to provide child care if I am away	1	2	3	4
FF	I can take a break if I need to do	1	2	3	4
GG	There is someone I can call if I am struggling	1	2	3	4

Please return to kaley.budden@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Ranking Comments

HH	I feel like I can ask for help if I need it	1	2	3	4
II	I don't trust others to care for my child	1	2	3	4
JJ	I have trouble winding down/turning off	1	2	3	4
Comments:					
Relationship with health system In the past month...					
KK	I feel like I can ask questions if I need to	1	2	3	4
LL	I feel like medical staff talk down to me	1	2	3	4
MM	I feel like medical staff do not listen to me	1	2	3	4
NN	I feel like medical staff do not take me seriously	1	2	3	4
OO	I feel like medical staff think I am stupid	1	2	3	4
PP	I feel like medical staff don't believe me	1	2	3	4
QQ	If medical staff ask me if I understand, I say yes, even if I don't	1	2	3	4
RR	I feel like I have to get angry to be heard	1	2	3	4
SS	I feel like medical staff are here to help me	1	2	3	4
TT	I feel like I am treated with respect by medical staff	1	2	3	4
UU	I feel like my culture is respected by medical staff	1	2	3	4

Please return to kaley.buten@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Ranking Comments

Comments:					
Communication with health system In the past month...					
VV	I feel like medical staff explain my child's health situations well	1	2	3	4
WW	I feel like medical staff do not give me enough information	1	2	3	4
XX	I feel like the information I get from medical staff is too hard to understand	1	2	3	4
YY	I feel like I can ask medical staff to slow down when talking	1	2	3	4
ZZ	I feel like I can ask medical staff for more information	1	2	3	4
Comments:					

Please return to kaley.buten@hdr.qut.edu.au or call/msg 0448 949 735. Thank you, Kaley

Appendix B: Participant information and consent form and draft HR-QoL tool

PARTICIPANT INFORMATION and CONSENT FORM - Parent		
	Measuring health-related quality of life in young Indigenous children Queensland Health Ethics Approval Number HREC/18/QCHQ/44186	 

RESEARCH TEAM

Dr Maree Toombs	Phone (work):07 4633 9716	Email:m.toombs@uq.edu.au
A/Prof Peter Newcombe	Phone (work):07 3346 0773	Email:newc@psy.uq.edu.au
Prof Anne Chang	Phone (work):07 3068 1111	Email:anne.chang@menzies.edu.au
Dr Jeanie Sheffield	Phone (work):07 3365 6690	Email:jeanie@psy.uq.edu.au
Ms Kaley Batten	Phone (work): 07 3069 7572	Email:kaley.batten@hdr.qut.edu.au

DESCRIPTION

THIS MEANS YOU CAN SAY NO

This information is to help you to decide whether or not you would like to take part in the study.

We will explain the study and you can ask any questions you want. If you would like to take part, we will ask for your written permission. You can also change your mind at any time and drop out of the study.

What is this project about?

When children are sick, it's important to try and make them healthy, but also improve their quality of life. We have created a questionnaire that measures a young Aboriginal and Torres Strait Islander child's health-related quality of life, which can be used in clinical and research settings to find out if treatments or interventions are working. We need to know if the questionnaire we have written is good enough to use in those settings. We will compare this new questionnaire with ones that have been used elsewhere for children. However, we think those questionnaires may not capture all aspects of health-related quality of life for Aboriginal and Torres Strait Islander children.

Why have I been asked to be in this study?

You have been asked to take part in the study because you have an Aboriginal and/or Torres Strait Islander child under the age of 13. We are asking parents/carers of children with and without health issues to be in this study to trial our questionnaire.

What does the Indigenous community think about this study?

We have consulted with Indigenous Elders and leaders in the greater Brisbane area and within the South East Queensland region, including Toowoomba. There is support for this study to improve health services.

PARTICIPATION

Who is allowed to be in this study?

We are asking parents and carers of Aboriginal and Torres Strait Islander children under 13 years old to be in this study. Participants must provide written consent.

What do I need to do in this study?

A researcher will explain the study to you. If you would like to be involved, we will ask you to sign a consent form.

Your participation will involve reading the questionnaire or listening to the questions and answering the questionnaire. The questionnaires ask about different aspects of health and well-being and the

new questionnaire has been developed following lots of yarnings with Aboriginal and Torres Strait Islander people in Queensland and Darwin. If you consent, we would like to try the questionnaire again in 4 weeks' time. This is up to you. You can choose to do it once or twice or not at all.

EXPECTED BENEFITS

Will being in this study lead to good things for me or other families?

Yes. The information we collect from you will help us to eventually develop health services that are culturally appropriate and help to improve the well-being of Indigenous children and their families.

Will I get paid to be in the study?

No, there is no payment for being in this study.

RISKS

Can I be harmed by being in the study?

No. There will be Indigenous staff to debrief with you if you are feeling uncomfortable and you can stop at any time.

If I take part in the study, will I be treated differently by my doctor?

No. Your treatment by your doctor or medical clinic will not be affected if you agree to take part or not.

Can I pull out of the study at any time?

Yes. Your decision whether or not to participate will not cause problems for any future relations with the researchers or your medical service. You are free to withdraw (pull out of the study) at any time.

PRIVACY AND CONFIDENTIALITY

What will happen with the results of the study?

We will analyse whether the questionnaire works to measure quality of life and then write a report. The results will be published in a medical journal that will tell other doctors and researchers about the study. We may also talk about the study at community meetings and conferences.

What will happen with my information?

The personal information the researchers collect about you in this study will be kept private unless we are asked to provide that information by our Human Research Ethics Committee. All of the information collected in this study will be kept in a locked cabinet and on a password protected computer at QUT indefinitely as instructed by the Queensland Government. You can ask to see your information at any time. To request this to happen, please contact study staff on the below contact information.

QUESTIONS/CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

This study has received ethical approval. You are, of course, free to discuss your participation with project staff. If you would like to speak to an officer of the University not involved in the study, you may contact QUT Ethics Office on 3138 5123 or by email at: humanethics@qut.edu.au or Childrens Health Queensland on 07 3069 7002 or CHQETHICS@health.qld.gov.au

Thank you for helping with this research project.

CONSENT FORM - Parent		
	Measuring health-related quality of life in young Indigenous children	 
Queensland Health Ethics Approval Number HREC/18/QCHQ/44186		

RESEARCH TEAM CONTACTS

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Prof Anne Chang	Phone (work): 07 3068 1111	Email: anne.chang@menzies.edu.au
Dr Jeanie Sheffield	Phone (work): 07 3365 6690	Email: jeanie@psy.uq.edu.au
Ms Kaley Butten	Phone (work): 07 3069 7572	Email: kaley.buten@hdr.qut.edu.au

STATEMENT OF CONSENT

Participant ID number: |_____| |_____| |_____| Study ID number: |_____| |_____| |_____|

You have had the Quality of Life Study explained to you by: _____

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty. Understand that you can contact the Childrens Health Queensland Research Ethics Unit on 07 3069 7002 or CHQETHICS@health.qld.gov.au or QUT on 07 3138 5123 or humanethics@qut.edu.au if you have concerns about the ethical conduct of the project.
- Understand the combined study results will be used to inform other research projects about the health and well-being of Indigenous children. The results will be published in a medical journal that will tell other doctors and researchers about the study. None of your personal details will be revealed at any time.
- Agree to participate in the project.

Name

Signature

Date

Name, signature and date of person obtaining informed consent (research assistant)

Name

Signature

Date

Health-Related Quality of life

Study ID ____/____/____

Below is a list of statements, thinking back over the past month, please answer how frequent the statement applies to your child. There are no right or wrong answers. Some questions seem to repeat or sound similar. Please try to answer every question anyway.

In the past month have you felt ...						
1	You have enough knowledge to care for your child when they are sick	Never	Almost Never	Sometimes	Often	Almost Always
2	You could teach your family about your child's health needs	Never	Almost Never	Sometimes	Often	Almost Always
3	You could manage when your child is sick	Never	Almost Never	Sometimes	Often	Almost Always
4	Confident about the care you can provide your child	Never	Almost Never	Sometimes	Often	Almost Always
5	You know what to do if your child has a health emergency	Never	Almost Never	Sometimes	Often	Almost Always
6	Worried about your child's health	Never	Almost Never	Sometimes	Often	Almost Always
7	Your family could manage your child's health if they needed to	Never	Almost Never	Sometimes	Often	Almost Always
8	There is someone you can trust to provide child care if you are away	Never	Almost Never	Sometimes	Often	Almost Always
9	You could ask medical staff questions if you needed to	Never	Almost Never	Sometimes	Often	Almost Always
10	The medical staff talk down to you	Never	Almost Never	Sometimes	Often	Almost Always
11	The medical staff listen to you	Never	Almost Never	Sometimes	Often	Almost Always
12	The medical staff take you seriously	Never	Almost Never	Sometimes	Often	Almost Always
13	The medical staff think you don't understand	Never	Almost Never	Sometimes	Often	Almost Always
14	The medical staff don't believe you	Never	Almost Never	Sometimes	Often	Almost Always
15	You could call someone if you are struggling	Never	Almost Never	Sometimes	Often	Almost Always
16	You could ask for help	Never	Almost Never	Sometimes	Often	Almost Always
17	You could trust others to care for your child's health	Never	Almost Never	Sometimes	Often	Almost Always
In the past month when dealing with health services have you...						
18	Said you understood even if you didn't	Never	Almost Never	Sometimes	Often	Almost Always
19	Felt frustrated	Never	Almost Never	Sometimes	Often	Almost Always

Health-Related Quality of life

Study ID ____/____/____

20	Felt like medical staff are there to help you	Never	Almost Never	Sometimes	Often	Almost Always
21	Felt respected by medical staff	Never	Almost Never	Sometimes	Often	Almost Always
22	Felt like your culture is respected by medical staff	Never	Almost Never	Sometimes	Often	Almost Always
23	Felt like your child's health situations were well explained	Never	Almost Never	Sometimes	Often	Almost Always
24	Felt like you had enough information	Never	Almost Never	Sometimes	Often	Almost Always
25	Felt like information from medical staff is too hard to understand	Never	Almost Never	Sometimes	Often	Almost Always
26	Felt like you could ask medical staff to slow down when talking	Never	Almost Never	Sometimes	Often	Almost Always
27	Felt like you could ask medical staff for more information	Never	Almost Never	Sometimes	Often	Almost Always
In the past month, has your child been well enough to...						
28	Do activities they enjoy	Never	Almost Never	Sometimes	Often	Almost Always
29	Do things with playmates/friends as usual	Never	Almost Never	Sometimes	Often	Almost Always
30	Spend time with family as usual	Never	Almost Never	Sometimes	Often	Almost Always
31	Go to school/day care	Never	Almost Never	Sometimes	Often	Almost Always
32	Go to sports or organised activities (ex. swim, dance)	Never	Almost Never	Sometimes	Often	Almost Always
In the past month, how often has your child...						
33	Slept through the night	Never	Almost Never	Sometimes	Often	Almost Always
34	Been ok to sleep alone	Never	Almost Never	Sometimes	Often	Almost Always
35	Had very little energy	Never	Almost Never	Sometimes	Often	Almost Always
36	Eating as normal	Never	Almost Never	Sometimes	Often	Almost Always
37	Been extra clingy	Never	Almost Never	Sometimes	Often	Almost Always
38	Felt strong/good/deadly	Never	Almost Never	Sometimes	Often	Almost Always
39	Felt connected to their culture	Never	Almost Never	Sometimes	Often	Almost Always

Appendix C: Results of bivariate and multivariable model

Total HR-QoL			Bivariate		Multivariable model	
Characteristic		N	Mean (SD)	p-value	mean (95% CI)	p-value
Chronic child status	No (R)	59	64.7 (10.6)	0.002	58.1 (53.9, 62.2)	0.011
	Yes	80	61.2 (11.9)	0.079	59.6 (56.1, 63.0)	0.446
	Unknown	13	52.4 (11.0)	0.001	50.1 (43.8, 56.4)	0.017
Indigenous status of parent/carer	Non-Indigenous (R)	49	63.3 (11.2)	0.099	58.7 (54.9, 62.4)	0.035
	Aboriginal	80	61.9 (11.3)	0.507	57.8 (54.7, 60.8)	0.633
	Torres Strait Islander	7	64.0 (6.8)	0.884	58.4 (50.4, 66.5)	0.957
	Both	9	59.3 (14.6)	0.340	59.2 (52.2, 66.1)	0.895
	Declined	7	50.7 (16.4)	0.008	45.6 (37.4, 53.7)	0.002
Do any of the children you care for have a chronic condition (long term illness?)	No (R)	78	62.4 (11.6)	0.011		
	Yes	45	58.0 (12.3)	0.039		
	No other children	29	66.1 (9.4)	0.144		
Care type at home	Both Parents (R)	87	61.4 (12.5)	0.607		
	Single parent	48	61.6 (11.6)	0.917		
	Shared Care/Relative /Carer	17	64.5 (7.0)	0.323		
Age of parent/carer	18-25 years (R)	20	64.2 (10.6)	0.482		
	26-35 years	63	62.3 (12.6)	0.523		
	36-45 years	46	59.7 (12.0)	0.155		
	46+	23	62.5 (9.6)	0.622		
Age of child	<2 years (R)	29	63.1 (11.4)	0.482	56.2 (51.3, 61.1)	0.990
	2-4 years	37	63.8 (12.6)	0.816	56.1 (51.4, 60.8)	0.965
	5-7 years	30	60.6 (11.0)	0.407	55.4 (50.6, 60.1)	0.764
	8-12 years	56	60.5 (11.6)	0.327	56.0 (52.0, 60.1)	0.955
In terms of your child's health, how	Not at all (R)	20	70.9 (10.4)	<0.001	65.4 (59.6, 71.1)	<0.001

much of worry is money for you?	A little bit	65	65.1 (8.6)	0.032	60.6 (56.8, 64.5)	0.081
	A big worry	31	57.5 (11.9)	<0.001	53.0 (48.0, 58.0)	<0.001
	A very big worry	16	56.7 (11.7)	<0.001	52.6 (46.8, 58.3)	<0.001
	A very, very big worry	20	52.6 (11.8)	<0.001	48.1 (42.8, 53.3)	<0.001
Carer chronic condition	No (R)	119	62.7 (11.9)	0.071	57.6 (54.3, 60.9)	0.119
	Yes	33	58.6 (10.7)	0.071	54.2 (49.5, 59.0)	0.119
Sex of child	Male (R)	95	61.4 (12.6)	0.605	54.7 (50.9, 58.4)	0.156
	Female	57	62.4 (10.1)	0.605	57.2 (53.1, 61.2)	
Do you maintain cultural connections at home?	No (R)	56	62.3 (10.0)	0.870		
	Yes	82	61.4 (11.8)	0.656		
	Unknown/Declined	14	62.7 (17.5)	0.912		
Level of parent/carers education	Did not finish high school (R)	25	62.8 (10.7)	0.688		
	Highschool	35	62.9 (13.7)	0.964		
	Cert/trade	38	60.3 (12.6)	0.425		
	Diploma	20	61.2 (10.1)	0.656		
	Bachelor	22	60.1 (10.2)	0.449		
	Postgrad	12	65.4 (10.6)	0.527		

R=Reference group

Appendix D: Demographic and behavioural factors eligible for inclusion into a regression model

		All Screened N=111 (%)	Dmft 'no' N=97(%)	Dmft 'yes' N=14 (%)	P Value*
Gender	Female	56 (50.4)	50 (51.5)	6 (42.85)	0.54
	Male	55 (49.5)	47 (48.4)	8 (57.1)	
Age group	< 12 months	14 (12.6)	13 (13.4)	1 (7.1)	0.05
	12 - <24 months	36 (32.4)	35 (36.0)	1 (7.1)	
	24 - <36 months	26 (23.4)	22 (22.6)	4 (28.5)	
	36 - <48 months	18 (16.2)	12 (12.3)	6 (42.8)	
	>= 48months	17 (15.3)	15 (15.4)	2 (14.2)	
Total number of people in house	<=2	7 (6.3)	7 (7.2)	0 (0.0)	0.09
	3-4	53 (47.7)	49 (50.5)	4 (28.5)	
	5-6	44 (39.6)	34 (35.0)	10 (71.4)	
	7+	7 (6.3)	7 (7.2)	0 (0.0)	
Total number of people in bedroom with child	0	16 (14.4)	16 (16.4)	0 (0.0)	0.17
	1	55 (49.5)	49 (50.5)	6 (42.8)	
	2	28 (25.2)	22 (22.6)	6 (42.8)	
	3+	12 (10.8)	10 (10.3)	2 (14.2)	
Indigenous status of mother	Indigenous	73 (65.7)	66 (68.0)	7 (50.0)	0.18
	Non-Indigenous	38 (34.2)	31 (31.9)	7 (50.0)	
Paternal age at birth	<25 years	42 (37.8)	40 (41.2)	2 (14.2)	0.12
	25-30 years	33 (29.7)	28 (28.8)	5 (35.7)	
	30+ years	36 (32.4)	29 (29.9)	7 (50.0)	
Mother highest education	Tertiary	1 (0.9)	0 (0.0)	1 (7.1)	0.07
	Certificate/diploma	13 (11.7)	13 (13.4)	0 (0.0)	
	High school	50 (45.0)	42 (43.3)	8 (57.1)	
	Did not complete high school	46 (41.4)	41 (42.2)	5 (35.7)	
	Unknown/missing	1 (0.9)	1 (1.0)	0 (0.0)	
Frequency of brushing	> 2 per day	5 (4.5)	5 (5.1)	0 (0.0)	0.19
	1 to 2 per day	89 (80.1)	79 (81.4)	10 (71.4)	
	<1 per day	4 (3.6)	3 (3.0)	1 (7.1)	
	None	2 (1.8)	1 (1.0)	1 (7.1)	
	Unknown/missing/NA	11 (9.9)	9 (9.2)	2 (14.2)	
Child has been to dentist	No	100 (90.0)	90 (92.7)	10 (71.4)	0.15
	Yes	9 (8.1)	5 (5.1)	4 (28.5)	
	Unknown/missing	2 (1.8)	2 (2.0)	0 (0.0)	
Carer has received education on dental health for child	No	57 (51.3)	51 (52.5)	6 (42.8)	0.05
	Yes	49 (44.1)	43 (44.3)	6 (42.8)	
	Unknown/missing	5 (4.5)	3 (3.0)	2 (14.2)	
* Chi2 test for trend excluding unknown/missing, Fisher's exact if cell size <5					

Appendix E: Dietary factors eligible for inclusion into a regression model

		All Screened N=111 (%)	Dmft 'no' N=97(%)	Dmft 'yes' N=14 (%)	P Value*
Water in bottle	None	88 (79.2)	74 (76.2)	14 (100.0)	0.18
	<1 per day	0 (0.0)	0 (0.0)	0 (0.0)	
	1 to 3 per day	4 (3.6)	4 (4.1)	0 (0.0)	
	>3 per day	18 (16.2)	18 (18.5)	0 (0.0)	
	Unknown/missing	1 (0.9)	1 (1.0)	0 (0.0)	
Carbonated drink in a cup	None	70 (63.0)	65 (67.0)	5 (35.7)	0.01
	<1 per day	33 (29.7)	27 (27.8)	6 (42.8)	
	1 to 3per day	6 (5.4)	4 (4.1)	2 (14.2)	
	>3 per day	1 (0.9)	0 (0.0)	1 (7.1)	
	Unknown/missing	1 (0.9)	1 (1.0)	0 (0.0)	
Flavoured milk	None	74 (66.6)	67 (69.0)	7 (50.0)	0.04
	<1 per day	29 (26.1)	25 (25.7)	4 (28.5)	
	1 to 3 per day	6 (5.4)	4 (4.1)	2 (14.2)	
	>3 per day	1 (0.9)	0 (0.0)	1 (7.1)	
	Unknown/missing	1 (0.9)	1 (1.0)	0 (0.0)	
Cereal	None	71 (63.9)	65 (67.0)	6 (42.8)	0.08
	<1 per week	31 (27.9)	23 (23.7)	8 (57.1)	
	1 to 3 per week	4 (3.6)	4 (4.1)	0 (0.0)	
	>3 per week	5 (4.5)	5 (5.1)	0 (0.0)	
Potato chips 'crisps'	None	48 (43.2)	45 (46.3)	3 (21.4)	0.16
	<1 per week	43 (38.7)	36 (37.1)	7 (50.0)	
	1 to 3 per week	13 (11.7)	11 (11.3)	2 (14.2)	
	>3 per week	7 (6.3)	5 (5.1)	2 (14.2)	
Fresh fruit	None	12 (10.8)	12 (12.3)	0 (0.0)	0.20
	<1 per week	3 (2.7)	3 (3.0)	0 (0.0)	
	1 to 3 per week	31 (27.9)	24 (24.7)	7 (50.0)	
	>3 per week	65 (58.5)	58 (59.7)	7 (50.0)	
* Chi2 test for trend, Fisher's exact if cell size <5					

Appendix F: Focus questions to guide the yarning sessions in Study 3

- What does health, healing and wellbeing mean to you?
- What areas of being healthy are important to you?
- What does health, healing and wellbeing as it relates to your child's health mean to you.
- What areas of your child's life do you think are most affected by his/her health?
- When you think about your child's health, what worries you most?
- What areas of your life are affected most by this child's health?
- Thinking of your own family and relationships with others, in what ways are these influenced by this child's health?
- Thinking of this child's relationships with others, in what ways are these affected by his/her health?
- The World Health Organization (WHO) categorises health and wellness aspects into physical, mental, and social well-being. Do you think these categories capture aspects of health for Indigenous Australians?