"Have You Received Appropriate Care and What Does That Mean to You?"

Exploring Oral Health Care and its Effect on Wellbeing for Newly Arrived Refugees and the Perspectives of their Oral Health Care Providers

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Abstract

Currently there is little known of the oral health practices, beliefs, and experiences of the refugee population in Australia, particularly those from the Middle East. Although the health status and condition of people with a refugee background has been increasingly documented, an obvious paucity of exploration into the population's own experiences of oral health and health care services remains. There is also strong scientific evidence that the oral health status of individuals, especially children and other complex needs groups, directly influences overall health and wellbeing. This paper seeks to gain insight into the importance of both oral health and oral health care experiences (that is, experiences at the dentist or with other oral health professionals) from the perspective of 20 service recipients and six oral health service providers. The data from 26 semi-structured interviews was examined using thematic analysis. Participants with refugee backgrounds highlighted that their experiences of oral health care had both direct and indirect effects on their overall wellbeing. It is evidenced in Australia that the provision of culturally appropriate health care is lacking, however this was not supported by the current study which rather highlighted the system level issues that prevent appropriate healthcare outcomes. Furthermore, this study found that oral health care professional participants had a keen and sympathetic understanding of the needs of their refugee patients. This exploratory study has added to the current literature surrounding oral health and wellbeing and, distinctively, has addressed this complex relationship from the personal perspectives of people with refugee backgrounds and their health care practitioners.

Keywords: Oral health, wellbeing, refugee, qualitative research

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and to the best of my knowledge, this thesis contains no materials previously published except where due reference is made.

I give consent for this copy of my thesis, when deposited in the University Library, to be available for loan and photocopying.

Briellen Beard

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Importantly, I would like to thank all my participants for their time, candor, and priceless insight. I hope I have represented their words accurately but acknowledge I could never represent their stories with the depth of experience they have. I dedicate this thesis to those who reach our borders in search of safety. I hope that this thesis adds to the growing literature and support for those we promise to protect.

Chapter One

Introduction

1.1 Overview

Australia has provided humanitarian protection for over 800,000 refugees since the second world war, and most recently has focused on high priority areas, particularly the Middle East (Department of Immigration and Border Protection, 2017). Conflict and cultural or religious persecution has led to record numbers of forced migration and displacement in Middle Eastern countries, including Afghanistan, Iran, Iraq and Syria (Finney Lamb, Klinken Whelan & Michaels, 2009). In 2017, Australia saw the inclusion of over 17,000 humanitarian entrants, of which over 10,000 were from Middle Eastern countries (Phillips, 2017). Displaced people and forced migrants endure diverse experiences, including persecution, trauma, substandard environmental conditions and disrupted access to health care and help. These circumstances frequently have pervasive and long-lasting adverse effects on health and wellbeing, both before migration, during the migration journey, and often in resettlement (McCarthy & Marks, 2010). While a body of research has focused on general or mental health (McBride, Block & Russo, 2017), very little has considered oral health for people with refugee backgrounds. As such, the purpose of this paper was to explore the oral health and oral healthcare experiences of recently arrived refugees in an effort to shed light on an area that presently has very little review in Australia. This paper further seeks to gain an insight into the importance of appropriate and culturally sensitive oral health care from the perspective of both the service recipients and providers. Specifically, the research questions were:

1) How does oral health status impact wellbeing for people with refugee or asylum seeker backgrounds from the Middle East?

2) How do experiences of oral health care services impact wellbeing for people with refugee or asylum seeker backgrounds from the Middle East.

1.2 Definitions

1.2.1 Defining People with a Refugee or Asylum Seeker Background

It is important to define the terms "refugee" and "asylum seeker". This paper uses the United Nations High Commission for Refugee (UNHCR) definition for a refugee as someone who "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country. The refugee category also includes persons in a refugee-like situation" (UNHCR, 2017). An asylum seeker is a person who has fled their country but has yet to have their claim for protection assessed or formally recognized. However, literature increasingly uses the term 'people with a refugee or asylum seeker background' to acknowledge that this experience is only a part of their identity, and this term will be used in this thesis, together with the term's "refugee" or "asylum seeker" at times for brevity.

1.2.2 Defining Wellbeing

While a contested term for the purpose of this thesis, wellbeing is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in complex ways by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (World Health Organization, 1997).

1.3 Refugee Health Care in Australia

As part of resettlement services, people with refugee or asylum seeker backgrounds typically receive some level of settlement support (d Maio, Silbert, Jenkinson & Smart, 2014), including general and specialist health services (McBride, Block & Russo, 2017). However, evidence suggests that this range of publicly funded services may not provide appropriate and effective support to humanitarian entrants (Curry, Smedley & Lenette, 2017). Indeed, "successful" resettlement is currently assessed in a generic top-down style of evaluation that rarely consults the lived experiences of refugees in Australia, as such, it is important to explore resettled refugees' experiences to inform how they conceptualise "successful" resettlement for themselves (Curry, Smedley & Lenette, 2017).

The health status of refugees resettled in Australia has been increasingly documented, as well as the challenges and barriers they face in accessing services, however there is an obvious paucity of literature that explores the health care experiences of refugees themselves. Importantly, investigation into whether interactions with these services can impact wellbeing in and of themselves is lacking (McBride, Block & Russo, 2017). In addition, there are currently no clear evaluation frameworks for such services (Curry, Smedley & Lenette, 2017), with existing evaluations primarily focused on service performance, with minimal focus on lived experiences (e.g., Jewson, Lamaro, Crisp, Hanna & Taket, 2014). Exploring the experiences of resettled refugees is essential in developing successful policy for such programs, however, research in this area is surprisingly lacking (d Maio, Silbert, Jenkinson & Smart, 2014). In fact, globally there has been limited investigation into the experiences of resettled refugees and their perspectives of their own wellbeing (McCarthy & Marks, 2010).

1.4 Oral Health and Wellbeing

Oral health is inextricably linked to overall health and wellbeing (Slade, 1997). Indeed, Australia's National Oral Health Plan, "Healthy Mouths, Healthy Lives" outlines the importance of oral health, oral health care, and the significant impacts of oral disease and poor oral health stating that "Oral health is fundamental to overall health, wellbeing and quality of life. A healthy mouth enables people to eat, speak and socialise without pain, discomfort or embarrassment" (Oral Health Monitoring Group, 2015, p. 1). There is strong scientific evidence that the oral health status of individuals, especially children and other complex needs groups, directly influences overall health and wellbeing (Drummond, Meldrum, Boyd, 2013). Research has also suggested that poor oral health can influence social wellbeing and interactions, through its effect on self-esteem (Renzaho & de Silva-Sanigorski, 2013).

Specifically, in Australia various reviews of oral health status reveal oral health as an integral component of overall health and wellbeing (Bilic, Blomberg, Burry, Chong, Yeung, & Ariyawardana, 2016; Drummond, Meldrum, Boyd, 2013; Jamieson, Paradies, Gunthorpe, Cairney & Sayers, 2011). For example, Bilic et al. identified that half of the respondents (identified as representative of a rural North Queensland population) to their Queensland based study were experiencing negative wellbeing due to the impacts of their oral health. There is also strong evidence that the experiences and oral health status of children has direct implications on their health, wellbeing and even development (Renzaho & de Silva-Sanigorski, 2013).

Global research suggests that generally refugee oral health is poorer than comparative non-migrant populations (Riggs, Rajan, Casey & Kilpatrick, 2014). In a study of refugees in the United States, Singh, Scott, Henshaw, Cote, Grodin, & Piwowarczyk (2008) found that approximately 90% of participants required immediate or near immediate oral health care. These

figures are perhaps unsurprising, as forced migration is known to have negative associations with physical health due to exposure to substandard conditions, disease, lack of available hygiene, lack of resources, and lack of access to appropriate (or any) healthcare (McCarthy & Marks, 2010). This is also reflected specifically in Australia, where refugees generally suffer poorer oral health than the broader Australian population (McBride, Block & Russo, 2017). It is also evidenced that refugee oral health outcomes are poorer than other migrant classes, such as economic migrants (Riggs et al. 2014), however, there is only a small amount of research on this topic, both internationally and in Australia, and specific details such as accurate prevalence rates are almost non-existent.

Despite this lack of research, the experiences that many people with refugee or asylum seeker backgrounds face are likely to impact oral hygiene practices; whether due to altered priorities, reduced accessed to oral hygiene tools, or minimal access to oral health care (Finney Lamb, Klinken Whelan & Michaels, 2009). Often, the disruption to oral hygiene care continues post settlement in Australia, when other issues such as housing, food, income and mental health tend to take obvious priority (Nicol, Al-Hanbali, King, Slack-Smith, & Cherian, 2014). Finney Lamb, Klinken Whelan and Micheals found in their study that each of their six Middle Eastern refugee participants had poor oral health status, multiple missing teeth, and had placed a low priority on oral health. As a result, they had lived for extended periods of time with oral pain and untreated oral health issues and had sometimes resorted to home remedies and methods for treatment and extraction (Finney Lamb, Klinken Whelan & Michaels, 2009). Nicol, Al-Hanbali, King, Slack-Smith, and Cherian (2014) found in their qualitative study involving the parents and grandparents of children with refugee backgrounds in Australia that many, if not all, of the children had severe dental disease when they arrived in Australia, which often worsened after

resettlement. Despite such evidence of oral health status disparities for this population, there is little research and understanding regarding the reason for such gaps, with many reviews of care for refugees with complex health needs, such as McBride, Block and Russo (2017), focusing on general and holistic care but failing to include any review of oral health care. The experiences of poor oral health of people with refugee backgrounds and the lack of available literature and review in Australia highlight the need for related services and circumstances to be explored to ensure they minimise oral discomfort in resettlement (Finney Lamb, Klinken Whelan & Michaels, 2009).

1.5 Oral Healthcare and Impacts on Wellbeing

As noted in the previous section, poor oral health is likely to affect wellbeing through a range of pathways, including due to the disruptive, painful and sometimes noticeable nature of oral problems – and this is especially true of refugee and asylum seeker populations for whom these issues may be exacerbated (Finney Lamb, Klinken Whelan & Michaels, 2009). However, a small body of research indicates that refugee and asylum seeker populations in Australia also face a range of barriers to accessing culturally appropriate health services, particularly oral health services, which in turn further impairs oral health outcomes (Riggs et al., 2016; Nicol, Al-Hanbali, King, Slack-Smith, & Cherian, 2014). Currently documented barriers include language, financial and transport matters, as well as interpreting and culturally appropriate care (McBride, Block & Russo, 2017).

However, documentation of the experiences of people with refugee or asylum-seeker backgrounds who overcome such barriers and obtain health care are sparse. McBride, Block and Russo (2017) have however provided valuable insight into the general health care experiences of refugees in Melbourne, Australia engaged in a specific and resource rich program. They reported

that participants revealed the most valuable aspect of the program was the friendly and helpful staff, highlighting the value of trusting relationships with service providers (McBride, Block & Russo, 2017). McBride, Block and Russo also highlight the potential for settlement services not only to improve health, but to positively affect resettlement outcomes for refugees.

More broadly, Curry, Smedley and Lenette (2017) in their investigation of resettlement in New South Wales, Australia found that participants felt that the government provides sufficient and appropriate initial healthcare, however they did not specifically explore oral health care. Finney Lamb, Klinken Whelan and Michaels (2009) in their exploration of refugees' oral health experiences prior to arrival in Australia found that the provision of oral health care that is culturally sensitive can redress former human rights violations by providing the patient with informed consent and the right to decision making about their own health and wellbeing (Finney Lamb, Klinken Whelan & Michaels, 2009).

1.6 Oral Health Professionals Experiences of Providing Care for Refugees

The barriers to accessing oral health care do not end when services are provided but are further compounded by the time and resource constraints of health facilities and practitioners, who may have limited familiarity with refugee or asylum seeker health issues (McBride, Block & Russo, 2017). Further complexities lie in the fact that the healthcare needs of refugees differ across time, culture, geographical location and more (Phillips, 2014). All health care providers, including dental clinicians, are required to provide culturally appropriate and sensitive care (Finney Lamb, Klinken Whelan & Michaels, 2009). However, many health care providers lack a clear understanding of the complex health needs of refugees (Nicol, Al-Hanbali, King, Slack-Smith, & Cherian, 2014). This may be due to the simple fact that providers of mainstream oral health services may have had little experience and opportunity to understand refugees' oral

health experience as they may represent only a limited portion of their patient base (Finney Lamb, Klinken Whelan & Michaels, 2009). Furthermore, literature outlines the need for specific cultural and trauma-sensitive training for carers of refugees, which is currently lacking (Jewson, Lamaro, Crisp, Hanna & Taket, 2015). McBride, Block and Russo's (2017) study mentioned above outlines the importance of trusting and respectful relationships between provider and patient, and Jewson, Lamaro, Crisp, Hanna and Taket, (2015) suggest that any lack of understanding by provider was not due to unwillingness, but rather organisation level barriers. Oral health care providers are asked to consider the experiences of refugees, and their impact on oral health and health care experiences (Nicol, Al-Hanbali, King, Slack-Smith, & Cherian, 2014). However, there is little exploration into the perceptions and experiences of service providers, which may assist in outlining the challenges and facilities to caring for patients with refugee backgrounds (Jewson, Lamaro, Crisp, Hanna & Taket, 2015).

Chapter Two

Method

2.1 Participants

The participants were 20 newly arrived refugees (n = 17) and asylum seekers (n = 3) from the Middle East (defined as Afghanistan, Iran, Iraq and Syria; 8 males and 12 females), ranging in age from 18 to 52 years (M = 32.85, SD = 9.26). Participants had lived in Australia from one to six years (M = 3.35, SD =1.53). For the purpose of the study, a newly arrived refugee is defined as a person forcibly relocated to and seeking protection in Australia within the past 10 years. 11 participants were from Syria, six from Afghanistan and three from Iran. Two participants

held Safe Haven visas, one a bridging visa whose claim for asylum has not yet been processed and 17 participants hold permanent visas or citizenship. 13 participants have children.

Six oral health care professionals were also interviewed (2 males, 4 females). Oral health professional participants were eligible if they had self-identified experience in working with clients from a refugee or asylum seeker background and were currently practicing in the South Australian community. The oral health practitioners consisted of three dentists, one Oral health therapist and senior dentist, one practice manager and dental assistant and one director and dental hygienist who together had an average of 8.3 years' experience working with clients from refugee backgrounds. Further demographic detail is not provided for practitioners to ensure appropriate anonymity.

Table 1. Refugee and Asylum Seeker Participant Demographics

Name	Age	Gender	Children	Country of Origin	Years in Australia	Visa Status	Cultural/ Ethnic Background
[redacted]	35	Female	0	Iran	5	SHEV[1]	Iranian
[redacted]	32	Male	0	Iran	5.5	SHEV	Iranian
[redacted]	23	Male	0	Iran	5.5	Bridging Visa[2]	Ahwazi Arab
[redacted]	52	Female	6	Afghanistan	5	Permanent Visa[3]	Hazara/Farsi
[redacted]	21	Female	0	Afghanistan	4	Permanent Visa	Hazara
[redacted]	19	Female	0	Afghanistan	5	Australian citizen[4]	Hazara
[redacted]	29	Female	1	Afghanistan	6	Australian citizen	Hazara
[redacted]	34	Male	4	Afghanistan/Iran	3.5	Permanent Visa	Afghani
[redacted]	42	Female	4	Afghanistan/Iran	3.5	Permanent Visa	Afghani
[redacted]	36	Male	6	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	36	Female	6	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	29	Female	4	Syria	3.5	Permanent Visa	Arab/Muslim
[redacted]	43	Male	4	Syria	3.5	Permanent Visa	Arab/Muslim
[redacted]	30	Female	2	Syria	1.5	Permanent Visa	Arab/Muslim

Name	Age	Gender	Children	Country of Origin	Years in Australia	Visa Status	Cultural/ Ethnic Background
[redacted]	37	Male	2	Syria	1.5	Permanent Visa	Arab/Muslim
[redacted]	45	Male	4	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	35	Female	4	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	18	Female	0	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	40	Female	4	Syria	2	Permanent Visa	Arab/Muslim
[redacted]	21	Male	0	Syria	2	Permanent Visa	Arab/Muslim

[1] A Safe Haven Enterprise Visa (SHEV) allows recipients to stay in Australia for up to five years, work, study and apply for certain other visas if they have arrived in Australia to seek asylum

[2] A bridging visa is a temporary visa provided while a recipients claim for asylum are being processed

[3] A permanent visa allows recipients to live, work and study indefinitely in Australia and is granted on referral by the UNHCR

[4] An Australian citizen has lived permanently in Australia for 4 years and is afforded the rights of a natural born citizen (Department of Home Affairs, 2018).

2.2 Procedure

This study gained approval from the Adelaide Human Research Ethics Committee, approval number [redacted]. Recruitment was facilitated by a previous quantitative study on Oral Health and Wellbeing that had included a survey, led by academic supervisor (CD). At the end of the survey, participants were asked to indicate if they were happy to be contacted for a further interview on the topic. Emails and text messages were sent to participants that had agreed to be contacted. In addition, two researchers (BB and another honors student, IA, exploring help-seeking for oral health) recruited participants for additional surveys through organisations such

as the Australian Refugee Association and the Muslim Women's Association. Again, interview participants for this study were recruited from the sample of people who agreed to an interview as noted on the survey form. Oral health care practitioners were recruited through two local oral health organizations that advertise their care of refugee patients. The practitioner participant information flyer (Appendix A) was distributed to employees through management. Oral health care practitioners willing to participate in the study contacted the primary researchers directly.

Researchers contacted participants who had indicated they were interested in further involvement in the study to arrange interview times. From the initial 25 survey participants who said yes, seven were interviewed. The next stage of recruitment led to the contact of six oral health professionals, all of whom were interviewed, and a further 10 refugee participants, all of whom were interviewed. The final stage of recruitment led to the contact of three refugee participants, all of whom were interviewed. Participants with a refugee background were asked at initial contact if they required an interpreter, with 10 participants advising interpreters would be required, and as such an interpreter was present at their interviews. Informed consent was gained at the interviews and participants were provided with a Participant Information Sheet (Appendix B) and Consent Form (Appendix C). Refugee participants were each provided with a $45 gift card as compensation and thanks for their time and effort in attending interviews. No compensation was offered to oral health professional in line with ethical process. All interviews were completed between April and July 2018. The interviews were completed at public places such as library's, or at the workplaces of practitioners where appropriate. All interviews were recorded using an iPhone Application, and recordings were saved directly to a secured file. Each interview was transcribed verbatim by the researcher that had completed the interview (IA 15 and BB 11). Oral health practitioners were provided opportunity to review their transcripts,

however all declined in favor of receiving completed reports. Pseudonyms were given to all participants and transcripts were de-identified due to the vulnerable nature of refugee participants and the somewhat easily identifiable nature of the oral health professionals.

Two pilot interviews were conducted – one for the current study and one for researcher IA's study concerning help-seeking – as the interview schedule covered questions pertaining to both research projects. These pilot interviews were conducted with supervisor CD. For the current study, the pilot interview led to some points of clarification for questions around wellbeing, to ensure participant understanding. For example, the piolet participant was unsure of the wording of the question, "Do you feel your experiences of oral health care have impacted your overall wellbeing?" which was re-worded for clarity as follows: "What impact have these experiences with healthcare practitioners had on your wellbeing". Data from this interview was not included in the final analysis as the participant was a migrant from Syria, without a refugee or asylum seeker background.

The interviews were semi-structured with open questions asked based on responses, due to the exploratory nature of the research aims. The interview schedule was informed by the existing literature on measures of oral health related wellbeing (Bilic et al., 2016; Naik et al. 2016; Slade, 1997), and oral health and oral healthcare experiences. Please refer to Appendix D for the full interview schedule. Demographic data was also collected. At the completion of each interview, the primary researcher kept a diary (or audit trail) to ensure that any prominent reactions or thoughts were recorded for review during transcription. Notes included an examination of the researchers' impact on the interaction, to fulfill the requirement of self-reflective practice (Tracy, 2010, 842).

Data saturation was reached by the 17th interview with refugee participants, however a further three interviews were completed with participants with refugee or asylum seeker backgrounds from Iran to explore the cultural differences for refugees from different countries of origin. Six oral health practitioners responded to the recruitment efforts and all six were interviewed. The data gained from interviewing oral health practitioners was used primarily for triangulation and as such six was determined to be a sufficient number.

Finally, self-reflexivity encourages the author to reflect on her shortcomings and strengths, and to highlight the ways in which her own position have influenced this process (Tracey, 2010). Although the researcher (BB) does not have a refugee background, she is a current volunteer for the Australian Refugee Association, and an advocate for the rights of forced migrants. She has worked and studied twice internationally in the field of human rights in migration. It is her history working with refugees and displaced persons that inspired this project. The researcher is aware that these experiences may have influenced the context of this research and has taken steps to mitigate and understand any such influence, before and during the process such as; keeping a diary (as noted above); having themes reviewed by supervisor (CD) and using an exploratory and realist foundation for analysis.

2.3 Data Analysis

Thematic analysis was used to analyze the transcribed interviews due to its theoretical flexibility and ability to analyze rich data without theoretical underpinning. This analysis took a realist approach, as it was exploratory in nature and focused on the lived experiences as told by refugees. Braun and Clarke (2006) outline a six-phase guide to thematic analysis which has been utilized in the analysis of the current data. Initially the researcher became familiarized with the data through transcription, notation of ideas and repeated reading. Secondly initial codes were

developed to begin to organize the data into meaningful groups. An entirely inductive or bottom up approach was used in the initial coding, as there was no firm theoretical basis to the research questions, which are concerned primarily with the experiences of the participants. These codes were subsequently group into potential or preliminary themes. At this stage, the initial themes and raw data were reviewed by the academic supervisor (CD) who identified that some initial themes were irrelevant to the research questions or re-identified as part of similar themes. This allowed the data to be reviewed from a different perspective and the researcher (BB) was able to examine their own personal influence on data analysis, aligned with self-reflective practice (Tracy, 2010). The data was then reviewed entirely in relation to the themes and the research question. Using a more focused system of reviewing raw data within the framework of the research questions helped to redefine initial themes and ensure the themes were inductively representative of the data, as well as aligned to the current study. Finally, the themes that were found to map to the raw data were refined and labelled and the most relevant extracts were selected to support the themes as results of the study.

Chapter Three

Results

Results are organized according to the two research questions. Section 3.1 refers to the question “How does oral health status impact wellbeing for people with refugee backgrounds from the Middle East” and Section 3.2 refers to the question “How do experiences of oral health care services impact wellbeing for people with refugee backgrounds from the Middle East”

3.1 Oral Health Status Can Impact General Wellbeing

This section outlines the three themes identified in the study. Namely: 1. The Cosmetic Nature of Oral Problems can Affect General Health and Habits, 2. The Painful Nature of Oral Problems can Affect General Health and Habits, and 3. Missing Teeth can Affect General Health and Habits.

3.1.1 The Cosmetic Nature of Oral Problems can Affect General Health and Habits

A prominent effect of oral health on wellbeing identified by participants across the sample was in relation to cosmetic or aesthetic factors. Participants highlighted that the sometimes the highly conspicuous nature of poor oral health affected confidence, self-esteem and at times social relationships. When asked about how oral health influences overall wellbeing, Zaynah specifically discussed her concern about having visibly missing teeth:

> But even I'm not in pain, but when my tooth was broken, because it was exactly next to the one that I extract before, if I extract this one then I can have anything in this side, and if I, have a bigger smile, actually it's really clear you can see it ([redacted] Refugee, 34-36).

Deborah also outlined this general concern for the aesthetic complication of having teeth removed for her patients and stated that:

> …people don't want to have like gaps… they lose their confidence and stuff like that so yeah I don't think it's just a refugee thing… Just think it's a self-esteem thing… ([redacted] Oral Hygienist, 210-211, 213).

The concern over the aesthetic implications of poor oral health is a clear indication of the negative impact of poor oral health on wellbeing. This was highlighted by medical professionals; Florence for example drew clear links between cosmetic and psychological factors, stating that:

> …I think it's (.) self-confidence as well that if people's mouths are comfortable they are more comfortable… The anxiety drops back so you have this roll on effect and when you look at the two groups of people if you want to call them two groups of people [refugee and non-refugee populations] that for both for all of them it's about comfort it's about appearance and how the world sees them… So the psychology and I think the personal feelings about identity and self-respect(.) are tied very much in with it as well ([redacted] Oral Hygienist, 194-195, 197-199, 201-202).

[redacted] also discussed the psychological impact of having missing teeth:

> Yes of course. It's a massive impact on everyone's wellbeing and his attitude generally. Because when people have trouble, or they are in pain it may affect their looking as well, how they look. Sometimes when you laugh or smile if there is any missing teeth or something it emotionally and psychologically affects the person ([redacted] Refugee, 133 - 136).

[redacted] also voiced a particular concern for how such dental issues might impact him socially:

> Um well I know my teeth if I talk my teeth… I smile you know I… sort of the most ah… prominent or you know of um… the the very they will be very conspicuous, you know… Yeah so if I, for example if I, if I didn't have good teeth people would be like 'what's happening with me?' ([redacted] Refugee, 250-251, 253-254).

3.1.2 The Painful Nature of Oral Problems can Affect General Health and Habits

Every participant commented on the nature of dental pain and its ability to inhibit normal healthy behaviors. For example:

> …it has so many um… aspects to it. I think number one pain, which exacerbates the anxiety… So you can't sleep... um you can't rest if you've got this constant pain. ([redacted] Oral Hygienist, 175,178).

[redacted] also highlighted the unique and protracted ways that oral pain can impact general wellbeing:

> When… you have pain in you in your mouth in your teeth it would be hard to enjoy your life everyday… Teeth pain is a little bit hard it's not just like when you have a stomach ache, it's easy goes away after a while, normally it's prolonged ([redacted] Refugee, 223-224).

[redacted] also mentioned that oral pain impacts your ability to think and speak:

> You know, uh, if the tooth is swollen or infected, you can't think really. It's like headache – you have something heavy on your face and can't talk a lot ([redacted] Refugee, 42-43).

[redacted] also discussed the ways in which dental pain can affect one psychologically:

> … yeah, they affected her eating and what uh mainly affected her the psychologically she starts feeling the pain if she eats 'no I won't eat this no I won't eat that' because it will hurt ([redacted] Refugee, 36-38)

3.1.3 Missing Teeth can Affect General Health and Habits

Participants also highlighted that it is not just pain that affects their general health and habits, but also the removal of teeth that were previously causing pain. Missing teeth were a cause for concern for a variety of reasons, the removal of teeth impacted wellbeing by both leading to practical issues such as difficulties chewing, as well as cosmetic concerns as noted in the first theme above. [redacted] outlined her regret at missing teeth and noted that:

> …because the main teeths are missing so I have some issues with chewing… It's irritating… ([redacted] Refugee, 135).

[redacted] was not unique in this – many refugee participants commented on their annoyance at missing teeth, and the ways this affects them, such as [redacted]

> …after taking out these two teeth, right now when he is chewing foods its really difficult for him. Yeah so its difficult chewing the food after taking these teeth out ([redacted] Refugee, 157-158).

[redacted] also commented on the ways in which her child's missing teeth had impacted her own wellbeing. She felt a sense of failure that she had not been able to protect his teeth, showing a keen understanding of the importance of keeping one's natural teeth – and a general lack of understanding of why they were extracted:

> …I'm very disappointed with my child teeth as well…Even [though] I had a bad experience with my teeth, I couldn't protect his teeth…I don't really know what was the reason that I lost his teeth…I didn't really notice what went wrong, what did I not do right? ([redacted] Refugee, 288-296)

This excerpt hints at the complex and sometimes hidden nature of poor oral health. Lina was not the only participant to question how the teeth had gotten so bad that they required removal, and certainly not alone in her disappointment at their eventual extraction. Extractions, though they may relieve pain, were seen as a failure of treatment by participants, who primarily would have preferred to save their teeth and avoid the complication of extraction.

3.2 Healthcare Services Can Impact General Wellbeing

While there were clear pathways between oral health and wellbeing as noted in the previous section, participants also highlighted important pathways between oral healthcare or

service delivery and wellbeing. Themes identified in this section were: 1. Expectations and Experiences of Quality of Services and Feelings of Safety, 2. Receiving Successful Treatment can Impact General Wellbeing and Feelings of Relief, and 3. Trust and Rapport in Provider/Patient Relationship Affects Experiences, which includes four subthemes, and 4. Health System Level Issues Can Affect Wellbeing in the Provision of Service.

3.2.1 Expectations and Experiences of Quality of Services and Feelings of Safety

Participants highlighted that an important aspect of oral health care experiences was their understanding that they would receive good quality treatment from professional dentists, with a focus in particular on hygiene:

> …..to be specific if I have if I want to have fillings um I would be concerned about the material that they use to put in my teeth... because that's important, you know, how long will it last if you know that would have consequences, side effects… ([redacted] Refugee, 311-312, 314-315).

When asked about the differences between visiting a dentist in Australia as compared to oral health care experiences from their home countries, participants spoke openly about the differences, notably in hygiene and procedural safety. For example, when asked about differences between Iran and Australia, [redacted] said:

> "I think in Australia there is um… more thorough and it's a better treatment… uh yeah… you feel, you feel very safe in their clinics to be honest…I think it's um OK it's maybe… I think it's the whole set up of the office and you go into the room and how they're body language and, you know, their talk to you and, you know, how they are how smooth they are and they get you into the process(.) of the treatment you know, nicely and no rush

> um… I know in Iran and they try to do things bit rush, yeah so… um here they take their time which is good yeah so" ([redacted] Refugee, 327-328, 330, 332-335).

[redacted] had the same concerns regarding hygiene in Iran:

> "we are quite happy with the cleaning that they take care of here in the dental service in Australia. For example in Australia if they use one pair of glove to do something, then they usually change that, taking a fresh pair of gloves, um where back in Iran… when I took my son to the dentist out there um so that dentist had that pair of glove and he was using the phone and touching the phone, having the one pair of gloves, touching the pen, touching everything else and also touching my sons teeth during the treatment as well. So he was using one pair of gloves to do everything. Where right here it's not" ([redacted] Refugee, 458-465).

In comparison to the statements above, Samir commented on the differences in the perceived skill of the oral health practitioners in Australia and Syria, and highlighted that he felt Australian dentists were lacking both the skill and confidence of the dentists he had visited in Syria:

> I'm sorry, but I have to tell the truth. In comparison to the services that we that we had in Syria the doctors there seem to be much more confident and much more on top of their practice… I'm so surprised, the country is much more advanced than Syria but I don't know why the doctors in Syria are more skilled so what can the government do? I'm not sure what they can do in this relation to make them more skilled, more confident. ([redacted] Refugee, 352-354, 358-360).

Although there were individual preferences and differences in relation to comparison of Australian or origin country services, it is clear that participants highlighted safety in their dentist experiences as a key pathway through which oral healthcare impacted upon their wellbeing.

Participants highlighted that they want to know their dentist is a professional, who knows what they are doing – and this was especially important in parents' experiences of their children's oral health care.

3.2.2 Receiving Successful Treatment and the Relief of Pain can Impact General Wellbeing

When participants were asked about the ways in which their experiences of oral health care affected their wellbeing, positive outcomes were highlighted as affecting wellbeing in different ways. When asked about her patients experiences of oral health care [redacted] said:

> "Um I think if they have a positive experience then they come out thinking, and that's not just for refugees that's for everybody, you know 'oh that wasn't, that was good that didn't hurt'… 'I'm out of pain' or 'my teeth look so much better now' so the experience definitely impacts everything… ([redacted] Dentist, 223-226).

And when discussing the same topic, [redacted] discussed the opposite situation, equating the failure to relieve pain with a form of trauma. He pointed out that:

> … I think that if they've attended an appointment and it's gone really bad or they haven't good outcomes and they're still in pain, it would [impact wellbeing]… I would say that there is a huge potential of a dental visit being if it was traumatic enough. Kids tend to overcome trauma quite well from what I've seen. Adults, I'm not so sure. ([redacted] Dentist, 527-528)

[redacted] went on to emphasise, as [redacted] had, that it is the relief of pain that he feels is essential to a person's experience, and a lack of pain relief could lead to negative outcomes – especially in the case of the treatment of children:

> I'd say the big thing is if they came in pain and they left in pain… didn't have that problem fixed, um or if we were absolutely unable to provide care for a child and they

had to go on a waiting list and then they'd be in pain for you know up to a year that would definitely have a massive effect. ([redacted] Dentist 534-539).

When asked about experiences of oral health care, refugee and asylum seeker participants also discussed the importance of pain relief and receiving what they perceived to be good care. Interestingly, participants noted that the relief of pain when attending the dentist was of more concern that culturally appropriate care (although this was identified as important, as seen in subsequent themes). For example, when asked if her experiences had been culturally appropriate, [redacted] pointed out that cultural sensitivity wasn't a priority for her and her family, but rather what they want is quality care:

> … my family we are not really we are not that fussy. Yeah so even if they ask to like take our headscarf a little bit like this or a little bit further back we don't mind we just want a good treatment that's it. Yeah so my Mum's uh when I took her she didn't mind like she was happy with it yeah she like she just wants her tooth repaired… that's what she cares about. ([redacted] Refugee, 212-215).

In addition to pain, dental practitioners also discussed teeth removal as having a psychological impact. For example:

> Well if they have a tooth out and they don't wanna hav- ya know, if you we say 'we really can't save this tooth' it can be devastating from them ([redacted] Dentist, 231-232).

Refugee and asylum seeker participants also discussed concerns about tooth removal and indicated negative wellbeing outcomes as a consequence. For Example, [redacted] said that she "regrets [her] missing teeth" and went on to discuss ongoing fears concerning seeing the dentist as a result:

> Um, because my teeths were pulled out and it was quite painful and disappointing for me because I lost this beautiful teeths so yes it is quite disappointing going to the doctor and then seeing the decays… ([redacted] Refugee, 225-227).

However, interestingly when asked if she felt she had received appropriate care, [redacted] again brought up the importance of pain relief, and admitted that:

> Yes… because my teeth were quite damaged and painful so it was taken out at the right time. So I'm happy with that. ([redacted] Refugee, 784-788).

Overall, it was clear that receiving successful treatment was paramount to the wellbeing of refugees and asylum seekers and was measured primarily by the relief of pain. Participants outlined that receiving successful care took priority over cultural considerations and also showed concerns about having teeth removed. This concern was noted also by oral health practitioners as a significant impact on wellbeing for this population.

3.2.3 Trust and Rapport in Provider/Patient Relationship Affects Experiences

Participants frequently discussed trust and rapport between provider and patient, and they ways in which trust and rapport can influence the experience for both parties, including in relation to ongoing wellbeing outcomes. This theme concerning trust and rapport includes five sub-themes, related to various aspects of these elements as discussed by participants.

3.2.3.1 Personal Preference and Cultural Differences

Participants often mentioned that the difference in their dentist's cultural background to their own could affect the way that they trust them, or perceive their care. When asked about wanting a dentist that does a good job, [redacted] clarified that:

> …it's a matter of trust and, I remember in erhh, when we have been with MRC um they found 2 Iranian doctor… they necessary wasn't very good one but I don't know people

> they felt preferred go to that one than see what they say and get treatment or if they couldn't go to… and, and…. usually the doctors they have been on contract with them they were very…like just recently got doctor or just recently arrived to Australia, and, because we were just arrived to Australia you feel another understanding, we feel the other person is the same ([redacted] Refugee, 160-165)

However, [redacted] made it quite clear that he would prefer not to see an Iranian dentist:

> I prefer to see Australian dentist… I think they're more honest ([redacted] Refugee, 283).

When asked why, [redacted] said:

> … well that Iranian dentist I think he got me to pay a little bit of extra money…. Yeah and I think he got me to pay a little bit of extra money where he ah you know, could've done all the service that was sort of just you know the money that I paid for him um… initially the money that I was going to pay plus the help um but he got me to pay a little bit extra little bit extra money ([redacted] refugee, 287-290).

Interestingly, when asked why [redacted] felt she would receive more appropriate care in Australia she highlighted that the cultural differences were less important here than she had experienced back in Iran, stating that:

> [I had a] bad experience back to Iran actually because one of the dentists back to Iran was educated in overseas and when he came back to Iran all the people were saying 'ooh that's uh foreign doctor that's coming from overseas and it's not from us it's from overseas'. She's saying but here everyone's equal. So no one just seeing us as a refugee or from overseas and she think probably the doctors here will be better ([redacted] Refugee, 105-109).'

Although participants did show variation in personal preference and experiences of difference in cultural background, it was a salient aspect of oral health care experience for refugee participants. Such experiences and preferences highlight the importance of culturally sensitive care.

3.2.3.2 The Demeanour of the Service Provider

Participants also spoke about the importance of the demeanour of their healthcare provider in building trust and rapport. Notably participants mentioned positive aspects as being important, such as being friendly, gentle and respectful, along with more negative aspects, such as dentists being rude or nosey. When explaining why she had felt comfortable with an Australian dentist, [redacted] said:

> [The dentist I went to] is a like a man around 60 and as soon as he opened the door and said 'Hi' to you, you feel the person is, is just a matter of connection I think. It's not a matter of 'this person is good this person is bad', it's a matter of trust you know? ([redacted] Refugee, 170-172).

And later when asked about how this trust relationship affected her [redacted] stressed the importance of rapport, particularly in relation to initial fear or anxiety:

> …It's doctors and dentists because you go through a process that you're a bit afraid that what is gonna happen, you need a bit of like, friendship, relationship… even in that 2 hours you're there ([redacted] Refugee, 312-313).

[redacted] also spoke directly about the influence on the demeanour of the dentist and it's impact on his comfort:

> the behaviour and the demeanour of the doctors, they way he is communicating with us is comfortable so we don't feel any fear or apprehension ([redacted] Refugee. LINE)

When asked about what would make Rashid more comfortable at the dentist, he also stressed that:

> …he was happy with him, with the dentists and uh… the assistant as well(.) and uh they are very friendly, friendly service… they uh… respect them and the way they treat me and the way they talk they're nice nicely and uh… you know, he feels comfortable. He is got, he's got no problem with the doct- dentists or the assistants or anyone… ([redacted] Refugee, 287-294).

Refugee and asylum seeker participants also highlighted that the demeanour of the dentist affected them in their countries of origin also, suggesting that the importance of trust and rapport surpasses cultural differences. [redacted] explained:

> …so when I was in Iran I saw two dentist so I went and I ask, visited one it was a female and she was very rude, the way she talked and um and then I saw an… another dentist um it was an old man um… he was nice he was nicer he was gentle, yeah so… ([redacted] Refugee, 322-324).

Oral health professionals also discussed the importance of trust, and suggested they felt their was a heightened need to establish rapport with patients with refugee backgrounds. When asked about the importance of building trust, [redacted] said:

> …it's a very big thing go (.) you know, we've had to go 'so…why don't you trust me? OK you've come from a background where you have been tortured you have been marginalised severely you haven't lived safety safely so why should you trust me? You don't know me you've never met me before and this is just….' So it's a lot it's about building trusting relationships ([redacted] Dentist, 93-96).

[redacted] also told an anecdote of how successfully building trust and rapport with patients can mitigate some of the barriers both she and her patients with diverse backgrounds face:

> …I've had (laughs) an old Chinese man who didn't speak word of English brought his Grandson with him the first Jacke (laughs). And after that didn't bring anyone and I said to him you know, 'can you understand me?' and he went 'no' and, and (laughs) and I said do you want to bring someone with you? 'No, because I trust you' (laughs)… it's sort of a compliment if someone can agree after their first meeting that they trust you enough to do things to your body! (Laughs) ([redacted] Dentist, PAGELINE)

3.2.3.4 The effect of Informed Consent and Decision Making on Experiences of Oral Health Care

When asked about how the oral health care providers actually go about building trust and rapport, most highlighted the importance of informed consent, not just as a protocol, but as a tool for building trust. When asked about the perceptions of her clients with refugee backgrounds, [redacted] noted that her informed consent approach seemed new to her clients and said:

> …I think yes… Their dentist would just say 'OK I'll do it, it'll cost you this much'… so we have a much more informed consent approach so we explain what the situation is, what the advantages and disadvantages of certain treatments are, we give options…I get the impression that most people haven't been given options they assume they're getting the best, and some of the quality of treatment is not good either. ([redacted] Dentist, 163-167).

When asked about the challenges faced with clients of a refugee background, [redacted] asserted that:

> …mainly it's mainly making sure they understand… clearly and [you have] explained procedures well enough… ([redacted] Hygenist, 432).

[redacted] also highlighted that from experience, she knew this was an important aspect of caring for clients of a refugee background:

> um and also, just sort of I guess my sort of… creating that rapport with the patient um, and to make it comfortable for them at the clinic, I would – and this probably comes from my background of working with children as well – really thoroughly explain what I would actually do before I actually go ahead and do it, so that they fully know ([redacted] Dentist, 419-423).

She also comments on the challenges of ensuring that informed consent is given, freely and without misinterpretation, or misunderstanding:

> … because they're not speaking English it's just sometimes you know hard to know if, well they're always very accepting of treatment and um but just wanting to sort of know if they're feeling okay about certain things, where as if it was their first language that you were speaking they probably would speak more freely maybe, or feel to speak more freely… ([redacted] Dentist, 225-232).

When asked about how trust and rapport impact on [redacted] care of patients with a refugee background he said:

> …it's a huge problem when they already clearly don't like us, um, but we got plenty of you know, we get lots of people that don't like us so we're used to that and I suppose… I definitely don't hold that against anyone, especially the new migrants. They're scared of dentists, that's all. I think generally once they're here, and the I've explained to them in

> detail what we're doing, why we're doing what we're doing.. they're comfortable ([redacted] Dentist, 447-451).

Participants with refugee and asylum seeker backgrounds also highlighted the importance of informed consent. When asked what makes her more comfortable at the dentist, [redacted] said:

> I like really know(ing) what is happening, and step by step he was telling me what was doing and yeah ([redacted] Refugee, 317-318).

[redacted] went further to explain that this kind of communication helps him and his family to prepare, practically and emotionally for the visit:

> Everything is being explained beforehand and we are happy because we know what's going to happen so they are mentally prepared for the treatment or the therapy… They keep us posted and informed always, for example, in the visit today they tell us what will happen next time. So long as we know what is going to happen down the track, in the future. ([redacted] Refugee, 233-235, 292-294).

Majid also commented that it wasn't just that the oral health care provider obtained informed consent, but that they were provided with options for treatment, and asked what would be the more appropriate for them:

> … And they ask him "do you agree to carry on with this treatment or not?" they always ask the patient so they have a very positive and effective communication with the patient to see whether they are happy with the treatment or… And sometimes they give him options… they might have 1,2,3 options and this is you know better for you but you have to choose at the end, what, what's suitable for you… ([redacted] Refugee, 353-357).

3.2.3.5 The Treatment of Children can Build Trust and Rapport

When discussing the differences in experiences of oral health care, participants with refugee backgrounds noted that they felt the way their children were treated in Australia was markedly different to their countries of origin, and that this impacted their oral healthcare experiences and also their own wellbeing. [redacted] told the following story, highlighting the ways in which the treatment and comfort of his child led to his own improved care:

> …when we initially come here I took one of my daughter... to the dentist here, so the dentist can actually put a crown on the teeth. Ah, so during the treatment my daughter fall asleep. And the dentist or the doctor who was doing the treatment he was surprised as well that how she can sleep while having the treatment? One of the other teeth that the doctor meant to give me another appointment for it, in a later date. So once the doctor saw that my daughter is sleeping um then he said that "okay, perhaps since she is sleeping right here, perhaps I do the treatment of the other teeth right now." So that what happened. ([redacted] Refugee, 486-500).

When asked about what he does to help his clients with a refugee background feel more comfortable, [redacted] also highlighted the importance of parental satisfaction in their child's care.

> It's more just I suppose it's the way you approach people at the way you speak to them. It is booking interpreters when they need it, it's getting along with the kids. I think that parents seeing the kids happy and comfortable is nice. SomeJackes the kids actually even enjoy coming here and I think that helps. Parents wanna keep coming back. If you're able to provide the service and get the child out of pain. It definitely makes a big difference to the perception of us ([redacted] Dentist, 502-507).

3.2.4 Health System Level Issues Can Affect Wellbeing in the Provision of Service

When discussing their experiences of oral health care in Australia several participants with refugee backgrounds mentioned system level issues that were either preventing them from getting what they perceived to be appropriate care, or delaying their access to pain relief. Oral health practitioners were aware of these systematic issues, for example when asked about the challenges she faces when treating patients with a refugee background, [redacted] said:

> … they don't understand 'I'm sorry, we can't fix that… all we can do is take it out and give you a denture' and they don't want a denture they want implants and you know we sort of can't offer that sort of stuff here we don't offer crowns and bridges and stuff like that 'cause the lab work… 'cause you send it off and it's something that's made ([redacted] Dentist, 369-373).

Participants with refugee backgrounds commented often on the wait times for dental appointments, and the length time between appointments, and the way that this can affect their experiences of oral health care. When discussing his experiences in Australia, [redacted] said:

> "He he's got no problem with the dentists here they are very nice they are very uh… polite and respectful and the only problem is the delay" ([redacted] Refugee, 202-203).

When asked about how he felt about visiting the dentist, [redacted] also commented on the delays between appointments:

> As far as the service concerned we are happy the service is very good, but to get the service is very hard because the appointment takes too long in between or even sometimes when we are in pain it can take too long to, to see the dentist ([redacted] Refugee, 70-72).

Later in the interview he re-iterated the issues with delays, and pointed out that the treatment and the demeanour of the dentists had been acceptable, but the waits between appointments caused their perception of the overall experience of oral health care in Australia to lessen:

> As I explained in the beginning we are happy with the service with the way that they treat us, they deal with us, but the main issue is that the appointments take too long and we need- when we need to have a quick service that that's- the speed is the main issue that we are suffering from ([redacted] Refugee, 166-169).

Chapter Four

Discussion

The aim of this study was to explore the oral health care experiences of recently arrived refugees and asylum seekers from the Middle East, and their health care providers in South Australia. This section discusses key findings as well as considering implications for practice and future research.

4.1.1 Oral Health Impact on Welling

The effect of oral health on general wellbeing is extensively documented in other populations (i.e., non-refugee populations) and is often labeled as a crucial determinate of positive health outcomes (Drummond, Meldrum, Boyd, 2013). Participants of the current study identified that oral health was an imperative component of their overall wellbeing, which extends the current consensus of this common understanding to the specific population of refugees in South Australia. Most notably participants outlined the cosmetic or aesthetic effects of poor oral health, such as visibly missing teeth, on their wellbeing. Participants noted that the somewhat conspicuous nature of poor dental health has the ability to affect social relationships, specifically through the degradation of self-esteem and confidence. This is a particularly unique finding, and has rarely been reported in the literature as a determinate of wellbeing in relation to oral health. Renzaho and de Silva-Sanigorski, (2013) and Nicol, Al-Hanbali, King, Slack-Smith, and Cherian (2014) both did identify similar factors in their study of refugee children and wellbeing, for example that having healthy teeth was an integral part of looking good and fitting in in Australia, however the current study adds to the understanding that it is not age specific. The improvement of appearance as a push factor for seeking oral health care is not unique, however it is relatively unexplored in the refugee population, which tends to focus on pain (Bilic et al., 2016). In fact,

this aspect of oral health was highlighted by both participants with a refugee background and their health care professionals, both male and female, across ages and cultural backgrounds.

Consistent with the current literature on oral health and wellbeing, all participants commented on the nature of dental pain and its ability to inhibit normal behaviors and impact wellbeing, physically and emotionally (Bilic et al., 2016). Finney Lamb, Klinken Whelan and Michaels (2009) outlined that refugees from developing countries are likely to be living with untreated dental pain or un-diagnosed issues, and this was consistent with the circumstance of the majority of participants of the current study. As suffering from physical health problems has been identified as a significant risk-factor for wellbeing in this population (McCarthy & Marks, 2010), the prevalence of such poor oral health in participants is alarming. Participants further commented on the unique and protracted nature of dental pain, and the ways that it is different to general ailment, such as stomach aches, which is consistent with most populations' description of oral pain (Slade, 1997). However, the unique circumstance of the participants with a refugee background makes this a notable element of the interaction between oral health and wellbeing. Participants also discussed the ways that oral health care has impacted their wellbeing, discussing the ways in which missing teeth (from extractions) impacts their general habits, appearance, and causes discomfort or pain. Finney Lamb, Klinken Whelan and Michaels (2009) identified that refugees may see loss of teeth as an inevitable part of ageing, however the disappointment and frustration expressed by participants in relation to missing teeth in this study outlines a different belief about tooth extraction, one more closely aligned with the desire to maintain one's oral health and keep their natural teeth.

4.1.2 Oral Health Care Experiences and Impact on Wellbeing

Globally, there is little available research into the effects of oral health care on wellbeing for refugee populations, especially that which considers the experiences of refugees (McBride, Block & Russo, 2017). One of the most notable themes discussed by refugee participants in the current study was that of their expectations of the quality of oral health services in Australia. Participants discussed a general understanding that the standard of care would be higher in Australia as compared to origin countries, which is identified as a foundation for their feelings of comfort and safety in oral health care clinics. A further aspect of oral health care experiences discussed by both groups of participants was the building of trust and rapport between patient and practitioner. The concept of trust and rapport came up regularly in interviews in relation to comfort and safety, retention and commitment to therapeutic plans, and perceptions of care. The importance of trust and rapport in the building of therapeutic relationships in health care settings is not a novel finding and is evidenced to be an important component of care by both patients and practitioners regarding general and mental health care (Arias, J., Justicia, Casanova, & Trianes, 2003; McBride, Block & Russo, 2017). However, the current study extends understandings of trust and rapport in health care settings, through both a focus on oral health care, and through understandings of the role of these issues in health care with culturally diverse refugee populations. For example, an important part of this discussion was the differences in personal preference as to the cultural heritage of the oral health practitioner, with some suggesting that having a dentist with a similar background provided a level of similarity from which rapport could be built. Conversely, some participants commented that their impression of 'Australian' oral health practitioners meant that they would prefer and feel more comfortable with Australian dentists. The complex interaction between previous oral health experiences in origin countries

and how they affect perception and experience of oral health care in Australia has been largely unexplored. As such the current study extend previous the current study extends this conversation to include trust and rapport as an essential tool in oral health care that enables the provision of appropriate care and affects the wellbeing of patients with refugee backgrounds.

This study also found that the cultural competence and the understanding of needs of the oral health professional was an important factor in a patient's perception of them, and the relationship that formed consequently, regardless of cultural differences. Previous research has highlighted that dental health practitioners largely required cultural-competency training to be able to meet the oral health care needs of refugees (Finney Lamb, Klinken Whelan & Michaels, 2009). Furthermore, Nicol, Al-Hanbali, King, Slack-Smith, & Cherian (2014) specifically highlighted that there was a lack of understanding of the complex resettlement difficulties faced by refugees, and how they affect their attendance and adherence to therapeutic oral health care. In contrast, this study has found that oral health practitioner participants have a growing knowledge of the complex backgrounds of their refugee patients and expressed a keen and sympathetic understanding of the importance of culturally sensitive care.

Specifically, oral health care practitioners in this study discussed the importance of informed consent in their treatment of refugee patients. This was also an aspect of trust that refugee participants spoke about with vigor. When asked about what in particular lent them to feel they could trust their oral health care providers, participants with a refugee background highlighted the informed consent approach of practitioners. Participants described the ways in which practitioners kept them informed of their process, both before and during appointments. This approach meant that participants felt prepared for appointments and comfortable that they had an accurate expectation of the appointments. More importantly, this approach helped

participants to understand that they have choices in their oral health care options. Practitioner participants also outlined that this was not only a way to assist patients comfort and trust in them, but to engage them in their own oral health and encourage them to have a better understanding of oral health care. Finney Lamb, Klinken Whelan and Michaels (2009) outline that providing information to refugee patients that upholds their rights to informed consent and enables them to make oral health choices in a new setting has important implications for the oral health of the individual and their overall wellbeing. The results of this study further support this.

Although refugee participants outlined generally positive experiences of oral health care in Australia, there were system level issues discussed by both groups of participants that they believed prevented the achievement of appropriate care, or successful treatment, and delayed patients access to effective relief from pain, negatively impacting their wellbeing. Exactly as Nicol, Al-Hanbali, King, Slack-Smith, & Cherian (2014) found, though generally happy with the actual service of oral health care professionals, more common were stories of long wait times and experiences of delayed treatment that lead to prolonged pain and inhibited normal healthy behaviors. These system level aspects of oral health care experiences had notable effects on wellbeing. Firstly, refugee participants in this study highlighted the wait times experienced before and between appointments affected their perspectives and experiences of their oral health care in Australia. Participants explained that outside of initial formal care plans, they could wait months before being able to visit the publicly funded dentists. These wait times often meant participants were left experiencing dental pain, or inhibited eating or social practices for long periods of time. Participants commented that the prolonged wait times wore away at mental wellbeing. As highlighted by Nicol, Al-Hanbali, King, Slack-Smith, & Cherian (2014), this is not a unique finding in the literature on oral health care for refugees in Australia. Curry, Smedley

and Lenette (2017) found regarding the provision of most settlement services that though needs were being met through initial appointments, the timeframes for access to services in Australia caused major limitations to appropriate healthcare outcomes. Oral health care professional participants further outlined that the restriction on care able to be provided by public clinics also prevented patients from experiencing what they perceived to be effective care, or successful treatment. Again, this is not a unique finding. Finney Lamb, Klinken Whelan and Michaels (2009) found that the provision of health services for refugees posed various system level challenges to health care providers. These challenges were primarily characterized by practitioner participants in this study as resource related; either time or money. This is neither unique in the literature. The shortcomings of most practitioners and clinics in effectively addressing the health needs of the refugee population in Australia have been documented as either cultural or system level issues that are founded primarily in funding issues and budgeting priorities (Jewson, Lamaro, Crisp, Hanna & Taket, 2015).

4.2 Strengths

The most notable strength of the current study is its effective use of qualitative research methods to explore the research question and capture the lived experiences of participants with refugee or asylum-seeking background and their service providers. The use of triangulation between these groups provides a unique view of the current environment of oral health care for this population in South Australia. This research contributes to the currently sparse literature both in the field of oral health and wellbeing for this population, and in the area of patient and practitioner perspective driven research. For example, the finding that oral health practitioners have a deep understanding of the importance of trust with this population contradicts current literature that there is a lack of culturally appropriate care available (Nicol, Al-Hanbali, King,

Slack-Smith, & Cherian, 2014). The demographic variability in relation to age, gender, and country of origin of the participants with refugee backgrounds provided further strength to the research as it allowed consideration of these factors on participant responses and strengthen the recognition of themes across groups.

4.3 Limitations and Future Research

Two notable limitations of the study are in relation to the participant samples. Firstly, all six of the oral health professionals had extensive history of practice within the public system caring for refugee populations. Though this enabled the participants to speak of their experiences, it also means that the general population of practitioner's perspectives were not explored. Secondly, the participants with refugee and asylum seeker backgrounds showed particular interest in the study and were referred primarily through social organisations. This means that they are in contact with support organisations, and therefore may not represent a population with the highest health and access inequities. The same people that were not respondents to this research may also be missing opportunities for health care, which could explain the overall positive perspectives provided. Furthermore, though the refugee participants were of Middle Eastern background, this study has been unable to draw insight or perspective into how this may affect oral health and experiences of oral health care on settlement in Australia. Further recruitment was completed to enable a broader participant perspective, however, cultural heritage and country of origin where not significantly discussed by participants. The paucity of available literature means that the exploratory nature of this study has been unable to draw insight into this facet of refugee experience. It is imperative that further qualitative studies include refugee participants from other backgrounds in order to compare and contrast the experiences and gain further insight into how cultural heritage may influence these experiences.

A further limitation is the generalisability of this research to the greater Australian refugee population. Though Australia does have national oral health care plans and initiatives the services, both in the government and non-profit sectors, vary from state to state and as such the experiences may not be nationally representative. Furthermore, the sample size has generally prohibited the ability to comment on other individual factors such as gender and age. This study has however outlined aspects of oral health and wellbeing for this population that were previously unexplored. It is for this reason that further qualitative research into this area is required. Specifically, the perspectives of private practitioners should be explored to identify if there is a growing understanding in the profession of the needs of patients with refugee backgrounds, or if it is indeed the exposure of the participants in this study to the population that has provided them with insight.

4.4 Implications

This study contributes to the current literature concerning oral health, oral health care and wellbeing for refugees settling in Australia, and potentially globally. Most importantly, it has outlined the ways in which experiences of oral health care can impact the wellbeing of refugee participants. Although the study outlined the understanding of providers of the need for culturally sensitive care, which has been noted as lacking in previous literature, there still exists an opportunity for cultural training to assist them in their care of this population. It is possible that the simple exposure to refugee patients has encouraged and educated providers to find effective ways to service this population, however this does not equate to formal cultural-sensitivity training. Our study suggests that the level of cultural understanding shown by oral health practitioners improves the oral health care experiences of refugees as shown by generally positive experiences with practitioners. The education of practitioners could therefore improve

experiences and adherence to care and may begin to address oral health inequities faced by refugee populations in Australia, and in turn assist in the development of their wellbeing during and post-settlement.

This study also outlined a level of confusion or frustration from refugee participants in relation to expectations of care. It is imperative that refugees are provided with sufficient information and explanation of the importance of oral health care, and the services available to them in Australia. It is important that oral health education addresses the disruptions faced by refugees and supports the establishment of good oral health practices in Australia. Finally, the current study adds to the literature surrounding system level issues in the health care of this population, which undoubtably extends to oral health care. Most notably, the time and resource constraints of clinics and practitioners were identified as significant barriers to achieving appropriate oral health outcomes. The provision of timely and appropriate oral health care to refugees resettled in Australia is imperative to their wellbeing and continued health. The wait times experienced by participants of this study were considered unacceptable to them and hindered their achievement of good oral health outcomes. Such system level issues add to the oral health inequalities faced by this population, and specific attention should be made to reducing delays in treatment to assist in addressing such inequalities.

4.5 Conclusions

Despite Australia's commitment to and provision of oral health care for the refugee population, significant inequities remain (Riggs et al. 2014). The available literature on refugee health care describes the need for approaches that are culturally competent and uphold the rights of refugee patients (Finney Lamb, Klinken Whelan & Michaels, 2009). This study has outlined that practitioner participants have a deep and sympathetic understanding of the needs of their

refugee patients, which was specifically shown through their assertions of the importance of informed consent. However, it is re-iterated that this may not be reflected in the general population of oral health practitioners and highlights the need for enforced and supported cultural training. The experiences of refugee participants in this study support the finding that oral health status has a direct impact on wellbeing, and further asserts that experiences of oral health care also impact wellbeing. Generally, individuals seek oral health care due to pain or cosmetic factors, and the resolution of such issues in turn leads to improved wellbeing (Bilic et al., 2016), and this has been further evidenced by this study. Furthermore, this study highlights that for refugee participants it was the system level issues, such as prolonged wait times, that prevented them from achieving appropriate oral health care and negatively impacted their wellbeing. It is therefore essential that refugees are able to achieve appropriate oral health care in Australia that is both culturally sensitive and timely, and it is likely that the lack of such care will have consequences on overall wellbeing throughout their re-settlement (Curry, Smedley & Lenette, 2017). By documenting refugees experiences of settlement services, such as the provision of oral health care, we are able to identify possibilities for improved care and may begin to reduce health related inequities for this group.

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PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Exploring oral health, healthcare experiences and access to health services in Australia for refugees and asylum seekers

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: [redacted]

PRINCIPAL INVESTIGATOR: Dr Clemence Due

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project aims to consider experiences of healthcare in Australia, particularly oral health, for refugees and asylum seekers from the Middle East. We are also interested in help seeking for this group of people, and how best to provide support for them to access services.

The project involves an interview which will take around 60 minutes. We will ask you about your experiences working with people with refugee and asylum seeking backgrounds from the Middle East, including how best to support them to access services.

Who is undertaking the project?

This project is being conducted by Clemence Due, Briellen Beard, and Isadora Aldam at The University of Adelaide.

This research will form the basis for the degree of a Psychology Honours degree for Briellen and Isadora at the University of Adelaide under the supervision of Dr Clemence Due.

Who is being invited to participate?

You are being invited to participate if you:

- Are a healthcare practitioner (e.g., dentist, oral health practitioner)
- Are over 18
- Have worked with people with refugee or asylum seeker backgrounds from Afghanistan, Iran, Iraq or Syria in the past two years

What will I be asked to do?

You will be asked to take part in an interview in which will ask you some questions about your experiences working with refugees and asylum seekers from the Middle East, including a small number of questions about children if you have worked with children. This will take about 45 to 60 minutes, and we can do the interviews at a time and place which suit you, or over the telephone or skype. Interviews will be audio recorded and transcribed (typed up) by the researchers.

Are there any risks associated with participating in this project?

We do not think that the questions will cause any distress, or that there is any risk in your participation.

What are the benefits of the research project?

While there are no direct benefits to you in participating we hope that the research findings will increase understandings of community concerns and service experiences for refugees and asylum seekers in Australia.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time until the end of the interview.

What will happen to my information?

You will not be able to be identified in any publications. Only the researchers will have access to the data obtained in the project, and data will be stored for 7 years on a password protected computer and then deleted. If you are interested in the results of the project you will be able to access a report summarizing the main findings. The findings will be included in journal papers and reports and we will send you a copy of the report.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-071). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. Contact the Human Research Ethics Committee's Secretariat on phone +61 8 8313 6028 or by email to hrec@adelaide.edu.au. if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I have questions or want to participate, what do I do?

If you are interested in participating, please contact Clemence (clemence.due@adelaide.edu.au or 8313 6096) to ask questions.

Yours sincerely,

[redacted]

Isadora Aldam

Briellen Beard

Appendix B – Participant Information

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Exploring oral health, healthcare experiences and access to health services in Australia for refugees and asylum seekers

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: [redacted]

PRINCIPAL INVESTIGATOR: Dr Clemence Due

STUDENT RESEARCHERS: Briellen Beard and Isadora Aldam

STUDENT'S DEGREE: Honours Psychology

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project aims to consider your experiences of healthcare in Australia, particularly oral health or the health of your teeth. We are also interested in what sorts of experiences you have had in seeking healthcare in Australia.

The project involves an interview which will take around 60 minutes. We will ask you about your teeth, what sorts of experiences you have had in healthcare in Australia (for example, with dentists or doctors), and why you went to see someone about your health.

Who is undertaking the project?

This project is being conducted by Clemence Due, Briellen Beard, and Isadora Aldam at The University of Adelaide.

This research will form the basis for the degree of a Psychology Honours degree for Briellen and Isadora at the University of Adelaide under the supervision of Dr Clemence Due.

Who is being invited to participate?

You are being invited to participate if you:

- Came to Australia as a refugee or an asylum seeker
- Are over 18
- Arrived in Australia less than 10 years ago.
- Are from Afghanistan, Iran, Iraq or Syria
- Can speak English well enough to participate in an interview

What will I be asked to do?

You will be asked to take part in an interview in which will ask you some questions about your health, including your teeth, and physical and mental health. We will also ask what sorts of healthcare professionals you have seen in Australia, and why you chose to go and see them. If you have children, you will also be asked a small number of questions about your children's health. This will take about 45

to 60 minutes, and we can do the interviews at a time and place which suit you. Interviews will be audio recorded and transcribed (typed up) by the researchers.

Are there any risks associated with participating in this project?

We recognize that some of the questions may make you feel upset if you have had bad experiences with your health or healthcare in Australia. In order to help you if you do feel distress, we will give you a list of the contact details of organizations that can provide some support.

What are the benefits of the research project?

You will receive a $45 shopping voucher. While there are no other direct benefits to you in participating we hope that the research findings will increase understandings of community concerns and service experiences for refugees and asylum seekers in Australia.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time until the end of the interview.

What will happen to my information?

You will not be able to be identified in any publications. Only the researchers will have access to the data obtained in the project, and data will be stored for 7 years on a password protected computer and then deleted. If you are interested in the results of the project you will be able to access a report summarizing the main findings. The findings will be included in journal papers and reports and we will send you a copy of the report.

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-071). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. Contact the Human Research Ethics Committee's Secretariat on phone +61 8 8313 6028 or by email to hrec@adelaide.edu.au. if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I have questions or want to participate, what do I do?

If you are interested in participating, please contact Clemence [redacted] to ask questions.

Yours sincerely,

Dr Clemence Due

[redacted]

Isadora Aldam

Briellen Beard

Appendix C – Consent Form

CONSENT FORM

1. I have read the Information Sheet and agree to take part in the following research project:

Title:	Exploring oral health, healthcare experiences and access to
Ethics Approval	[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the researcher. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand the purpose of the research project, it has also been explained that involvement may not be of any benefit to me.

5. I agree to participate in the activities as outlined in the participant information sheet.

6. I agree to be audio recorded.
   ☐ Yes ☐ No

7. I understand that I am free to withdraw from the project at any time until data analysis.

8. I have been informed that the information gained in the project may be published in a journal article, Honours theses and a short report.

9. I have been informed that in the published materials I will not be identified and my personal results will not be divulged.

10. I am aware that my information will only be used for the purpose of this research and it will only be disclosed according to the consent provided, except where disclosure is required by law.

11. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: _____ Signature: _____ Date: _____

Researcher/Witness to complete:

I have described the nature of the research to _____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____ Position: _____ Date: _____

Appendix D- Interview Schedule

Questions for Participants of Refugee and Asylum Seeking Backgrounds

Demographic questions:

Age, Gender, Children, Marital status, Country of origin, Length of time in Australia, Visa status, Private healthcare, Cultural and ethnic background, Level of education

Oral health status and practices:

1. Can you tell me about what you do to care for your teeth?
   - What do people in your broader community do to care for their teeth?
2. Are you satisfied with your dental health?
   - Why/why not
   - Are you experiencing any dental issues?
3. Prompt for children if applicable

Oral health beliefs, QoL and wellbeing

1. How do you think that your dental health impacts your wellbeing?
   - In what ways?
   - Prompt for children's dental health and wellbeing if applicable

Previous use of dental services

1. Have you accessed dental services in Australia?

   IF YES:

   - How often (e.g. per year) do you (and your family) access dental health services?
   - How does this compare to your use of other services?
   - Who within your family or close social circle used dental services? Is it everyone or only some members, and why?
   - For what reasons have you (and your family) used dental services? (i.e. regular check-ups, critical situations)

     IF NO:

   - For what reasons have you not accessed dental services?

     Prompts for psychological factors:

     - How do you feel about seeing a dentist?
     - In your home country, is it common for people to use dentists?

- Do you think it is different seeing a dentist here compared to other countries?

  Prompts for practical factors:

- Do you know about dental services that are available to you?
- Do you feel that you are able to get to dental appointments?
- Do you think that dental services are affordable?

2. Had you accessed dental services before coming to Australia?

   IF YES:

   - How often did you (and your family) access dental services?
   - How did this compare to your use of other services?
   - Who within your family or close social circle used dental services? Was it everyone or only some members, and why?
   - For what reason did you use dental services

     (i.e. regular check-ups, critical situations)?

     IF NO:

     Prompts for psychological factors:

   - For what reasons did you not use dental services?

     Prompts for psychological factors:

     - How did you feel about dental services in your home country?
     - Did any experiences or heard stories make you not want to see a dentist?

     Prompts for practical factors:

     - How easy was it to access dentists?
     - Did you know about dental services that available to you?
     - Were dental services affordable?

<u>Help-seeking</u>

1. How important do you think it is to go to the dentist?
   - How important do you think it is compared to other healthcare services?
   - Why do you think this?
2. How easy or hard do you find it is to go to the dentist?
   - How about compared to other healthcare services
   - Why do you think that is?
3. What are the barriers that you find prevent you from accessing a dentist in Australia?

   Prompt for psychological factors:

- How do you feel about going to see a dentist?
- Do you have any worries about seeing a dentist?
  Prompt for practical factors:

- What do you know about available dental services?
- What do you think a dental appointment might be like?
- Do you feel that dental services are culturally appropriate?
- In what ways might language effect your use of dental services?
  Potential further prompts:

- Cost/childcare/transport

4. What would help you to access dental services more easily in Australia?
   Prompt for psychological factors:

   - Is there anything that would make you feel more comfortable about seeing a dentist?
     Prompt for practical factors:

   - Do you feel that you have enough information about dental services?
   - Is there anything that might make appointments more culturally appropriate?
     Potential further prompts:

   - Cost/childcare/transport

<u>Experiences with dentists and dental services</u>

1. Can you tell me about your experiences with health care services in Australia?
2. Can you tell me about your experiences with dental services in Australia?
   - Did you see a dentist on arrival to Australia? If yes, how did you find that experience?
   - Have you felt satisfied with these experiences in Australia?
   - How did the oral health practitioner (dentist or other) make you feel?
     (Comfortable? Welcome? Cared for? Happy?)

   - How do dentists make you feel like you can trust them?
   - What other things made your experience more positive or negative?
     (Availability of interpreters? Affordability?)

3. How did you find out about the dental healthcare providers that you have seen?
4. What would make you want to go back to see that dentist?
   - What does appropriate care mean to you?
5. What impact(s) have these experiences had on your wellbeing?

6. How have your experiences with dental services compared with previous healthcare experiences in Australia or other countries?

Recommendations

1. What would you recommend for dentists to provide better care for you and others in your community?
2. What about on behalf of the government or other groups?

Questions for Oral Health Practitioner Participants

Prior experience and expertise

1. Can you tell me a bit about your career and work so far in general?
2. Can you tell me about your experiences with clients from refugee and asylum seeking backgrounds?
   - Prompt for: years worked, type of work, client demographics
   - Do you necessarily know if clients have a refugee background?

Oral health and health status among refugees and asylum seekers

1. To what extent do you think that oral health impacts quality of life or wellbeing for these clients?
   - *How* do you think oral health impacts this?
   - Do you think that oral health issues are different for these clients compared to those without refugee or asylum seeking backgrounds?
   - Are there any particular cultural considerations?
3. Do you think that people's experiences with oral services impact their wellbeing?
   - How is that so? What is or isn't important?

Help seeking

1. At what stage of care do you typically see these clients? (E.g. preventive, acute symptoms)
   - Does this differ to other types of clients?
2. What do you believe are the barriers that people of refugee and asylum seeking backgrounds face in accessing dental services?
   - Prompt for individual (e.g. demographic) and system level factors (e.g. cost)
3. What do you believe helps these clients to access dental services?
   - Prompt for individual (e.g. demographic) and system level factors (e.g. cost)

Experiences working with refugees and asylum seekers

1. What are some of the challenges that oral health practitioners in general face when working with clients of refugee or asylum seeking backgrounds?

- Prompt for language barriers, cultural differences, cultural/trauma training

2. What are some of the challenges that you specifically have faced working with this group?
3. What sorts of initiatives or processes are in place for the retention of refugee clients where you work or know of?
    - How do you make sure clients feel comfortable enough to return?
4. What do you think support is like for refugees and asylum seekers to access dental services in Australia?
    - Do you think there is sufficient support? Why or why not?

<u>Future recommendations</u>

1. How do you think we can improve access and experiences with services for these clients?