



**Father's Experiences of Access to Oral
Health Care Services for Children with
Disabilities in the Kingdom of Saudi Arabia**

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In the Name of God, Most Gracious, Most Merciful

I would like to dedicate this thesis to:

My beloved parents “Abdulrahim” and “Saliha”

Your endless support, love and prayers are the reasons for my successful achievements in my life

My wife “Sara”

Your presence beside me the whole period of my studies to give me strength, your continuous emotional and moral support and encouragement kept me going pursuing my dreams

For my son “Amir”

For being the source of joy and happiness in my life

And my entire brothers and sisters

For your support, advices and prayers

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Abstract

Background: Children with disabilities experience poorer oral health and have higher oral health needs than their non-disabled peers. The poor oral health status of children with disabilities has been attributed to a variety of factors; from chronic diseases and conditions, to the varying knowledge and negative attitudes of oral health providers. Other barriers include accessibility and availability of oral health services, the skills of oral health professionals, and family support to maintain oral health. Access to oral health services would also appear to be an issue, but it has not explored in depth. This thesis employed a city in the Kingdom of Saudi Arabia as a case study to explore the ways that fathers of children with disabilities access oral health services.

Methods: Ethnography was used as the methodology and this involved observation of 4 dental settings, interviews with 25 participants and 2 focus groups with 13 participants in total. All interviews were carried out in Arabic, recorded and transcribed where possible and then translated from Arabic to English. Thematic analysis was used to identify themes.

Results: Parents, mainly fathers, of children with disabilities acted as gatekeepers for accessing oral health care services. Saudi culture played an active role in accessing oral health services because *wasta* (is a form of connection, contact, network and nepotism) and social networks were identified as means to ease the process. Affordability, availability, accessibility and geographical location of services were an issue within Al-Madinah and related to an inequitable distribution of services and resources.

Conclusion: Overall, the findings of this thesis suggest that access to oral health care services for children with disabilities in Saudi Arabia exhibits some similarities to the evidence base, but there are also differences to access compared to those described in western countries. The differences could be attributed to lack of oral health policy and guidance for children with disabilities, cultural perspectives around oral health and service provision within the Saudi community and structural contrasts in commissioning and oral health service provision in the Kingdom of Saudi Arabia.

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Preface

Oral health inequality is a major issue around the world for people with disabilities (Silver and Stein 2001; Gondlach *et al.* 2019). Oral health needs appear to be the second highest in frequency of needs for children with disabilities (Lewis *et al.* 2005). Oral health needs for children with disabilities appear to be higher than their peers in the general population (Scully and Kumar 2003; Hallberg *et al.* 2004; Cooper *et al.* 2004; Paschal *et al.* 2016; Lewis 2009), and there is a lower reported access to oral health care services (Hennequin *et al.* 2008; Oliveira *et al.* 2013). Adults and children with disabilities appear to encounter a variety of barriers when accessing oral health care services (Hernandez and Ikkanda 2011; DeMattei *et al.* 2012).

Studies around children with disabilities tend to focus on the medical conditions and the treatment of oral disease, such as treating oral lesions (Ricketts *et al.* 2013; Marinho *et al.* 2013). In contrast, there appears to be a paucity of research around parents' role in accessing oral health care for children with disabilities, even though parents play a major role in accessing services. Currently, there are no studies that explore this area in Saudi Arabia.

It is relevant to note that no study in the Saudi Arabia, or globally, that has explored access, using Penchansky and Thomas's definition, from the perspectives of parents, and particularly fathers. This highlights a gap in the literature. This thesis plans to address that gap by exploring in depth the different perspectives including the perspective of parents of children with disabilities, particularly fathers, around access to oral health care services.

Therefore, the main question for this thesis is:

In what ways do fathers of children with disabilities experience access to oral health care services in the Kingdom of Saudi Arabia?

Thesis structure

Chapter 1:

This chapter reviews the literature around access to oral health for children with disabilities. It positions them as a marginalised group who are subject to oral health inequalities, discussing the concept of access and the ways it links to quality and continuity of care. It also discusses how social capital is related to barriers and facilitators of access for children with disabilities.

Chapter 2

This chapter introduces the Kingdom of Saudi Arabia and contextualises the study by discussing, religion, culture, the structure of Saudi health system and differences between the various provinces. It focuses down on perceptions of disability in Saudi Arabia and the oral health care needs of children with disabilities within the Kingdom. It also discusses the structure and delivery of oral health services.

Chapter 3: Methodology

This chapter justifies the reasons for choosing ethnography as the methodological approach by comparing and contrasting it with other qualitative methodologies. From methodology, the chapter discusses the sampling method and data analysis. It then proceeds to discuss the different ways qualitative research ensures credibility.

Chapter 4: Methods

This chapter is a practical account which begins with the search for literature and then proceeds to the ways data was collected, transcribed, translated and analysed. The chapter also highlights the various difficulties encountered during data collection and translation of the data and how these were overcome. The section on reflexivity explains my own position as a researcher. The chapter finishes with ethical considerations.

Chapter 5: Mapping the oral health care services within Al-Madinah

This chapter focuses on the site where the research occurred and provides an overview of the geographical location and the accessibility of oral health care services for children with disabilities in Al-Madinah, including public and private services. It describes oral health care services generally for the region and then proceeds to describe each centre visited during data collection.

Chapter 6: Results and Analysis: Pathways of access to Oral health care services for children with disabilities

This chapter presents the findings that are related to access from the perspectives of dental professionals and dental students. Penchansky and Thomas' model of access was used as a framework to view the data and assist in identifying barriers and facilitators of access to oral health care services for children with disabilities. The chapter identifies the presence of a variety of barriers from the perspectives of dental professionals and dental students. Furthermore, this chapter illustrates the referral system and its usefulness as a way to overcome those barriers to oral health care services for children with disabilities.

Chapter 7: Results and analysis: The experience of parents of children with disabilities around access to OHC services

This chapter presents the findings of the study from the perspectives of parents. These perspectives compared and contrasted with those of dental professionals and students. Some of these barriers are similar to those identified in chapter 6 such as: affordability and availability of dental appointments. On the other hand, this chapter highlights other barriers that are related to the parents of children with disabilities, which are: parents' attitude toward dental professionals, parents' act as gate-keepers and parents' oral health literacy. The chapter introduces *wasta* as a way of facilitating access to oral health care services for children with disabilities. *Wasta* can be a barrier and a facilitator of access to oral health care. Crucially, it may also widen inequalities for those who have smaller networks to draw upon and can also be linked to social capital.

Chapter 8: Discussion, Recommendations and Conclusion

This part of my thesis summarises and discusses the main findings of the study and links it to the wider literature, while highlight what this thesis adds to the current academic literature. It adds to the current evidence base because it includes the voices of fathers. In focusing on parent's experiences in Saudi Arabia and exploring access to oral health care services from different perspectives, it offers a wider understanding about how oral health services operate for children with disabilities in the Kingdom of Saudi Arabia. The thesis highlights different barriers to accessing oral health care and suggests ways of overcoming these barriers whilst taking into account the cultural context in Saudi Arabia.

Chapter 1:
Background and
literature review

1.1. Introduction

This thesis is about access to oral health services for children with disabilities. Disability is a term used within various contexts. It is considered a broad term describes the impairment of individual's ability (WHO 2011). Various organizations attempt to define disability such as the Disability Discrimination Act (1995), which defines a disabled individual as *"a person with physical or mental impairment which has a substantial and long term adverse effect on his ability to carry out normal day to day activities"* (p.3). A similar definition of disability has been embraced by the American with Disabilities Act of 1990 (ADA), which was *"the term disability means, with respect to an individual, a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such impairment or being regarded as having such impairment"* (ADA 2008, p.2).

On the other hand, the international classification of functioning (ICF) defines disability as umbrella term for impairments, activity limitations and participation restrictions (WHO 2001, 2002). An impairment is defined as the ability of individual's body to normally function while activity limitations considered as the difficulties faced by individual when doing anything, while participation restriction referred to the obstacles faced by individual when countering various life events (WHO 2011). Disability is a complex term describing a complicated phenomenon, and it reflects the daily interaction between biological body of a person and both environmental and social conditions that surrounds him (WHO 2015).

The generalization of disability can be misleading, since disability or people with disabilities are highly diverse and they are not present as a homogenous group (Smiley 2005). Each individual with disability has a different experience depending on the interaction of several factors. These factors could be environmental, social, economical, psychological, biological conditions of the person, age, religion and ethnicity (WHO 2011). Disability as a term could include a wide range of disabilities such as a child who born with hereditary condition like Down syndrome to an old individuals with dementia (Bickenbach 2011).

The World Health Organisation (WHO) documents that there are about 1000 million people with disabilities globally; this is approximately 15% of the worldwide population, with up to 190 million adults classified as having a severe disability, which is about 2.9% (WHO 2015). There are about 93 million disabled children with severe or moderate disabilities, and that is about 1.4% of the worldwide child population (WHO 2015). It appears that disability is associated more with at risk populations (Lee 2003), such as those in low-income countries and with a low socioeconomic status (SES) (WHO 2004; WHO 2011). For example, the World Health Survey reported that the range of disabled individuals among low-income countries to be 18% of their population compared to 11.8% in high-income countries (WHO 2004).

In September 2000, the United Nations (UN) endorsed a framework for development in the form of Millennium Development Goals (MDGs) (United Nations 2000) and in 2015 Sustainable Development Goals (SDGs) (United Nations 2015). Whilst several MDGs relate to health, almost all SDGs are health related. The 8 MDGs, are; eradicating extreme poverty and hunger, empowering women and promoting equality, achieving universal education, improving maternal health and reducing child mortality, combating diseases, ensuring environmental sustainability and developing global partnership, came to the end of their term in 2015 and 17 SDGs took their place (WHO 2015). SDGs address many health-related issues through promoting health and healthy lifestyles, simultaneously broadening the scope of action across three areas of sustainable development; economic, social and environmental. So, for example, reducing poverty, inequality, creating the circumstances for economic growth to occur and increasing population health are now seen as interlinked and interdependent. This means a greater focus is necessary on partnerships, collaboration and inter-sectoral development and working, it also means a move away from a vertical approach to development and towards ways of addressing the needs and priorities of different countries. The WHO works in partnership to support and achieve SDGs and previously argued that *'If countries are to sustain and accelerate progress towards the MDGs, people need equitable access to a health system that can deliver high quality services, where and when they are needed'* (WHO 2010, p.4). It would appear that

access to quality health care is essential to maintaining the goals. Moreover, SDGs place accountability for non-communicable diseases at country level by monitoring specific health targets. Paragraph 26 of the 2030 agenda for sustainable development in health states; '*We are committed to the prevention and treatment of non-communicable diseases, [...] which constitute a major challenge for sustainable development*' (UN 2015, paragraph 26.). Poor oral health, for example dental caries and periodontal disease are non-communicable diseases and therefore largely preventable (Casamassimo *et al.* 2009).

Research suggests that children with disabilities have greater unmet health and oral health needs than their non-disabled peers (Halberg *et al.* 2004; Lewis 2009). In addition, they are more likely to visit health care services than their peers. For example, a study, reported that children with disabilities (3 to 17 years old) were nine times more likely to access health care services (Altarac and Saroha 2007). This study sample was about 6 million children, but it was based on responses from a national US survey, which means that it was limited by the answers provided by parents, carers, health professionals and teachers without having further details. However, this study represents a conservative estimate of the outcomes since it was reported by an objective third party.

It appears that accessing health care services, including oral health care services, is an important aspect to maintaining good general and oral health for children with disabilities. In addition, parents and carers as guardians play a role in accessing services. Whilst most research tends to take a biomedical position and focuses on treating oral diseases of children with disabilities such as preventing or treating decayed teeth (Ricketts *et al.* 2013; Marinho *et al.* 2013), the role of parents and carers in maintaining good oral health and accessing oral health care services appears to be an area that receives little attention. While the biomedical aspect and ways of offering and carrying out treatment is important, the social aspect also plays a major role in shaping, eliminating barriers and facilitating good oral health for children with disabilities. This focus on treatment and barriers tends to neglect the roles of parents and carers in maintaining optimum oral health. It can therefore be

suggested that there is a paucity of research, which explores the perspectives of parents around accessing oral health services for children with disabilities.

1.2. Determinants of health.

A determinant has been described by Porta (2008) as “*any factor that brings about change in health condition or other defined characteristics*” (p.101). In addition, John (2001) defines a determinant as “*an attribute or exposure that increases the probability of occurrence of disease or other specified outcome*”. While determinants of health influence the health and the oral health of the population or a community, they refer to the many factors that combine together to eventually influence and shape the health of communities and individuals (WHO 2019). These various factors include social and economic status, level of education, environment conditions and many other factors. Oral health should be seen as part of general health and the FDI World Dental Federation has recently changed its definition from one that is focused on an absence of disease to one that recognises that oral health does not occur in isolation but is embedded in the wider framework of overall health (Glick *et al.* 2016). This takes a new position on oral health because it integrates it as part of general health instead of separating the mouth from the body. The separation of oral health from general health and indeed from the body was first noted by Nettleton (1992) and is considered a limitation on the progression of modern dentistry due to the focusing of dental research on the biological aspects of the disease (Daly *et al.* 2013, Mertz 2016; Simon 2016). Focusing merely on the biological aspects of disease means that other more political and social issues which construct health and oral health as a fundamental human right, as argued in the FDI’s strategic plan, ‘*Vision 2020*’ tend to be minimised or even forgotten (Glick *et al.* 2012). The new definition of oral health produced by the FDI recognises that oral health is multi-faceted and a product of complex interactions which in turn affect health outcomes. In order to improve health outcomes, research and guidance argues that we need to tackle the determinants of health (WHO 2008; Bambra *et al.* 2010; Daly *et al.* 2013). Tackling the various determinants of health and oral health across

society is considered to be a core function of dental public health and it has become the focus of various governments across the world (WHO 2011).

1.2.1. Social determinants of health

The social determinants of health have been defined as the conditions of the environment, in which people are born, grow up, live, work and aged alongside the systems put in place to deal with illnesses (Marmot 2005; WHO 2019). The social determinants of health are responsible for varying levels of health inequity. Inequalities are the differences in health status, or differences in determinants between individuals and groups, while Inequity is when these differences can be seen as avoidable or unfair (Whitehead 1991; Kawachi *et al.* 2002). Some aspects of inequality are produced by natural biological differences, genetics or free choice and others are frequently beyond the control of individuals or groups. As far back as the 1980s the Black Report argued that numerous social inequalities influenced health, these were income, education, housing, diet, employment, and conditions of work (Berridge and Bloom 2002). Unfortunately, the Black report was politically unpopular at the time and although it focused entirely on inequalities as the root cause of ill health it was quietly placed on one side. The Acheson Report followed, and this repeated the findings of the Black Report, although the political situation had changed and it was received more favourably, further arguing in favour of prioritising the health of families and children (Acheson 1998). In 2008, Sir Michael Marmot led the Global Commission on the Social Determinants of Health Report, which suggested that social and economic inequalities were key factors in helping to determine health outcomes (WHO 2008).

There have been different frameworks and diagrams that elaborate the effect of the social determinants on health, one of these models is often called the policy rainbow and was introduced by Dahlgren and Whitehead in 1991. Dahlgren and Whitehead's (1991) framework provided a visual representation of the major factors that affected the health of the population (Graham 2009). It emphasised the importance of the social determinants of health, which

included several social, environmental and cultural conditions to promote and maintain the oral health of a population (Daly *et al.* 2013). This model shows the main social determinants in concentric curves surrounding the individual as shown in figure (1).

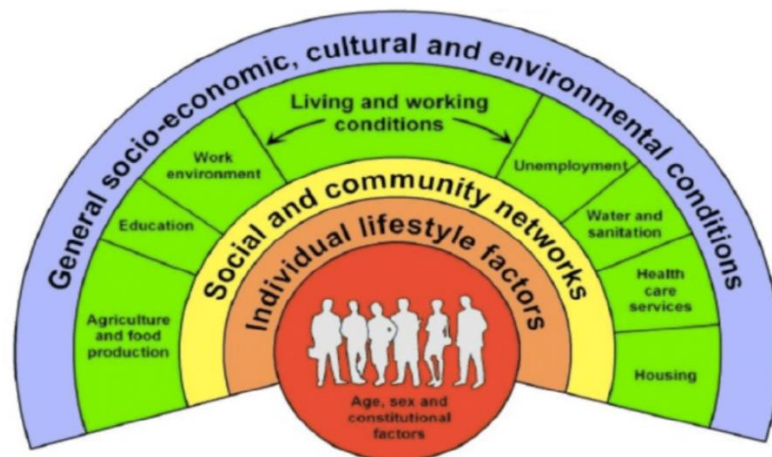


Figure (1). Dahlgren and Whitehead framework

(Dahlgren and Whitehead 1991)

Dahlgren and Whitehead's model represents the relationship between individuals, their environment and their health. This model suggest that health is determined by various, multiple and inter-related variables and it ranges from innate factors to social and cultural influences and environmental conditions (Estacio 2006). The model places individuals at the centre, surrounded by layers of influences on health. Influences on health can all be modified, for example, individual lifestyle factors can be modified by behavioural change; living and working conditions can be ameliorated by more political means alongside more general socioeconomic and cultural conditions. This model has helped researchers to produce a variety of hypotheses about the social determinants of health and explore the influence of relative factors on various health outcomes. Dahlgren and Whitehead's model has been useful in raising questions about the magnitude of the contribution of each layer on health and the actions needed to influence various factors in other layers.

A more recent updated model has been adopted for Healthy People 2020 (figure 2) to pursue their overarching goals. The overarching goals for Healthy People 2020 are:

- Eliminating any preventable disease, disability, injury and premature death.
- Achieving health equity, reducing and eliminating disparity and improving the health of all individuals.
- Promoting good health via creating healthy social and physical environment.
- Encouraging and promoting healthy behaviours and development across all life stages.

(US Department of Health and Human Services 2008)

However, an action model has been used by Healthy People 2020 through assessing, monitoring and implementing interventions as a continuous process to achieve the above-mentioned overarching goals.

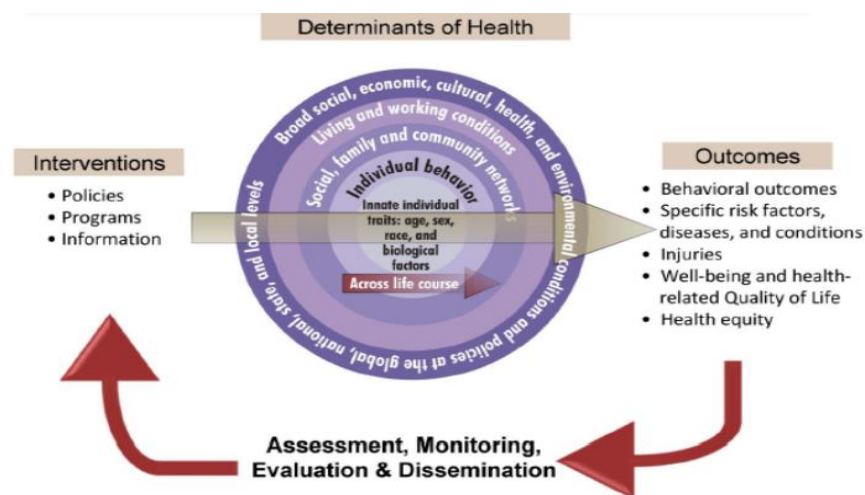


Figure (2). Model to achieve Healthy People 2020 overarching goals

Source: US Department of Health and Human Services

This model locates the individual at the centre, surrounded by a layer of social and familial networks. The next layer highlights the living and working conditions and the outer layer represent broad social, economic, cultural, health and environmental conditions. This framework differs from that of Dahlgren and Whitehead because it shows the interventions that can be made

to modify outcomes while simultaneously illustrating the need for a constant assessment, monitoring and evaluation process to maintain health. It also illustrates that changes and interventions through time are able to achieve desirable health outcomes as it is demonstrated in the diagram using arrows emerging from interventions through concentric layers of various wider determinants to reach the outcomes. 'Healthy People' 2020 also differs from Dahlgren and Whitehead's model in that it takes a life course approach to illustrate that various factors exert an influence over the lifetime of an individual.

Although these models differ in shape, style and complexity, they represent health as the product of a complex interplay of social impacts at both the individual and the population levels. These models help to explain the complex relationships produced by the social determinants instead of looking for direct causal pathways, which fail to explain how social experiences and structures are related to health status.

Although people live their life in various social contexts, the quality and the quantity of these social determinants and the fairness of their distribution determine the differences in their health on population and community level. People's health status is determined by the environment that surrounds where they live and work (Wilkinson and Marmot 2003). Thus, having different health status among people is considered a result of living very differently in a variety of social contexts, which suggests that reducing health inequalities means addressing the differences in the social contexts that people encounter in their daily lives. The next section gives examples, which illustrate how the social determinants may influence the oral health of people including children with disabilities.

1.2.2. Social determinants of health and health inequalities

The social gradient of health is a term used to describe a phenomenon where the more disadvantaged people are, in terms of their socioeconomic status, experience worse overall health status than those with greater resources

(Marmot 2005; Donkin 2014). The social gradient in health is generated by the effects of the social position of an individual in a community where the occurrence and progression of illnesses can be seen at each level of the social hierarchy with poorer health statuses present among people with lower social positions in the social hierarchy (Lopez *et al.* 2006). A marked social gradient has been illustrated through health inequalities; where differences in health status are associated with the socio-economic status (SES) of an individual (Marmot and Bell 2012). This suggests that people with a high social hierarchy and SES have better health status than those in the lower social hierarchy and poor SES. For example, Marmot *et al.* (1991) in the Whitehall study II examined longitudinal health inequalities among 10,314 British civil servants using a questionnaire and a physical screening examination. They reported the presence of a social gradient between SES and health and concluded that health improves, and mortality decreases with each increment of social grade. This research was used as evidence to argue in favour of tackling the social determinants of health in order to achieve health equity and reduce the inequalities created by social class divisions (Marmot and Bell 2012).

Different social indicators are used to reflect the SES of an individual amongst the academic literature for different countries. These indicators include level of education, income and occupation and are used to underline the relationship between health and oral health and SES (Sabbah *et al.* 2009; Kumar *et al.* 2009). Using a variety of social indicators can lead to confusion and differing results in studies. For example, on particular study by Kumar *et al.* (2009) in India where they recruited 171 children with Down syndrome or cerebral palsy aged 8-19 years old attending special schools. They documented the demographic and social data for each child, carrying out an oral examination and checking their periodontal status. The study reported poorer oral health status among children with disabilities whose parents had lower levels of education, SES and income. One of the main limitations of this study is the strict linking of oral health status to social factors and ignoring the roles of other factors such as affordability, availability and the ability to utilise oral health care services and whether there was any presence of oral health promotion.

Since the social determinants of health influence the lifestyle of individuals and their development and access to work, it would be reasonable to suggest that these same determinants affect the health of young children and their way of living (Daly *et al.* 2013). One explanation for this is children living in families with higher socioeconomic statuses are more likely to access medical and preventive dental care with greater ease because they have access to more resources (Cohen *et al.* 2010). Resources can be educational, financial and social. In contrast, young children of families with a lower socioeconomic status could be affected through their exposure to lower standards of education, poor housing conditions, poor nutrition, and income insecurity, which then persists across the life course (Sen 2001). This suggests that inequalities are cumulative and increase throughout transitions in life.

Children with disabilities are considered to be a marginalized group because they frequently experience social exclusion by being undermined and restricted from participation in their community to the same extent as their peers who are not disabled (Maulik and Darmstadt 2007; Farrugia 2009). For example, children with disabilities may be prevented from taking part in leisure and creative activities in their communities because of a lack of support for their families, lack of provision, or because of discrimination, which is linked to the fact they are disabled (John and Whewey 2004; Shields and Synnott 2016). These inequalities can also link to health and oral health. There are different explanations for the relationship between oral health inequalities and poor oral health status among children with disabilities. This next section will highlight the main explanations.

1.2.3. Explanations of inequalities

The main explanations for inequalities in health and oral health fall into three main areas; the material, the behavioural and the psychosocial. This next section uses the three main areas as frameworks within which to explore the links to oral health.

1.2.3.1. Material or structural conditions

Material or structural conditions have a direct impact on health inequality and may be linked to the surrounding environment and unequal access to resources such as goods and services (Lynch *et al.* 2000). Examples of poor material resources are an unequal distribution of poverty and wealth; absolute or relative poverty; poor access to education and educational opportunities; insecure employment; poor working conditions related to many manual occupations; poor quality or crowded housing; inadequate diet and other aspects of daily life (Mackenbach 2005).

If we consider a material explanation of oral health, we can infer that this relates firstly to purchasing power for food to enhance oral health status (Sisson 2007). For example, families with low SES tend to purchase low quality foods that are saturated with fats and high in sugar (Thompson *et al.* 2009). High sugar intake is considered a risk factor for caries development (Mobley *et al.* 2009; Nunn *et al.* 2009; Chaffee *et al.* 2015). This may also be the result of having a low income and less accessibility to high quality food, because low quality foods are frequently cheaper than health enhancing foods such as fruits and vegetables (Turrell and Kavanagh 2006; Harrington *et al.* 2009; Layte *et al.* 2011). Having a balanced and healthy diet ensures that the right nutrients are present to maintain positive health (WHO 2003; Lloyd *et al.* 2011). Furthermore, there is evidence to suggest that children who are from deprived backgrounds are more likely to miss meals and experience poorer nutrition than children from families who do not experience deprivation (Kristjansson *et al.* 2007; Utter *et al.* 2012). This is of particular importance for children with disabilities who frequently live on or below the margins of poverty (Tinson *et al.* 2016; Equality and Human Rights Commission 2017). Secondly, the high cost of dental treatment can pose an obstacle to people with a low SES and prevent them from accessing oral health care services (Watt *et al.* 2015; Cookson *et al.* 2016). However, the material explanation has been questioned because it is not able to fully explain the relationship between inequalities and health. It has been argued that inequality would still persist in a community even if there was an increase in wealth and more equitable living conditions

(Wilkinson 1996). This hints at wider factors that exert an effect on health and in order to obtain a fuller picture, other explanations have been proposed. The next section will discuss the behavioural and cultural explanations.

1.2.3.2. Behavioural/cultural explanation

The behavioural explanation explains inequalities in health by the differences in norms, values and habits between people with low SES and people with high SES (Smith *et al.* 1994). According to this hypothesis, there is an inverse relationship between socioeconomic status and health impairing behaviours such as increased use of tobacco; alcohol consumption; lower levels of exercise; poorer diet and excess weight (Beckfield 2004; Polk *et al.* 2009; Pampel *et al.* 2010; Singh *et al.* 2013). Consequently, people with low SES have worse health when compared to people who have a higher SES (Sanders *et al.* 2006). This explanation fails to include the motivational factors, or the influence of the family and the social networks which may influence a person to adopt different behaviours.

Bartley (2004) further argues that people with a low SES adopt risky behaviours as a result of cultural influences. Using this argument, it could be implied that culture plays a role in people adopting either positive or risky behaviours. Adopting positive or utilising risky behaviours appear to be influenced by social norms and cultural habits, and these norms and values vary between different SES groups in any given society (Sisson 2007). For example, a comparative study of health inequalities between European countries and the USA suggested that social class was heavily implicated (Kunst 1997). The study involved the use of a longitudinal approach where they measured the SES of participants and followed them overtime. Where there was no available data, the researcher used unlinked cross-sectional studies and case studies. Some of the findings suggested that there were greater inequalities in terms of mortality between social classes in Sweden and Norway than in Italy. Although, Bartley (2004) argued that *“having a healthy diet was not some kind of special kind of lifestyle..... so, eating fruits, salads and olive oil was not seen as any kind of lifestyle choice and therefore was not*

associated with social advantage or disadvantage” (p.74). This suggests that having a healthy diet is a part of social norms and habits among societies where culture influences the eating behaviour of a particular society.

In relation to oral health, behavioural explanations suggest that people of a lower SES engage in clustering of risky health behaviours such as: consuming sugary food (Sabbah *et al.* 2015), decreasing brushing habits (Singh *et al.* 2013), low attendance to the dental care services and only attending when pain (Polk *et al.* 2009). All of these health-damaging behaviours are associated with an increased risk of oral disease development and this is frequently present among people with a low SES (Duijster *et al.* 2017).

However, it is important to consider many variables and different factors to explain and interpret SES and the social gradient in relation to health and oral health (Sanders *et al.* 2006). It appears that this can be done by utilising the different explanations (material, social/cultural and psychological explanations) to achieve a better understanding of this phenomenon. The next section will address psychological explanations in relation to the social gradient of health.

1.2.3.3. Psychological explanation

The psychological explanation for health inequality recognizes that the social environment plays a role in influencing individual behaviours (Elstad 1998). It highlights the role of social networks in providing social support, which is beneficial to health (Sisson 2007). In addition, it suggests that health inequalities result from differences in experiencing psychological distress among various social groups within a social hierarchy.

The psychological explanation suggests that psychological stress affects the health of individuals negatively in two ways: via direct and indirect pathways (Elstad 1998). The direct pathway is when psychological stress exerts an impact on the development of disease. For example, studies suggest that high levels of psychological stress are associated with a higher prevalence of periodontal disease and slower wound healing processes (Genco *et al.* 1998;

LeResche and Dworkin 2002; Vettore *et al.* 2003). There is a lack of clarity about how this mechanism works (Trombelli *et al.* 2005), but it has been suggested that psychological stress activates the neuroendocrine system and the hypothalamic-pituitary-adrenal axis, leading to a reduction in the activity of the immune system (Breivik *et al.* 1996). This process results in increasing the level of infection and reducing the healing process. The indirect pathway is expressed via adopting health damaging behaviours (Eltad 1998). For example, psychological stress may indirectly lead people to indulge in health impairing habits such as increasing the frequency and intake of sugary snacks, which increase the risk of developing dental caries through the number and type of acid attacks on the teeth (Sisson 2007).

However, Duijster *et al.* (2018) did a cross sectional study where they used data from the fifth wave of the Gezondheid en Levens Omstandigheden Bevolking Eindhoven (GLOBE) cohort study. The GLOBE study started in 1991 in the Netherlands; it recruited 4886 participants with an age range of 15-74. Participants were recruited from 18 municipal population registers in Eindhoven city and the surrounding villages. Duijster and colleagues used the collected data from the fifth wave of the GLOBE cohort study (2014), and posted a questionnaire to 10,668 individuals. The questionnaire was developed to obtain data on material factors (such as financial difficulties), behavioural factors (such as smoking), psychological factors (such as psychological distress), and a self-reported oral health including number of teeth. The study had 45.8% responses (n=4851). The authors found that material, behavioural and psychological factors were important in explaining SES inequalities in oral health. However, a complete understanding of inequality in oral health has not been achieved because it did not include many other explanatory factors such as; working conditions. In addition, it could not employ a life course approach to explain inequality in oral health because it lacks the presence of longitudinal data.

1.2.4. Life course approach and health inequalities

One further explanation for oral health inequalities is the life course approach, which highlights the interaction of different factors over time. The life course approach presents health at any age as an outcome of not only the current condition but also the presence of the previously living conditions that are experienced over time since birth (Kawachi *et al.* 2002). Furthermore, the events that happen during the life of an individual, which can be viewed as advantages or risks, will influence the health of the individual by lowering or increasing the risk of adult disease (Ben-Shlomo and Kuh 2002). These risks can be biological or social (Thomson *et al.* 2004). Biological means during the gestational period or during early childhood while social refers to the socioeconomic conditions during the adult life, which are the social circumstances and individual behaviours and choices that may affect health. An example of events during the gestational period, which may affect health is poor foetal nutrition may lead to a lower birth weight and make the child more vulnerable to disease in later life (Graham 2002).

There are three main conceptual models that have been widely used within the life course perspective, and they are the accumulation model, the critical period model and the pathway effect model (Graham 2002; Nicolau *et al.* 2003). The accumulation model is concerned with health effects that result from exposure to long-term conditions or life events, which affect health status of individuals (Arcaya *et al.* 2015). These exposures can affect people's lives either through the continuous presence of the risks or by the layering of various risks and exposures throughout the life of an individual (Pearlin *et al.* 2005). There are two main fields within accumulation models, which are the accumulative risk model and the cumulative advantage and disadvantage model. The accumulation of risk model is concerned with the sum of risks and negative life events during the life course of an individual. In addition, the ways that these negative exposures influence the health outcomes during the life of an individual (Burton-Jeangros *et al.* 2015). The second model is the cumulative advantage and disadvantage model, which suggests that people of more advantageous origins tend to experience a more positive life course

(O'Rand 2009). This leads to increasing gaps and rises in inequality in health between advantaged and disadvantaged social groups over time.

The critical/sensitive period model suggests that health differences between various social groups are a result of positive or negative exposures which occurred at specific key points during the individual's life and development (Sisson 2007). Deprivation, illness, divorce and risky behaviours, such as smoking, are all considered to be exposures and the timing of the exposures would also appear to be important. For example, some of these exposures may hit the individual during critical periods of their life course and could affect them irreversibly (Marmot and Wadsworth 1997). Ben-Sholmo and Kuh (2002) further defined the critical period as a *"limited time window in which an exposure can have an adverse effect on development and subsequent disease outcome. Outside this window, this developmental mechanism for mediating exposure and disease risk is no longer available"* (p.288). Critical periods have been related to the biological, cognitive, social and psychological development during different periods of people's life such as foetal, infancy and childhood (Barker 1998). In addition, other authors have suggested that social and psychologic development could exert an impact on people's life course such as divorce, job insecurities and the transition to parenthood (Elder 1998). The critical/sensitive model partially explains exposure of effects, but it does not explain the impact on future behaviour and this next section explains this phenomenon.

The third model is the pathway model, which explains health adverse effects caused by early life conditions that continue to influence future behaviour (Arcaya *et al.* 2015). In addition, Graham (2002) pointed out that the effect of the negative effects is indirect since the effect may start at early stages of life while the consequences appears in later life. In addition, other different factors such as social class, education and health behaviours appear to act as mediators between early life and adult health status (Graham 2002). Furthermore, the pathway model suggests that the effect of early life factors on health status in later life can be manipulated and modified to an extent by

the presence of different circumstances in various life stages (Power and Hertzman 1997).

It appears that the life course approach uses materialist, behavioural and psychological explanations to explain the presence of inequality among various social groups through time. The major strength of the life course approach comes from understanding that causations are based on combining the material, psychological and behavioural factors. In relation to oral health, there are several studies which have adopted the life course approach to explaining inequality in oral health among different social groups. For example, Thomson *et al.* (2004) conducted a cohort study where they obtained data from assessments taken at ages 0, 3, 5 and 26 as part of the Dunedin Multidisciplinary Health and Development Study (DMHDS). The DMHDS is a longitudinal study of children born in Dunedin, New Zealand in 1972-1973. The participants were assessed at different ages, the first assessment occurred at the age of 3 years. A total number of 980 participants were finally assessed at the age of 26 years. The aim of the study was to determine whether adult oral health is predicted by SES during childhood, and whether changes in adulthood SES has an impact on the oral health status of adults. The study revealed that childhood SES and childhood oral health play a major role in determining oral health status in adult life. Additionally, positive or negative changes in SES were associated with different levels of oral health during adulthood. Another study conducted by Nicolau and colleagues (2003) at the first phase of their study examined 85% of all children aged 13 years in a Brazilian town. The second phase involved the selection of 330 families of these children in a random manner of which 94% participated. Nicolau and colleagues concluded that the presence of biological risk factors and disadvantages arising from the socioeconomic determinants in early life such as poor housing when born, are significantly related to dental caries experience at 13 years of age.

Children with disabilities are more likely to encounter a variety of social factors and other behavioural and psychological barriers, which have the potential to worsen their experiences of disability (WHO 2011). These factors include

poverty, low socioeconomic class, discrimination and restricted access to health services (Beresford and Oldman 2000, 2002; MacInnes *et al.* 2014). All of these barriers and the factors leading to disadvantaged experiences, result in greater inequalities in the oral health status and oral needs among children with disabilities compared to their peers, which will be discussed in the next section (1.4.).

1.3. Social capital and access to oral health care services

Social Capital was considered as one of the social determinants in the late 1990s and originally was linked to income inequality but in reality there was little clarity around its definition (Adams and White 2003; Stephens 2008). For example, Wilkinson argues that income inequality and health inequality were tightly linked and independent of individual income (Wilkinson 1992). This created a debate that exists until today with academics like Lynch and Davey Smith arguing that individual income did exert an effect (Lynch and Davey Smith 2002). Other academics argue that social capital is about many things and not merely income, for example issues such as social support, community capacity and empowerment (Lynch *et al.* 2000; Harriss 2001; Kawachi and Kennedy 2002). It is probably important to note at this stage that up to now, there have been no definite constructs for social capital and that this adds to the confusion around the term (Morrow 2002).

The Organisation of Economic Cooperation and Development (OECD) define social capital as “networks together with shared norms, values and understandings which facilitate cooperation within or among groups” (OECD 2000). There have been many suggestions around the definition of the social capital (Coleman 1988, 1990; Loury 1992; Putnam 1993). These authors argue that the definition started in 1986 when Bourdieu argued that social capital is inherent in the structure of social networks, both within or between communities and it can be identified in the form of social resources such as interpersonal trust and channels of information. Coleman (1990) in particular defined social capital as:

“Social capital is defined by its function. It is not a single entity, but a variety of different entities having two characteristics in common: they all consist of some aspects of social structure, and they facilitate certain actions of individuals who are within the structure. Like other forms of capital, social capital is productive making possible the achievement of certain ends that would not be attainable in its absence” (p.302).

What Coleman appears to be saying here is that social capital has a facilitative aspect to it because it enhances individual agency. Coleman also suggests that social capital is productive but also through actions it becomes reproduced and without it people would not be able to act as flexibly, or at all. Putnam in particular regards social capital as emanating from society, as a result of social relationships and involves issues such as reciprocity and trustworthiness that arise from them (Putnam 1996, 2000). More recently, Uphoff and colleagues have argued that social capital is not a function of free choice but is restricted by the way a community is constructed (Uphoff *et al.* 2013). So, for example, sports clubs may be used as a way to promote health and develop social relationships, but they can also inadvertently create barriers and reproduce marginalisation because certain ethnic and cultural groups may not approve of women participating (Walseth 2007). This again highlights inequality but also refers us back to context.

Currently, the academic literature suggests that the definition of social capital still lacks clarity and that ways of measuring it are still developing (Reynolds 2013). In relation to health, Kawachi and Berkman (2000) argue that social capital affects health via three mechanisms: health related behaviours, access to services and amenities and psychological processes. These three areas of access will now be explored in a little more depth

1.3.1. Health related behaviours

Kawachi and Berkman (2000) suggest that social capital can affect health behaviour in two ways. Firstly, it can aid rapid distribution of health information and facilitate the development of norms for healthy or health improving

behaviours. Secondly, it can restrict the development on unhealthy or health impairing behaviours through social control. Social control is where the network or environment of an individual influences health related behaviour. For example, in Australia it was suggested that social de-normalisation of smoking, alongside tobacco control policies could assist with smoking cessation (Schoenaker *et al.* 2018). In France, motivation to quit smoking successfully came from pressure within the individual's social group (Baha and Le Fanou 2010). However, adjustment or adoption of health-related behaviours appears to be subject to context. For example, one study explored stigma in relation with sustained smoking and suggested that people in Mexico who believed that smokers are increasingly marginalised were less likely to quit successfully, while there was no association among smokers in Uruguay (Lozano *et al.* 2018). This indicates that the area is complex, subject to a variety of influences and not merely the result of individual behaviours in isolation.

An example of social control can be seen in communities where a given society has a close-knit nature and the individuals (teachers, neighbours or strangers) exert some form of social control over minors when they are caught breaking the laws (Reynolds 2013). One issue with defining social capital in this way is that it can lead to victim blaming because it concentrates on individual behaviours and ignores the wider social context (McKinlay 1993; Pearce 1996).

1.3.2. Psychological process

It appears that social capital affects health positively through the presence of increased social support. Feeling safe in the lived environment, feeling connected and supported socially have a protective effect on the general and mental health of an individual (Cho *et al.* 2005; Phongsavan *et al.* 2006). This suggests that communities with high levels of social capital can be supportive and this can lead to better health outcome via two ways (Kawachi *et al.* 2008). Firstly, social capital can be involved in facilitating an increase in individual ability to cope with stress, such as the presence of social support. Secondly, social capital may be involved with directing people or providing resources to

enable a reduction in stressful events. For example, Song (2011) have examined the different roles of social capital, specifically social resources and social networks, in the production of health. The author used a unique national U.S. sample and employed a path analysis model to explore the direct and indirect effects of social capital on the psychological process on health. The findings suggested that social capital can mediate various factors, which may cause an inverse relationship to psychological distress. In addition, the study highlighted that social capital acts as an intervening mechanism to link seven social factors with psychological distress, and these factors are age, gender, race-ethnicity, education, occupational prestige annual income and voluntary participation.

1.3.3. Access to services and amenities

Kawachi and Berkman (2000) suggest that access to local services is improved among communities by increasing a group's collective efficacy and are willing to carry out changes in their community. For example, if a local medical clinic is going to be closed in a community with high social capital, people of the community are more likely to work together to prevent such an event happening (Kawach and Berkman 2000).

Social capital, in terms of access to services and amenities, has two dimensions: horizontal and vertical dimensions. The horizontal dimension includes bonding and bridging while the vertical dimension is the linking part of the social capital (Rouxel *et al.* 2014) as shown below in figure (3).

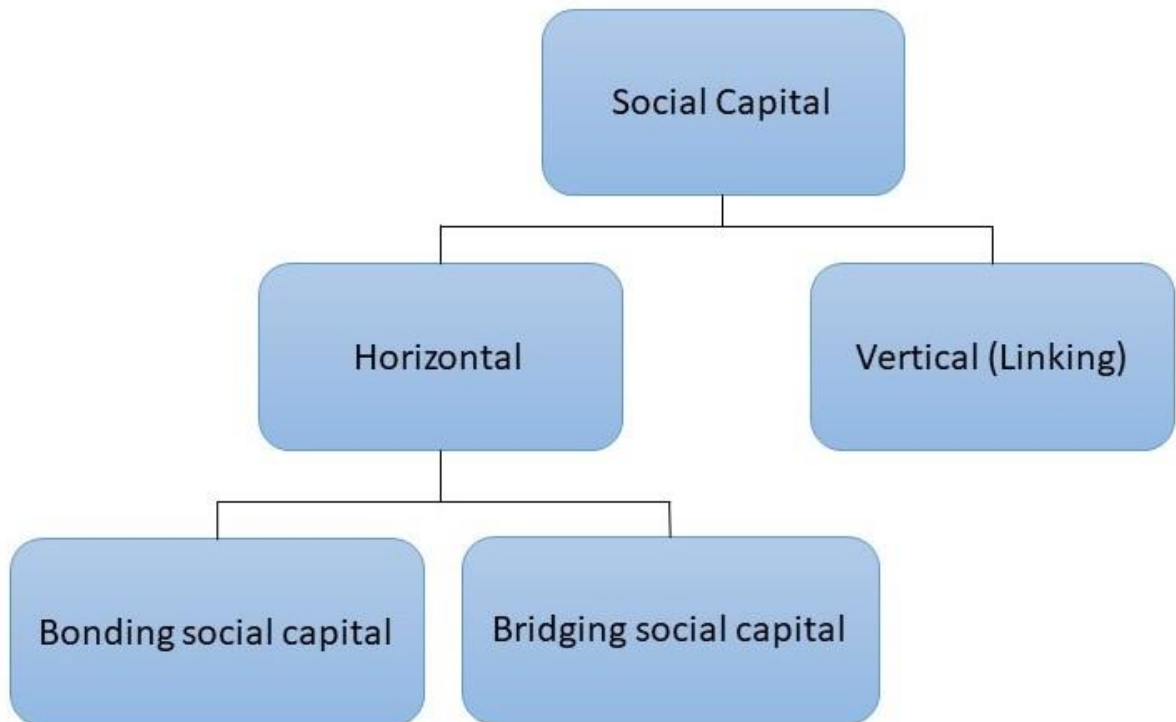


Figure (3). Social capital dimensions

(Islam *et al.* 2006)

Bonding social capital:

Bonding social capital describes a horizontal strong relationship between members of a network who are similar to one other such as family members or close friends. It is often referred to as a form of social ties or social trust (Sampson *et al.* 1997). For example, Prentice (2006) reported that people who are living in a neighbourhood that is willing to help others are more likely to report having a regular source of care and preventive health measures. Another study reported that people who have a supportive social network that are willing to help financially during illness have fewer reported barriers (Perry *et al.* 2008).

Bridging social capital:

Bridging social capital describes a weaker relationship between individuals who are not similar and have different access to resources. It is a relationship

between members of different groups and refers to the social resources that crosscut social grouping (Derose and Varda, 2006). It is often operationalized as social participation such as volunteering and membership in community associations (Derose and Varda, 2006).

One argument about bridging social capital is that in unequal societies it is only freely available to those who are considered better-off financially and who have a higher social status and so can leverage more access to resources and by default may be closer to linking social capital (Coburn 2000, 2004).

Linking social capital:

Linking social capital is described as a vertical relationship where connections made between people who are interacting across formal power or authority. It links people who are in position of high social capital to those who are lacking social capital to provide access to relationship or services that were not accessible.

In relation to oral health, social capital can have both beneficial and detrimental effect on accessing oral health care services depending on the type of social capital. It can be beneficial, for example, when using linking social capital to provide access to those who are in need and lack access to services. In contrast, social capital can have potentially negative effects on health and oral health when we use the bonding social capital where negative health behaviours can be reinforced (Villalonga-Olives and Kawachi 2017; Herberholz and Phuntsho 2018). Social capital can have health damaging effects in some cases such as: a company where the social norm in a work community is to socialise by drinking alcohol and the individuals who choose not to drink alcohol are ostracised (Villalonga-Olives and Kawachi 2017).

1.4. Oral health of children with disabilities

Adults and children with disabilities have poorer general and oral health than people without disabilities (Bimstein *et al.* 2014; Norderyd *et al.* 2015). For

example, Zhou and colleagues conducted a systematic review and a meta-analysis aiming to provide a summary of the existing literature to compare oral health status of children and adolescents with and without intellectual disabilities. The systematic search were formulated using PICO (population, intervention/interest, comparator and outcome) were conducted on four electronic data bases (Pubmed, Web of Science, Embase and Scopus) from their start date until March 2017. The systematic review were conducted according to PRISMA statement (Preferred Reporting Items for Systematic reviews and Meta-Analysis). The selection process was performed by two authors using inclusion criteria, which were: written in English, the presence of two groups (with and without intellectual disabilities) to compare, participants aged below 18 years and the study design: observational studies. The study revealed 2393 initially, and 1629 study after removing the duplications. Screening the titles and the abstract resulted in 76 potential study among, which 39 studies were identified to be eligible and formed the bases of qualitative analysis, and 26 were eligible foe meta-analysis. Zhou and colleagues found that participants with intellectual disabilities had higher dental plaque, worse gingival status and fewer decayed and filled permanent teeth, but there were no significant difference between males and females' experiences. These findings were supported by both qualitative and quantitative analysis. One limitation to this study was the high number of children and adolescents without intellectual disabilities (n=53092) compared to low number of children and adolescents with intellectual disabilities (n=3325), which create discrepancy in terms of power to detect the true effects size between the two groups.

Poorer health may often be the result of barriers to physically accessing services such as a facility without lifts or ramps (Singh and Lin 2013), negative attitudes of general and oral health care providers towards disabled individuals (Melville *et al.* 2005), lack of oral health promotion (Owens 2011), poorer living conditions (Mathers and Loncar 2006), for example the physical conditions of the dwelling and the surrounding environment, lack of financial support and the issue that many people with disabilities live either in or on the margins of poverty (Hughes 2013), poorer access to education (Goodley and Runswick-

Cole 2011), as well as other health related factors such as co-morbid or genetic conditions which can affect the health of people with disabilities across the life course.

Children and adolescents with disabilities can be at high risk of developing dental diseases such as: dental caries and periodontal disease. Although some studies have argued that the number of children with disabilities who are caries free may be higher than for non-disabled children (Nelson *et al.* 2011; Koch 2017), it can also be suggested that management of dental disease was different. Children with disabilities are more likely to have untreated dental disease and this was managed in the past by extraction rather than restoration. However, as dental care is developing, we can see a simultaneous improvement in both oral health and management/treatment techniques (Koch 2017), such as: familiarisation, short appointment time, continuity of dental personnel, sedation and general anaesthesia (The Royal College of Surgeons of England 2012). Preventive dental services vary in different countries. In some places, prevention is provided and well organized while in others it is only accessible for a minority of the population who may be more privileged such as in the Kingdom of Saudi Arabia (Waldman *et al.* 2010).

Some risk factors may be said to be more prevalent in children with disabilities compared with the rest of the population. For example, many children with disabilities ingest sweetened liquid oral medicines long term which has consequences for poor dental health including dental caries and erosion (Jaber 2011). In addition, an increase in the prevalence of another form of tooth wear and bruxism can be seen in children with disabilities as one of the findings related to their syndrome. For example, cerebral palsy which can result in motor alterations and dyskinetic movements leading to tooth grinding (Nelson *et al.* 2011). Periodontal health is often poor in children who are impaired because of the underlying risk factors, which may be related to their condition. For example, the dysfunction of the neutrophils and leukocytes that play a major role in reducing susceptibility to infection in the gingival tissues of children with Down syndrome (Morgan 2007). Another reason is the presence of a poor manual dexterity and ineffective plaque removal, for example children

with cerebral palsy, who may have poor motor skills or children with intellectual impairments who may have poor motor skills, development delays, poor manual dexterity or who may lack understanding of the need for oral hygiene practices (Koch 2017).

1.5. Oral health needs of children with disabilities

Children with disabilities have higher dental needs than their peers in the general population (Scully and Kumar 2003; Cooper *et al.* 2004; Paschal *et al.* 2016). For example, a national survey done in the US reported that around 78% of children with disabilities needed dental care, which was second to prescription medications in the frequency of need (Lewis *et al.* 2005). It also identified about 33,866 children with special health care needs for interviews and weighted the data to represent 9.32 million children with special health care needs nationally. One limitation to this study is the reliance on interviewing the parents to identify the level of oral need of children with disabilities, which may not give an accurate picture. A more holistic approach may be to include everyone involved in the oral health setting and that includes dental practitioners and dental care professionals, as well as parents.

Children with disabilities appear to demonstrate even higher oral health needs when they have more complex health needs such as epilepsy, respiratory disorders and behavioural issues (Jansen *et al.* 2004; Kwok and Cheung 2007; Akpan *et al.* 2010). One example of complex needs is children with cerebral palsy since cerebral palsy is associated with disturbance of communication, cognitive impairment and seizures (Bax *et al.* 2005). Children with cerebral palsy may experience limitations in self-care functioning and daily care activities, leading to a greater need for support with general and oral care (Rodrigues dos Santos *et al.* 2009). Furthermore, children with disabilities who are dependent on the support of others for self-care and daily activity appear to have higher unmet needs than children without disabilities (Rodrigues dos Santos *et al.* 2009).

It appears that the severity, or degree, of disability plays a role in facilitating dental care since accepting oral care and preventive measures influences the oral health status of children with disabilities (Desai *et al.* 2001). However, this neglect to consider the level of diversity between children with the same label. For example, if we consider two children, each having Down syndrome and similar health conditions we may find that one accepts routine dental treatment and the other may need general anaesthesia (GA) for the simplest treatment (Waldman *et al.* 2001).

The health needs of children with disabilities are often poorly met and many children face barriers in accessing appropriate general and oral health care services (Melville *et al.* 2005). Research performed in the US concluded that oral health need was the most prevalent unmet health care need for children with disabilities but failed to identify why this may be (Newacheck *et al.* 2000; Lewis *et al.* 2005). Adults with disabilities also experience poor oral health status (Tiller *et al.* 2001; Al-Shehri 2012), more tooth extraction (Martens *et al.* 2000), periodontal disease (Campanaro *et al.* 2014), oral lesions (Cumella *et al.* 2000) and decayed teeth (DeMattei *et al.* 2012). If we take a life course approach, we could argue that poor oral health status begins during childhood and extends to adulthood. For example, Poulton *et al.* (2002) did a cohort study in New Zealand aiming to examine the relationship between the experience of children to disadvantaged SES and different health risk factors and outcomes in later adult life. The participants were born between 1972-1973 and they were assessed at age of 3, 5, 7, 9, 11, 13, 15, 18, 21 and the last one was at the age of 26 years old. During these assessments, data collection to reflect SES were obtained, and physical and dental examinations were carried out. The number of the participants were 980 individuals. Poulton *et al.* (2002) have found a significant difference in the dental measures such as people from low SES families as having poorer periodontal disease compared to those families with high SES (11.9% - 31.1%), which is 106 – 305 individuals respectively. Similarly, significant differences were obtained in caries levels where (9.9%, n=97) amongst people who had low SES compared to (32.2%, n=316) among families with high SES

Increased unmet oral needs appears to be associated with multiple barriers to accessing health services, which may result in further increase of the unmet oral needs among children with disabilities (Leroy and Declerck 2013). For example, a study done in the central region in Kingdom of Saudi Arabia reported that 84.7% of persons with disabilities saw a dentist only for emergency care and it was suggested that this was because of fear and cost (Al-Shehri 2012). The study did not differentiate between adults and children and therefore fails to explain whether children have the same difficulties or not. Access appears to be a factor involved in improving the oral health of adults and children with disabilities, suggesting that not only should they receive high-quality clinical care, but also that they gain continuous access to those services (Balzer 2007).

Despite the increased oral health needs of children with disabilities, there is lack of awareness among medical professionals about the oral and dental needs of their child patients with disabilities and dentists express an unwillingness to treat because of the uncertainty, as well as lack of commitment, to such groups in the population (Koch 2017).

1.6. Quality of care

Many authors have defined quality of care in different ways (Crosby 1979; Maxwell 1984; Donabedian 1980; Juran 1988). Quality of care is a concept that is difficult to measure and conceptualise since there is no single criterion can be used to define it and therefore quality essentially possesses many variables. Furthermore, Attree (1996) concluded that quality is a concept that contains a level of diversity and it cannot be measured using a single empirical measurement. Campbell *et al.* (2000) highlighted that the proposed definitions of quality may be divided into two approaches: generic and multidimensional. The generic approach identifies quality as excellence (Samuel *et al.* 1994), expectations that have been met (Ellis and Wittingham 1993) and fitness of use (Juran 1988). Another example that is more complicated, which was proposed by the Institute of Medicine who defined quality of care as “*the extent*

to which health services provided to individuals and patient populations improve desired health outcomes. The care should be based on the strongest clinical evidence and provided technically and culturally competent manner with good communication and shared decision making” (Pelletier and Beaudin 2008, p.3). This hints at the complexity of quality. Furthermore, the Institute of Medicine proposed six goals to achieve and improve the quality of care provided and these aims are:

Safe: means to avoid any injury that can be prevented and to reduce the medical mistakes.

Effective: is to provide the medical services based in scientific knowledge and bases.

Patient-centred: is concerned with providing health care that is respectful and responsive to patients.

Efficient: concerned with avoiding wasting any resources including time.

Timely: means providing health care services while improving the flow of patients and reducing the waiting time needed for care.

Equitable: providing consistent health care services for all patients regardless of their background and demography.

(Medical Education Institute 2019)

On the other hand, the second approach to defining quality has been embraced by many authors through suggesting that quality is a multidimensional complex (Donabedian 1980; Øvretveit 1992; Maxwell 1981). Donabedian (1980) examined quality of care and defined it as *“the application of medical science and technology in a manner that maximises its benefit to health without correspondingly increase the risk”* (p.5). Furthermore, Donabedian (1980) suggests that quality of health care has three components: technical quality, interpersonal quality and amenities. Technical quality relates to whether the health care provided is effective in producing achievable health outcomes. Interpersonal quality is related to the patients’ needs and

preferences and to what extent the services can accommodate those needs. The amenities are the physical features of the surroundings and extent of service provision. Another definition of quality of care had been suggested by Øvretveit (1992), where he proposed that quality of care has three dimensions. The three dimensions are:

Professional quality: is concerned with the perspective of professionals on how to assess the patient needs and whether those needs have been met using the appropriate procedures.

Client quality: this is related to whether the patients feel that they got what they needed and wanted from the health care services or not.

Management quality: to ensure that the health services have been provided in an efficient way regarding the resources.

(Øvretveit 1992)

However, Maxwell (1984) argues that quality of care cannot be measured in a single dimension. Furthermore, to define quality of care he suggested that it has six dimensions, and those dimensions can be used to identify and measure quality of care of health care services on various levels (Maxwell 1992). The six dimensions are as presented in Table (1).

Table (1). Maxwell's dimensions of quality of care.

<i>Dimension</i>	<i>Questions that help to define and expand the quality</i>
<i>Effectiveness</i>	<i>Is the treatment given the best available in a technical sense, according to those best equipped to judge? What is their evidence? What is the overall result of the treatment?</i>
<i>Acceptability</i>	<i>How humanely and considerately is this treatment/service delivered? What does the patient think of it? What would/ does an observant third party think of it ("How would I feel if it were my nearest and dearest?") What is the setting like? Are privacy and confidentiality safe guarded?</i>
<i>Efficiency</i>	<i>Is the output maximised for a given input or (conversely) is the input minimised for a given level of output? How does the unit cost compare with the unit cost elsewhere for the same treatment/service?</i>
<i>Access</i>	<i>Can people get this treatment/service when they need it? Are there any identifiable barriers to service - for example, distance, inability to pay, waiting lists, and waiting times or straightforward breakdowns in supply?</i>
<i>Equity</i>	<i>Is this patient or group of patients being fairly treated relative to others? Are there any identifiable failings in equity - for example, are some people being dealt with less favourably or less appropriately in their own eyes than others?</i>
<i>Relevance</i>	<i>Is the overall pattern and balance of services the best that could be achieved, taking account of the needs and wants of the population as a whole?</i>

(Maxwell 1992, p.171)

It appears that access to health care services plays a major role in determining the quality of service provided since it represents a dimension and can be used

as an indicator for having good quality of health care services. Therefore, having good access to health care services can affect the quality of service provided.

Taking a life course approach, having good quality of care and good access to general and oral health care services for children with disabilities appears to influence their general and oral health in adulthood. In addition, access to oral health care and preventive services can also affect the oral health status of children and adults with disabilities. For example, a study in the USA examined 353 adults with disabilities residing in Los Angeles, alone, with family and friends or living at community care facilities. The study examined participants and collected data about their general and dental health. Although those living in a community care facility had a dentist, most of them had fair to poor oral health status. In addition, three-quarters of those living at home and two-third of those living alone had also fair to poor oral health status. The study mainly addressed having fair to poor oral health status to the failure of delivering preventive oral care for those patients (Lewis *et al.* 2016). Although the study claimed generalizability it could be suggested that a limitation would be representing all people with disabilities as the same, including children with disabilities, but it can be said that it does represent part of the oral health status of people with disabilities and highlights one of the reasons for having poorer oral health status.

Furthermore, taking a life course approach to provide oral preventive measures for children with disabilities would affect oral health status of those children with disabilities during adulthood. Therefore, addressing barriers to access oral health care services for children with disabilities is essential to address their needs and reducing the experiences of disadvantage for oral health between children with disabilities and their peers (WHO 2011). The next part of the thesis discusses access and highlights some of the models of access to health care services.

1.7. Access

Access to health care services is considered to be a major issue for children and adults everywhere regardless of their health condition (Silver and Stein 2001). It appears that access to health care services for children with disabilities is even more critical because they often have co-morbid conditions, which exerts an increased impact on their development and health (Newacheck *et al.* 1997). The concept of access to quality dental care appears important for policy and decision makers (Penchansky and Thomas 1981), but it can be suggested that it appears devoid of a clear universal definition and limited in the way it can be measured (Harris 2013). One example is the statement from the chair of the British Dental Association during a Parliamentary Health Select Committee *“what is access? Is it the number of times somebody goes to the dentist? Is it the amount of care a patient needs to make sure his or her oral health is corrected? What is it? There is no definition of access and therefore measuring it on an ongoing basis is flawed”* (Harris 2013, p.95).

Frequently, access as a term has been minimized and misinterpreted by suggesting that it means availability only (King 2015) or interpreting it as the potential for using health care services (Guagliardo 2004), which results in more confusion as to what access means. It appears that the term access often refers to mainly two meanings, either to “have access” means to have a physical access to existent services or to “have access” where the service has been used successfully (Alborz *et al.* 2005).

Several authors have interpreted access to oral health and health care services for children and adults with disabilities in different ways (Shakespeare 2006; Owens *et al.* 2010; Harris 2013). Guay (2004) identified access as whether an individual is able to obtain oral care. In contrast, Dougall and Fiske (2008) interpret access in relation to dentistry as physical access only and they identify four areas of access that they suggest are important for obtaining physical access to oral care for patients with disabilities:

- Access to the building.
- Access to dental surgery.
- Access to the dental chair.
- Access to mouth.

(Dougall and Fiske 2008, p.610)

Awareness of the dental team about people with disabilities is considered essential because they act as gate-keepers to care (Royal College of Surgeons of England 2012). Therefore, taking steps to make the dental practice more accessible is an important factor for facilitating accessibility including parking areas, ramps and ensuring that the reception area includes non-slip floors, appropriate seats and space for wheelchair users (Dougall and Fiske 2008).

In addition, access to the dental chair means that the dental chair should be accessible to all patients, wherever possible. This means that the majority of people with disabilities should be able to use and sit on the dental chair with ease and comfort (Dougall and Fiske 2008). Access as described here is clearly not reasonable for some people who may be unable to transition from their wheelchair to a dental chair and again it places the responsibility on the person with a disability to adapt rather than the environment. For example, all wheelchairs are designed differently because of the varying needs of their users and any technological requirements are often intertwined with social, political and historical developments (Woods and Watson 2002).

The last area is to have access to mouth, which means that the professional needs to gain access to the mouth of the patient using maximum precautions to prevent injuries for both the patient and the dentist. This is because people with disabilities are not homogenous group and there are various types of disability, all with different levels of risk to consider when performing dental treatment (Smiley 2005). Therefore, using various techniques to ensure safe dental treatment for disabled individuals is critical. This includes using behavioural techniques to establish good rapport (Dougall and Fiske 2008), using a bite-guards, resting the patient in a relaxing position (Ahlbor 2001),

using sedation or GA when treatment cannot be done in any other way (Dougall and Fiske 2008). These suggestions are to ensure better oral care for people with disabilities, but they are about the physical barriers to oral care, which only considers the basic dimension of access to services and fails to consider the multiple social dimensions.

Access to the mouth is important because it adds to physical access in considering the clinical and communication skills and techniques of dental professionals. This can make the treatment more accessible because it involves acceptability and appropriateness for the patient. The attitudes of dental professionals to facilitate and eliminate barriers to oral health care should be considered along with the presence of policies. For example, a study done in the UK by Baird *et al.* (2007), used a questionnaire to ask about the impact of multiple sclerosis on attending dental visits and examining the factors that may act as barriers or facilitators to attendance. The sample was obtained from local authority records and they were 476 individuals. There was a 61% response rate or 289 answered questionnaires. Baird *et al.* (2007) found that most patients with multiple sclerosis felt their dental treatment was acceptable and appropriate because they felt the dental staff respected them and understood their condition and needs (Baird *et al.* 2007). The concept of feeling understood and valued as a person would appear to be important because patients preferred to stay with their dentist rather than travel to other specialised dental clinics. However, multiple sclerosis is a progressive disease and the need for a physically accessible dental clinic would appear essential, this means that although patients may value the care they receive from their dental care professionals, access to health care services and continuity of care may not be possible as their physical condition deteriorates.

Most of Dougall and Fiske (2008) arguments are about physical access to dental care services such as their suggestions about removing what would be considered as structural and environmental barriers (presence of parking spaces and ramps). This follows a social model of disability approach where physical barriers are removed to enable access and participation in society for disabled people (Oliver 1990, 2009). Even though physical barriers may be

addressed, although in the case of wheelchair users discussed previously, we can see this may not be quite as simple and access to oral health care services appears to be highly complex and about more than just gaining physical entry. Some research argues that there is a difference between “entry access” and “effective access” (Harris 2013). Entry access is related to the availability of and the process of getting into the services, and effective access is concerned with efficiency, effectiveness and equitable health care (Harris 2013). I am now going to discuss the most cited models of access and how they have been adapted by different authors. These models of access are: the behavioural model of access (Andersen and Davison 2001) and Penchansky and Thomas’s model of access which focuses more on policy development in relation to service delivery (Penchansky and Thomas 1981).

In the behavioural model of access, Andersen and Davidson (2001) interpret access and suggest a framework utilizing the determinants of using health care services (such as attendance for dental visits) and the contextual factors; such as social class and availability of care (Anderson and Davidson 2001). One argument is that improving access to healthcare is best done when we focus on the contextual and individual factors (Anderson and Davidson 2001, 2007). Andersen and Davidson (2001) describe access as a multidimensional construct where it has many factors including availability of resources, providing care in an effective, efficient and equitable way for all individuals. They suggest a behavioural model for access depending on enabling, predisposing and need factors and identify six dimensions for access:

- **Potential access:** refers to the presence of enabling resources such as facilities, health care work force and knowing how to use those services.
- **Realized access:** means the actual use of a service.
- **Equitable access:** the rate of utilizing a service, which depends on variation of needs and demography that may lead to variation in utilization of healthcare services. In addition, it is considered a key part when used at population level. It appears that equity has two further dimensions: horizontal equity (equal access to all individuals) and vertical equity (greater access to effective care for those with greater needs) (Campbell *et al.* 2000).

- **Inequitable access:** refers to the social structure such as race, ethnicity and health beliefs that influence getting the health care service.
- **Effective access:** means the impact of using health services where best health outcomes achieved by accessing and using the health care services.
- **Efficient access:** refers to the influence of resources on the outcome.

(Andersen and Davidson 2001, p.10-15)

From Anderson and Davidson's work, it appears that the presence of enabling resources would increase the use of services. In addition, the distribution of healthcare services should be based on people's need not on their social characteristics in order to increase access to health care services. One suggestion is that the equitable distribution of healthcare resources based on people's need would minimize the disparity in accessing healthcare services among subgroups of a society (Andersen *et al.* 2013). A benefit of this model of access is that it helps to identify the influencing factors needed to inform policy to promote or limit the use of a health care service (Karikari-Martin 2010). On the other hand, obtaining a limited insight about the differences in health care service use between subpopulations can be a limitation for this behavioural model of access (King 2015).

Harris (2013) tried to apply the six dimensions for dental care in a slightly different way; she argues that access has multidimensional aspects and combines the six dimensions in Anderson and Davidson's work (2001), concluding that access has four dimensions. The four dimensions that Harris included are; opportunity of access (availability of services), realized access (service utilization), equity and outcomes of care.

Opportunity of access or the availability of service implies both the presence of a service and getting the opportunity to enter the system. In this way, a definition of access to oral care is whether the patient can obtain and make use of dental care (Guay 2004). Harris (2013) has described the notion of opportunity of access as "*whether the individuals or groups have the opportunity to obtain dental services that they need*" (p. 98), since knowing need is essential for policy makers. In addition, Harris adapted Aday and

Andersen's (1981) idea, which was that the utilisation rate is the proof of access and considered it as a key element in her access model to dental care. Knowing the utilisation rate of a health care service is important for service provision and identified by measuring access to health care services through knowing how many patients were treated in the dental clinic per year. However, the utilisation rate can be interpreted in different ways, for example, it can be interpreted as the availability of services or by mirroring patient needs. While measuring the rate of utilisation of a service can be the result of an increase in the availability of the service, it can also reflect patient disease which would moderate the utilisation of that service and that would add more confusion and complexity in defining access.

Harris argues that to achieve optimal access, we need to measure and monitor outcomes of care. "*Optimal access*" has been defined by Roger *et al.* (1999) as "*providing the right service in the right time at the right place*" (p.866), and that based on the belief that access to care can affect people's lives because Millman (1995) defined access as "*the timely use of personal health services to achieve the best possible outcomes*" (p.4). However, Harris (2013) has explained and proposed ways of measuring access for health policy and for decision makers to evaluate and monitor the oral health care system, which perhaps adds more layers of complexity to the definition of access to oral health care services.

The second model of access, which is the one that I am going to use in my thesis, is that of Penchansky and Thomas (1981), which suggests that access should be interpreted from the service delivery point of view and involves quality of care. Penchansky and Thomas took Donabedian's idea of access that is '*the proof of access is use of services, not simply the presence of a facility*' (Donabedian 1972, p.111) to develop the concept of access (Gulliford *et al.* 2002). So, they have extended the concept of access beyond the availability of the services to include the personal, financial and organizational barriers to service utilization (Gulliford *et al.* 2002). The concept of access has been defined as the '*degree of fit*' between the client and the system and they emphasized the concept of fit between patient's needs and the ability of

health services to meet those needs. They identified access as having five dimensions and these dimensions are: availability, accessibility, accommodation, affordability and acceptability (Penchansky and Thomas 1981, p.128) and they are further defined as:

- **Availability:** is the relation of the volume and type of services to the existed services (Owens *et al.* 2010). It represents the presence of adequate number of health care and oral health care staff members (Penchansky and Thomas, 1981) and the extent of which those resources are meeting individual needs (Campbell *et al.* 2000).
- **Accessibility:** represents the relation of the location between the services and the clients, including the way and time of transportation.
- **Accommodation:** it demonstrates the ways the service is organized to deliver and accept clients.
- **Acceptability:** refers to whether the client is satisfied with the service provided. This may influence whether individuals access the same service in the future or look for an alternative healthcare provider.
- **Affordability:** refers to the ability of the client to pay for the services provided. Its importance increases in countries where health care is not provided by the government and insurance policies have to be used, or the service is entirely private.

Those dimensions are overlapping to some degree. One example is that the acceptability of service would not be achieved if the service was not accessible, affordable and available to patients, and in the same time the service would not be accessible unless they are available and accommodate the patient's needs, so they are related to each other. In addition, each dimension of the access model is measured by surveying the user of health care services and system including health care facilities and providers (Karikari-Martin 2010).

One strength of using Penchansky and Thomas' model of access is that it is useful to apply when we would like to know the effect health policies on a specific population or subpopulation. For example, a survey (Thomas and

Penchansky 1984) investigated access for patients while using health care services. They found that health care services were more affordable for younger individuals and housewives than other population subgroups, finding that greater homogeneity of the sample led to better outcomes. However, a limitation to Penchansky and Thomas model of access should be considered and that is the need for primary data collection and the subjectivity of patient's perspectives, which could be variable because it is reliant on patient's experiences, time of the day and other factors.

Another addition was made by Owens *et al.* (2010) where they blended these five dimensions of Penchansky and Thomas (1981) with Maxwell's six dimensions (1984) for the quality of health care (effectiveness, efficiency, equity, access, acceptability and appropriateness) and identified that access has six dimensions. The six dimensions of access, which Owens *et al.* (2010) was referring to, are: availability, accessibility, accommodation, acceptability, affordability and appropriate to need while appropriate to the need in this context is:

- **Appropriate to need:** refers to whether the client got what he needed (Owens *et al.* 2010).

Owens *et al.* (2010) argue that the six dimensions of access are more workable and practical to all health care practices, but they used the dimensions in relation to quality care and it would appear that context is important as to which model of access is used because it is related to outcomes. Appropriate to need appears to be important as it includes the patient's perspective on the health service. Their particular work was about access for adults with disabilities but there appears to be little work which identifies whether issues around access are the same from the perspectives of parents of children with disabilities.

From the patient's perspective, access to health care services was interpreted by the European Patients Forum (EPF 2016). The EPF argue that the patient has an important role in understanding access to health care services and that to ensure an equitable, sustainable high-quality access to health care services we need to address the perspective of patients and the health care work force

(EPF 2016). It furthermore suggests that access is a multidimensional concept and in order to gain a more comprehensive view, we need to reflect upon the patient's experience of access (EPF 2016). Patients are frequently in contact with health care services and have expertise around the barriers and gaps to accessing health care services. The EPF brought a new dimension to the concept of access and that is 'adequacy'. They interpreted access and applied the same concept of access of the Patients Access Partnership (PACT), which is a European committee that launched in 2014 to tackle the issues of health inequalities from the perspective of the patients and to ensure equal access to healthcare institutions (EPF 2017). PACT has interpreted access based on Penchansky and Thomas's access to health care services delivery (EPF 2016). PACT defined access as having five dimensions: adequate, accessible, affordable, appropriate and available. These dimensions are defined as:

- **Adequate:** means that care should be constantly provided and adapted to patient's needs. It refers to the service quality of care including patient-health care team relationship and decision making.
- **Accessible:** that means that health care services and all stages of care are accessible starting from prevention and health promotion programs to all levels of treatment including supportive and non-medical treatment. It includes access to information (information about types of care and treatment and their availability) and the elimination of geographical barriers.
- **Affordable:** refers to the ability of the individual to access and get the needed health care service without financial difficulties.
- **Appropriate:** means that health care services should be inclusive for all types of needs for different communities, groups or populations.
- **Available:** refers to the presence of all type of health care services including specialised health care services and treatment and their availability to all individuals.

(PACT 2014)

It appears that introducing adequacy as a dimension may lead to more confusion since it is so similar to the dimension appropriate. While the EPF

promotes constant care to patients through adequacy as a dimension for access, a similar concept has been introduced along with access from the point of quality care and that was the continuity of care. Continuity of care is one of the items that constitute quality of care and discussed by many researchers, this will be discussed further in the next section (1.8).

It appears that access is very complex term containing multi-dimensional aspects because it includes many concepts that are intimately entangled (Harris 2013). For example, the potential access of Andersen and Davidson's framework refers to the presence of enabling resources, which also refers to the availability dimension of Penchansky and Thomas's model of access. Each dimension provides a partial aspect when seen on its own, while together they provide specific detail and more insight in defining access. In addition, identifying the oral health needs of individuals, changing the attitudes of community and oral care providers towards positive ways of regarding and working to deliver better oral health, may insure optimum oral care delivery (Owens *et al.* 2010).

Although many authors have interpreted access as a concept to promote it at individual and population level both for the general population and for people with disabilities (Penchansky and Thomas 1981; Dougall and Fiske 2008; Owens *et al.* 2010; Harris 2013), little has been said about access and barriers to healthcare and oral health care services for children with disabilities. It appears that access to dental services for children with disabilities differs from adults since they are dependent on others to gain access to various services and engage in routine oral care (Weil and Inglehart 2012). This means that children with disabilities may encounter different barriers to access compared to adults.

1.8. Continuity of care

Continuity of care is considered to be a characteristic of good quality care (Uijen *et al.* 2012) because it has a positive impact on the health of people (Stange and Ferrer 2009). Continuity of care is associated with patient

satisfaction because research has reported that a longer relationship between patient and health care provider will result in greater satisfaction, fewer tests and hospital admissions for the patient (Newbery 2000). Continuity of care could therefore be related to higher quality of care, better health care provider confidence and fewer financial costs for health care providers and patients.

One interpretation of continuity of care is the continuous relationship between patient and health care provider over time (Newbery 2000). However, other researchers suggest that continuity of care has three dimensions; personal, team and cross-boundary continuity (Uijen *et al.* 2010):

Personal continuity refers to the relationship between a patient and a health care provider where the health care provider knows his patient and cares for him.

Team continuity refers to the communication of relevant patient information between care providers within one care setting to ensure that care is optimum and connected.

Cross-boundary continuity means that the sharing of relevant patient information between different care providers across many care settings.

These three dimensions of continuity of care are important in relation to children with disabilities. The informational continuity is essential for parents of children with disabilities because they are frequently dealing with multiple care providers, often in the form of teams. Therefore, continuity of care involves good quality communication with everyone concerned in the provision of health care and having an oral health care plan in place for children with disabilities may result in optimum oral care. Some authors argue that informational continuity should extend to cover the coordination between different sectors as well (Johnson *et al.* 1997). For example, having continuous care is extended to social care for children with disabilities and their families such as education, housing, employment and facilitating health and social services.

Team continuity would appear to be an important aspect of health care for people with disabilities. This dimension can be applied to oral health care

although it may be concerned with primary care. For example, some children and young people with Down syndrome can have heart conditions, which may need antibiotic cover when having tooth extractions in dental clinics or endodontic treatment. Others may be anxious or fear certain aspects of the dental environment; this is where continuity of care becomes important and different forms of knowledge, apart from medical, become important in order to deliver appropriate care because one of the benefits of continuity of care is to decrease the level of fear and establish a good rapport between the dental staff and patients.

Personal continuity of care is considered as the basis of providing continuous health care for all patients (Haggerty *et al.* 2003) since continuity implies affiliation between patient and health care provider where it develops via longitudinal relationship and builds up over time being characterized by trust and responsibility (Saultz 2003). Personal continuity is considered an important aspect when dealing with children with disabilities, especially children with learning disabilities. For example, children with autism may need more than one visit to get used to the dental environment; layout of the surgery and waiting room, smells, sounds and the dental team before starting their oral care. Enabling children to become familiar with the environment and team may help to develop trust and potentially deliver better dental care in the long term.

Measuring continuity helps to identify gaps and improve the health care system (Uijen *et al.* 2012). Studies on general health and medical practice have examined continuity of care and measured it in different ways (Saultz 2003). Continuity of care has been measured using levels of satisfaction, whilst other research identifies continuity of care as the level of loyalty and trust between patients and physicians (Saultz 2003). This appears to suggest that there is little clarity as to what the term actually means. Most of the studies measuring continuity focus on one disease (Padhi and Saultz 2006) or measured continuity in a health care setting such as: primary care (Uijen *et al.* 2010). The limitations of these studies are that they did not measure continuity of care as multilevel concept and only one from the patient's perspective (Uijen *et al.* 2011).

Continuity of care, if defined carefully, may be useful to consider quality of care especially for those who need constant care. For example, if we take a life course approach for children with disabilities, small and initial oral lesions, such as initial caries, would need preventive measures and continuous provision since many children with disabilities have more risk factors than children without disabilities (Koch 2017). In addition, Penchansky and Thomas' model of access may be useful for identifying gaps in health care service delivery for children with disabilities. This is because exploring their parent's experiences and subjective experiences of health care access can also inform policy makers and commissioners with the aim of providing quality care (Karikari-Martin 2010).

1.9. Barriers

Children with disabilities appear to have high unmet needs regarding their general and oral health compared to their non-disabled peers (Hallberg *et al.* 2004; Lewis 2009). Sometimes, their additional medical conditions may also contribute to their oral health condition and inequalities in their environment and financial conditions may also negatively impact on their health and their oral health quality of life (DeMattei *et al.* 2012). Children with profound disabilities may become hospitalized as the result of a crisis and often undergo GA to carry out appropriate dental treatment (Owens 2011; Gerreth and Borysewics-Lewicka 2016). Various barriers may be said to contribute towards the negative oral health status of children with disabilities (Hernandez and Ikkanda 2011; DeMattei *et al.* 2012). Some of these barriers that need to be considered are: policy barriers, social barriers, oral healthcare professional barriers, structural-environmental barriers, behavioural barriers and financial barriers, which the next section will discuss in more depth.

1.9.1. Policy barriers

Children with disabilities face many political barriers derived from policies, which act to exclude them from accessing different public services (Scotch and

Schriner 1997). For example, for children with learning disabilities, the policy guidance in the UK for *Valuing Better Oral Health* (DOH 2007) does not take into account the voices of children with learning disabilities and their families, nor does it consider their determinants of health (DOH 2007). Furthermore, policies may not always act in favour of children with disabilities and may not be applied within the clinical field (Dougall and Fiske 2008). This is possibly because of the gap between policy recommendations and what may actually be achievable in practice.

Gaps may be said to be evident in the increasing levels of poorer health and related to lack of financial resources, social protection and social support services for children with disabilities and their families (WHO 2011). For example, education policies are changing globally in favour of children with disabilities, but dissatisfaction and inequality still persists (Goodley and Runswick-Cole 2011). For example, “*Every Child Matters*” (DfES 2004), which is considered to be an important governmental policy in the UK, has reported that some policies for disabled children must be included and particularly their safety and well-being, but for the policies to be effective this needs various sectors to work in collaboration. However, different definitions amongst different sectors for children with disabilities creates difficulties for children, including children with disabilities. For example, in the UK, social services identify disabled children as ‘children in need’ and in education they are ‘children with special educational needs’ while the World Health Organization and the International classification of Functioning, Disability and Health (ICF) defines disability as an Umbrella term for impairments, activity limitations and participation restrictions (WHO 2018). These different definitions create more confusion, complexity and challenges for the families and children with disabilities who are in need of services. For example, a child with a disability who has a statement for special educational needs with high level of support might not be able to access the disabled children’s social work team because their needs are not judged as being extensive enough to require the extra intervention.

Policies are needed to enforce an equitable approach to promote access and to address health differences between children with disabilities and the general population. The equitable approach has horizontal and vertical dimensions (Campbell *et al.* 2000), which has already been discussed (p.35). It is important for children with disabilities to have health care services that accommodate their needs because some of them may need health care more than others. One example is that the medical needs of a child with a physical impairment such as cerebral palsy may not be the same as a child with Down syndrome who can have other associated medical conditions such as congenital heart defects, poor vision, hearing, hypothyroidism, blood disorders, hypotonia (poor muscle tone), atlantoaxial instability (problems with the spine), epilepsy, mental health problems, gum disease, digestive problems and celiac disease (Goldberg-Stern *et al.* 2001, Hardy *et al.* 2004, Bull *et al.* 2011, Khan *et al.* 2011). Having policies that ensure good access to oral and health care services for all individuals should in theory promote better health and aim toward reducing disparities among the population.

1.9.2. Social barriers

It appears that societal attitudes are considered to be a major social barrier for adults and children with disabilities (WHO 2011). People with disabilities often experience exclusion, which leads them to be marginalized and they then experience participation restrictions (Abbott and McConkey 2006). Participation restrictions comes from The International Classification of Functioning, Disability and Health [ICF] (WHO 2002) and is about the barriers people experience through societal reactions. For example, a person with Vitiligo could be excluded from societal relationships because they may have a visible facial difference. The exclusion could be related to lack of awareness and reduced societal knowledge about the differing needs of a range of people with disabilities.

Social inclusion is often defined as the participation in the daily activities within society and its social networks; it includes acting as a consumer of goods and social services (Burchardt *et al.* 2002). A focus group study done by Abott and

McConkey (2006) invited participants from a range of supported living schemes and residential homes in Northern Ireland. The authors reported that perceived social inclusion by people with learning disabilities meant that they wanted to be accepted, treated similarly to people without learning disabilities and with respect. On the other hand, lack of societal interaction may diminish the presence of various skills including social skills which may then contribute to social exclusion of people with learning disabilities. However, this study had several limitations such as under-representation and excluding people with learning disabilities who were living with family carers and it represented the local context which could be different in other regions and countries. Care staff may also fail to support people with disabilities due to their own low level of appropriate skills to teach others (Mansell *et al.* 2002). This may also apply to parents of children with disabilities who may lack appropriate oral health skills and dietary knowledge in order to adequately support their children's oral health.

It appears that the location of the social activities and the cost of transportation was often one of the reasons for the restriction of disabled people's participation in society (Abott and McConkey 2006). Furthermore, housing location alongside varied ways of living appear to be important factors for promoting social inclusion (McConkey *et al.* 2007). For example, *Valuing People* suggests that appropriate and adequate housing is a factor in promoting social inclusion for people with learning disabilities (DOH 2001). In addition, several studies reported that social networks, campus-style settings, group homes and supported housing may be factors in improving social inclusion, but these studies failed to identify the extent of improvement, or the ways these different configurations could be effectively achieved (Emerson *et al.* 2000).

Social norms and ethnic beliefs differ from one country to another and within countries as well. Cultural and social habits affect access to and utilization of oral health care services (Royal College of Surgeons of England 2012). For example, female patients in some countries, such as Bangladesh, prefer to be seen by female dentists as a result of their social and religious habits and

backgrounds (Doshi *et al.* 2010). In Jeddah, Saudi Arabia research suggests that pain was the only reason for parents seeking dental care for their children and routine examinations were viewed as unnecessary (Farsi *et al.* 2004). Limitations were that the study used self-reported questionnaires which could result in misinterpretation of some questions because they were devised by clinicians without the input of parents. The study also displays a lack of depth because parents could not be asked to clarify their answers.

Health care professionals also have an impact on social inclusion; whether using health care services or changing the attitudes of society towards a more inclusive perspective (Edelstein 2007). In addition, the level of knowledge within the family about disability, cultural differences, alongside the attitudes of families towards health services could also have an impact on the utilization of health and oral health care services and increase level of need as a result (Choi and Wynne 2000; Krahn *et al.* 2006; McGrother *et al.* 2002).

1.9.3. Oral health care professional barriers

It appears that oral health care professionals' knowledge, skills and attitudes play a major role to acting as a barrier or a facilitator for people with disabilities (Faulks *et al.* 2012). Oral health care professionals can act as facilitators to deliver services because they are also considered gate-keepers (Dunfield 1996). A limiting factor may be the knowledge and communication skills of oral health care professionals, which are often obstacles faced by people with disabilities (Hahn *et al.* 2012). For example, the communication skills of oral health care providers are a key part in creating acceptable and equitable access when treating people with learning disabilities and improving communication is seen as a way of reducing the inequality gap between people with disabilities and general population (Faulks *et al.* 2012).

It appears that level of knowledge is often related to the dental undergraduate level of contact and communication with people with disabilities (Dougall *et al.* 2014). Training of future dentists in environments with various ethnicities, disabilities and social backgrounds would have an impact on their skills and

develop more positive attitudes toward various ethnic groups and people with disabilities (Albino *et al.* 2012). In addition, the role of health care providers and their abilities to identify oral needs of people with disabilities may have an impact on people with disabilities and their oral health. For example, Hahn *et al.* (2012) educated (using lectures and practical exercises) nurses about the oral health of people with disabilities and their oral health needs, they then assessed their knowledge and perceptions around disability. Although the study had a small number of participants (n=8 gerontology nurse practitioners) and there was no control group, they reported that once the nurses were educated about the oral health of people with disabilities there was the potential to provide more effective primary care and better oral health services.

Accounting for the voices of people with disabilities in decision-making regarding their treatment and their needs is also considered important to meet unmet needs (Ziviani *et al.* 2004; Alborz *et al.* 2005). Many disabled individuals, mainly those with learning disabilities, are dependent on their carers, families and health care professionals to support them with decisions regarding their treatment even though there appears to be a shift toward more inclusive services and policies in terms of treatment delivery (Bowes and Dar 2000). One of the duties of health care and oral health care providers is to act as decision-making facilitator for disabled people (Ziviani *et al.* 2004). However, a lack of communication skills and essential knowledge about the needs of disabled individuals often results in poorer health care and more unmet needs of people with disabilities (Alborz *et al.* 2005).

People with disabilities experience difficulties finding suitable oral health practices that are willing to provide appropriate oral health care (Gallagher and Fiske 2007). For example, it has been reported that people with disabilities are four times more likely to find unsuitable or inaccessible dental practices than those without disabilities. However, a study done in 2005 where they interviewed 6 parents of children with Down syndrome and sent postal questionnaire to about 200 adults with Down syndrome. They found that once the parents find an accessible and acceptable dental practice, they are more likely to visit the dental practice regularly with their child compared to parents

of non-disabled peers, increasing continuity of care (Kaye *et al.* 2005). This study, although small, illustrates that children with disabilities can become regular visitors and their parents will seek dental care once they find suitable and accessible oral health care service.

1.9.4. Environmental-structural barriers

Structural-environmental barriers include the lack of physical features that facilitate and make the practice more accessible to all people (Kaye *et al.* 2005). For example, the presence of inaccessible physical features related to the building such as: lack of disability parking space, narrow doorways and a small waiting area or examination room (Kroll *et al.* 2006). Furthermore, the presence of inaccessible equipment can be a barrier such as: the lack of adjustable dental chairs or x-ray equipment (Dougall and Fiske 2008).

Physical mobility represents a significant barrier for attending a general dental practice (Kroll *et al.* 2006). The location of the dental practice represents an issue of accessibility to people with disabilities in terms of transportation and difficulties in making and keeping appointments (Veltman *et al.* 2001). A study reported that about 38.8% in Canada and 34.8% of disabled people in the US find difficulties in keeping medical appointments due to transportation problems (Allen and Mor 1997). Although this study involved surveying people by telephone, people who did not have one have been excluded and those people could be the most needing services and experiencing more barriers than others. This study again focused on adults, but it can also indicate the level of barriers and transportation barriers which may also apply to parents of children with disabilities.

Many authors drew conclusions regarding their environment, living conditions as barriers experienced by children with disabilities and their families and carers (WHO 2011). Disabled children were more likely to be living with several social and environmental factors that are considered barriers and facilitators (WHO 2011). For example, children with disabilities were more likely to be raised in poor housing conditions, be from lower socioeconomic classes, and

encounter discrimination and get limited access to social services compared to their non-disabled peers (WHO 2011).

Epidemiological studies highlight that environmental factors may produce influences regarding the prevalence of disability (Wang *et al.* 1997). For example, malnutrition and poor housing conditions are associated with a higher prevalence of children with disabilities (Mathers and Loncar 2006). In addition, some authors conclude that changing societal attitudes and improving the environment such as; improving the accessibility of health and social services may result in increasing social participation and the health of people with disabilities (WHO 2011).

According to the World Health Organization (WHO 2011), there is a wide range of evidence, which demonstrates the presence of relationships between poverty and disability. Studies show increased poverty among disabled people at working age compared to their non-disabled peers in developed countries (Parodi and Sciulli 2008; Mitra 2008). In developing countries, studies found that people with disabilities had fewer opportunities in the labour market and lower educational levels than people without disabilities (Loeb *et al.* 2008). While in low-income countries, 50% of people with disabilities are likely to experience difficulties regarding finance due to the situation of their country (McNeilly 2011).

Furthermore, the presence of physical barriers, environmental barriers and the previously discussed social and attitudinal barriers would result in full limitation and restriction of social participation for people with disabilities (Thomas 2004). However, improving access requires policy changes along with proper implementation using systems to reduce both structural and environmental barriers (Kroll *et al.* 2006).

1.9.5. Behavioural barriers

The most commonly cited underpinning barriers to oral health care services among children generally are fear and anxiety (Band 1998). Children's fear of

dental care and treatment is associated directly with low levels of attendance (Royal College of Surgeons in England 2012). Emerson (2001) reported that fear of dental care and anxiety for adults with learning disabilities in particular could perhaps result from previous traumatic incidents and result in difficulties with cooperation. This requires management skills and knowledge of anxiety from the dentist (Connick and Barsley 1999). A greater need for conscious sedation and GA is suggested as a requirement, which may lead to an increase in demand and more financial support from Central Government (Royal College of Surgeons in England 2012).

Communication difficulties are considered a major barrier amongst people with learning disabilities, which would result in their inability to express their perceived needs (Royal College of Surgeons in England 2012). However, this takes a medical model approach to communication because it places the problem firmly within the individual and expects them to alter for the professional. In contrast, a social model of disability approach would argue that the dentist needed to get to know the person as an individual and find out how they communicate the best. This places the responsibility on the professional to adjust the environment and develop more effective communication skills that aim to include patients in their oral health encounters. All children, not merely those with disabilities, may not be able to explain their toothache and pain if they lack the requisite communication skills. This being said, advanced communication skills would be required on the part of the oral health care provider in order to effectively improve the communication environment of the child. One example is working closely with the person who knows the child the best and understands their way of communication. Otherwise, the oral health care provider may not notice until there are reports of behavioural changes, which may then be linked to a patient's oral health status.

Poor oral health status may negatively affect an individual's quality of life and may include sleeping, drinking and eating (Norwood and Slayton 2013). Poor oral health includes dental decay, periodontal disease and other oral diseases, which may result in chronic pain (Campanaro *et al.* 2014). Preventing oral

disease and maintaining good oral health would result in long-term benefits across the life-course and can be done via routine daily oral health practices with support from family, carers and oral health care services working in collaboration with one another (Campanaro *et al.* 2014). This also applies to children with special care needs and more profound disabilities who may encounter greater difficulties regarding daily oral health care practices because they require a higher level of attention and care from their family or paid carers (Macias *et al.* 2006).

One of the barriers to maintaining good oral hygiene is oral health priorities for family, parents and carers and their knowledge and attitudes towards oral health (Adair *et al.* 2003). The child's behaviour, medical condition, needs and the presence of external constraints such as lack of time in a tight schedule may be considered as barriers and interfere with oral health status (Huebner and Riedy 2010). In addition, medical insurance for some countries and the cost of treatment are considered as barriers to accessing oral health care services with some people being unable to afford the insurance and this again increases oral health inequalities (Singh and Lin 2013).

1.9.6. Financial barriers

People with disabilities, around the world, are more likely to have poorer general and oral health status than their non-disabled peers (Singh and Lin 2013). In addition, higher rates of obesity, unemployment, lower SES and encountering more barriers in accessing various services, including: social and health care services, were reported to be associated with disabled people (Altman and Bernstein 2011). It appears that in some countries, health insurance for disabled individuals is considered a major determinant of access to health care services (Szilagyi 2012).

Research has shown that uninsured people are more likely to experience delayed or reduced attendance to preventive medical services and to be diagnosed with diseases in their later stages (Singh and Lin 2013). This particular study could not identify if the types and severity of disability had an

impact on using health services, but it suggested that insurance played a role in accessing health services. Furthermore, there appears to be an association between higher mortality rates and uninsured children in some countries (Caskey and Davis 2008). For example, a study done in the USA in 2009 reported that a lack of insurance for children might lead to worsening health outcomes, increasing the costs of health care and increasing the mortality risk by up to 60% (Abdullah *et al.* 2009).

Health insurance can improve access to various health care services because it plays a key role in providing appropriate access to needed health care services (Szilagyi 2012; Newacheck *et al.* 2000). It appears that children with disabilities in countries with private health insurance are more likely to visit primary health care regularly, to reach a specialist and to access and utilize oral and general health care services (Newacheck *et al.* 2000). Szilagyi (2012) reported that insured children with disabilities in US have better quality of life and fewer unmet health needs than children without insurance. This position is supported by Newacheck *et al.* (2000) who report that, in the USA, children with disabilities who are not insured were 4 times more likely to have unmet needs for medical and oral care services than children with disabilities who have insurance. Moreover, insured children visit health care services twice as often compared to uninsured children with disabilities.

1.10. Parental perceptions around access to oral health care services

Parental perspectives about their children's oral health and about access to oral health care services for children with disabilities appears to have great impact on the oral health status of the disabled children (Barnett 2006). For example, parents and carers are responsible for oral health care within the home and ensuring access to oral health care services for their children (Kagihara *et al.* 2011). They are considered as decision makers for their child's oral health and their perceptions appear to influence preventive and treatment options both positively and negatively (Kenney *et al.* 2008). Research

suggests that the level of parental oral health awareness and the priority of oral health appear to be important factors in maintaining positive oral health for children with disabilities (Klingberg and Hallberg 2012).

Globally, studies have investigated parental perceptions of access to oral health care services (Al-Agili *et al.* 2004; Kenney *et al.* 2008; Nelson *et al.* 2011; Shyama *et al.* 2015). The studies indicate several barriers experienced by parents while accessing oral care services and those were: cost of the dental treatment, finding a dentist willing to treat children with disabilities, waiting time at the office, the distance travelled to get oral care and the priority of oral health.

The cost of the dental treatment and the ability to afford the cost of dental care generally has been highlighted in several studies as a barrier to accessing dental care services for parents of children with disabilities. A cross sectional study conducted in the USA (Butani *et al.* 2009) using self-administered questionnaires to examine the perceptions of parents of children with disabilities about access to oral health care services. Their sample was classrooms from special education and classrooms from the mainstream school as control groups. They found that parents complained about the high cost of dental treatment along with the difficulty in finding a dentist to provide dental treatment for their child (Butani *et al.* 2009). This study had several limitations, one was the selection of the classrooms which was done by the principal, not by the researcher and could result in selection bias. Another issue was that the study relied on children to deliver the questionnaire to their parents, thus failing to ensure delivery. Another study (Williams *et al.* 2015) revealed similar findings were conducted in the USA using questionnaires for the parents and they highlighted that finding a dentist willing to treat, alongside finance, in terms of affordability through the right level of insurance cover, as the main findings (Williams *et al.* 2015). Other barriers were long waiting times at the office, distance and transportation (Williams *et al.* 2015). However, more than half of the sample of this study was aged 18 years and older, or adults, which is not the focus of my thesis, although it is important to know that adults

with disabilities experience similar barriers to accessing dental services and that these may begin in childhood and persist across the life course.

Similar findings were reported in France by Allison *et al.* (2000) where they surveyed parents of children with Down syndrome. They found that children with Down syndrome were twice as likely to face difficulty in finding a dentist willing to treat their child compared to their peers. One of the limitations of the study was the sample of parents who were drawn from a French organization for people with Down syndrome, which may affect the validity of the study. The members of this organisation cannot be generalised to all parents of Down syndrome in France because they represent the most motivated parents who knew and acted upon their children's oral health needs. However, you could therefore expect these parents to have better access than possibly less motivated parents who may find getting access even harder.

Parental attitudes and priority of oral health appears to have an impact on the oral health status of children with disabilities and their ways of accessing oral health care services. Some research argues that parenting a child with disabilities puts a strain on the family (Seltzer *et al.* 2001) because the child may require more medical attention. A study in Sweden by Klingberg and Hallberg (2012) involved interviewing mothers of children with disabilities regarding accessing oral health services with their disabled children. It revealed that they were aware of the importance of oral health, but that the everyday circumstances of the family meant that the focus was on general health and well-being more than on oral health and that it is essential to look for oral health care services as early as possible to employ preventative measures.

On the other hand, a study done in Nigeria by Oredugba (2006) demonstrated contrasting perspectives and attitudes of mothers of children with disabilities. Families of 109 children with disabilities answered a questionnaire and about 33% of the sample had no clue as to the role of a dentist. Over half of the mothers in the study reported that the reason for not visiting a dentist or dental clinic for more than a year for check-up is that their children did not have any dental problems. One limitation of this study is the relatively small number of

participants which the author attributed to the cultural norms of the community, which had a tendency to hide children with disabilities, or send them away to live with their older relatives (Oredugba, 2006).

It would appear from the small number of studies that the attitudes and perspective of parents are essential factors to maintaining optimum oral health status for their children because they are responsible for ensuring daily oral care and for accessing oral health care services. What the majority of studies have done is send out questionnaires which mostly involve mothers; very few have interviewed fathers and not in depth.

1.11. Father's roles in accessing health care services

It appears that the role of parents is essential in accessing oral health care services for their children, because children are dependent on their parent when it comes to accessing and utilizing services (Kumar *et al.* 2014). However, studies rarely address the role of fathers in accessing services while the majority address mother's views, perceptions and healthcare-seeking behaviours (Sato *et al.* 2018). Research tends to ignore or exclude the role of fathers for many reasons; one reason is mothers tend to be viewed by society as responsible for the health of their children in many cultures (Correa *et al.* 2011). Other reasons include the complicated structure of the family where the father may not have biological or a legal relationship to the child (Higham and Davies 2013). Alternatively it may be that the views of healthcare professionals focus more on considering mothers as being better at caring for a sick child than fathers (Hughes 2007). This places the responsibility for caring firmly in the domain of the mother.

However, a study done in 2011 by Pani and colleagues showed that fathers have less of a role compared to mothers when accessing oral health care services (Pani *et al.* 2011). The study aimed to compare fathers and mothers' perceptions around oral health related quality of life of their children aged 2 -6 years old by using the Early Childhood Oral Health Impact Scale (ECOHIS). The ECOHIS was used to collect the data and was administered to both

parents of 97 children. The study suggested that fathers are significantly less aware than mothers about the oral health related quality of life of their children. Additionally, fathers scored higher 'do not know' answers than mothers, suggesting that they had lower levels of interaction with their children around oral health related issues.

On the other hand, a study done by Higham and Davies (2012) aimed to increase understandings of fathers' experiences when their children stayed at the hospital for an unplanned admission for an illness or injury. The study employed an ethnographic observation and interviews of fathers. It appeared that fathers played an important role in caring for their children. These roles were protecting their children by being there and strong for other family members, providing and ensuring others' needs were met, and participating in and sharing the care for their child. However, the study had a limitation of having a small sample of fathers (n=12) and explored their subjective views and experiences, so this could not be generalised to a larger cohort of fathers. Another limitation was that fathers could be acting in a way they thought researchers wanted during observations and this was called "*parenting in public*" (Derbyshire 1994, p.32).

It appears that fathers have an essential part in seeking health care and providing support during child illness or injury (Higham and Davies 2013). However, the voice of fathers is often absent from studies in healthcare and many papers tend to address the voice of mothers when accessing and receiving healthcare for their children (Hobson and Noyes 2011; Swallow *et al.* 2011, 2012; Garfield and Isacco 2012).

1.12. Summary

Children with disabilities are not a homogenous group; they are individuals with different disabilities that have different levels of severity and who experience various barriers to service provision in different ways (Smiley 2005). They have different needs to their non-disabled peers. Their oral health needs appear to be highest among their medical needs (Lewis 2009), and the literature

suggests that this needs to be addressed by providing access to oral health care services providing high quality of care and oral preventive measures.

Children with disabilities have poorer oral health status and higher oral needs than their peers from the general population (Paschal *et al.* 2016). The poor oral health of children with disabilities has been attributed to different factors and barriers. These barriers include barriers to the accessibility to oral health care services, the availability of the needed resources, the affordability and the cost of dental treatment. Other barriers that are considered as factors of poor oral health among disabled children are the knowledge and skills of oral health professionals, carer and family, the priority of the family and their support to maintain oral health, and limited access to oral health care services, which increases the poor oral health of disabled children (Shetty *et al.* 2014).

Access to oral health services appears to play a key role in maintaining a positive oral health status for children with disabilities. Access to health care services has been interpreted from various perspectives and there are different models that have been employed to interpret access with different dimensions. One of the models that has been employed to interpret access and oral health care service delivery is Penchansky and Thomas' model of access. Penchansky and Thomas' model identifies access as a degree of fit between children with disabilities (the patients) and their parents (their carers) and the oral health care services (the system).

It appears that ensuring better oral health for children with disabilities and better access to oral health care services is usually achieved by using different approaches. Ensuring better oral health requires the provision of better access along with improved oral health promotion to address various oral needs, changing the attitudes of society and oral care providers in a positive way regarding oral health and working to deliver better oral for children with disabilities (Owens *et al.* 2010).

Chapter 2: Kingdom of Saudi Arabia

2.1. Introduction

The Kingdom of Saudi Arabia (KSA) is considered as the largest country in the Middle Eastern region and the 2nd largest Arabian country (Central Intelligence Agency 2016). It is known to be the largest oil exporter and possesses the 2nd largest oil reserves (Berger 2013). Through the Organization of the Petroleum Exporting Countries (OPEC), the Kingdom of Saudi Arabia plays an important role in shaping the price of the oil and supporting the growth of the global economy (Berger 2013).

Geographically, as show below in figure 4, the Kingdom of Saudi Arabia is located in the Southwestern area of Asia and covers most of the Arabian Peninsula in the Middle East, which is approximately 830 thousand square miles (Central Intelligence Agency 2016). It is bounded on the west by the Red Sea and from the east; Bahrain, United Arab Emirates and the Arabian Gulf. On the south side, it is bounded by Yemen and Sultanate of Oman from the south and from the north Jordan, Iraq and Kuwait (Bowen 2014, p.2-6). Most of the country is covered with deserts and sands. Saudi Arabia has 13 provinces, five of them are considered as the main one and they are: the central province 'Najd', which is the largest, it has the capital city Riyadh and most of the governmental sites. The western province is called the Hejaz, which has the most important city for all Muslims across the world: Makkah. One of the major provinces is called Al-Madinah, which has the second most important city for all Muslims 'Al-Madinah Al-Munawara' (Alquraini 2011).



Figure (4). Map of Kingdom of Saudi Arabia (OCHA, 2014)

2.2. Religion and politics

Saudi Arabia was founded by King Abdulaziz bin Abdulrahman Al Saud and was named as Kingdom of Saudi Arabia in 1932 (Vassiliev 2013). King Abdulaziz unified the tribes of Arabia and created the Kingdom of Saudi Arabia after a 30year campaign (Central Intelligence Agency 2016). Today his descendants under the family name 'Al Saud' rule the country and its provinces as governors; or in prominent positions within the Ministries and government with succession passing from brother to brother (Nevo 1998). The King also has the title of the Custodian of the Two Holy Mosques (Al-Saud 2016).

Al-Saud stated, "Our Kingdom is the Land of the Two Holy Mosques, the most sacred sites on earth, and the direction of the Kaaba (Qibla) to which more than a billion Muslims turn at prayer" (Al-Saud 2016, p.6). Saudi Arabia is the guardian of the two most holy places on earth for all Muslims: Makkah is the site of the Al Haram mosque which houses the Kaaba and Al-Madinah which is the site of the mosque of the prophet Mohammed, peace be upon him (pbuh)

(Raj 2012). Furthermore, Makkah is the place where Islam emerged, and Al-Madinah is the place where Prophet Mohammed has travelled to and where Islam begun to spread to the world (Raj 2012).

Islam is the official religion of the Kingdom of Saudi Arabia and Islamic teachings influence the Saudi way of living (Al-Saud 2016). Islam as a religion constitutes the basis of laws, goals and actions (Al-Saud 2016). The Qur'an and Prophet Mohammed's teachings (pbuh) are considered to be the only sources of Kingdom of Saudi Arabia laws (Nevo 1998). The Prophet Mohammed's teachings are taken from Sunnah and Ahadith (sayings) that include his actions, speeches, talking, morals and manners and provide guidance and structure for the daily living of all Muslims (Johnson and Sergie 2014). Governmental regulations and decrees act to complement Islamic laws, not to replace them (Nevo 1998).

2.3. Health, health system and health indicators

The Saudi Arabian government has a key role in ensuring that all individuals of the Saudi population have access to general and oral health care services and provided with needed services and treatment (Qutob 2009). The health care system in Saudi Arabia includes public and private sectors (Al-Shahrani *et al.* 2016). The Ministry of Health is the part of the Saudi government, which deals with the health of the population and all the Saudi citizens and residents working in the public and private sectors have the rights for free and full accessibility to utilize the health services (Walston *et al.* 2008; Al-Shahrani *et al.* 2016). The Ministry of Health monitors, evaluates and supports both sectors along with coordinating with other governmental sectors. In addition, it monitors the health indicators of the population, is responsible for providing various public healthcare services and the regulations that runs all of health facilities (Saudi Ministry of Health 2014). The next table shows some key demographic indicators for the population of Saudi Arabia compared to the United Kingdom (UK) and the United States (USA):

Table (2). Demographic key indicators for the Saudi Arabia compared to the UK and the USA:

Indicators	Data		
	Saudi Arabia	UK	USA
Total population	30,770,375	63,136,000	322,583,000
Crude birth rate (per 1000)	22	12.2	13.9
Annual population growth rate	2.55	0.5	0.9
% Population under 15 years	29.5	18	18.8
% Population 15- 64 years	67.5	59	65.9
% Population from 65 and above	2.9	23	15.2
Total fertility rate	2.75	1.9	2
Life expectancy at birth			
• Male	• 73.1	• 78	• 76.7
• Female	• 75.6	• 82	• 81.4
• Total	• 74.2	• 80	• 79.1

(Saudi Ministry of Health 2014, p.33; WHO 2012, p.58-118)

In terms of life expectancy, Saudi Arabia life expectancy for individuals is more than the global average by 4 years while exceeds the regional average by 6 years (Saudi Ministry of Health 2014). In addition, crude birth rate (22) is more than in developed countries. During the past few decades, Saudi Arabia has improved significantly in terms of quality and quantity of health care services (general and oral health services) (Almalki *et al.* 2011). The Ministry of Health in Saudi Arabia has improved health on a broad national scale with a relatively

high level of care to all segments of the population (Gallagher, 2002). In addition, the WHO ranks the health system of Saudi Arabia at 26 compared to other countries such as Canada (30), USA (37) and Australia (32) (WHO, 2000).

Although the health care system has improved recently, a variation in resources still exists between the provinces (Saudi Ministry of Health, 2014). In addition, the variation of human and financial resources within the same province exists due to uneven distribution of health care services and health professionals across geographical areas (Almalki *et al.* 2011). The variation between provinces is demonstrated in table (3) below.

Table (3). Population, health care workforce and health care services in different provinces:

Province	Population	Primary health care	Public Hospital	Dental center	Rehabilitation center	Physicians	Nurses / 100 physicians
Riyadh	8,446,866	447	49	3	1	7261	253.5
Al-Madinah	2,188,138	159	19	3	1	2633	219
Makkah	2,386,900	85	10	3	1	3040	191.8
Al Baha	487,108	108	10	2	0	933	171.3

(Saudi Ministry of Health 2018)

There are inequalities in the distribution of health care services between various provinces in Saudi Arabia (Almalki *et al.* 2011). According to the numbers in the previous tables, the number of primary health care services in Riyadh is three times more than in Al-Madinah while the population is three times more than Makkah. In addition, the number of hospitals in Al-Madinah is twice that of Makkah while the population in both provinces is similar to each other. Furthermore, the need for rehabilitation centres is greater for Riyadh in relation to the number of populations to other provinces. Comparing Riyadh to Al Baha province in terms of health care professionals, a difference is observed regarding the number of physicians and nurses in Al Baha is fewer than Riyadh. However, still there is a need for various healthcare services and professionals in different provinces.

It appears that there is a shortage in terms of healthcare professionals is present in Ministry of Health of Saudi Arabia (Almalki *et al.* 2011; Saudi Ministry of Health 2014). Expatriates represent much of healthcare professionals (such as; physicians, dentists, nurses and allied healthcare personnel) in the Kingdom of Saudi Arabia (Saudi Ministry of Health 2014). The increased number of expatriates has led to a high turnover, lack of continuity of care and instability of the healthcare workforce (Almalki *et al.* 2011). This is an area that the Kingdom is currently trying to address by increasing training and employment of Saudis in the workforce. According to the Ministry of Health, at present, Saudis constitute about 38% of the total workforce (Almalki *et al.* 2011).

One of the actions taken by the Ministry of Health to reduce expatriates in the healthcare workforce is to increase training for healthcare professions and jobs to substitute the expatriates with qualified Saudis (Aldossary *et al.* 2008). There are around 73 colleges to teach various medical professions as well as private institutions (Saudi Ministry of Health 2014). In addition, the Ministry of Health supports those who would like to pursue their studies abroad (Saudi Ministry of Health 2014). These strategies are not enough but could raise the skills of employees, improve the healthcare quality and reduce the high level of turnover amongst the healthcare workforce (Almalki *et al.* 2011).

There are 20 regional directorates of health covering all parts of Saudi Arabia, they are connected administratively to the Ministry of Health offices in Riyadh (the capital city) for monitoring and supporting purposes (Al-Khamis 2012). The public healthcare system in Saudi Arabia has 3 categories: Primary, Secondary and Tertiary (Saudi Ministry of Health 2014) and each of those categories provide certain types of care for different parts of Saudi Arabia as shown below in the table (4).

Table (4). Different categories of the healthcare system in Saudi Arabia.

Health service	Covering area	Types of care
Primary	Covers all cities, towns and villages	It provides preventive care mainly along with providing simple treatment. It also focuses on enhancing, maintaining health and educating people about health issues.
Secondary	Cover cities and some towns	It provides medical care that is beyond primary health care limits. Healthcare provided by general hospitals and specialized clinics that has operating rooms for surgeries.
Tertiary	Main cities	It includes big specialized hospitals and oncology centres. It provides far more complex medical care than those in primary and secondary medical facilities.

(Saudi Ministry of Health 2014)

In Saudi Arabia, there are other governmental sectors that provide healthcare services for parts of the Saudi population. Those sectors provide their recruits and their families with needed healthcare, but they also provide healthcare to Saudi citizens and residents in case of emergencies (Walston *et al.* 2008). The sectors are shown in table (5) below.

Table (5). Different governmental sectors that provide health services to different parts of the Saudi population.

Governmental sector	Population	Health services
Ministry of Health	Saudi and non-Saudi population	Health care centres, medical, dental and medications
The National Guard	Employees of the National Guard and their dependant families	Health care centres, medical, dental and medications
The Armed Forces	Employees of the Armed Forces and their dependant families	Health care centres, medical, dental and medications
The Interior Security Forces	Employees of the Interior Security Forces and their dependant families	Health care centres, medical, dental and medications
The Ministry of Education	Saudi and non-Saudi population	University hospitals, medical, dental and medications
	Governmental school children	Primary care (medical and dental) and medications
The Saudi Intelligence Agency	Employees of the Saudi Intelligence Agency and their dependant families	Health care centres, medical, dental and medications

(Saudi Ministry of Health 2014)

In 2015, the Ministry of Health started to employ a Private Health Institution Regulation which is considered to be one of the outcomes of “Saudi Vision 2030” (Elaraby *et al.* 2016). “Saudi Vision 2030” lays out the future of Saudi Arabia including economic growth, increasing job opportunities for Saudis and promoting investment for the private sectors (Elaraby *et al.* 2016). So, moving

to privatization of the health sector involves establishing public private partnerships and developing new health care programs (Almalki *et al.* 2011). In addition, the need for more healthcare professionals such as dentists and for more healthcare products such as medical equipment has been increased to successfully facilitate the achievement of the “Saudi Vision 2030”.

2.4. The referral system in Saudi Arabia

The presence of an appropriate referral process within the health care system is an essential key part to ensure good access to health care services provided. It appears to be in a relation with the availability, appropriateness and accessibility as the main dimensions of access (AlKindi and Nunn 2016).

The referral system in Saudi Arabia was introduced as part of the primary health care services in 1989 after realizing the importance of referral systems within health services (Khattab *et al.* 1998; Qureshi *et al.* 2009). Referral was defined as the process in which a physician is seeks the help of a better equipped facility and specially trained person to manage and take over the management of a clinical condition (Al-Mazrou *et al.* 1990) and there were two types of referral:

- **Emergency referral:** that is made in case of an emergency that could not be managed within the same health facility.
- **Routine referral:** is usually made to seek expert opinion about a patient, seek admission and management of a patient or to find a facility for further investigations (Khoja *et al.* 1997).

Since implementing of a referral system within the health services in Saudi Arabia, a reduction has been noticed in the number of patients visiting the outpatient clinics and a reduction in the duplication of services and the inefficient use of services (Al-Yosuf *et al.* 2002). However, the work also cautioned that the Ministry of Health should commit to the referral system and reflect on adherence in its policy making to improve the deliverance of their health care services.

2.5. Determinants of oral health

Previously in section (1.2.) determinants of health were defined as “determinants of health referred to the many factors that combine together to eventually influence and shape the health of communities and individuals” (WHO 2019). However, in Saudi Arabia, I am going to focus three main determinants of health to discuss some of the determinants of health in the society of Saudi Arabia, and they are as follows:

2.5.1. Socio-economic determinants

Saudi Arabia is considered as one of the countries with a social hierarchy and inequity regarding oral health (Al Agili 2013). The SES of a family in Saudi Arabia depends mainly on the level of education of the parents, family income, housing conditions and school location, which results in an unclear picture of the influences on health (Al-Shammery 1999; Al-Malik *et al.* 2001; Al Agili 2013).

Similar to Western studies, it appears that low levels of dental caries appear to be associated with families with high social class (this is especially associated with high family income and private schooling in Saudi Arabia) (Al-Malik *et al.* 2002). In addition, low SES is associated with higher prevalence of oral diseases and limited access to health care services (Al Agili 2013). For example, one study carried out in the Saudi Arabia reports a high rate of dental caries among school children, which are from families with a lower SES (Gandeh and Milaat 2000). Other research argues that parental educational level and maternal literacy is very important in relation to the prevalence of caries among children regardless of family income, housing quality, school location and type (Amin and Al-Abad 2008).

Gender inequality has also been found to influence the prevalence of caries among females and males in Saudi Arabia (Gandeh and Milaat 2000). Gender discrimination is also ascribed to cultural habits, for example, research conducted in Saudi Arabia by Alyaemni *et al.* (2013) suggests that the general

health of most women was worse than men and this was attributed to different reasons such as some restrictions of the women's freedom of movement in the Kingdom, psychological stress related to their child rearing responsibilities and marital conflict. Other research done in the south-eastern region of Saudi Arabia investigates the general health risk factors between boys and girls at different ages and found that girls are more prone to health problems than boys (Mahfouz *et al.* 2011). On the other hand, there are reports of a higher prevalence of caries among male children than females in Riyadh and Al-Qasim regions and the suggestion is that this was due to socio-cultural factors related to those regions since parents pay more attention toward the aesthetics and hygiene of female children to increase their prospects as marriage partners (Al-Shammery *et al.* 1999).

Although there are no national data about the prevalence of caries among children in Saudi Arabia, Al Agili (2013) have estimated the national caries prevalence among children in Saudi Arabia to be around 80% for the primary dentition with a mean dmft of 5 while 70% for permanent dentition of the children with a mean DMFT of 3.5. In Al-Madinah, a survey was done to estimate the level of caries among children aged 9-12 years old and they reported that DMFT/dmft scores for male children to be 1.5/1.7 while female children scores were 1.7/5.3 (Al-Samadani *et al.* 2017). Another reported caries prevalence (87%) for children aged 6-12 years old in Al-Madinah with a mean DMFT/dmft scores 6.4/2.9, and there would appear to be a need for an epidemiological survey to be done on a national scale using a standardised methodology to make the data more comparable and reliable.

2.5.2. Environmental conditions

Sea water (desalinated water) is the main source of water for the cities of Saudi Arabia, while rural areas are dependent on well water (Akpata *et al.* 1997; Aldosari *et al.* 2004). In addition, there is no planned fluoridation of water for all cities of Saudi Arabia, although it is present in all bottled water with different percentages (Alabdula'aly 1997). The fluoride content within well water differs

from one region to another and most rural areas are dependent on well water (Akpata *et al.* 1997). For example, a study has estimated the level of fluoride in the water of 87 wells and they reported that level of fluoride ranged from 0.543 to 2.848 ppm (Akpata *et al.* 1997).

A study done in the central region of Saudi Arabia reported that each village drinks from only one well for generations because they are accustomed to its taste and aroma (Akpata *et al.* 1997). Moreover, the fluoridated well water that found in the central region was unlikely to change since it is confined in deep aquifers in the earth's stratum (300m deep) (Bras 1990).

Recently, the consumption of bottled water has increased, and people nowadays are demanding for more palatable water in contrast to the mineral rich tap water in Saudi Arabia (Al-Otaibi *et al.* 2004). In addition, there are other factors, which could increase the exposure to fluoride other than water, which include: diets and toothpaste (Aldosari *et al.* 2004). For example, Al-Shammery *et al.* (1998) reported higher prevalence of caries in rural areas compared to urban areas, where awareness about good oral health and access to toothpaste is better than rural areas. It appears that the cause of this higher prevalence of caries is due to the variation in diet and amount of sugar consumption which has increased with access to more Westernised goods through the globalisation of food (Al-Shammery *et al.* 1998).

There are different toothpastes with different fluoride concentrations such as: toothpaste for children (<6 years old), which should contain <500 ppm of fluoride concentration while 1100-1500 ppm of fluoride as the standard fluoridated toothpaste for adults and children (>6 years old), and >1500 as a prescribed toothpaste only (Ullah and Zafar 2015). To ensure the safety of food and to control it, the Saudi Food and Drug Authority was established in 2003, but similar to the UK it has yet to control sugar consumption (Al-Kandari and Jukes 2012).

2.5.3. Cultural determinants

There are many cultural habits related to Islam and oral health, and there are oral practices that have gained acceptance and supports from the World Health Organizations such as Miswak (Riggs *et al.* 2012). Miswak, is commonly used by Muslims to clean the teeth in Saudi Arabia and in many countries (Al-Otaibi 2003). A study done in Saudi Arabia to determine the prevalence of Miswak use in one of the main cities (Makkah) reported around 65% of the participants used Miswak (Al-Otaibi *et al.* 2003). Miswak has strong religious and cultural associations since it has been used since ancient times as an oral health aid (Riggs *et al.* 2012). Islam recommends the use of Miswak 5 times a day with each prayer call since the Prophet Mohammed (pbuh) has encouraged its use (Naeem 2002).

Miswak has proven to be an effective oral health tool as being effective to remove plaque by its mechanical effect (Sathananthan *et al.* 1996). One example is a study which concluded that using Miswak would effectively reduce the plaque formation among Ethiopian school children (Olsson 1978). Furthermore, Miswak inhibits the cariogenic activity of pathogenic bacteria such as *Streptococcus Mutans* (Al-Otaiba 2003). For example, a study reported low caries level incidence among school children that reported using Miswak (Sathananthan *et al.* 1996). In addition, Miswak has been known to contain about 1.0 µg of Fluoride/g, which may contribute to the antimicrobial effect (Halawany 2012; Ullah and Zafar 2015).

However, several authors reported disadvantages regarding the use of Miswak (Halawany 2012). For example, the excessive use of Miswak, specifically in the anterior region, may result in gingival recession and enamel abrasion (Eid *et al.* 1991). The excessive use of Miswak can be avoided by dentists promoting methods, time and duration of use (Halawany 2012).

2.6. Disability in Saudi Arabia

Disability is considered as one of the primary social and medical issues in Saudi Arabia (Al-Jadid 2013). The prevalence and incidence of disability and their socio-demographic data are unavailable due to the limited number of studies that are done despite the level of awareness (Kisioglu *et al.* 2003). However, very limited epidemiological research has been done on the prevalence of disabled individuals in the Saudi Arabia and most of the research done fails to differentiate between types of disability (Al-Jadid 2013).

It appears that the prevalence of people with disabilities in Saudi Arabia differs due to the definition used (Harris and Lewin 1998). Moreover, there are no nationwide census' or surveys that are representative for the Saudi population (Elsheikh and Alqurashi 2013; Japan International Cooperation Agency 2002). The social affairs representative in Al-Madinah estimates that around 4% of the total population is disabled, which amounts to about 720,000 people (Abanumy *et al.* 2005). Another study reports that the number of disabled individuals is about 900,000, which is more than 8% of the Saudi population (Elsheikh and Alqurashi 2013). Furthermore, a survey revealed around 0.8% of the population was disabled, which is about 135,000 of the Saudi population (Al-Jadid 2013). Another study revealed that people with disabilities comprise about 3.73% of the population (Al-Gain and Al-Abdulwahab 2002). Research done in 1997 on a close-knit military community in the central region of the Saudi Arabia, reported the prevalence rate of disability among children to be about 145 per 1000 children (Ansari and Akhdar 1998). None of these rates can be claimed to be accurate because it depends on how disability is defined and whether families wish to disclose disability within the family.

These studies are not representative for the whole population since their focus aims to find the aetiology of the disability (Al-Shehri and Abdel-Fattah 2008). Inexplicably, these studies excluded people with learning disabilities and did not count them as disabled (Elsheikh and Alqurashi 2013). This again points to what is regarded as disability and it would appear that any form of intellectual disability is inexplicably disregarded.

It appears that people with disabilities are more prevalent in rural areas of Saudi Arabia; 59%, while in urban areas 41% (Japan International Cooperation Agency 2002). The number of people with physical disabilities is 33.6%, Visual impairments about 29.9%, hearing 10.7% and intellectual disability about 9.7% of the population (Japan International Cooperation Agency 2002).

Within Saudi Arabia, the leading causes of impairment are road traffic accidents and consanguineous marriages (Al-Jadid 2013). The overall number of road traffic accidents is considered high; about 293,000 traffic accidents in 2004 compared to other Middle Eastern countries such as the United Arab Emirates (UAE) which reported around 8,300 traffic accidents in 2004 (Barrimah *et al.* 2012). Furthermore, most of the accidents were mainly due to speeding followed by other violations of road regulations (Mansuri *et al.* 2015). Another common cause of disability is consanguineous marriages, which accounts for about 56% of all marriages and this would result in disabilities related to genetic factors (Al-Gain and Al-Abdulwahab 2002).

Research about people with disabilities in the Saudi Arabia faces many obstacles (Elsheikh and Alqurashi 2013) such as: high incidents of car accidents and the fact that some families prevent their disabled members from participating in Saudi society and from attending the social gatherings (Al-Gain and Al-Abdelwahab 2002). Decades ago, it was thought that there were a low number of disabled individuals in Saudi Arabia (Aljadid 2013). This assumption was wrong due to the classification of and cultural notions around people with disabilities (Al-Gain and Al-Abdulwahab 2002).

Those notions and assumptions meant that many people with disabilities were left behind closed doors and prevented from attending social gatherings (Aljadid 2013). Disabled individuals were ignored, and relatives were rarely seen out with them (Elsheikh and Alqurashi 2013). They were seen in public only when they attended hospitals and when sick (Aljadid 2013). This happened because they were viewed as bringing shame on their family who were then stigmatized as a result (Aljadid 2013). For example, if it was known that there was a disabled family member, daughters would not to be considered marriageable and the family would be avoided (Elsheikh and

Alqurashi 2013). Families would also avoid any participation in research, since they felt ashamed of having a disabled child and did not wish the matter to become public (Al-Gain and Al-Abdulwahab 2002). This has been termed as disabled by association because of the interactive effective of living with a disabled individual (Burke 2010). This does not mean that the disability is the issue; rather it is the way it is reacted to in wider social settings. This emphasises the privacy of Saudi families and reflects the structure of Saudi society.

It appears that disabled people experience marginalization for many reasons such as: the lack of knowledge around the nature of disability, the inability of society to deal with it, being made to feel ashamed to be involved within the community and poverty which may sometimes be the cause of disability initially, for example malnutrition, poor housing and unsafe living environments (Japan International Cooperation Agency 2002). The ignorance of health care and lack of availability of social facilities for people with disabilities and their families could be a contributory cause of increasing marginalization (Aljadid 2013). We can also suggest that social exclusion may also be a cultural factor and related to the conservatism of Saudi society and the privacy of families.

2.7. Oral health of children with disabilities in Saudi Arabia

Over the whole world, the oral health status of children with disabilities is worse than nondisabled peers, and the oral health of children with disabilities in Saudi Arabia does not differ (Brown 2009). Caries prevalence in Saudi Arabia may be said to be related to social class and the SES of the family. For example, some studies infer that the high rate of caries (5.0 dmft) is associated with low SES, poor housing conditions and location and type of the school that children attend (Al-Malik *et al.* 2001; Al Agili 2013).

In addition, children with disabilities appear to have higher unmet needs than their non-disabled peers. It appears that their disabilities and sometimes related diseases exert an impact on oral health, for example the involuntary muscle movements of children with cerebral palsy, which makes daily oral

health practices such as tooth brushing very difficult (Wyne 2007). Other children who have Down syndrome and have certain dental features, previously mentioned, would make some of them at risk of having poor oral health (Alsarheed 2006). On the other hand, the poor oral health status of children with disabilities can be a risk factor in itself for exacerbating their existing general health conditions.

In Saudi Arabia, parents are responsible for the health of their child, including maintaining the oral health of their child via supervising child oral habits and diet. Although the patriarchal society in Saudi Arabia means responsibility falls mostly on women (Wyne 2007). Parental oral health knowledge and attitudes plays a key role in the formation of their child oral habits and in maintaining the positive oral health of their child (Al-Tamimi and Peterson 1998). The inability to perform self-care oral hygiene practice of the child increases the risk of dental disease (Shyama *et al.* 2015). A study done by Pani *et al.* (2012) in Saudi Arabia reported that mothers have better knowledge and are more concerned about their children's oral health than their fathers. In contrast, other studies in Saudi Arabia have indicated that both parents demonstrate a reasonable knowledge and favourable attitudes toward oral health and oral hygiene practices (Pani *et al.* 2012). Whether this also applies to parents of children with disabilities is unknown.

Saudi children with disabilities still have higher unmet oral health needs compared to their peers (Waldman *et al.* 2010). We can suggest here that parents of children with disabilities may experience several barriers in gaining access to appropriate oral health care services; one barrier may be finding appropriate oral health care facilities, another may be finding oral health care professionals possessing the knowledge and skills and willingness to treat children with disabilities (Shyama *et al.* 2015).

One particular study in Riyadh, the capital city of the Kingdom of Saudi Arabia, reported a positive attitude of dentists toward treating patients with disabilities (Alsarheed *et al.* 2001). Although, the attitude of dental practitioners was reported as positive, it was also claimed to be less favourable than those of dental professionals from Europe and North America (Alsarheed *et al.* 2001).

It appears that a less favourable attitude may be related to the dental curriculum and cultural background in Saudi Arabia because other studies explained that dentists who were in more contact with people with disabilities showed a more positive attitude and willingness to treat them (Waldman *et al.* 2010). A study carried out in Saudi Arabia suggested that only dentists during their postgraduate studies (Department of Pediatric Dentistry) have come into clinical contact with patients with disabilities and undergraduates received 1 or 2 lectures as a part of medically compromised patients programmes, but little or no direct contact with people with disabilities (Waldman *et al.* 2010). This lack of exposure during training may also be part of the reason why dentists are unwilling to treat disabled patients.

2.8. Summary

Children with disabilities have poorer oral health status than non-disabled children (Bimstein *et al.* 2014; Norderyd *et al.* 2015). Parent and dental professional's knowledge and attitudes towards the oral health of children with disabilities is considered as an important factor in maintaining good oral health of disabled children and in accessing oral health services (Al-Tamimi and Peterson 1998). In Saudi Arabia, dental professionals who know how and are willing to treat children with disabilities appears to be limited to those who have postgraduate experience in paediatric dentistry (Waldman *et al.* 2010). Whether there are any specialists in special care dentistry in Saudi Arabia, similar to the UK, is at present unknown.

2.9. Rationale

Saudi Arabia has a substantial tribal population with large families descended from common ancestors and migrant families originating from diverse ancestries and it has a high consanguinity of marriages, creating a genetic basis for disability within the family (Basit *et al.* 2015). Saudi society is very conservative and there are strict social rules of conduct for men and women to observe. For example, it is not acceptable socially and religiously for a woman to sit with a man who is not related to her or be alone in a room, especially if the man is not closely related to her i.e. her father, brother or husband.

Apart from 1 scoping review (Ummer-Christian *et al.* 2018) that presented different barriers to access dimensions (accessibility, affordability, availability, accommodation, acceptability and appropriateness) for children with intellectual and developmental disabilities existed among 11 countries, there is a paucity of studies that have attempted to explore access to oral healthcare services for children with disabilities globally and no studies in Saudi Arabia. Although there are a few studies that have investigated the knowledge and attitudes of dental professionals and dental students towards treating people with disabilities (AlSarheed *et al.* 2006; Waldman *et al.* 2010; Alkahtani *et al.* 2014; Salama *et al.* 2015) these focus only on attitudes and no other areas of access. It is pertinent to note that no study in Saudi Arabia, or globally, has explored access, using Penchansky and Thomas's definition, from the perspectives of parents, and particularly fathers.

The lack of studies that conduct an in-depth exploration of access to oral health care from the perspective of parents of children with disabilities globally and particularly in Saudi Arabia highlights a gap in the literature.

This thesis plans to address that gap by exploring in depth the perspectives of parents of children with disabilities, particularly fathers, around access to oral health care services.

2.10. The main question of the study

In what ways do fathers of children with disabilities experience access to oral health care services in the Kingdom of Saudi Arabia?

2.11. The objectives

The objectives of this study are:

- To explore father's perspective around access to oral health care services for children with disabilities in Saudi Arabia.
- To critically assess oral health care professional perspectives around the provision of oral health care services for children with disabilities.
- To enable the voices of Saudi fathers of children with disabilities to be heard in oral health research.
- To use Penchansky and Thomas's framework of access to ascertain examples of good practice around quality care for children with disabilities in Saudi Arabia.

Chapter 3:

Methodology

3.1. Introduction

This chapter will introduce the methodology used in the study. Methodology is important because it reflects a way of thinking about and doing research. So, for example, my study wants to explore fathers' perspectives of oral health services for their children. It also wants to look at the context in which services for children with disabilities are delivered and received within Saudi Arabia. I will therefore discuss the rationale for my choice of methodology and compare it to others. Then, I will finally relate some of the issues of using ethnography to my study.

3.1.1. Qualitative methodology

Qualitative methodology refers to *“research that produces descriptive data using people’s own written or spoken words or observable behaviour”* (Taylor et al. 2015, p.7). As it has been highlighted by Ray Rist (1977), qualitative methodology is more than a set of techniques to collect data and to approach the empirical world. Denzin and Lincoln (2005) defined qualitative research, as *“Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them”* (p. 3). Qualitative research is the way of understanding people’s views from their own perspectives and within their own frame. In addition, qualitative researchers should identify with people they study to understand how those people are seeing and understanding things (Taylor et al. 2015).

There are several methods used to conduct qualitative studies and these are constantly evolving alongside the ever-changing patterns of human interaction

and communication (Creswell and Poth 2017; Qualitative Research Consultants Association 2016). The different qualitative methodologies that could be considered for this study are: ethnography, narrative, grounded theory and phenomenology.

This study will be an ethnographic study because it will be trying to gain insight into the perspectives of parents from a particular culture. Ethnography may be said to be a qualitative methodology because it means the researcher enters the lives of participants to gain a deeper understanding of the issues and circumstances (Newman 1994; Atkinson *et al.* 2003). The next section will consider some of the main qualitative methodologies and justify my approach.

Narrative

Narrative is both a method and phenomenon of research (Connelly and Clandinin 1999), this means that the actual representation of research is a narrative in itself. A narrative is a story that is told by an individual or a group of individuals (Plummer 2001). It has many different forms such as moving pictures, photographs, paintings, films and so on (Barthes and Duisit 1975). The role of the researcher using narrative is to enable the participant to tell their story in order for readers to gain understanding and clearer insight into different lives as people tell them through the researcher collaborating with the participant in order to represent their narrative in text (Plummer 2001). Narrative does not suit my thesis because it deeply explores the story and the life of an individual or group of individuals but does not really engage with the impact of culture, which is part of the aim of my thesis.

Phenomenology

Phenomenology is a philosophy of experience and a methodology of qualitative research. Its main aim is to fully understand an event or a phenomenon by describing its different aspects within the lifeworld (Creswell and Clark 2007). It is about the subjective lived experiences and perspectives

of participants and its early origins are grounded in philosophy. Phenomenology suggests that there are multiple ways of interpreting the same experience (Van Manen 1990). The meanings attributed to these experiences by a participant are what constitutes reality (Van Manen 2014). There is a heavy reliance on one form of data collection and that is multiple and in-depth interviews with participants. There are no other forms of data included in a phenomenological study and the skills of the researcher in conducting in-depth interviews is important (Polkinghorne 1989). During analysis, descriptions of what was experienced by individuals are separated from how it was experienced and the analysis is complex (Vagle 2014). Phenomenology does not fit the main question of my study because I am interested in the cultural setting in which parents negotiate their everyday lives. This takes a more holistic approach than phenomenology can accommodate.

Grounded Theory

Grounded theory (GT) has undergone development since the 1960s work of Glaser and Strauss (Glaser and Strauss 1967). GT is usually used to develop a theory while collecting data that based on participants' views to study the social and psychological process (Creswell and Clark 2007). The original approach came from Glaser and Strauss's work on dying patients and focuses on individual interviews with people undergoing or having undergone a life transition (Glaser and Strauss 1965). The goal of GT became to study a process or action. Its rigour is through its inductive coding from the data to memo writing and documenting analytical decisions then moving backwards and forwards between data, theory and concepts without letting them drive the study. This allows for an inductive approach, which constructs a conceptual framework and categories. Constant comparative analysis allows the researcher to examine contrasts across participants or situations (Creswell and Poth 2017). GT does not fit my study because I am not looking for contrasts between my participants and developing categories and their properties.

Ethnography

Ethnography involves the use of interviews and observation, but it differs from GT because the goal is to observe, describe and interpret a shared pattern of behaviours and experiences in their natural setting (Hammersley and Atkinson 2007). Participant observation is one of the main tools that differentiates ethnography from other qualitative approaches; it closely observes participants' activities providing a deeper understanding of people's daily lives (Herbert 2000). Ethnography has a long history and originates from anthropology; it emerged when studies of humans instead of animals became its focus (Ellen 1984), this point has been expanded in the next section. It is about cultural relativism, which argues that cultures can only be understood on their own terms and not judged by other more powerful cultures, which is a reflection on colonialism (Brewer 2000). My aim is to explore access from different perspectives; parents, professionals and dental care professionals, whilst observing people in their natural everyday settings in order to gain as broad a view as possible.

The cultural context of this study is the Kingdom of Saudi Arabia; this study explores people's experiences and ways of accessing oral health care services in their cultural context. As a Saudi, a dental professional and a parent myself I am already part of three cultures; Saudi Arabia, parent and professional. I am also male and therefore part of a dominant and privileged part of Saudi society. The biggest problem I may encounter will be trying to reduce the power imbalance between other parents and myself, because I am a dental professional. I will also need to listen carefully to parents who have children with disabilities because the academic literature implies that parenting can be more difficult. I intend to immerse myself within the participant's oral health environment in order to observe and understand their challenges and barriers in accessing oral healthcare services for their children.

3.2. Ethnography

Fetterman (1998) defined ethnography as “*the art and science of describing a group or culture. The description may be of a small tribal group in, for example New Guinea, or a classroom in middle-class suburbia*” (p.474). Ethnography is a qualitative research method used to tell a rigorous account about authentic events, while giving a voice to people in their own context (Fetterman 2010). Ethnography relies on verbatim quotations and a heavy description of life events.

Ethnography is the best methodology to conduct this study because it allows me, the researcher, to gain access to different perspectives; in this case, of parents, dental professionals and dental students, which is the main goal of my thesis. I have already highlighted that ethnography has deep roots in anthropology from the early 20th century with researchers such as: Malinowski and the work of Margaret Mead. Ethnography further developed in Chicago from the 1920s and 1930s with the monograph that explored the life experiences of Polish immigrants (Thomas and Znaniecki 1918-1920) and also when other cultural groups in the US were studied, for example disabled people’s experiences of everyday life and black Americans’ experiences of discrimination (Bogdan and Biklen 1992) and the deconstruction of how youth was represented by the media (Marsh *et al.* 1978). Recently, ethnography has been used to explore the lives of people who share similar cultures and the environment.

One of the main features of ethnography was inherited from anthropology, where researchers stayed in the field for years, is staying with people in their own environment for as long as possible (Creswell 2007). This involves observing the participants, listening to them and what they say and asking questions in formal and informal interviews to gather data. Furthermore, one of the goals of ethnography is to freely describe without external ideas or concepts to provide an understanding of what is happening within a culture from the inside. Studies that use ethnography often focus on small scale settings. For example, a few cases or a single group of people to examine the

cases in depth (Hammersley and Atkinson 2007), and employing different resources including documents, interviews and field notes for different purposes (Robson 2002). The process of analysis might involve exploring human actions and the specific practices of institutions (Atkinson 1990, 1992; Hammersley 1989, 1991, 1992; Atkinson and Hammersley 1994, 2007).

Participant observation

One main tool in ethnography is participant observation. Participant observation is used to uncover norms and values of people that influence our understanding about the participants (Bailey 1996). Participant observation differs from a one-to-one interview because it involves the researcher observing and recording what happens in the setting and this has the potential to yield rich meanings about participant's life (Geertz 1973). The observations are used when interviews and focus groups are transcribed in order to create another layer of meaning for the data; the observations are themselves a source of data because they add meaning.

Participant observation is considered an important part of ethnography when used in a natural setting (Clifford and Marcus 1986). The ethnography in my study employs participant observations alongside the interviews and focus groups to give more depth when explaining access to oral health care services for children with disabilities in Saudi Arabia. I observe the interactions in the dental setting between the parents, their child and the dental professionals; the interactions themselves are a rich source of data and assist in understanding access. Guidance for conducting participant observations comes mostly from Angrosino and de Perez (2000), DeWalt and DeWalt (2002), Merriam (1998), and Taylor and Bogdan (1984). Collectively they have defined the types of participant observation and the limitations:

1. The first type is ***descriptive observation***, where the researcher attempts to observe everything in the setting. The disadvantages of this type of observation is that data can be collected that is of little relevance or use and it can create confusion.

2. The second type is ***focused observation***, the researcher uses observations supported by interviews and the participants' views guide the researcher about what to observe. The limitations of using this approach is that important details may be missed that could add more depth to the study.
3. The third type of observation is ***selective observation***. This is considered to be the most systematic. The researcher focuses on different types of activities in the setting and this helps to create insight into the differences in activities (Angrosino and dePerez 2000, p.677).

Guided by the literature, I have used Angrosino and de Perez's (2000) definition of selective observation and observed;

- Interactions between dentists and fathers and children with disabilities.
- The dental setting and its structure (appointment making, inviting the parents and child into the treatment area, the waiting area).

I also observed the clinics and the individual appointments of parents and children with disabilities generally. This was in order to gain as broad an idea of access as possible. The observations outnumbered the number of interviews and extended to a 3-month period in the field.

Interviews

In addition to using observations, ethnography also uses in depth interviews. Interviewing is one of the many tools in a researcher's tool-box (Bogdan and Biklen 1992) and it is mostly considered a good strategy to collect data even though it relies on one-to-one interaction between the researcher and participant. This means that a good level of rapport will need to be built with the participant and a minimising of power differences, although it may not be possible to completely reduce the power differences between researcher and participants. Interviewing has the benefit of providing the insider's view of point and explanations about situations that concern them, they are the best people to approach because they are experts on their own lives (DiCicco-Bloom and

Crabtree 2006; Teddlie and Tashakkori 2009). There are four different types of interviews (Patton 2002):

- **Informal conversational interviews:** Questions are not predetermined; interaction occurs naturally and is free flowing
- **General interview guided approach:** Topics are predetermined by the interviewer but with no sequence or wording and the participant is enabled through probes and prompts to describe the areas that they feel are important to them
- **Standardized open-ended interview:** The sequence and the wording of questions are predetermined and there is very little freedom for the participant.
- **Closed fixed-response interview:** Questions and answers are predetermined, and the interviewee must choose from those responses. This is extremely rigid and probably of more use in market research.

(Patton, 2002, p.349).

Looking at Patton's descriptors for interviews, I used a general interview guided approach with a topic guide that helps to keep me focused on the interview and stops the conversation from drifting into an area that was not the focus of the study. The disadvantage of interviewing is that it is time consuming for both the researcher and participant. On the other hand, it enables exploration and understanding from similar and dissimilar point of views (Fetterman 2010). For example, I interviewed dental professionals (including dental specialists, general dentists, dental hygienists and therapists), dental students as well as parents of children with disabilities, which provided different experiences and perspectives around access to oral health care services and gave a broader level of understanding, which was the aim of my study.

Participants were recruited when attending dental clinics, which treated their child. I know from my experiences as a dentist that children with disabilities are treated in specialised dental clinics in rehabilitation hospitals and other specific dental clinics in governmental hospitals such as: the King Fahad Armed Forces Hospital. I therefore contacted these dental clinics in Al-Madinah and arranged

to visit, observe and then invited fathers to participate in an interview after explaining the purpose of my study to them.

It appears that ethnography is the best approach to be used in my study since it provides the best way of gaining access to the different perspectives of fathers, dental professionals and dental students and I will contrast and compare these different views.

Focus groups

I also recruited two focus groups; this is called a multimethod approach to qualitative data (Morgan 1997). This is in contrast to a self-contained focus group which would be used as a primary means of collecting data. Focus groups have become a popular and an important method to collect data in health research (Duggleby 2005). The technique not only collects data from participants, it is also used to explore interaction within a group to elicit rich experiential data, for example when opinions differ and then difference becomes resolved through discussion (Asbury 1995). The goal of using two focus groups in this study was to add to participant observation and one-to-one interviews so they broadened and added to the understanding of access. A focus group is usually made up of between 5 to 12 participants who are similar in a way and brought together to discuss a specific topic or an issue of interest to the researcher (Kitzinger 1995, p.299). Using a focus group can help a researcher to explore different people's views on issues in ways that could be less accessible in a one-to-one interview because people may feel supported and so more inclined to share and debate in a group.

One of the advantages of employing focus groups is that participants can feed off each other and support or disagree with one another, and that would potentially create richer data because there is more depth to the discussions. I found that the dental students added to one another's perspectives of access to care for parents of children with disabilities. For example, one student started with the statement that they felt there were issues and another student then said what they felt some of the issues were and other students then added

to the discussion. In addition, focus groups can be used to explore attitudes, perceptions and experiences more effectively than quantitative surveys.

On the other hand, managing the discussion in a focus group may be more difficult compared to an interview. For example, one participant can dominate the discussion leading to the exclusion of others who may be too shy to participate. This is where an interviewer has to effectively moderate what is being discussed and encourage contribution of all group members (Barbour 2008). Sometimes, conflicts and disagreements may arise and inhibit the discussion within the group. So, the moderators need to be skilled to manage these situations. Focus groups were helpful in uncovering the perceptions of the dental students towards children with disabilities and how they perceived access to oral health care for them.

3.3. Reliability and validity in qualitative research

In ethnography, the understanding of individuals' actions arises from the interpretation of the ethnographer about an event (Hammersley 1992). Quantitative studies have a standardised method to measure reliability, but among qualitative approaches, it is difficult to measure reliability since there is no standardised method (Bloor 1997). This way of thinking poses a struggle for those who support quantitative methods (Mason 1996). The applied scientific criterion to evaluate and assess quantitative methodologies differs from those used to evaluate qualitative data such as ethnography in relation to an experiment (Beck 1993). For example, the criteria of external validity, which is about the ability to generalise a conclusion or certain findings from the research sample to the population (Payton 1994), is considered as one of the criteria of good research (Krefting 1990). On the other hand, external validity is not relevant to qualitative research since most of the qualitative studies are looking to generate hypothesis meaning and create a theory, not test it (Sandelowski 1986; Krefting 1990).

In contrast, not all qualitative studies can be assessed in the same way or through using the same strategies (Krefting 1990). Qualitative research should

represent a variety of realities to help the reader with insight to multiple realities and to understand the experience or the phenomenon. Schwandt *et al.* (2007) suggested four criteria to evaluate the trustworthiness of qualitative research and they are credibility, audibility, confirmability and transferability:

- **Credibility:** it is used to refer to internal validity because it replaces the value of the criteria for truth among qualitative studies. It encompasses the faithfulness of a description in the explored setting, which should enable the reader to recognise researcher's experience (Guba and Lincoln 1981). There are different techniques that can be used to test or enhance the credibility of a qualitative study:
 - *Prolonged engagement:* means intensive and prolonged contact with the phenomena or participants in the field to assess various possible discrepancies and identify saliences in the event.
 - *Persistent observation:* pursuing salient elements in depth.
 - *Data cross checking:* this method is also called triangulation and this can be pursued via the use of a variety of sources, methods, investigators or analysts and at different times.
 - *Peer checking:* or peer debriefing which can be achieved via asking a professional peer to help in developing working hypothesis, develop and test a study design and provide an emotional catharsis.
 - *Negative case analysis:* this means the active continuous search of negative patterns to develop insights and adjusting until no negative instances are found.

(Schwandt *et al.* 2007)

- **Transferability:** This constructs external validity or generalisability among qualitative methodologies where it involves with how much the results could be extended to the public (Guba and Lincoln 1981). The notion of generalisability as is known in quantitative studies is difficult to achieve in qualitative studies because this is not the aim of the majority of qualitative research, although some qualitative studies do

suggest the use of theoretical generalisability (Sandelowski 1986). For example, theoretical accounts of social behaviour which also links in with other social theory and extends or adds to it (Green 1998). Additionally, qualitative research has the criteria of situational uniqueness, meaning a certain group studied may not be related to other groups within a community (Krefting 1990). However, transferability can be achieved via thick description of the data, this means using in-detail description about the context to make the judgments about the similarity which can be made by other researchers who would like to apply all or part of the findings elsewhere (Schwandt *et al.* 2007).

- **Dependability:** Guba (1981) suggested that dependability is related to the consistency of the collected data, since many qualitative methods are adopted to the research situation. So, the exact method used to collect, interpret and analyse the data should be described in detail in qualitative studies. Dependability or audibility involves the process of one assessing another investigator's work as to whether the work can be exactly followed to reach the similar way of analysis in all stages of the study in similar conditions (Krefting 1990). However, reaching the same findings and conclusion may be difficult because people's opinions and perspectives can change as they can develop more insights over time and with experience (Guba 1981). So, consistency among qualitative research embraces an element of transparency where explainable changes among participants are made clear (Guba 1981).
- **Confirmability:** This criteria refers to the degree of neutrality or the extent in which the results of a research are shaped by the participants and the conditions and not by the researcher's motivation, values or interests (Lincoln and Guba 1985). The researcher can achieve the element of confirmability via describing and drawing on how conclusions and interpretations were developed, and explaining how the findings and themes emerged from the data (Cope 2014). Among qualitative studies, this can be exhibited by providing rich quotes from

the participants to point out how each theme developed (Schwandt *et al.* 2007). This criterion of confirmability can be pursued using triangulation of different data collection tools (observations, interviews and documentary evidence) and their results to get a non-biased analysis. The main point of triangulation is to achieve and examine the consistency of the collected data rather than demonstrating that using different approaches or sources yield the same result (Patton 1999; Leech and Onwuegbuzie 2007). Triangulation has four different types, and they are:

- *Triangulation of methods*: it involves the process of comparing the collected data using qualitative methods with the data collected via employing quantitative methods.
- *Triangulation of sources*: it means comparing and cross-checking the qualitative data collected via different means within a qualitative method.
- *Triangulation through multiple analysts*: it involves using multiple investigators or analysts. For example, using multiple interviewers or observers during data collection as an attempt to minimise the potential bias that may come from a single data collector.
- *Theory/perspective triangulation*: this means the use of different theoretical perspectives to examine the collected data.

(Patton 1999)

3.4. Sampling

Purposive sampling was employed to select participants for interviews and the focus groups. Purposive sampling differs from convenience sampling which selects the nearest individual (Cohen *et al.* 2007). Purpose sampling involves choosing individuals in terms of their typicality for the needs of the study. So, for my study I focused on fathers of children with disabilities attending oral health services, dental professionals and dental care professionals who provide the services and dental students who are being trained to provide services.

The participants in the interviews were selected based on specific criteria:

- For fathers of children with disabilities:
 - Participant observations of fathers of disabled children whilst attending dental clinics.
 - The age of disabled children from 1-17 years old.
 - Face to face interviews of 20 fathers of children with disabilities attending dental clinics.
- For the dental professionals:
 - Dental professionals who have treated children with disabilities.
 - Face to face interviews of 10 dental professionals and dental care professionals.

I originally planned to use 3 focus groups, 2 male groups and 1 female group of dental students. However, I only used 2 male focus groups and couldn't use a female focus group because of the cultural norms, and I was not granted permission from Taibah University to research with females. The participants were invited to participate from the last year of the Dental School at Taibah University in Al-Madinah and the groups had 7 and 6 participants.

For the participant observations, I visited the dental clinics treating children with disabilities and closely observed the interactions between fathers, their child and the dental professionals. I also observed the dental clinics as they were working and gained an understanding of the everyday routines of dentists and dental care professionals.

The sampling process in qualitative studies differs and sample size is smaller than quantitative research from many reasons. One of the reasons is that more data does not necessarily lead to more information and the quality of the information is seen to be of greater importance (Teddlie and Tashakkori 2009). Furthermore, qualitative research is concerned with meaning making, not generalizing or proving a hypothesis (Mason 2010). One more reason is having a large sample could be impractical and time consuming (Malterud *et al.* 2016). Although "*one size does not fit all*" (Fusch and Ness 2015, p.1408), Morse (1994) suggests that ethnographic studies should have up to 30 interviews but

that does not mean we neglect the quality of data. Quality of the data in qualitative studies considered a key part as it is about making sure the study is genuine and truthful, and it can be achieved by reaching the level of saturation; theme saturation, codes saturation or data saturation (Fusch and Ness 2015). Saturation means that no new data, no new themes, or no new coding arises and the ability to replicate the study can occur with the given sample size (Guest *et al.* 2006). Guest *et al.* (2006) argue that the level of saturation can be achieved by having merely 6 interviews; in contrast Fusch and Ness (2015) suggest that saturation is achieved by getting rich (quality) and thick (quantity) data which may not be possible in 6 interviews. This indicates that there is a lot of discussion and conflicting guidance around the area. I tried to make my data as in depth as possible and spread it between observations, descriptions, focus groups and individual interviews.

Although Morse suggest that ethnographic studies should have 30-50 interviews (Morse 1994, p.225), 15 participants in most qualitative studies is considered the smallest acceptable sample size, but again this is reliant on quality and epistemology (Bertaux 1981, p.35). For example, if an oral history approach is used then it could be that the sample size is 1 and it is also dependent on the area under exploration. I have taken the guidance provided by Morse and Bertaux and employed a sample of 16 parents who were mostly fathers, 9 dental professionals and 13 dental students.

3.5. Qualitative data analysis

Walcott (1994) define the analysis process of qualitative data as:

“Analysis refers quite specifically and narrowly to systematic procedures followed in order to identify essential features and relationships” (p.24).

This definition goes beyond the process of describing a relationship and accounts for other factors and connections within relationships. It differs from the interpretation where it involves making sense of the data. In addition, Hatch (2002) illustrates and emphasises analysing qualitative research by stating:

“Data analysis is a systematic search for meaning. It is a way to process qualitative data so that what has been learned can be communicated to others. Analysis means organizing and interrogating data in ways that allow researchers to see patterns, identify themes, discover relationships, develop explanations, make interpretations, mount critiques, or generate theories. It often involves synthesis, evaluation, interpretation, categorization, hypothesizing, comparison, and pattern finding. It always involves what Wolcott calls “mindwork” . . . Researchers always engage their own intellectual capacities to make sense of qualitative data” (p. 148)

The analysis process of qualitative data is an important step in qualitative research (Leech and Onwuegbuzie 2007). This process can be daunting and may create confusion for many researchers since there are different types of data and various way to analyse it (Leech and Onwuegbuzie 2011). There are various types of qualitative analysis:

- Constant comparison analysis.
- Phenomenological analysis.
- Narrative and discourse analysis.
- Ethnographic analysis.

I will proceed with describing each approach of the qualitative data analysis then I will provide justification for my choice for this study.

3.5.1. Constant comparison analysis

Constant comparative analysis is considered as one of the most common approaches to analyse qualitative data. It was developed by Glaser and Strauss (1967) to analyse data for grounded theory [GT] studies. Few authors use the term “*coding*” when they are referring to constant comparative analysis (Miles and Huberman 1994; Ryan and Bernard 2000). The constant comparison approach can be used deductively (codes are identified before starting the analysis and then the researcher searches for them in the data, or it is done via software packages), and inductively (codes are identified while

analysing the data) or abductively (the researcher employs an iterative process to organise or initiate codes (Timmermans and Tavory 2012).

To perform a constant comparative analysis, the researcher reads his/her entire data set. Then, each part of data is combined into small meaningful parts and each chunk of data is labelled. Then the researcher compares the new data to the previous labelled chunk of data. After coding all the data, the codes are grouped and themes are identified (Leech and Onwuegbuzie 2007).

Constant comparison analysis is well suited for GT studies because it is designed to study phenomena, which the researcher assumes that fundamental social processes explain something about human behaviour and experience such as the process of illness recovery (Thorne 2000). Constant comparison analysis allows the researcher to explain and create knowledge that is descriptive or interpretive, but within GT it has its own structured way of carrying this out. GT differs from either qualitative content analysis or thematic analysis because it has its own distinctive set of procedures, including theoretical sampling and open coding. In contrast, the procedures in the other two are not specified at the same level of detail.

3.5.2. Phenomenological approach

Phenomenological analysis helps to uncover some of the underlining essence of experience via thoroughly studying an individual case (Thorne 2000). It essentially describes the nature of a phenomenon and orients the researcher towards a deeper analysis via a systematic reflection of the participant's experiences.

The aim of this strategy is to understand the contents and its complicated meaning rather than trying to compare it or measuring their frequency. This can be achieved when a researcher builds a sustained interpretative relationship with the content. Additionally, this strategy requires the researcher make attempt at capturing the essence and learning about the mental and social world of the participants (Smith and Osborn 2004). For example, Pisarik

et al. (2017) employed a phenomenological approach to examine the phenomenology of career anxiety among college students. The phenomenology of career anxiety is the experience of anxiety that is built among college students as they engage in the process of their career development. The researcher aimed to frame this phenomenology via describing those experiences in order to understand and develop new measurement approaches to capture the essence of career anxiety. Purposive sampling was employed to select seven individuals as participants. The participants were selected from different years in college to examine various levels of career related anxiety across developmental positions within college years. The researchers interviewed participants and each interview lasted between 40-50 minutes. Seven themes emerged from the interviews and they were: general symptoms of anxiety, existential concerns, pressure, lack of career guidance, cognitive distortion, social comparison and occupational uncertainty. Those findings provided an insight to the development of perspectives on career-related anxiety, which can guide counsellors to implement various interventions to reduce the anxiety regarding career choices and development.

The difference between phenomenological and constant comparison analyses for GT is that phenomenological analysis looks deeply for meaning within the accounts, whereas the aim of constant comparative analysis in GT is to construct categories and then build theory. I am not looking to construct categories or look for deep meaning, in contrast I am looking to explore how people with a given culture negotiate and make sense of their interactions with oral health services.

3.5.3. Narrative analysis

Narrative analysis recognises that the stories we tell can shape lived experiences and help in understanding the social and cultural structure of the story (Sandelowski 1994). Using narrative analysis can allow us to discover how participants lived their lives through detecting main themes in the content. Narrative analysis can be structured thematically, or chronologically, it can

involve visual analysis or dialogue/performance analysis and also semiotic analysis (Reissman 2008). The difference between a narrative analysis and a GT analysis is that GT 'fractures' data whereas narrative analysis uses a case-centred approach, seeing each narrative as a 'whole' and does not theorise across cases (Reissman 2008). However, there are many approaches to perform narrative analysis and there is no single way to do it (McCance *et al.* 2001). For example, Mishler (1995) identified three main typologies for narrative analysis, and they are:

- *Reference and temporal order*: this category provide a relation between the sequence of the real events and their ordering in the narrative account. It concerns with telling the story as a series of events ordered temporally.
- *Narrative functions*: This category identifies which function the story serves. This means each story has a purpose that they must fulfil, and each told story has a setting and an impact they produce.
- *Textual coherence*: this category focuses on the language, structure and coherence of the story.

(Mishler 1995)

Mishler (1995) identified these categories to highlight the differences among various approaches of narrative analysis but not to limit the narrative analytical approaches to these three categories. He pointed out that these categories are initial and preliminary approaches (McCance 2001). Whilst I am interested in people's narratives, I am not interested in individual in depth accounts and want a broader account to give me more depth of understanding of the area.

3.5.4. Ethnographic analysis

This strategy of data analysis uses an iterative process in which notions about the social and cultural world of the participants that researcher observes and interrogates during fieldwork are transcribed, transformed and translated into written data. This involves sorting and representing each piece of data thoroughly to identify themes. Searching for themes in the data set requires

looking for categories and inconsistencies to draw conclusions about how and why phenomena happen. This is similar to constant comparative analysis in GT and phenomenological analysis, but it lacks the same sort of structure and level of detail. This way of analysing the data suits ethnographic methodologies since ethnographers immerse themselves in a culture to understand and record variations of how people live and experience certain aspect of life.

In my thesis, I used an inductive ethnographic thematic approach to analyse the data. Thematic analysis considered as one of the main approaches within ethnographic analysis of the data (Braun and Clarke 2006). Themes were emerging as I was involving and engaging with fieldwork and the collected data. It is of course easy to miss salient points in a set of data if only thematic analysis is used and the context is given minimal attention. This is why I have included the context of Saudi Arabia, the context of the social structure and the way people live their lives. I will describe how the analysis took place in the next chapter (section 4.12).

3.6. Challenge of translation

The interviews were all in Arabic and translation imposed a challenge to my study because I translated the recorded interviews from Arabic to English. There is a possibility of losing some information as translation is considered an interpretive act (Van nes *et al.* 2010). For example, one of the parents told me that he used to go to his friend who is a dentist and get an appointment for his son as an emergency where this act was prohibited. So, he told me that he went to his friend and used him as *wasta* "واسطة". The verbal translation for this word is "favouritism, bias or social network", but this captures only half or part of the meaning of the Arabic word and the closest translation for this one word in this situation is "the dentist is considered as agent that eases the access of his friend and violates the rules while no one can reject him or object to this act". As a result, the overall translation of this word and act can be lost during translating the words verbatim without considering the whole meaning of the text. In addition, due to cultural background differences of the participants and

the different Arabic accents, translation is considered a critical process to ensure that data are obtained correctly (Munet-Vilar'o and Egan 1990; Maneesriwongul and Dixon 2004). Although I tried my best to remain as faithful to the original meanings of the participants, there are obviously times when I had to use the nearest meaning in order for the translation to make sense to an English reader.

3.7. Summary

This chapter has explored qualitative methodologies and different forms of analysis. Through comparing and contrasting their strengths and utilities, I have decided to use ethnography as my methodology for this study. This is because ethnography will enable me to understand the cultural influences and life events of Saudis from their own perspective. Furthermore, the voices of parents of children with disabilities are often hidden from oral health research and ethnography will be a vehicle to help their voices to be heard. The issue of access to oral healthcare for parents of children with disabilities in Saudi Arabia has not previously been explored and this study will add to the existing oral health literature and further expand our understandings. The next chapter will explain the process of the study for my thesis and the different methods employed.

Chapter 4: Methods

4.1. Introduction

The previous chapter justified the methodological approach of ethnography by considering a range of qualitative methodologies that can be used. This chapter aims to provide an overview of how the study was carried out and the particular tools that were used.

To clearly define my area of focus, I examined the literature to find the gap related to children with disabilities in Saudi Arabia (see Appendix no.1). I found that there was little on parent's views of access, nothing about father's perspectives and nothing about this area in Saudi Arabia. This study therefore adds to the literature by providing an extended account of access to oral health care in the Kingdom of Saudi Arabia from the perspectives of fathers of children with disabilities.

My study involves the combination of ethnographic observation of the dental settings for treating children with disabilities, interviewing fathers of children with disabilities and dental professionals and using focus groups of dental students to provide different views about accessing oral health care services for children with disabilities.

The strategy was developed to address questions and objectives of this study, which involved recruiting fathers of children with disabilities, dental professionals and dental students in Saudi Arabia. The initial stages involved negotiating access to observe the dental clinics and then recruiting participants from the different centres where children with disabilities were treated.

4.2. Sample

The sample was divided into 3 categories: parents of children with disabilities, dental professionals and dental students and they are as shown below:

Table (6): Characteristics of the sample

Participants	Parents of children with disabilities	Dental professionals	Dental students
Males	13	7	13
Females	3	2	-
Total N=38	n=16	n=9	n=13

The selected participants were based on purposive sampling method, which depends on fulfilling certain criteria to be typical to the needs of the study (section 3.4.). The participants have been divided into three categories:

- Parents of children with disabilities.
- Dental professionals.
- Dental students.

The number of parents who participated in the study consisted of 13 fathers and 3 mothers while dental professionals consisted of 7 males and 2 females. For the dental students, the participants consisted of 13 male students and no female students. The low number of female participants was due to the cultural restrictions of Saudi society and the difficulties in getting the permission to recruit female students to participate in a focus group in my study.

In my sample, I wanted to get a wide range of experiences for accessing oral health care services and different perspectives of parents. Although impairment can be experienced differently from one child to another depending on its severity and the circumstances, I chose children with different types of impairments to get as many different views as possible around accessing oral health care services. There were a variety of impairments:

- Intellectual

- Physical
- Visual
- Hearing

Some children had multiple and complex impairments, for example, intellectual, physical and visual, whilst other children had moderate visual impairment.

Some participants were of different nationalities although the majority of them were Saudi Nationals. In addition, they were of different SES. For example, one of the parents, a mother, lived on the equivalent of social security payments and did not have a job while another father was a consultant in one of the public hospitals in Al-Madinah.

4.3. Accessing the field

In the early stages of any piece of study, establishing contact with informants is essential and should be achieved as quickly as possible (Stringer 1999). Permission was granted from Taibah University to visit four different dental and general clinics, and I am not going to mention those oral health care services to protect the privacy and to maintain confidentiality of those dental centres. Instead, I am going to name them A, B, C, and D. I will proceed with talking about the process of accessing those oral health care services.

At first, permission granted by the Vice Dean of Teaching Affairs at the Dental School at Taibah University and my mentor in Saudi Arabia. After receiving the official permission papers to gain access, I visited the centres that I mentioned above starting by the centre A. When I went to the A centre, I handed the manager my information sheet and consent form and explained my research to him. He expressed his full cooperation and personally showed me around the dental clinic, answering my questions about the everyday running. He asked me for a copy of the official permissions for their records. On my first day, he also introduced me to the dental professionals and they offered their full cooperation.

For the dental clinics within B and C centres, my mentor communicated with both facilities and arranged the visits for me because he already established a relationship with the centres. Then, I went to B centre to establish contact with the principal and handed him my study papers (information sheet and consent form) where he agreed to cooperate with me. Within all of the four institutions, a room within each facility was arranged and booked for interviewing either parents or dental professionals, all except centre A, where I couldn't interview the parents because of the restrictions, guidelines, data protection and the policies of the centre. On the other hand, interviewing dental professionals was easy since it was done at the dental clinics during their breaks or when there were no more patients.

I also, went to centre D for children with disabilities and spoke to the manager; I handed him the information sheet and consent form and explained the study to him. He asked for the permission papers and kept a copy of the permission as a record. Then he offered his full cooperation and introduced me to the Chief of Medicine, who showed me around the dental clinics.

4.4. The research process

As discussed previously, I visited four different centres and accessed their dental clinics to observe the dental settings, doing my interviews and focus groups. Those centres are:

- A centre.
- B centre.
- C centre.
- D centre.

For centre A, I couldn't interview the parents of children with disabilities as I stated before on section (4.3). However, I interviewed the dental professionals working within the centre. I interviewed 3 males and 2 females who were working in two different dental clinics; the male dental professionals work on a clinic located on the lower level and the females work on the other dental clinic

that is present on the upper level. One of the most important things to remember is the gender segregation within the centre. That means the centre was split into two halves; some areas were specifically for males and other areas for females. Additionally, male dental professionals treated only male patients with disabilities in one dental clinic and female dental professionals treated only female patients with disabilities in the other dental clinic. The patients were either residents in the centre or registered there. I was able to observe the two dental clinic settings for two weeks only as it was the only permitted time that they allowed me to observe. I will discuss my observation more thoroughly in the next chapter (5). After finishing my two weeks visit to centre A, I went to centre B to interview parents of children with disabilities.

My mentor communicated with both the dental clinics at centres B and C and arranged the visits for me while I was busy doing my visit to centre A. So, I went to centre B and planned further arrangements with the staff to recruit the parents as shown below in figure (5). The staff talked to parents to visit the centre on certain days at specific times. Parents were given one-hour slots arranged over two weeks to be interviewed and to speak about their children's oral health and accessing oral health care services. The children were given an information sheet (appendix no.2) and a consent form (appendix no.3) to give their parents and SMS messages were sent to the parent's mobile phones for the time and date of the visit. A room within the institute was booked for two weeks for the interviews. However, only 2 out of 48 parents showed up for the interview. A second attempt to interview the parents was done by phone via SMS messages sent to the parent's mobile phones with my mobile phone number to call me back if they wish to participate. Six out of Forty-six parents did call me back where I explained my study and answered their questions about my study. Then, their consents were taken over the phone where they agreed to participate and then proceed with the interview.

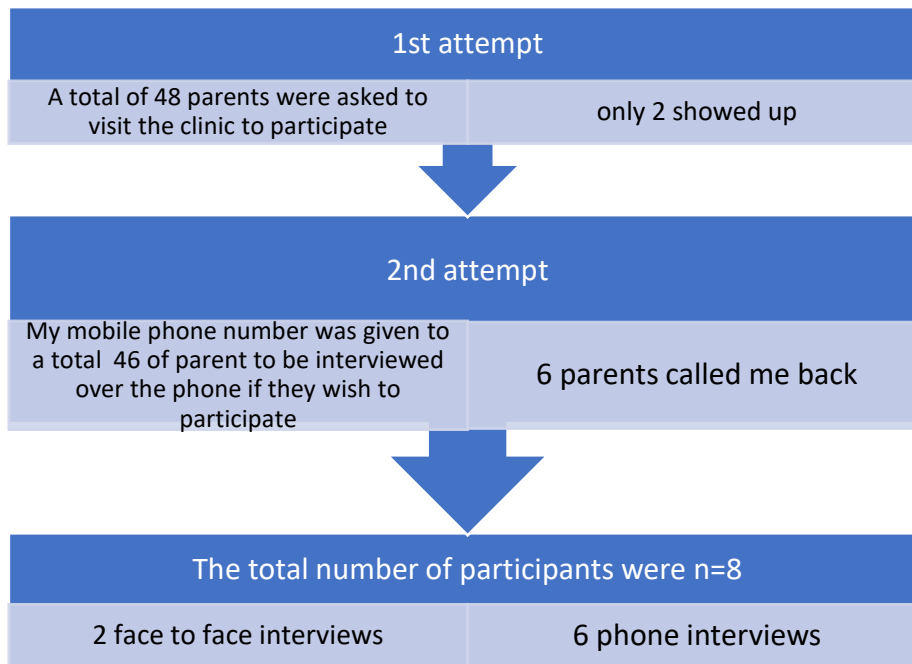


Figure (5). Recruiting participants from centre B

The dental clinic within centre B were not equipped nor working during my 2 weeks visit. In addition, they did not have a dental professional working there. Instead, the staff directed any patient who complained of dental pain or discomfort to the Dental School at Taibah University, because it was the nearest dental centre. However, I stayed for 2 weeks to recruit parents of children with disabilities visiting centre B at that time.

After visiting the centre B, I went to centre C to observe the dental clinics, recruit dental students as participants in focus group discussions and to interview dental professionals treating children with disabilities.

At centre C, the phenomenon of gender segregation was again present, and the males were working in a different building to the females. Moreover, only male patients were allowed to be treated in the male section and only female patients were able to be treated in the female section except for little girls aged less than 12 years old who could be treated in both sections of the Dental School. In the dental clinics, within the male section of centre C, I was able to observe the dental setting.

During my observations in centre C, a room was arranged and booked to be used for the interviews and the focus groups in the male section. I was able to

recruit and interview at different times, I also observed four dental professionals who treated children with disabilities during my five weeks of observation. For the focus group discussions, I initially contacted the supervisor and he agreed to contact seven of the male dental students to meet me. After 3 days, I contacted the supervisor again and it appeared that he had forgotten to talk to the dental students about the meeting. Therefore, I went to the dental students by myself and arranged everything with their group leader. I also contacted another group of dental students; six in total, who agreed to take part in the study.

For Centre D for children with disabilities, I went to the centre and spoke to the manager. He was welcoming and willing to help me with data collection and introduced me to the Chief of Medicine. However, I couldn't spend time observing the dental clinic because there was no dentist working there, I got to see the dental clinic setting and it was fully equipped and accessible except for the dental chair, because centre D did not have a wheelchair tipper for users to be treated. In addition, they did not have an employed dental professional working in the clinic. Instead, they relied on dentists who volunteered to work part-time in the dental clinic. The centre could not offer me a room to interview parents, but they were willing to give me the parent's phone number whose children were treated within the dental clinic in the last six months. Therefore, I was able to interview most of the parents over the phone.

When I called the parents, I called 22 parents of children with disabilities as shown in figure (6) and explained to them what I am doing and gave them time to decide whether to participate or not. In addition, I asked them if I could call them back after 2 days to interview them. Some parents agreed (7) right away and did not want me to call them again, giving their verbal agreement over the phone. So, I proceeded with the interview. The others (15) wanted some time to think about participating and I called them back. When I called them back I got different responses, which was refusing to participate (9), not answering their phone (4), rejecting my call (1) or willing to take part in the study (1).

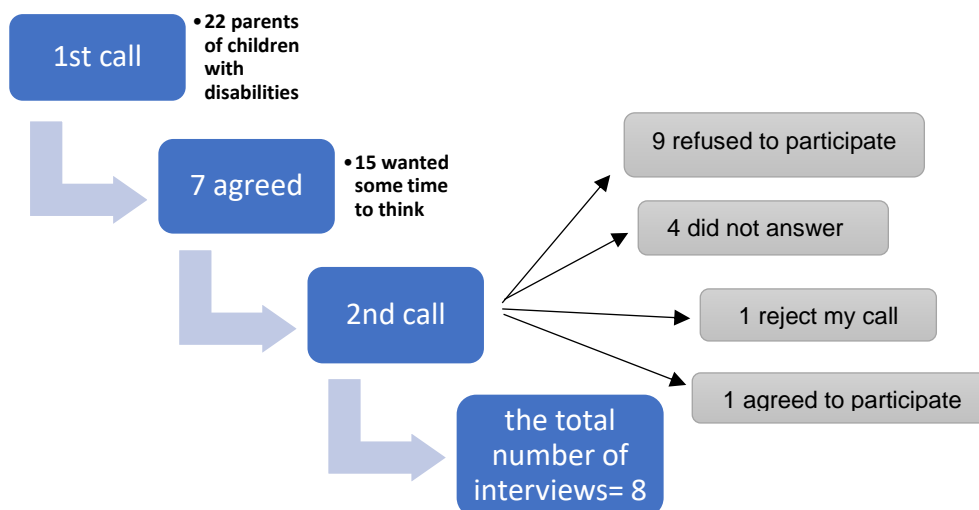


Figure (6). The process of recruiting participants from centre D.

During my observations for all dental settings, I took notes about the process of service delivery and asked about the process of having children with disabilities as patients, and how they got their appointments. Additionally, I asked if they were on a waiting list how long they waited and how they got their dental treatment and what types of dental treatment were available for them. Furthermore, I took some notes while interviewing others especially when their body language and tone of voice was emotive. For example, one of the parents was very sad and emotional, and I sensed that because of his tone, and his behaviour was changing as he was giving reasons for leaving the city and going back to his country such as: there were moments where he could not talk and his eyes were tearful.

However, in some interviews I couldn't take any notes since some participants refused to be recorded or for me taking notes and I will discuss this point further in the interviewing sections (4.7 and 4.8). On the other hand, the focus group didn't have any problem with me tape recording the discussion of the focus group.

Table (7). A summary for the research process:

Facility	Methods	Description	Duration
A Centre	Observation Interviews	I observed the dental settings of the male and female dental clinics. I was able to interview 5 dental professionals.	2 weeks
B Centre	Interviews	There were 2 attempts to recruit parents of children with disabilities who visited dental clinics. Managed to interview 8 participants	3 weeks
C Centre	Observation Interviews Focus groups	I observed the dental settings where children with disabilities were treated. I was able to recruit 4 dental professionals and 13 dental students for the interviews and focus groups.	5 weeks
D Centre	Observation Interviews	I observed dental settings and was able to interview 8 parents of children with disabilities who visited the dental clinic.	3 weeks

4.5. Phone interviews

Telephone interviewing is a method of collecting data that is increasing in popularity within qualitative studies (Burke and Miller 2001). This is possibly because large geographical areas can be covered in short time frames. Although telephone interviewing has several drawbacks such as: the inability of the researcher to see the nonverbal and informal acts of the participants which means that misinterpretation can occur because faces and bodies are hidden from view and a percentage of non-verbal communication is missed (Creswell 2007). Many authors have concluded that a phone interview is an acceptable method to collect data and it is frequently used for survey projects (Sobin *et al.* 1993; Sturge and Hanrahan 2004; Creswell 2007). In addition, it

is also considered appropriate for studies where the interviews are going to be short (Harvey 1988) and in specific events (Rubin and Rubin 2011). However, phone interviews are not meant to be only considered in those circumstances because they can be very useful in particular cases such as: discussing sensitive topics and for hard to reach participants (Sturge and Hanrahan 2004). These topics will now be discussed further.

Sensitive topics

Some authors reported that using phone interviews is appropriate as a tool to collect the data when discussing sensitive topics such as: embarrassing topics (Sturge and Hanrahan 2004). Sometimes the participants reveal more data when they have more sense of anonymity, which in turn may increase the data quality (Greenfield *et al.* 2000). In Saudi Arabia there is a lot of stigma around disability and families may consider having a disabled member within the family to be a sensitive topic to discuss. They may not wish to discuss these issues face-to-face and the relative anonymity of the telephone may aid them to disclose more. This is one of the reasons that made me consider phone interviews to collect some of the data.

Hard to reach participants

One issue faced by interviewers is that of reluctant respondents, who may find it difficult to articulate their thoughts when in a face-to-face situation (Creswell 2007). Therefore, interviewing people over the phone may provide an opportunity for the researcher to reach reluctant potential individuals. In other words, using phone interviews makes it possible to reach people who would not otherwise have their experiences and voices represented (Miller 1995). As a result, using phone interviews for my study was appropriate to employ since it was extremely difficult to recruit the parents to participate in face-to-face interviews. Again, this was for a variety of reasons, from stigma to geographical distance, also the pressures of work and time availability. In Saudi Arabia, the privacy of the family takes a central position and discussing family matters face-to-face may be seen as too personal an act.

However, using telephone interviews presumes that everyone has a telephone or the ability to own one. While interviewing people I found that some parents were unable to afford to call me because they were from a very low SES. For example, a mother I interviewed sent me a SMS asking me to call her because she could not afford a telephone call. I called her back, and she was welcoming and then we proceed with the interview after taking her consent. As a result of this interaction, I arranged to call other parents at different times through the day and on different days including weekends to ensure that I was calling at convenient times for them.

It appears that using phone interviews to recruit, and interview was a suitable method to collect some of the data for my study. The main reasons for employing phone interviews were: the sensitivity of disability as a topic and its attached stigma and the privacy of the Saudi families. In addition, geographical distance was an issue for some, time constraints and the presence of hard to reach and reluctant parents were justifiable reasons for considering and using telephone interviews.

4.6. Interviews and recording

As I mentioned before in Section (4.6), interviews were carried out as part of my research. I tried to use the recorder to record each interview since it is considered as practical helpful device that allows researcher to record detailed, accurate verbal information (Kvale 1996). I used the recorder to record parent's interviews and only 2 parents had issues with me recording their voices and taking notes which were related to privacy of the family, cultural restrictions and rules. For example, a mother refused to be recorded because her husband would not allow his wife's voice to be present on tape. For these instances I wrote copious notes from memory after the participant had closed the phone.

Using the recorder for every dental professional interview was not possible because despite my assurances to the contrary, some participants felt that I was evaluating them, that this was going to affect their career and that I would

report what they had said to their superiors. This lack of trust is quite common in Saudi society and can be a barrier to carrying out research. As a result, I used journalistic methods to interview dental professionals (Denzin 2001). I proceeded and afterwards, I used my topic guide to structure my thoughts. I then wrote as much as I could remember and what I felt were the key points, along with my feelings and interpretations, after the participant had left the room (Halcomb and Davidson 2006). I also tried to use verbatim statements made by the participant in order to preserve meaning, intention and voice.

For the focus groups, the dental students did not have a problem with me recording their discussion and their voices. All of the recorded interviews and focus groups were transcribed on the same day or the day after, which helped me to revisit the interview and in guiding my analysis. In addition, the notes taken during the interview were used as a supportive material that helped me in transcribing, managing and analysing the data.

4.7. Trustworthiness, credibility and dependability

Previously in the methodology chapter (p.90-93) I discussed the criteria that can be used to evaluate the trustworthiness of qualitative research and that it differs from those used among quantitative methods. Schwandt *et al.* (2007) suggested four criteria to be used in assessing the trustworthiness in a qualitative research and they are: Credibility, transferability, dependability and confirmability. I am going to describe how these criteria can be achieved in my study as follows:

Credibility

Credibility was discussed earlier (p.90), and is also known as internal validity. This involves the evaluating the ways in which the results may be seen to be believable. There are many ways to enhance the credibility of a qualitative research as discussed before in section (3.3), including member checking or/and peer checking. I did use member checking for my interviews with dental professionals as I was revising their answers and what they said during the

interviews. They agreed to most of my transcription and some of them added some things they thought were missing or they did not say and which they considered to be important. For example, one of the dental professionals explained his ideas and what he meant about some things he said in the interview previously, so he clarified his meanings for me. On the other hand, doing member checking with parents' after interviewing them was difficult due to the difficulties in recruiting them and most of the interviews were done over the phone. Most parents were reluctant to complete the interview although they were informed at the beginning that the interview is going to take more than 10 minutes. Additionally, some of them asked me to finish the interview because they were too busy as I mentioned above in section (4.7). I was however able to do peer checking as I shared my methods, results, analysis and discussion with my supervisors. Furthermore, I brought my translated data and results to have several discussions with my supervisors.

Dependability

The term dependability was introduced by Guba (1981) to describe the situation in which other investigator can easily track the trail used by the researcher in a study. I used thick detailed description of the thesis and context as a way to ensure that the study is repeatable in the future. However, a question can be asked here, would it be possible to get the same results of my study when repeating it even though using the same method, same context and similar participants? It is likely that I would get different results concerning context and the different people who could participate, but I believe similar results can be found to some extent because the analysis is focused on major themes and it is likely that these themes would re-emerge as important in future work. Other different themes can be identified and that can be addressed to variety of factors such as: different levels of disability and its complexity, different dental professionals and different attitudes and other factors that can alter and shape the answers of the participant which can be interpreted differently.

Confirmability

Confirmability represents the freedom from bias in the research data collection, procedures and findings (Sandelwoski 1986). This criteria has been pursued using triangulation. There are different types triangulation that can be used to enhance or achieve neutrality as has been discussed before in section (3.3). In my thesis, I used triangulation of different sources via triangulating data collected using observations, interviews and focus groups to examine the consistency of information and themes generated within collected data. The achieved consistency in overall patterns of data from divergent sources with having reasonable explanation for differences of data emerged from a variety of sources and contributed significantly to the overall confirmability and credibility of the findings (Patton 1999).

Transferability

This was difficult to achieve since children or people with disability are diverse group with various levels of complex situations and life events. Although, barriers and facilitators to accessing oral health care services can be similar, the ways a variety of people address and cope with the same barrier can be different and may additionally have different impacts on children's life and family. However, transferability or theoretical generalisation is going to be achieved via rich and thick description. Rich and thick description refer to the extensive thorough descriptive information about the research setting, participants and observation to enable readers to judge whether the study context is similar to their own environment (Polit and Beck 2010).

Trustworthiness is linked to how the researcher represents a range of realities to help readers to understand the experiences using member and peer checking, rich description and triangulation of the collected data (Source triangulation). This thesis used variable data collection tools to get variable data resources such as: observation, interviews and focus groups.

4.8. Reflexivity

Reflexivity is an important factor in qualitative research where the researcher reflects on his/her own values, perception and actions to influence the research process during the stages of his/her data collection and analysis (Lambert *et al.* 2010). The process of reflexivity is often unclear and indefinite (Lamb and Huttlinger 1989), but it requires an awareness of the degree of which the researcher's personality, behaviour, social background and assumptions can produce an impact on the data collection and analysis process (Lipson 1991). From this perspective, I wanted to be as transparent as possible in order to reduce my influence on the data.

I reflected that I already shared a similar social background, but not identical, to fathers of children with disabilities because I am a Saudi citizen and a father. I had some insight into women's roles in Saudi Arabia but could not claim to be an expert because I am a man. So, I had to be reflective and not presume that my experience as a father in relation to oral health for children was the same for all parents I encountered, particularly not the mothers even though there were only 3. In addition, I am a dentist and I had to restrict myself from interfering or advising parents about their children's oral health. It took a great deal of effort not to intervene and not to appear as if I was judging them for the decisions that they had made about their children's oral health. I was admittedly shocked by the low priority some parents appeared to place on their children and on their oral health, but I also reflected that I did not have the challenges that some of the parents had, nor had I experienced the level of inequality that some parents were describing. One of my attempts to minimize my influence during data collection with parents was to wear traditional formal Saudi clothes; ankle length white tunic with matching trousers (Thobe) and checked headdress (Ghutra) fixed in place by a black rope-like ring (Egal). I also moderated the language I used to make it simpler and refrained from using any medicalised terms. Throughout the process, I was painfully aware that no matter how hard I tried, I could not reduce the power imbalance

completely because I am also educated and hold a certain position in society because of my profession.

For the dental professionals, I tried to minimize my power and my position and tried to not interfere nor give advice about the types of treatment and behavioural management. This was an area that I was constantly asked about by various dental professionals. Although I dressed in traditional Saudi clothes, the other dental professionals were constantly referring to me as 'the doctor'. Additionally, some dental professionals were intimidated by me because they presumed that I was of a higher authority and that I could jeopardise their professional careers. For example, one of my dental colleagues is a paediatrician in Saudi Arabia and he has been treating children with disabilities in oral health care services within different sectors for the last three years. So, I presumed that interviewing him was going to be fruitful and add significantly to my thesis because ordinarily we can talk for hours and I thought it would be valuable to have his views on oral health care services within different sectors. I was surprised and a little hurt that he rejected my interview and he gave the impression that he was afraid of taking part in my study because he thought that I was going to jeopardise or harm his professional career. I did not interview him and accepted his decision with no further question.

On the other hand, dental students were slightly concerned about whether or not they gave their opinions and if it was alright to talk freely. This was because I am a member of the teaching staff at the Dental School in Taibah University, even though I am on sabbatical until I complete my PhD. One of my attempts to reduce the power created by my position was that I talked and explained everything and assured them that they could talk freely with no consequences. Having a private room, closing the door and having our focus group without any other teaching staff around was an attempt to get the dental students talk about their experiences and views freely in a safe environment. I could not be completely sure that they had offered as wide a variety of views as possible, or that they had talked without reservations.

However, as Allen (2004) suggests when an interviewer is a part of the same culture, I could not completely separate myself from the subject area being

examined, because I am a dental professional, a father and am interested in the oral health of children with disabilities.

4.9. Ethics

Before entering the field, considering the ethical aspects of the research is very important issue (Lincoln 1995). Engaging with participants in the field require from the researcher to conform to ethical dimensions of qualitative research such as fully informed consent, deception, anonymity, avoidance of harm and confidentiality (Punch 1994). This study considered the various ethical aspects as follows:

4.9.1. Ethical approval

Ethical approval was obtained from Taibah University in Al-Madinah, Saudi Arabia (Appendix 7). At first, Taibah University was approached to get the ethical approval from the Dental School at Taibah University, to ease the process of accessing the field and collecting the data from different facilities in Al-Madinah. A contact was made with the ethical committee and forms were submitted in both languages (Arabic and English). This included the consent and the information sheet, which were submitted along with the forms for the ethical approval. A conditional approval was granted until getting an ethical approval from the University of Sheffield. Then, ethics was granted from the University of Sheffield [014541] (Appendix 8) and finally a full ethical approval was obtained from the Dental School at Taibah University. This was the process of gaining consent, but I was aware that ethics was part of the way I handled people and presented myself throughout the study. I had to continually reflect on what people told me and moderate my responses accordingly.

4.9.2. Consent

One of the important issues within any research is to take consent from all of the participants (Ryen 2004) since it is considered as part of the ethical code

among qualitative and quantitative studies. An information sheet about the study was given to each manager of the four facilities then an informed consent was taken from them before the beginning of my observations. In addition, information sheets were given to each participant before each interview and focus group. Time was given to participants to read the information sheet and ask questions and whenever they had any doubts the opportunity to ask questions was provided. Participants were informed that they were free to choose whether or not to take part and were able to withdraw at any time, without giving any reason. Then, an informed consent was taken from each participant before starting the interviews (either written or verbally) and before starting the focus groups.

4.9.3. Anonymity and confidentiality

All of the data in my thesis were anonymised at transcription and all tapes destroyed at this point. I gave different names to all of the participants to mask their identity and to ensure the confidentiality of the collected data (Morse 1994). During transcribing the recorded interviews, I scanned them and altered any data that may identify participants. In addition, the recorded interviews were discarded since most of the participants asked me to do that so their voices cannot be identified. For the dental clinics that I visited during my observation, I presented each one of them as anonymous dental clinics and named them using A, B, C and D without referring to any details that may identify those places.

4.9.4. Privacy

In Saudi Arabia, privacy is of the characteristic features that Saudi society appreciates. During data collection, privacy was an important element and I ensured its protection at all time to prevent any social or psychological harm (Denzin 2000). All participants, especially parents, were informed before the start of the interviews (face-to-face or over the phone) and focus groups that they were not obliged to answer any of my questions if they felt uncomfortable.

4.9.5. Data protection

All transcribed data were kept on a computer secured by password. All recorded interviews and focus groups were destroyed after transcribing the data because this action was requested by most of the study participants.

4.10. Translation process

After transcribing the interview in its language (Arabic or English), I moved on to translate the Arabic interviews to English language, which was a difficult task. It is important to ensure that the process of translation has been accurately obtained since it was considered the core of my qualitative study. To ensure the accuracy of the translation process, steps were taken as follows:

- Forward translation: this step was done as soon as I transcribed the recorded data.
- Backward translation: this step was taken after the forward translation of all transcribed data.
- Comparing the translated data to the source to check for any missing information or errors in the translated materials.

(Maneesriwongul and Dixon 2004; Regmi *et al.* 2010)

The table (8) below show an example to explain the how process of translation took place.

Table (8). An example of the translation process.

First Step: Forward Translation	
1st Arabic version (transcribed data)	1st English version
<p>الباحث: ما شعورك حول دفع تكاليف علاج الأسنان؟</p> <p>المشارك: والله هي غاليه لكن ايش نسوي. خصوصا التخدير الكامل يكلف قرابة 6000 ريال وهذا كثير. غير شغل الدكتور يعني علاج جدا مكلف.</p>	<p>Interviewer: how do you feel about the fees paid for dental treatment?</p> <p>Participants: well, the prices are high but what we can do about it. Especially the general anaesthesia is about 6000 riyal and this is a lot, and this is without the cost of the dentist, it costs too much.</p>
Second Step: Backward Translation	
1st English version	2nd Arabic version
<p>Interviewer: how do you feel about the fees paid for dental treatment?</p> <p>Participants: well, the prices are high but what we can do about it. Especially the general anaesthesia is about 6000 riyal and this is a lot, and this is without the cost of the dentist, it costs too much.</p>	<p>الباحث: ما احساسك حول المبلغ المدفوع لتكاليف علاج الاسنان؟</p> <p>المشارك: حسنا الأسعار غاليه لكن ايش نسوي. خصوصا التخدير الكامل تقريبا 6000 ريال وهذا كثير. وهذا غير تكلفه طبيب الاسنان يعني التكلفة جدا عاليه.</p>
Third Step: comparing the translated data to the source in Arabic to check for any missing words or lost meaning	
1st Arabic version (Transcribed data)	2nd Arabic version
<p>الباحث: ما شعورك حول دفع تكاليف علاج الأسنان؟</p>	<p>الباحث: ما احساسك حول المبلغ المدفوع لتكاليف علاج الاسنان؟</p>

<p>المشارك: والله هي غاليه لكن ايش نسوي. خصوصا التخدير الكامل يكلف قرابة ٦٠٠٠ ريال وهذا كثير. غير شغل الدكتور يعني علاج جدا مكلف.</p>	<p>المشارك: حسنا الأسعار غاليه لكن ايش نسوي. خصوصا التخدير الكامل تقريبا 6000 ريال وهذا كثير. وهذا غير تكلفه طبيب الاسنان يعني التكلفه جدا عاليه.</p>
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Although there was a slight change in the words, the meaning of the sentences and the words has been preserved. This process was done to all the interviews and the focus group discussions to ensure the accuracy of the translation process and that no information was missing.

4.11. Data analysis

One of the main foundational analysis methods for ethnographic studies is thematic analysis (Braun and Clarke 2006). Thematic analysis has also been considered as a tool to be used across different qualitative methods (Boyatzis 1998). Thematic analysis is “*a method for identifying, analysing and reporting patterns (themes) within data*” (Braun and Clarke 2006, p.79). It is considered a flexible method that describes and provides rich and detailed complex data. I used ethnographic thematic analysis to analyse and generate themes from my data that has been collected. This means that not only did I use thematic analysis; I also contextualised it within Saudi culture. The steps taken toward analysing the data are as follows:

- **Familiarising myself with my data:** this refers to reading and re-reading the data while noting initial ideas. This step means that researcher actually keeps himself reading the text constantly to know them and identify the hidden meanings. This step involves the transcribing of the data and it is considered essential especially for those researchers who did not collect the data or transcribe it by themselves. This step was done by myself immediately after each interview or focus group. Transcribing the data was done on the same day or within two days after the interview at most. Then, the process of translation was carried out, which involved forward,

backward translation and comparing between the translated data with original to ensure accurate translation to keep myself familiar with my data. The translation of the transcribed data took some time (up to 15 hours for each interview) to ensure that it was carried out appropriately.

- **Generating initial codes:** this step involves coding interesting features of the data in a systematic manner through the whole set of the data, via combining the relevant data. Initial codes constitute the basic form of element of the raw data that can be used to assess phenomenon in a meaningful way (Boyatzis 1998). Highlighting initial ideas and generating initial codes was carried out simultaneously as I was translating the interviews and focus groups' discussions as shown below in table (9). In addition, I used my notes on the behaviour of the participants to express and infer any additional meaning for some of the interviews and focus groups' discussions. For example, during my interview one of the participants (dental professional) was afraid of me because he thought that I was going to jeopardise his career. I knew that because he was very nervous at the beginning of the interview and acted weird like he was in a hurry suddenly in the middle of the interview. In addition, he confirmed this observation by telling me at the end of interview that he would like me to not tell anyone about the interview although I made it clear that this interview is going to be anonymised and no one shall be able to identify any of the participants in my study. I felt that reassuring professionals about my intentions was important.

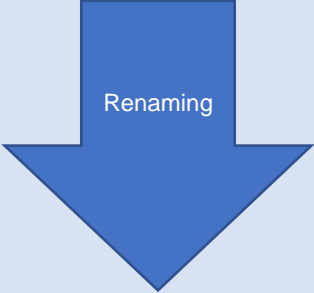
Table (9). An example of generating initial codes.

Interview excerpt	
<p>Mazen: children with disabilities supposed to be treated by the paediatrician and the treatment should include everything, except if the patient needs general anaesthesia because in this centre we cannot do that because we do not have the facility or the equipment. But because we do not have more paediatricians to treat all children, we tend to have a long waiting list.</p>	
Coding lines	Initial codes
<p>except if the patient needs general anaesthesia because in this centre we cannot do that because we do not have the facility or the equipment.</p>	Limited resources
<p>we do not have more paediatricians</p>	Limited workforce
<p>we tend to have a long waiting list</p>	Long waiting time for appointment

- Searching for themes:** this step where potential themes are generated using initial codes via gathering relevant codes and combining them into potential broader themes as shown below in table (10). At this stage, I focused on the data and looked for broader themes. This involved re-arranging of the codes and collating them into sub-themes and themes, to make sense and significance of each theme. This step was clear for most of the initial themes, but it took some time since it required reviewing and renaming some other themes. For example, some sub themes within chapter (7) required renaming such as: parental oral health literacy and gate-keeping. Those sub-themes were initially identified as part of enabling resources, which was not clear and did not fit the told story. It required some time, discussion with supervisors and more reading to be confident in renaming

those sub-themes.

Table (10). Gathering relevant initial codes and combining them.

Interview excerpt	code	Collating relevant codes
<p>Hamza: we do have insufficient knowledge that we can based on.</p> <p>Sultan: I think we got only one lecture and it was very brief.</p> <p>Hamza: the lecture was about the diseases and syndrome and it was about the symptoms, but not about the management of the patient</p>	<p>Limited knowledge</p> <p>Limited teaching</p> <p>No knowledge about managing the patient.</p>	<p>Curriculum issues</p>  <p>Training and curriculum issues</p>

- **Reviewing themes:** this step where the researcher checks if the work is in relation to the initial codes and entire set of raw data. This can be done via mapping the themes and analysing the thematic map. During this step, it is possible to identify new themes which you can be included in the analysis, but this may need to re-identify new codes as well. This step was done at the same time as I was searching for initial themes and renaming and re-identifying themes were carried out.

- **Defining and naming themes:** this stage required refining each of the themes and making the overall story clear via defining and naming each theme. The names of each theme needed to be simple, concise and give the reader a clear idea about the theme. In my thesis, coming up with main theme and connecting all codes to make clear sensible story was difficult. Although I used Penchansky and Thomas’s framework of access to identify some of the themes, the process of making a story out of themes was challenging and a

steep learning curve. For example, I found that being able to tell a logical clear story from the information and data collected was initially a difficult task to achieve. The first theme that I came up with was about describing access as “the reasons for seeking dental care and barriers encountered”, but it was not appropriate, and it was difficult to present as a coherent story because of the different perspectives. Therefore, I re-arranged my thoughts and came up with separating the perspectives into two main themes: pathways of access to oral health care services from the dental professionals and students perspectives and the actual experience of access to oral health care services from the perspective of parents of children with disabilities. Then telling the story to the reader became easier and more logical to follow.

- **Producing the report:** this step is about doing the final analysis and writing the report. It is concerned with telling a complicate story about the data. The report should be concise, coherent and logical while providing evidence of the themes within the data. Writing up the report was relatively faster than I had attempted previously since I now knew how to write and make sense of the results. Achieving coherence and logical report along with providing evidence were done via using multiple data collection tools and sources.

4.12. Summary

This chapter has described the process of developing the literature review and the background of my thesis. It also explained the methods used for data collection in Saudi Arabia and it illustrates the process of the data collection in each one of the four visited facilities in Al-Madinah. In addition, this chapter described and justified the used tools to collect the data and provided justifications for using them. The section on reflexivity reflects my own values, beliefs and attitudes. This undoubtedly influenced the process of data collection in the field and the subsequent analysis. For example, the ways I attempted to minimise my power and the ways participants were recruited and data collected. Data analysis for the study involved my reasoning for the style of analysis chosen and the steps I took to analyse the data, giving some brief

examples. The next chapter will contextualise the services in Saudi Arabia because this is important for how the data was analysed.

***Chapter 5: Results
and Analysis:
Mapping the OHC
services within Al-
Madinah***

5.1. Introduction

This chapter describes the public and private oral health care services in Saudi Arabia. I used my field notes during my observation to highlight the accessibility of the dental settings in terms of location, physical accessibility and parking areas. Although I visited public dental clinics, there were a lot of private dental clinics within Al-Madinah that I could not visit because Al-Madinah is a relatively big city (589 km² Urban and 293 km² Rural) (Saudi Central Department of Statistics and Development 2019) with a population of 2,188,138 it would be inconceivable that one study could cover all the services in depth. Furthermore, the focus of my thesis was about access to oral health care services and the ways oral care was delivered rather than presenting the type of services provided in Al-Madinah in both public and private sectors.

5.2. Mapping the oral health care services

All of the public and private oral health care services should accept patient with disabilities including children with disabilities (Al-Saud 2016). However, it appeared that the situation is a little different to that described in sections (2.3) and (2.4) from the interviews of parents of children with disabilities, dental professionals and dental students. The interviews, which I am going to highlight in the next chapters (6 and 7), explained that some of the dental clinics were either unable or unwilling to accept children with disabilities as patients.

I managed to use and triangulate different resources to create a map of the main public and private dental care services that accepted children with disabilities. I was able to use my field notes, observations, Google maps, the interviews and the focus group discussions to draw, describe and demarcate the main public and private dental clinics that treated patients and children with disabilities as shown below on figure (7).

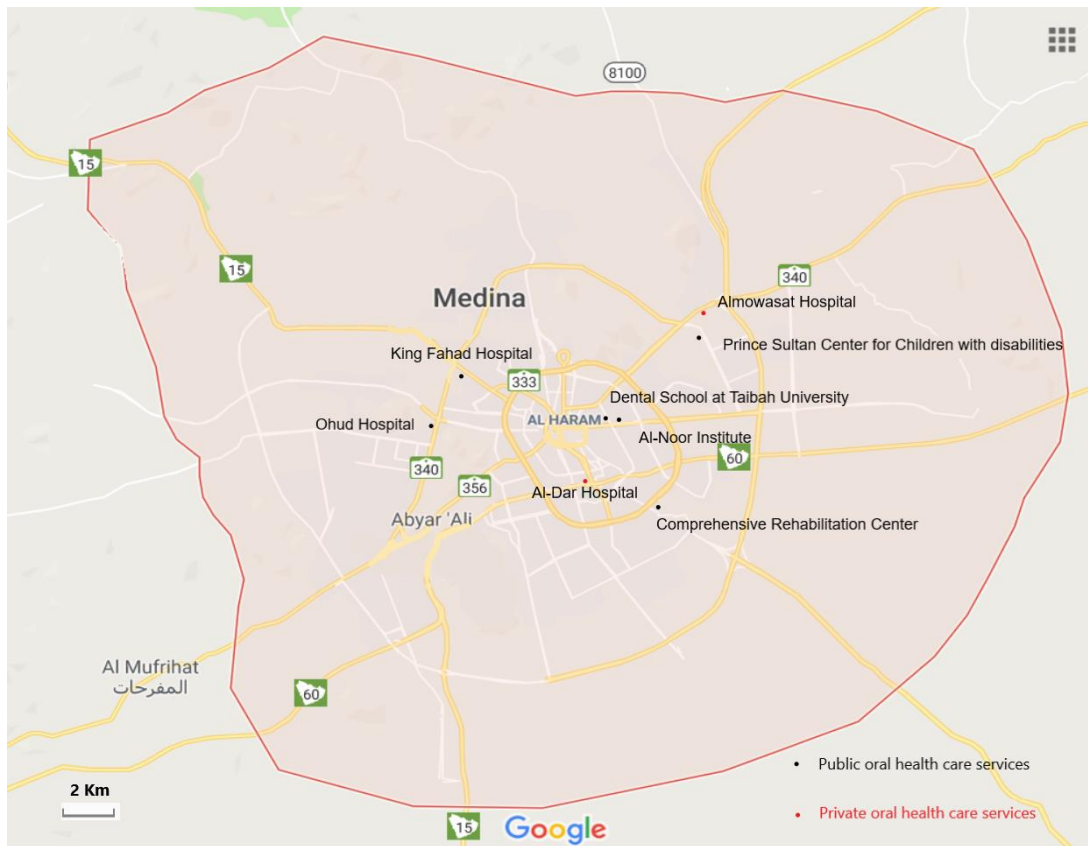


Figure (7). The oral health care services within Al-Madinah.

The public oral health care services that provide oral care for children with disabilities are:

- The Comprehensive Rehabilitation Centre.
- King Fahad Hospital.
- Ohud Hospital.
- Dental School at Taibah University.
- Prince Sultan Centre for Children with Disabilities.
- Al-Noor institute for Children with Visual Impairment.

The private oral health care services that provide oral care for children with disabilities are:

- Almosawat Hospital.
- Al-Dar Hospital.

It appears that most of the oral health care services are located on the eastern half of Al-Madinah while the population are scattered all around the city. This may pose a barrier for those living in the rural areas. In addition, it is a struggle

for people living in the western areas of Al-Madinah, and they may drive for up to 45 minutes by car in some cases to get the needed dental care in public oral health care services. In addition, there are some urban villages around Al-Madinah where they have unsurfaced roads which you can travel along for up to 20 kilometres. This adds more difficulty and some people struggle to acquire transport, so this affects the accessibility of services. Although I did visit only four of the above listed oral health care services (A, B, C, D), they were the main clinics that accept children with disabilities and provide oral care for them. In contrast, private oral health care services are numerous and scattered all over Al-Madinah and most of them do provide oral care for children with mild to moderate disabilities. However, they are not demarcated on the map since they are not having any data bases on the World Wide Web and therefore they are hard to locate. In addition, these private dental clinics are small and do not have surgeries for GA, nor do they have Nitrous Oxide for sedation. Hence, they are often unable to treat children with anxiety or more profound impairments.

In terms of physical accessibility, all of the public and most of the private oral health care buildings are structured to be accessible and provided patients with disabilities with adjustments such as: lifts, spacious waiting areas, parking areas, bathrooms for patients with disabilities and ramps. However, I observed that the dental chair was not accessible and that means there were barriers for wheelchair users with limited mobility. There are no wheelchair tippers in these clinics, and this can be an obstacle to providing oral care for patients and children with physical impairments as pointed out previously by Dougal and Fiske (2008, p.16-17).

Most of the public and private oral health care services provide various oral care services. However, some of them cannot provide a range of dental treatment because of the limited resources in terms of the work force. One example of this is centre A, which provides only minor oral care for children with disabilities since all of the oral care providers are hygienists and the dentist attends only for a short period (5 days) every 2 to 3 months. The outcome is that centre A refers patients needing complex oral care to King

Fahad Hospital for oral treatment under GA. Another example is centre D which provides only screening and very minor treatment such as superficial scaling because they do not have a permanent dentist attached to the centre. Instead, they rely on dentists to volunteer their own time to screen and examine the children and then to refer them to other hospitals for oral health treatment. Other public and private oral health care services and hospitals do provide a range of dental services such as: restorative, scaling, surgical and non-surgical extraction of teeth. During my observations in the field and interviews, I noted that there was only one hospital in Al-Madinah providing GA for oral care and dental treatment for children with disabilities. This is the King Fahad Hospital, which is located in northeastern part of Al-Madinah. Although Al-Madinah is one of the main cities in Saudi Arabia, and it still experiences shortages in terms of resources and facilities compared to other cities such as Riyadh (the capital) and Jeddah (second largest city). For example, Jeddah has 5 main general hospitals and other private hospitals that provide GA for treating different age groups for patients with disabilities.

5.3. The nature of the dental centres

This data collection for this study has been conducted in four dental centres within Al-Madinah as I established before in the previous chapter (4). I will describe each one of those centres and highlight how children with disabilities and their parents are accessing those oral health care services.

5.3.1. Centre A

Centre A is located within eastern half of Al-Madinah and about 5 to 6 Kilometres from the city centre. It is a facility where adults and children with disabilities can get a medical and dental treatment including physiotherapy treatment. Some people and children with disabilities can live there with their care staff who take care of people and children with disabilities and daily life activities such as eating and taking care of personal hygiene. The facility does have doctors, dental professionals, carers and other staff members and this

facility considered as one of the branches of the governmental department of social affairs. Additionally, the facility is connected to other buildings of the Ministry of Social Affairs.

To accurately describe the building and the dental setting within the building I need the exact measurement of the building and the floor map, which were not available for the public use and I was not able measure or estimate it. However, I managed to draw a sketch map of parts of the facility where I was able to access as shown below in figures (8, 9 and 10).

When you access this facility, you can see the parking area for both workers and visitors. The parking area provides parking spaces for up to 70 cars. Some parking spaces were specialised and reserved for workers and other were not and can be used for visitors. Spaces that were closer to the entry doors were marked for people with special needs. In addition, there were two parking spots at the front of entry doors of the facility that were specified for ambulances only. The facility had two ambulance cars specialised for patients with disabilities, some of whom lived within the facility, and there were paramedics as staff using the ambulance cars.

I will proceed with describing the lower floor, where the male dental clinic is located within the building, as I drew a sketch map of the lower floor based on my observations as shown below in figure (8).

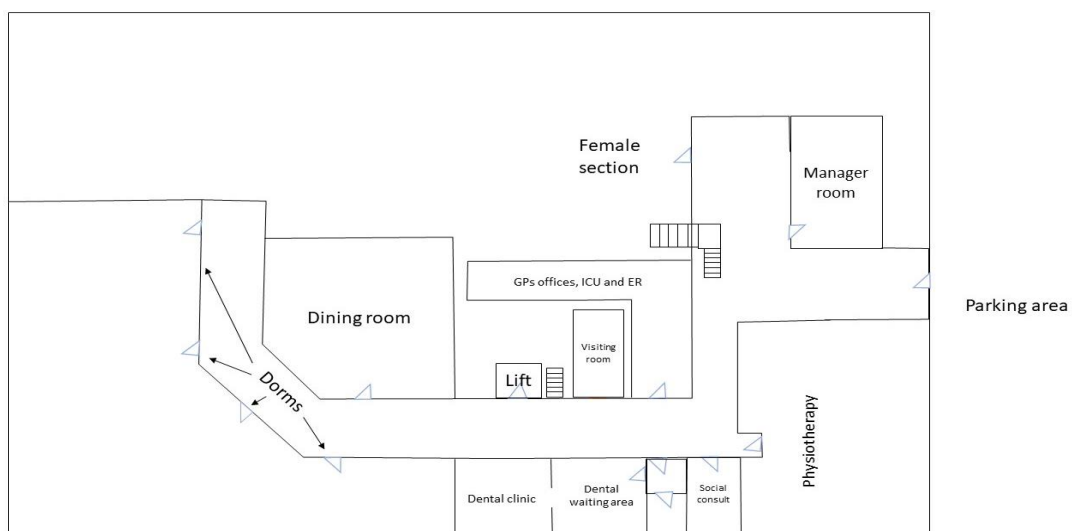


Figure (8). Lower floor map of centre A

After entering the building, the first thing you notice is that the facility has two storeys and you can reach the upper floor through stairs in front of you, where there are two closed doors. In addition, it is noticeable that the building has two separate sections: male and female sections, and there was a sign to point out for the female section on the right. The male section includes males with disabilities aged more than 10 years old and male staff members, while the female section contained all females with disabilities of various ages and male children with disabilities who were less than 10 years old. The reason for those children less than 10 years old to live in the female section is that those children were considered not ready to go to the male section and so they were raised in the female section by female staff. In addition, the transition process to the male section might have emotional implication for those children, so for the transition process to go as smoothly as possible it evolves slowly over a period of 5 to 8 weeks. The process of transition is decided by a committee, which include members from the medical, dental, social, and psychological departments within the facility to evaluate whether the child is ready to be transferred to the male section.

There was one dental clinic in both sections (male and female section), which contained male and female dental staff. The male dental clinic is located in the lower floor in between the lower male dorms, elevator, stairway and the medical department as shown above in figure (8). However, it was prohibited to get pictures of this place due to the restrictions, rules and confidentiality of those who were living and working within the facility. I will therefore proceed by describing the female and male dental clinics as follows:

5.3.1.1. Female dental clinic

The female dental clinic is located on the second floor and can be accessed from the male section through the stairs as show below in figure (9). To access the female dental clinic and to interview female dental professionals, permission was granted from the manager and the female dental professionals. However, accessing, observing dental setting, observing dental treatment on the female section and interviewing female dental professionals was highly

restricted so I was only able to observe the dental clinic without observing the waiting area or other parts of the female section. The female dental clinic has an old dental chair that has been used for more than 15 years, the dental nurses, who were working there informed me of its age. The rooms were smaller than the male dental clinic and there was no specific waiting area. The dental professionals told me that patients waited in the hall until they were called for treatment. However, for female patients to enter, they could use another door that opens to the female section where patients were waiting. In terms of room temperature, the room were neither cold nor hot, but I noted that a person would not be required to wear more one layer of clothes. The lighting was not too dark, or too bright and the female dental professionals were able to work and write things with no need for extra light except when providing dental treatment. However, the outside noises could not be heard inside the dental clinic. The rooms of female dental clinic were rectangular in shape with no windows but not too small or too big, and the surgery could accommodate a wheelchair user with their assistant for treatment.

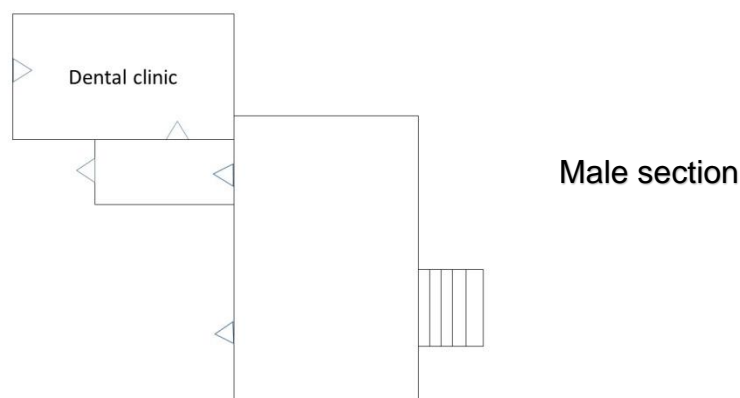


Figure (9). Female dental clinic within centre A

5.3.1.2. Male dental clinic

The location of the male dental clinic was near to lift, stairs to the upper floor of the male section and medical department. The lighting was similar to the hallway and other rooms of the facility, this means the room was not too dark or too bright and there was no need for extra lighting except when providing dental treatment in patients' mouth. The whole facility relied on air conditioning

and the room temperature in the dental clinic was close to being cold rather than hot, but there was no need to have a jacket or wear 2 layers of clothes. In addition, patients wore the same clothes that they wore in their dorms, which was one t-shirt with short or long sleeves. The noises in the hallways of the facility can be heard in the waiting area and the dental clinic since the door of the clinic was not closed except for when the dental professionals leave the dental clinic. The walls and the ceiling of the dental clinic were white in colour and the floor was grey. There was only one dental poster on the dental clinic describing how to brush teeth; this meant it appeared a little clinical. There were no models or other things that could be used as educational aids for patients with disabilities. The male dental clinic had a waiting area that could be accessed using a wheelchair and I observed that it could hold up to four wheelchairs users with their assistant/carers. The waiting area had more than 10 chairs to sit on. The dental chair looked new and one of the dental professionals told me they got it about six months ago as a donation from a wealthy man along with the other dental instruments such as: an X-ray machine and dental drilling hand-pieces. The location of the dental X-ray machine, dental store and dental bench are as shown below in Figure (10).

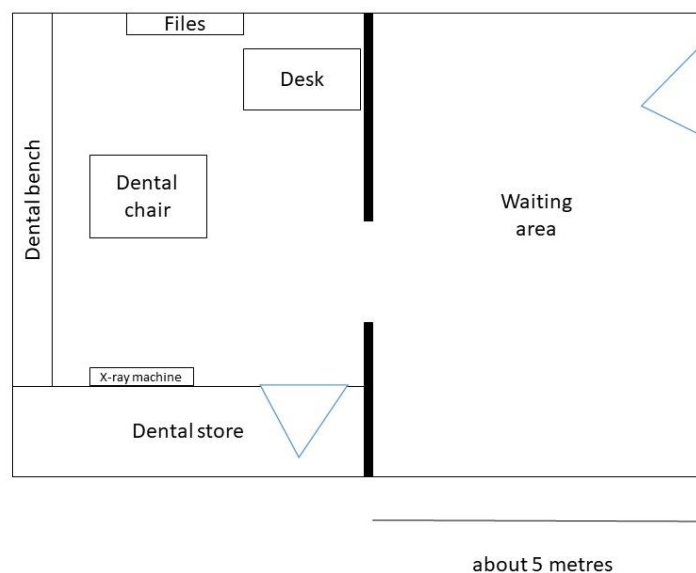


Figure (10). Male dental clinic in the lower level.

The dental clinic is accessible since the whole facility is provided with ramps, lifts and a little wider door that makes entering the dental clinic easy for

wheelchair users without any help. There is no door separating the waiting area from the dental clinic and it is an open connection, which makes the dental chair visible to those sitting in the waiting area. This connection does not provide privacy for those treated in the dental clinic. The reason behind eliminating this door is to ease the accessibility for wheelchair users so they can physically access the dental clinic by themselves.

Overall, the male dental clinic was better equipped than the female dental clinic because it was newly equipped by a charity about 10 months ago. However, the dental chair on both male and female dental clinic were not accessible, that means when a patient who used a wheelchair entered the dental clinic, dental professionals would either treat the patient on his/her wheelchair or manually transfer him/her to the dental chair. Furthermore, the dental professionals were dental hygienists or dental nurses and they appeared to have little knowledge of treating disabled children. In addition, due to the absence of a dental specialist and a general dentist, any slightly complicated or un-cooperative patients were immediately transferred to King Fahad General Hospital to be treated under general anaesthesia (GA).

5.3.2. Centre B

Centre B was an institution for teaching children with disabilities, so it was a school first and it had a dental clinic within its premises to treat children with disabilities. However, when I visited centre B, I found that the dental clinic was more of a room for medical emergencies. They did not have a dental chair or any dental equipment. The staff told me that there was a plan to establish a dental clinic, but the facility could not afford it. The medical emergency room was not located in the main building and instead it was in a building used for sports. The rooms were not dark or bright and had air conditioning to balance the room temperature. However, because of the proximity of the emergency room to the sport hall, the noises can be heard clearly in the room even when the doors were closed.

I asked staff what they did in case of dental emergency or when a child complained of dental pain or discomfort. It appeared that the followed protocol was to direct parents to seek dental care by going to the dental school at Taibah University. The reason for choosing the dental school was because of its proximity, but it was not known whether or not the dental school was routinely accepting and treating children with disabilities.

The medical emergency room was booked to arrange for interviews and to invite parents to take part in my study as described previously in the previous chapter in section (4.4.). I was able to perform two face-to-face interviews with parents of children with disabilities on my first attempt of recruitment. On my second attempt, I was able to recruit six other parents of children with disabilities.

5.3.3. Centre C

I will not describe the whole building since describing the facility would compromise the anonymity of the dental centre. I will describe the parking area and the floor where the dental setting is located. The parking area for centre C can hold up to 90 cars but it is usually filled with cars and sometime there is no space to park. In addition, there were no parking spaces for people with disabilities whilst visiting the dental centre. The dental clinics within centre C are located on the first floor and can be accessed using two lifts or stairs. The dental settings were separated into two sections on the same floor. The first section is dedicated for dental students and dental interns (who were in their last year of their dental degree). The second part is for dental specialists. Each part of the two sections had its own reception and waiting areas. The exact measurement and floor plan were not available for public use and were not readily available, so I drew a sketch map of the dental setting based on my observation as shown below in figure (11).

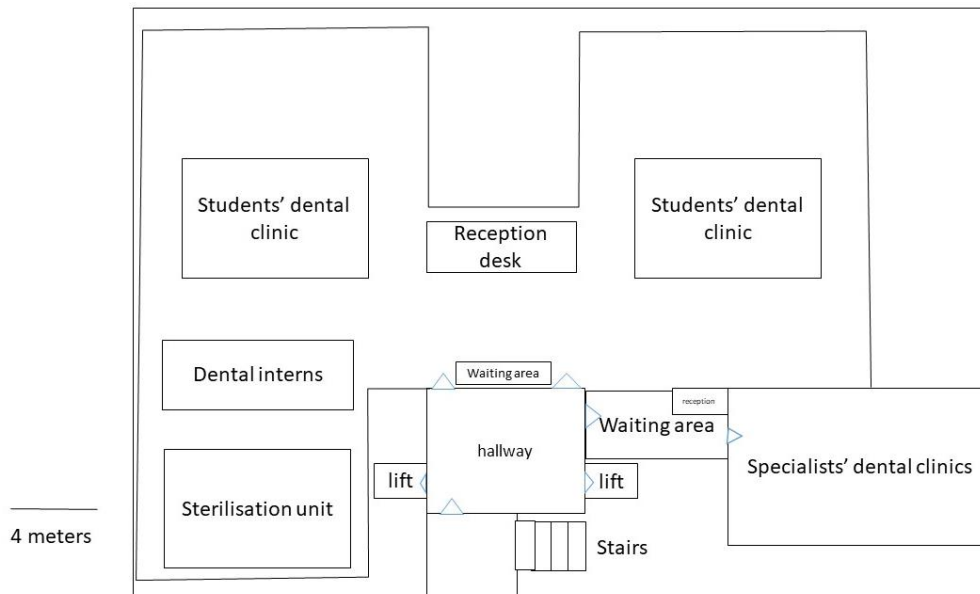


Figure (11). Male dental clinic within centre C.

As I highlighted before, the dental clinics within centre C were divided into two parts:

- First part where all of the dental students practice and have their dental clinics (N= 45 chairs in total) to treat patients. There was an area for dental emergencies, which included 6 dental chairs where the dental interns (last year of bachelor's degree in Dentistry) were practicing. It also included a waiting area within the dental clinic setting.
- Second part where the specialists and consultants are practicing, it comprised of 6 rooms for 6 dental clinics and a waiting area. This part of the dental clinic setting usually treats patients who needed further and/or treatment that is more complex.

The lighting within centre C was not bright or dark. In addition, the temperature was not cold or hot since most people (patients and dental professionals) were wearing a single layer of clothes and there was no need for further layer. Both sections of dental clinics were fully equipped including x-ray machines and dental materials and hand pieces. However, the waiting area for the dental students' part was relatively small and had few seats (up to 12 seats) since some patients were standing while waiting for their turn. In contrast, the waiting area for specialists' clinics had about 8 seats but there were no patients

standing while waiting for their turn. The students' dental clinic were 51 dental clinic for dental students to provide treatment compared to 6 dental clinics in the specialists section where the dental specialists provide treatment for their patients, which means that there were more patients to treat in the student dental clinics than patients treated in the specialist dental clinics. This would require more space in the waiting area for the dental students' clinic section.

In the dental students' section, the first point of contact was at the reception area where the patients register their presence and then wait in the waiting area for the dental students to call them. I observed that the receptionists sometimes rejected patients with disabilities, telling them that dental professionals within this facility were not able to treat patients with disabilities. I also observed that this attitude was challenged by one of the dental professionals and this has recently been changed as I will discuss in the next chapter (6). For the dental specialist section, the patients usually came to the reception to register their presence then wait in the waiting area. However, some patients approached the dental specialist directly, then waited in the waiting area and did not approach the receptionists. Those patients were either relatives, friends or came via their own social network, I am going to discuss this phenomenon in more details in both chapters (7 and 8).

Access for most patients appeared to be a smooth process, but not for patients with disabilities. Children with disabilities were assigned to paediatric consultants if they were 16 years old or younger and then waited for an appointment for up to 2 months. If the patients were adult, they would be assigned to one of the dental interns where the supervisors were ready to advise or step in in case of emergency.

5.3.4. Centre D

Centre D is located between 6 to 7 kilometres from the city centre of Al-Madinah. The centre is a primarily a charity for children with disabilities where they can have medical, physical, dental treatment and education. In addition, there was an attached building for those children who lived within the facility.

However, the registration processes within this centre had certain requirements including: being Saudi or one of the parents is Saudi, the child's age should be 18 years old or younger and the registration required committee approval. The registration committee consists of members from the medical, social administrative and physical therapy department.

This charity is based on donations from various members of the Saudi society as the manager stated:

Manager of centre D:

“This place from its start has been depending on the support of donations for everything such as: payrolls, medical equipment and teaching equipment. Donations for this charity come from different people of the Saudi society including members of the royal family and different wealthy people like tradesmen”.

I will proceed with describing the facility from my observation and field notes:

The facility has parking spaces available for staff members, visitors and patients with up to 100 parking spaces. The main building was available to access; it had two levels (upper and lower levels) with the administration department in the upper level. The lower level has the medical, dental and education sections. I accessed the medical, dental and physiotherapy sections after granting permission from the manager, otherwise accessing different parts were not available to those unknown visitors for security and confidentiality reasons. The exact measurements and details within the centre were not available nor readily for public use. A sketch map of the whole facility was established based on my observations and field notes as shown below in figure (12).

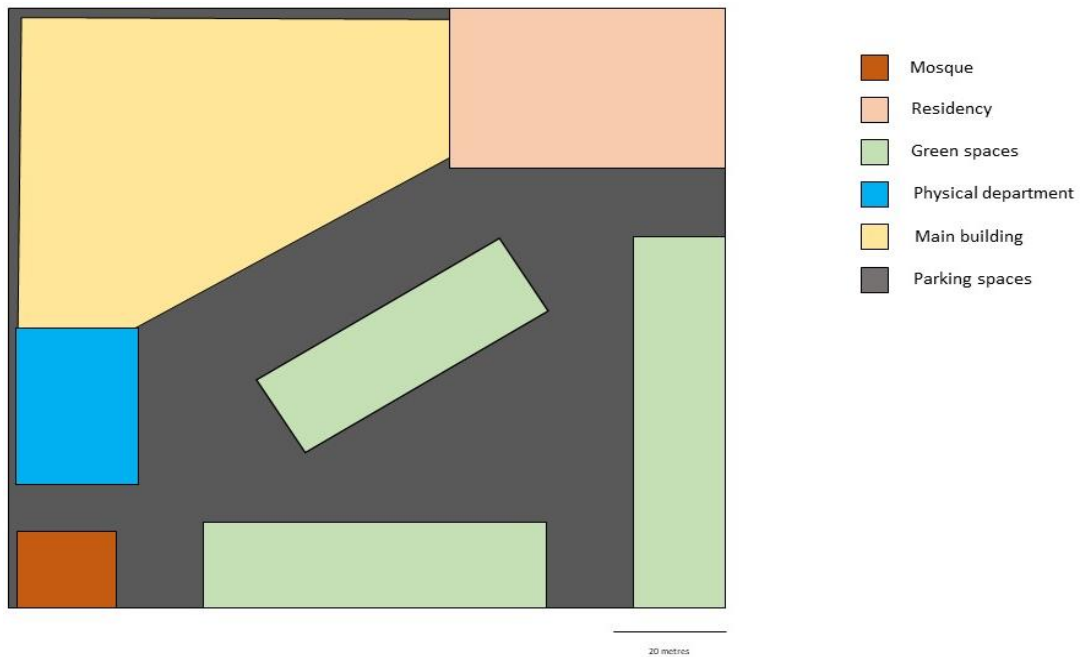


Figure (12). Centre D for children with disabilities

The dental clinic was physically accessible, but there were no dentists available to work in it. I had the chance to visit the dental clinic and observe the equipment and I was told that all of the dental clinic equipment was provided as a donation from one of Al-Madinah society members. The dental clinic was ready to use and had various dental materials and equipment such as permanent and temporary fillings, a digital x-ray machine and fluoride varnish. The reason for not using the dental clinic was the unavailability of an employed dentist. Instead, there was a dentist who volunteered his time every 2-3 months to treat simple cases of dental diseases and refer others who need further treatment to other public and private hospitals. The room temperature was not cold or hot since a central air conditioning was available in the whole facility. Lighting was more than adequate for the facility.

One of the observed barriers to access for parents of children with disabilities was the absence of a skilled dentist, even though the clinic was equipped and ready to be used to treat children with disabilities. In addition, some children with disabilities were wheelchair users but the dental chair was not ready to accept them, so either transferring the patient to the dental chair would need to be performed or children would have to be treated whilst seated in their

wheelchair. For patients with complex needs and complex disabilities, the answer was to refer them to King Fahad Hospital for treatment under GA.

5.4. Summary

It appeared from my observations and enquiries that parents of children with disabilities faced some geographical challenges while seeking dental care for their children. There are five main general public hospitals offering oral health care services, but only one hospital offers dental care under GA. In addition, the geographical positioning of these oral health care services is mainly in western half of Al-Madinah, which may pose difficulties for those living in eastern half. Furthermore, transportation appeared to be a barrier for those living in rural areas since some villages around Al-Madinah, which do not have oral care services, do have unpaved roads and so the infrastructure in rural areas acts as a barrier to access. I observed four dental centres and found that one of the main barriers that present in all of the four dental centres is the lack of availability of a wheelchair tipper or a dental chair that accepts wheelchair users. Additionally, the absence of a dentist who specialised in treating children with disabilities was a barrier and most places could only deal with minor cases that could be treated using the available dental clinics. Private dental clinics are scattered around Al-Madinah but there was no accessible data online, or anywhere to identify their exact location or assess the services provided. Despite these limitations, it appears that some parents do look for these private dental clinics to treat their children rather than attending public dental care services, and this will be discussed in more depth in chapter (7).

***Chapter 6: Results
and Analysis:
Pathways of access
to OHC services for
children with
disabilities***

6.1. Introduction

This chapter presents the pathways of accessing oral health care services for children with disabilities and their parents from two perspectives; dental professionals and dental students. The results present the perspectives of dental professionals working in dental clinics within centres A, B, C and D who treated children with disabilities. The results also include the perspectives of dental students at Taibah University which were gained from the dental students who participated in the focus groups. There was a difference between the perspectives of students and qualified dental professionals. Dental professionals tended to focus on the actual process of access to oral health care services and dental students tended to highlight the way the system worked. This chapter identifies the challenges that face parents and the current structures of the service delivery system. I used Penchansky and Thomas' framework (1981) as a lens through which to view the data and as a way of constructing sub-themes. The next table (11) presents the themes and the sub-themes that I am going to discuss on the following sections.

Table (11). Themes and sub-themes for pathways of access to oral health care services for children with disabilities.

Main theme	Themes	Sub-themes	Initial themes
Pathways of access to OHC services for children with disabilities	Need for care	Parental disease and pain.	
		Promoting of preventive OHC services	
	Barriers	Social barriers	The attitude of dentists toward disabled children
			Focusing on child cooperation
			Receptionists and gate-keeping
		Service barriers	Affordability
			Availability of: Dental specialists Dental resources Dental appointment
			Lack of collaboration
	Referral system	Saudi Nationals	
		Non-Saudi Nationals	

The journey of accessing oral health care services starts, according to the dental professionals in Al-Madinah, either when the child feels pain, or in a minority of cases, when the parents bring their child for check-ups. The Themes and sub-themes are as shown below in figure (13). These themes will be explored in more detail as the chapter progresses.

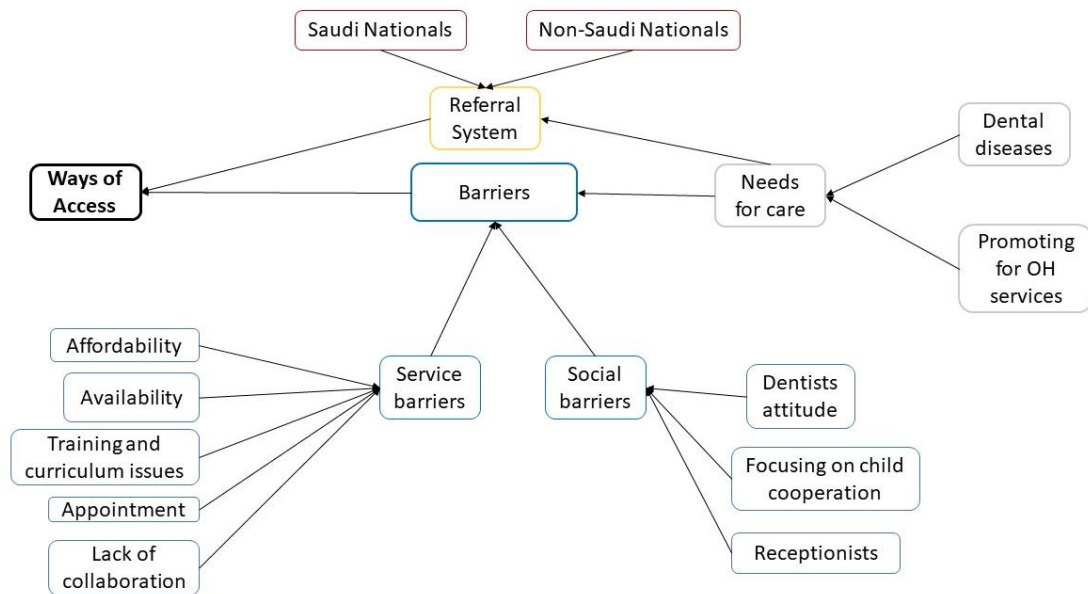


Figure (13) Pathways of access to oral health care services in Al-Madinah Saudi Arabia.

There are two ways of accessing oral health services;

1. By contacting private and/or public oral health care services and searching for a dentist willing to treat children with disabilities
2. Using the referral system.

The referral system only works if children with disabilities are members of a rehabilitative centre or a charity. Although there is a referral system built within the public health care system as described in sections (2.3 and 2.4), but in my research, it appeared that the referral system worked differently to how it was originally meant to work. As a result, parents of children with disabilities faced various barriers in accessing oral health care services and then in gaining treatment.

I will start describing the journey of accessing oral health care services whilst highlighting the sub-themes from the perspectives of dental professionals.

6.2. Need for care

Children with disabilities have higher dental needs than their peers (Hennequin *et al.* 2008; Paschal *et al.* 2016) as has been discussed in section (1.5.). In this current study, it appears that parents sought dental care only when symptoms appeared in their child's mouth or when their child complained of pain and discomfort. It has also been suggested that a low level of awareness about the importance of looking for preventive services for children with disabilities is one of the contributing factors for developing dental disease (Mouradian *et al.* 2000). Dental disease and pain and the promotion of preventive oral health care services are the sub-themes of the need for care.

6.2.1. Dental disease and pain

I interviewed dental professionals, who were working in centre A, about the oral health of the children with disabilities and ways of carrying out treatment.

Majid:

“Usually the patients have certain complains about their teeth, I mean they point to us to the tooth that hurts them. Then we do examine the tooth and decide the type of treatment that we should do and proceed with it”.

Othman:

“When the child comes to my clinic, I ask him about the problem and most of the time they do tell me or point out to the problem, it is either the gum or the tooth that hurt. In some cases, the carers do tell me the problem they noticed”.

The dental professionals, working at centre C, appeared to be suggesting that children arrived with a problem, usually pain. One dentist suggested that once pain was relieved the children failed to return for routine check-ups and oral hygiene instruction until pain recurred.

Mazen:

“Yes, we keep being in contact but some of them go away and never come back as soon as their pain is relieved”.

In the focus group discussions, dental students supported these perspectives arguing that many children with disabilities only sought treatment when they had dental disease.

Sultan:

“I had a patient with a visual impairment. He came to the screening clinic where I was working. I found that he has a lot of dental caries and pain, so I start treating him immediately”.

It appears that children with disabilities are seen by dental students and dental professionals when experiencing dental caries or facial pain. On the other hand, adults with disabilities sought dental care for other reasons, such as:

Hamza:

“One of the patients that I met was mentally retarded and he came seeking for a complete denture...His son brought him to me, and I took him by the hand and guided him to the dental clinic where I then took impressions and made a complete denture for him”

This would appear to be a life course approach to oral health for people with disabilities from childhood, parents seek dental treatment for their children and this proceeds into adulthood when family members seek treatment for adults with disabilities. Throughout the discussions, nobody mentioned preventative care from childhood to adulthood and the focus remained tightly on treatment rather than oral health promotion.

6.2.2. Promoting of preventive oral health care services

The lack of promotion for preventive oral health care services can be for different reasons. One reason suggested by dental care professionals would appear to be the lack of awareness of the parents about services.

Samir:

“I think one of the obstacles is not knowing where to go or what are the services that each sector can provide. For example, few people know what are the medical services that we are able to provide in this centre because a lot of people came to me and told me that they did not know about this place or the services that we do provide for children with disabilities. Parents are usually surprised by the services provided. In addition, the same thing happened to us when some parents told us that they are surprised that we provide insurance as well for the registered children. Although our flyers are everywhere around Al-Madinah, few people do actually look for us and reach us.”

Samir indicates that there appears to be a lack of knowledge around availability of services for children with disabilities in particular. This is despite advertisement of the clinics. In addition, some parents do not know which dentists will accept children with disabilities for treatment, or the necessity of prevention.

Yasin:

“Some fathers came to me asking about dental clinics that are capable of treating his child’s teeth and mouth”

From my research with dental care professionals I can argue that even if the parents were motivated and wanted to treat their children’ teeth, they would face additional barriers that make access to oral health care services difficult which I will now proceed to discuss.

6.3. Barriers

From the perspectives of dental professionals and dental students, there are many barriers facing the parents of children with disabilities when attempting to access oral health care services in Al-Madinah. Those barriers include service and social barriers as can be seen in figure (13). These barriers were the result of a shortage of service provision, which was a structural barrier while other barriers emerged as a result of how Saudi society was organised. For example, segregation which meant that mothers could not access clinics which were entirely run by male dentists and for male children, or if they did not have a driver and they were reliant on their husbands to provide transport to the clinics. Other barriers emerged as attitudinal barriers which related to the negative attitudes of dental professionals towards children with disabilities.

6.3.1. Social barriers

Social barriers represent the attitude of the dentist himself toward children with disabilities, toward the ways of treating that child and treatment options.

6.3.1.1. The attitudes of dentists towards disabled children

Many studies have highlighted the importance of health care professionals' attitude toward people with disabilities (Abdulwahab and Al-Gain 2003; Dehitem *et al.* 2008). These attitudes may be positive which can enhance the oral health care of people with disabilities (Wolff *et al.* 2004; Al-Zboon and Hatmal 2016) or negative which has a detrimental effect on the oral health care of people with disabilities (DeLucia and Davis 2009; Lee *et al.* 2015). People with disabilities face many psychological, financial, physical barriers as discussed in the previous section (1.9.), this means that the complexity of their lives can often be challenging, and oral health services should not add to that challenge but instead should be wholly accessible. We can suggest here that negative perceptions can only add to the societal and structural barriers that many parents of children with disabilities face on a daily basis. A work by Nick

Goss (Goss 2007) further argues that negative attitudes promote dependency, discrimination and powerlessness, which constitutes significant barriers to accessing oral health care for people with disabilities (Scambler *et al.* 2011). Consequently, we can argue that the more favourable attitude of dental health care professional towards people with disabilities, the more positive the dental encounter.

When the dental professionals were asked about whether they favoured treating children with disabilities or not, their answers varied:

Majid:

“I do prefer treating children with disabilities ... because they do not complain about the treatment and they are always grateful”

Othman:

“I do feel good when I treat them, actually I do prefer treating them they do not object or complain about the treatment”

Majid and Othman both preferred treating children with disabilities and found it rewarding, they also reported that patients and their families were grateful for what was done. Mazen and Sami contrasted with Majid and Othman.

Mazen:

“I do not prefer treating children with disabilities I felt pity for them and it is not nice to refuse treating patients. So, I offered treatment for those children”

Sami:

“I do not prefer treating children with disabilities, but I know how to do the treatment”

Sami and Mazen appeared obligated to treat children with disabilities but did not want to treat them. Socially, Islam guides us to care for people who are

less fortunate and who may be disabled, so these dentists are conforming, albeit grudgingly, to societal norms.

Other dentists appeared to gain spiritual comfort from treating children with disabilities and were guided by the teachings in Islam, which say a reward will be given for extending kindness to others. They also felt that people with disabilities did not challenge their treatment provision and were happier to accept what was offered. This perhaps constructs people with disabilities as 'the deserving poor' and appears almost patronising.

Samirah:

I do not prefer to treat children with disabilities, but I do treat them because I want the great reward from Allah”

When I asked Salman, why do you prefer treating children with disabilities? He answered:

Salman:

“I swear, it is because of the spiritual comfort that I get after treating those children”

Interviewer:

“What do you mean by spiritual comfort?”

Salman:

“I mean that when I treat those children with disabilities, I feel comfort for two reasons: the first one is I treated those who in great need and God will reward me for it. The second reason is that people with disabilities would accept whatever was the treatment”

In contrast, dental students during their internship year noticed varying attitudinal practices from different dental professionals in the public hospitals in Al-Madinah. For example, when the dental students were asked if dentists

can act as barriers for children with disabilities some of the dental students felt that the answer was yes.

Abdullah:

“There are problems when dealing with dentists; I mean they do not have patience when dealing with children with disabilities. So, they tell the receptionists to not put any patients with disabilities”.

Ahmed and Abdulrahman both nodded in agreement whilst Abdullah was speaking and so I turned to them and asked them to expand on what he was saying.

Ahmed:

“Yes, they are. Some dentists do not want to treat children with disabilities although he is a paediatric dentist”

Abdulrahman:

“Yes, I did have the same experience when I was doing my internship in one of the hospitals here in Al-Madniah”

Some dental students in the other focus group did observe similar attitudes from dental professionals toward children with disabilities. For instance, the second focus group were asked what they thought were the barriers to treating children with disabilities.

Mahir:

“I think, the dentists can be a barrier. I mean, I saw dental specialists were moving away from patients with disabilities. I mean, when a case of children with disabilities comes to them, the dentist would put the patient’s appointment to another dentist. In addition, some dentists were afraid of children with disabilities..... and I found parents who were searching and looking for a dentist willing to treat their children with disabilities”

Ali:

“There are dentists who do not want to treat children with disabilities because they do not know how, and they do not want to improve his abilities and dental skills in treating children with disabilities”

The unfavourable attitudes of dentists, even paediatricians, compounded with the process of searching for a dentist willing to treat children with disabilities. Children with disabilities and their parents appear to be facing barriers to accessing services, even though provision is not extensive, that were related to attitudes of dental professionals towards disability.

Interviewer:

“In your opinion, what are the barriers for children with disabilities and their parents to accessing oral health care services?”

Mazen:

“I think searching for a dentist, but as soon as you find a dentist willing to treat children with disabilities, I think life becomes easier”

Mazen indicates that he is aware about the issues with oral health service provision for children with disabilities, it is telling that he uses the words ‘willing to treat’, because he is indicating that there are many that are unwilling to treat children with disabilities.

6.3.1.2. Focusing on child cooperation

During the interviews, many dental professionals and dental students cited child cooperation during dental visits as a barrier to performing dental treatment. In response to the question ‘What do you feel are the barriers for treating children with disabilities? Male and female dentists answered using the same example of barriers.

Majid:

“The patient cooperation is the main obstacle. If he did cooperate, we will treat him and if he did not cooperate, we will transfer him to King Fahad Hospital to be treated over there”

Samirah:

“The patient cooperation only”

Transferring patients to King Fahad Hospital usually means dental treatment under GA and all the risks that this entails for the patient. What I could not ascertain was whether this was a regular event and whether other techniques had been tried and King Fahad Hospital was used as a last resort.

Five dental students had similar answers regarding the barriers for treating children with disabilities. One dental student used his personal experience, because his father had a hearing impairment:

Abdulrahman:

“I think the main barrier is the patient himself, for example, my father now refuses to go to dentists because he is afraid. I think that is because he had a very bad experience before when he visited a dentist for extracting one of his teeth”

Even though Abdulrahman has represented his father as a problem, the real reason for his father’s resistance to oral health care is fear acquired from a particularly negative experience with another dental professional.

When I asked dental students about whether they would treat children with disabilities in the future or not, a student answered me by refocusing on children with disabilities and representing them as a barrier:

Basem:

“I am afraid that children with disabilities may hurt themselves “

Basem is obviously worried about treating children with disabilities and represents them as the issue, rather than admitting to his discomfort and fear.

This representation may of course have a cultural basis because it is important to save face in Saudi culture and losing face means not upholding the dignity and respect of others, which can be interpreted as an inability to admit there is a problem (AlKhatani *et al.* 2013).

In contrast, other barriers were found to exist in the delivery of oral health care services, and these were also discussed at length by dental students and dental professionals. This contrasted with societal barriers such as attitudes and moved towards the structural barriers within society.

6.3.1.3. Receptionists' attitude and gate-keeping

During my time observing the dental settings at centre C, I noticed that similar to other studies in different countries, receptionists exerted a lot of power over arranging appointments and that they are usually the first person who has contact with patients (Ward and McMurray 2011). This can be a problem for parents of children with disabilities, if the receptionists did not work from an inclusive non-judgmental position. This is because they can act as powerful gate-keeper for accessing oral health care services and this exemplifies the power differentials at play (Hammond *et al.* 2013). Although Hammond *et al.* (2013) do emphasize that the days of the 'dragon behind the desk' (p.183) are numbered and the perception of the receptionist as being a barrier is somewhat unhelpful. In reality, it would appear that more training is needed for staff in these front-line roles.

Mazen:

"I saw the receptionists refusing and rejecting people with disabilities. They were telling them that we cannot treat you here in the dental college"

Mazen has observed disabling treatment of children with disabilities in centre C. What perhaps needs to occur is disability awareness and unconscious bias training for the receptionists and indeed some staff members.

6.3.2. Service barriers

Service barriers mentioned by dental professionals and dental students were: affordability of services, availability of services, training needs and curriculum issues, appointment availability, and a lack of collaboration between different sectors. Penchansky and Thomas' (1981) framework of access was used mainly to identify barriers within the oral health care services delivery system.

6.3.2.1. Affordability

Only one of the dental professionals who was doing an administrative role in one of the centres for children with disabilities acknowledged that not all parents were able to afford the cost of dental treatment.

Yasin:

“But I should say that parents may not be able to afford the cost of dental treatment some parents take their children with disabilities to dental clinics but there are other parents who cannot afford the cost of dental treatment. So, they call us to give them names of dental clinic or dentists who are willing to do dental treatment for free”

This immediately points to inequalities in access to oral health services for parents of children with disabilities and echoes the Inverse Care Law in that those most in need are less likely to receive (Hart 1971). In addition, only one dental student highlighted the importance of considering the cost of dental treatment, since non-Saudis pay for the dental services provided in public hospitals.

Basem:

“I noticed that some non-Saudis are not able to pay for the treatment even if it is just a small amount of money”

Basem has noticed that inequalities rise depending on whether you are a Saudi national or a non-Saudi national. Non-Saudi nationals are often economic migrants in domestic job roles, which receive a lower rate of pay, from

countries such as Africa, Pakistan, Bangladesh, Yemen, India and the Philippines (Gibney and Hansen 2005). The concept of being recognized as a Saudi citizen has implications for being able to access a wider range of health services. Parents themselves do stress the issue of affordability of dental services and treatment and we will return to this issue in the next chapter.

6.3.2.2. Availability

Availability can be subdivided into three more initial themes: the availability of dental specialists, the availability of dental materials and facilities and the availability of dental appointments. In Al-Madinah, each of these sub-themes appear to be problems by themselves and are linked to the shortage of services and the dental workforce.

6.3.2.2.1. Availability of dental specialists

It appears that there are institutions, which provide dental services, but there are a lack of dentists and the only available work force are dental hygienists. Dental hygienists can provide limited level of dental care (preventive and treatment) but they are unable to provide a full range of treatments and do not have the same training as a dentist.

Emad:

“If we have a dentist working here even if it is for a short period of time, it will have a good impact on the oral health of children with disabilities in our centre”

Nirmin:

“We do not have a dentist around to treat minor cases. Because if we had one, we would not need to refer children with disabilities to another hospital for dental treatment”

These two dental hygienists appear frustrated by their inability to provide a full range of treatment for children with disabilities. It was interesting that they were

treatment focused and chose not to discuss the importance of prevention. There were also a limited number of dental paediatric staff members within other centres around Al-Madinah generally.

Mazen:

“In our clinics, children with disabilities are supposed to be treated by the paediatric dentist but we have only one and there is a long waiting list to be treated by him”

All of the dentists echoed Mazen and the length of the waiting lists because there were so few specialists for children. This was seen as the same throughout the region and even when clinics did not have specialist staff trained to work with children.

6.3.2.2.2. Availability of dental resources

One of the areas of access is availability of resources which is often considered as being a characteristic of the health services delivery system (Aday and Andersen 1981). This is also termed as a process indicator and affects the ways in which a service is accessed. In turn, a process indicator also affects the outcome indicators of a service for areas such as satisfaction and utilisation because Donabedian argues that *“The proof of access is use of service, not simply the presence of a facility.”* (Donabedian 1972, p.111). This was apparent with Centre D which was equipped but lacked a full-time dental practitioner and instead had to rely on someone attending on a voluntary basis. Therefore, we can suggest that people accessing services may be unable to use them effectively because of a shortage of resources. Within Al-Madinah Province, the availability of dental resources includes: dental materials, facilities and equipment. Two participants suggested there was a shortage of dental materials to work with and this had an impact on the way they delivered care.

Emad:

“We have limited dental resources, for example, we do not have fluoride varnish to do some preventive measures for children with disabilities”

In addition, the problem of limited dental resources presents in Al-Madinah within different institutions as what has been highlighted by different dental students.

Sultan:

“There is one big problem and that is the distribution of the resources, I mean there are hospitals with good resources and dentists with different specialties and there are other hospitals that cannot treat simple cases because of limited resources and dentists”

The availability to deliver preventative treatment is diminished in this case because of the lack of availability of fluoride varnish. Fluoride varnish has been shown to have a positive effect in the reduction of dental caries in children (Marinho *et al.* 2013). If a population is already at risk, then it could be argued that a lack of availability of something that can be used to prevent the development of dental caries may have a significant impact. A lack of specialists to treat children with disabilities also has an impact on their care.

For many adults and children with profound and multiple impairments, or with anxiety or behavioural challenges, sometimes the only option is to do treatment by using a general anaesthetic, or other forms of sedation such as intravenous sedation (Enever *et al.* 2000, Lim and Borromeo 2017). In Al-Madinah, this essential facility appeared limited for treating children with disabilities and was mentioned by 5 dental professionals and by both focus groups of dental students.

Abdullah:

“Some hospitals may not be able to afford an operation room or not able to get one due to limited resources”

Samir:

“I know that children with disabilities may need to get GA to do the dental treatment and here in Al-Madinah, the private hospitals do not have GA. So, the parents will go either to the public hospitals or go to other cities to do the needed dental treatment like Riyadh”

The distance to Riyadh from Al-Madinah is 830 km by road and takes nearly 8 hours; alternatively, a flight takes one and a half hours and then a taxi for 30 minutes from King Khaled International Airport in Riyadh. Travelling places add an extra amount of stress on parents who may have other children to care for or may be unable to afford the journey, or the stay in Riyadh, both in terms of time and money. Participants also informed me that the present GA rooms for dental treatment in the public hospital had certain guidelines and times to perform dental treatment; for example, one session per week and certain criteria such as severity of need as to position on the waiting list.

Tareq:

“The operation room and GA available only a day each week and the dentists have a long list of names that need to get GA for the treatment”

Waiting lists and lack of availability for a GA add to access issues for parents of children with disabilities requiring dental treatment. There are also issues to do with length of time waiting and further deterioration of the child’s oral health, and possibly general health because of issues to do with sleep disturbance and nutrition because the child is having trouble chewing (Wogelius *et al.* 2003; Chung *et al.* 2010; Badre *et al.* 2014).

6.3.2.2.3. Availability of dental appointments

Access to routine dental services is often gained via appointment, being unable to gain an appointment is often cited as a barrier to accessing oral health care (Marshall *et al.* 2010). Within Al-Madinah, the availability to acquire a dental appointment was considered to be an issue by 7 out of the 9 participants, alongside the second focus group.

Othman:

“If the patient went on his own through normal procedures, they will give him an appointment after up to 6 months”

In addition, one of the dental students said during the focus groups:

Tareq:

“There are a lot of barriers and appointment is one of them. I mean the appointment usually can be after 3 months or more”

In Al-Madinah, it appears that the availability of dental materials, facilities, dental specialists, appointment and equipment is related to the appropriateness to the dental needs of children with disabilities since the services do not appear to be fully oriented or adapted to their needs. The low level of appropriateness of the dental services provided to the needs of children with disabilities in Al-Madinah can result in higher unmet needs.

6.3.2.3. Lack of collaboration

Collaboration between different services for children with disabilities appears to be critical for improving service delivery for children with disabilities using various and different health and oral health care services. The lack of collaboration and information sharing between different services can result in less care for children with disabilities (Owens 2011). The issue of lack of collaboration is present within services for children with disabilities

Yasin:

“There is no contact with any health facility to do regular dental treatment now there is no cooperation with any charity, public hospitals or private ones to treat the teeth of children with disabilities”

Yasin argues that there is no collaborative activity between the different health care services which could assist in more continuity of care for children with disabilities. Previous academic studies report a lack of oral health knowledge

amongst the various healthcare providers, but it was also suggested that greater insight into oral health and providing oral health care could be a facilitator to access mainstream oral health services (Maunder and Landes 2005, Tenenbaum *et al.* 2008, Pesaressi *et al.* 2014, Pourat *et al.* 2015)

6.3.2.4. Training and curriculum issues:

It appears that children with disabilities are less likely to use oral health care services than their peers due to various barriers (Schultz *et al.* 2001). One of those barriers is related to the attitude of dentists toward disability and children with disabilities as mentioned before in section (6.3.1.1.). It has been argued that developing favourable attitude toward children with disabilities requires educating dentists and raising their awareness around disability (Dao *et al.* 2005; Waldman *et al.* 2010). The lack of training within dentistry around special care and lack of teaching about people and children with disabilities are considered as contributing factor to develop barriers for treating children with disabilities.

Interviewer:

“How did you feel when you started treating children with disabilities?”

Othman:

“In the beginning, I did not know how to deal or treat children with disabilities, and I stayed like this for a while. Then I started to learn from my colleague about treating and dealing with children with disabilities”

It appeared that Othman was not taught how to treat children with disabilities during his dental degree since he was unable to treat any children with disabilities for a while. However, he believes that he gained his confidence and learning experience from his colleagues and via his own way of learning through observing other dental professionals.

It appears that teaching the undergraduate dental students about people with disabilities is an important issue and some countries have started teaching

their dental students about people with disabilities several years ago (Faulks *et al.* 2012). For example, in the UK, teaching the undergraduate dental students about people with disabilities via multidisciplinary approach to develop disability awareness and positive attitude among dental students as objectives (Thompson *et al.* 2001; Nunn *et al.* 2004). Another example is where the American Dental Education Association (ADEA) in (2006) reported that they will ensure that dental education programs would include both clinical and didactic teaching about the treatment of special needs. On the other hand, the amount, quality and methods are varying between dental school within the USA (Krause *et al.* 2010). It appears that undergraduate dental students in Saudi Arabia have had some lectures about people with disabilities as pointed out in the focus group discussions.

During the focus groups, the students discussed lectures about treating adults and children with disabilities and concluded that the lectures were mostly symptom based which medicalised people, but there was a deficit when it came to patient management skills.

Abdulrahman:

“We got some lectures in the pediatric dentistry course and it was about chronic diseases and syndromes, but I don’t think that we got any benefit from it”

Hamza:

“We do have insufficient knowledge that we can base on”

Sultan:

“I think we got only one lecture and it was very brief”

Hamza:

“The lecture was about the diseases and syndrome and it was about the symptoms not the management of the patient”

Tareq:

“The management was for the tooth itself rather than managing the patient”

The lack of training, exposure or learning about how to manage and treat children with disabilities is closely related to the unfavourable attitudes of dental professionals towards treating children with disabilities, although other factors may contribute such as: social background and traditional beliefs (Al-Abdulwahab and Al-Gain 2003). In addition, people who did not made any contact or attempt to learn are more likely to develop a negative attitude (Anderson and Antonak 1992). In terms of access, this may be seen as the acceptability and appropriateness of services offered by dentists.

6.4. Referral system

I have already introduced the referral system in the above section (2.4, p.68). The referral system initially appears to be a straightforward system when utilized by the population. However, after interviewing dental professionals and dental students, it appears that the referral system for children with disabilities is extremely complex. In order to overcome most of the barriers, parents of children with disabilities utilize the referral system to access oral health care services. However, it appears that to overcome those barriers you must: either have dental insurance or be registered with a charity or rehabilitative centre.

Being a member of charity has the advantage of having medical insurance and easier access to private dental clinics.

Samir:

“We do have a dental clinic where we do initial examination and simple treatment. Then we do refer children with disabilities to complete their dental treatment in one of the dental clinics in AL-Madinah. All registered children with disabilities have medical insurance that includes dental insurance that can use to get the needed dental treatment. The insurance has been provided by people’s donations to this charity”

There are other parents of children with disabilities who mentioned that having dental insurance to access oral health care services, and the perception of high cost of dental care, which I will discuss in more depth in the next chapter.

Being a member of the rehabilitative centre in Al-Madinah can make access to public dental clinics much easier

Othman:

“We do refer the patient to K.F. Hospital if he is not cooperative or he needs dental treatment that we are not allowed to do. The hospital is very cooperative in terms of treatment, appointment and procedures”

Interviewer:

“What do you mean that the hospital is cooperative?”

Othman:

“For example, they do give us appointments within a month, but if the patient went on his own through normal procedures, they will give him an appointment after up to 6 months”

After observing the dental settings, conducting interviews with parents and dental professionals and focus groups of dental students it appears that the referral pathway is a much more complicated and somewhat vague procedure. However, the referral pathway is different for Saudi nationals and non-Saudi nationals and I am going to explain it as a journey as the figures (14) and (15) below show:

6.4.1. Saudi National

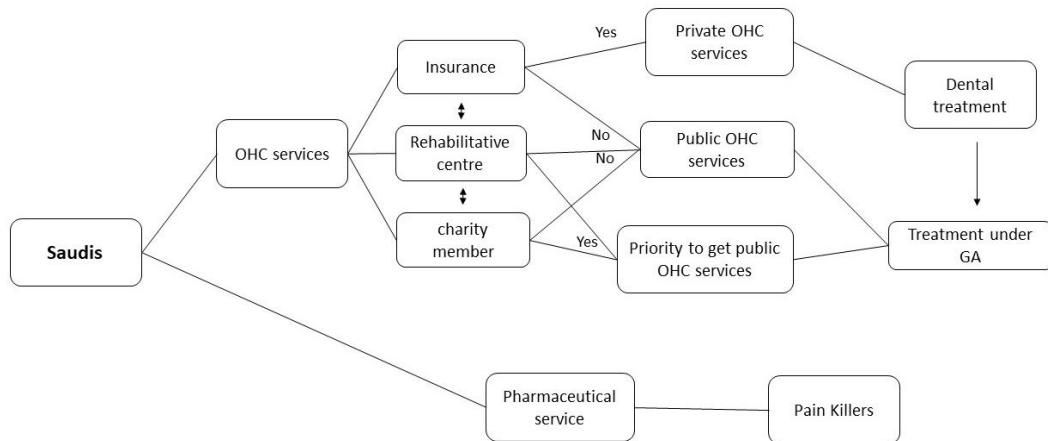


Figure (14) shows the referral pathway for Saudi Nationals

Saudi Nationals usually decide whether they go to the oral health care services or to the pharmacies if they have a child with dental need. If they have insurance, they can access private dental care quickly and there are more options for dental treatment. In addition, they can easily access and register with a charity or the rehabilitative centre. Furthermore, if they are registered within the rehabilitative centre or a charity, they have a smoother and faster access to the public oral health care services. One drawback here is that the public oral health care services offer GA as a principal form of dental treatment for children with disabilities while prevention and regular care are not viewed as a priority. For example, dental professionals often refer children with disabilities to GA without trying other forms of pharmacological interventions. For example, Nitrous Oxide (N₂O) inhalation sedation, diazepam in the form of tablets or syrup, or midazolam in tablet or intravenous form (Klingberg 2002).

6.4.2. Non-Saudi Nationals

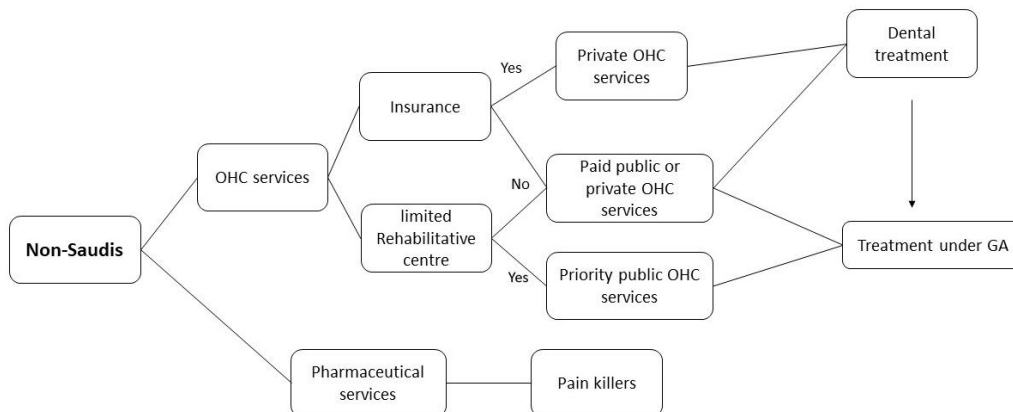


Figure (15) shows the referral pathway for non-Saudi Nationals

Non-Saudi Nationals can also decide whether to go to the pharmacy or to the oral health care services. The difference for non-Saudi Nationals is that the public oral health care services require payments for treatment. In addition, their ability to register their children with disabilities to the rehabilitative centre is much more complex. One example is that children must have more profound disabilities while Saudi children do not have to possess profound disabilities to register at the rehabilitative centre. Non-Saudi Nationals are unable to register with charities that support children with disabilities such as the Prince Sultan Foundation for Children with Disabilities. In contrast, there are some opportunities to register within the rehabilitative centre and use their referral pathway for any dental treatment.

6.5. Summary

From the dental professionals and dental student's points of view, access to oral health care services for children with disabilities usually begins with dental disease or pain. As soon as children with disabilities and their parents begin looking for dental treatment, they face many barriers including social and service related barriers. The social barriers include: dentists' attitudes, their perspectives about disability and focusing on the child as a barrier, while the services related barriers include: availability, affordability, training and

curriculum issues, lack of collaboration and receptionists. The lack of training in paediatric/special care dentistry and lack of disability awareness was also seen as a barrier to parents accessing oral health care for their children. One way to overcome some of the barriers is by using a referral pathway. It appeared, from the interviews and focus groups, that the referral pathway is complex and works in certain ways such as: being a member of a charity or rehabilitative centre or having dental insurance. Inequalities for children with disabilities appear to be greater if they are non-Saudi Nationals and this would link with lower income and educational attainment of their parents.

However, the referral system in Saudi Arabia for children with disabilities works in more complex ways than it has been described earlier in section (2.4.). In addition, there are different pathways for Saudis and non-Saudis to access oral health care services. Furthermore, the treatment options offered by the private and public oral health care services are different. For example, the private dental services do not have the ability to offer dental treatment under GA. In contrast, most of the dental treatment offered to children with disabilities in the public oral health care services is immediately referral for treatment under GA without considering other choices and options. This reliance on GA services to provide routine dental treatment for children with disabilities has associated risks that perhaps parents would not take if they fully understood. It is also an economically costly exercise and one that could be reduced if prevention was more at the forefront of dental care.

The next chapter will discuss the experiences of parents of children with disabilities when trying to or accessing oral health services.

***Chapter 7: Results
and analysis: The
experience of
parents of children
with disabilities
around access to
OHC services***

7.1. Introduction

In the previous chapter I explored professional perspectives of access to oral health care for parents of children with disabilities which fulfilled my first objective. This chapter will explore my second objective which is the experiences of parents when they are accessing oral health care services looking for treatment for their disabled children. It describes the process of access as a journey starting when the parents would like their children to be examined by a dentist, looking for treatment, or obtaining routine visits, all from their perspective. The results represent the parent's (mostly father's) voices and experiences around access to different oral health care services within Al-Madinah. This chapter presents contrasting views among parents and different attitudes toward dentists and oral health. However, the parents highlighted similar barriers to those discussed previously in chapter (6). One of the most prevalent barriers present in most of the parents' interviews is the affordability of dental treatment. This chapter identifies some of the challenges that faced parents and the current structure of the oral health service delivery system. Penchansky and Thomas' framework (1981) has been used once again as a lens through which to view the data and as a way of constructing sub-themes. The Themes and sub-themes are as listed in table (12) and shown below as a journey in figure (16). I will then explain them as the chapter progresses.

Table (12). Themes and sub-themes for the parental experience of accessing OHC services.

Main theme	Themes	Sub-themes	Initial themes
The parental experience of accessing OHC services	Need for care	Dental disease and pain	
		Routine dental care	
	Pharmaceutical services		
	Barriers	Parents' related barriers	Attitude toward dentist
			Parental oral health literacy
		Gate-keeping	
	Service related barriers	Affordability	
Availability of dental appointment			
Favouritism / Social Networks			

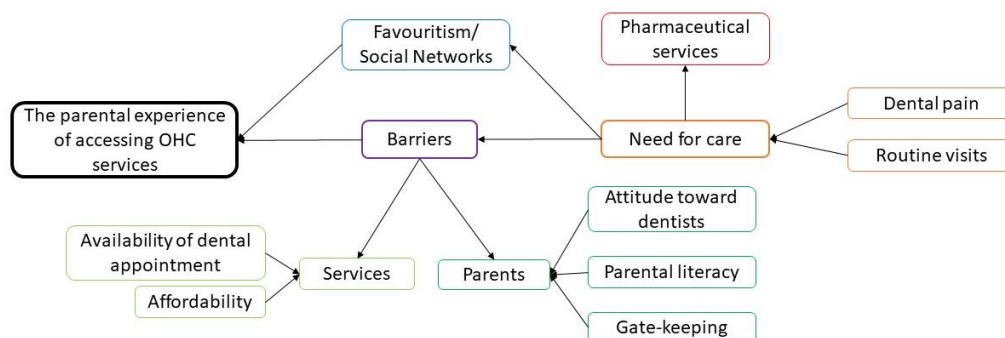


Figure (16). Access to OHC services: the experience of parents of children with disabilities.

7.2. Need for care

Dental professionals and dental students that were interviewed appeared to see children with disabilities only when they had symptoms and were complaining of painful mouths and teeth. On the other hand, the majority parents of children with disabilities interviewed brought their children to the oral health care services when their children were in pain and looking for dental treatment. This theme has two subthemes, which are dental disease and pain and routine dental visits.

7.2.1. Dental pain

Previous studies suggest that pain is the most common reason for children to visit dentists in Saudi Arabia (Farsi *et al.* 2004; AlHumaid *et al.* 2018). For example, AlHumaid *et al.* (2018) did a cross-sectional study of children aged 6-12 years old in six cities in the Eastern province of Saudi Arabia. They distributed 3000 questionnaires to parents and got 2306 (76.9% response rate) answered questionnaires returned. They found that pain was the most common reason to visit a dentist and there were significantly higher odds associated with visiting a dentist when in pain (odds ratio = 6.81) than visiting a dentist for regular check-up (odds ratio = 0.28). Al Humaid and colleague's study suggests that parents of children with disabilities may seek the advice of dentists only if their children complain of pain.

If we now return to my study, we can reflect on when parents seek the advice of dentists in Al-Madinah since most of the parents of children with disabilities (13 out of 16 parents) supported Al Humaid *et al.*, (2018) position of having dental visits in case of dental pain and emergency only.

Interviewer:

“Did your daughter visit a dentist before?”

Fahad:

“No, there was no need because my daughter never complained of her teeth and she never felt pain”

This response and similar responses appeared in the interviews of five out of sixteen. It appears that some of the parents think that the only reason for visiting a dentist is having a pain. This position was supported by the findings of Oredugba (2007) study that held in Nigeria where he asked parents of children with disabilities if their children with disabilities have visited a dentist or not. He found that about 59% of his sample did not go to a dentist and the major reason for that was not having a dental problem. In addition, this perception of visiting dentists only for emergencies is present in similar countries in the Middle East. For example, in 2006 in Jordan a study conducted by Al-Omiri *et al.* where they did distribute a questionnaire to evaluate the perception of oral health among the parents of primary school children (average age 13.5 years old). Al-Omiri reported that dental pain as the major reason for seeking dental care.

These studies showed that having dental pain and/or problem is considered the main reason for parents to go to the dentist otherwise parents feel that there is no need to visit a dentist for routine check-ups. It appeared that the perception of dental professionals and dental students in the previous chapter (6) support the conclusions of previous studies and reflects the perceptions of parents of children with disabilities in this study.

One addition to the previous research was that I found that there were parents who were motivated and prioritised their children's' oral health. I interviewed 16 parents of children with disabilities and only three of them displayed some motivation and enthusiasm about taking care of their child's teeth and mouth.

For example, when I asked Hathal how does he feel about his child's oral health? He answered:

Hathal:

“I do take a really good care of mouth and teeth of my children, I even taught my son how to brush by himself. Now he is taking a good care of his teeth and

even his younger brother became interested and start to brush his teeth every day”

Another example is a mother, Khadija, who took care of her son’s personal hygiene including his oral hygiene.

Khadija:

“I am taking care of all the aspects of his life, like personal hygiene and other matters. I even supervise him when he brushes his teeth and sometimes I do it for him by myself”

This way of taking care of their children’s oral health represents the importance and the level of enthusiasm and commitment to optimize the oral health status of their children.

7.2.2. Routine dental care

Although the most prevalent cause for visiting oral health care services is having dental pain, routine dental visits appeared to be scheduled by parents in several studies. For instance, Al-Agili (2004) explored parents’ perspectives about access to oral health care for children with special needs in the USA by using a questionnaire. Her sample was parents of children with disabilities aged (3-13 years old) and the questionnaires were sent to 2057 parents while the response rate was 38% (n=714). She stated that 85% of her sample received routine dental care, while 77% of the sample reported that they had scheduled another routine dental care appointment. A similar finding has been found among parents that I interviewed.

Interviewer:

“Did your son visit a dentist before? “

Hathal:

“Yes, of course. We went to the dentist about 2 months ago and my son had a dental appointment after 3 months for check-up”

It appears that there are some parents do take care about their children's teeth and mouth and seek routine dental care even if there were no complaints. In my study, three out of sixteen parents were taking care of their children's oral health and took their children for routine dental care. In Saudi Arabia, a study done by Abushal and Adenubi (2009) where they asked 505 parents to complete a questionnaire about the attitude of parents toward being separated from their children during dental treatment, reasons for visiting dental clinic and some social demographic questions. About 295 parents answered with having a dental pain or emergency as the main reason for visiting a dentist. Although the study was not clear whether they included children with disabilities or not, it still represents a part of the general attitude of parents in Saudi society toward reasons for visiting dental clinics. In addition, another study done by Murshid (2016) in Riyadh (the capital city of Saudi Arabia) aiming to assess the age and the reasons for the first dental visit in public and private dental clinics in Saudi Arabia. The author collected the data retrospectively from the dental records of public and private dental clinics, and the study included the data of 594 child. The researcher identified that pain was the most common reason to visit the dentist with 425 out of 594 children (71.5%). In contrast, routine dental care accounted for 27.3% of the total sample, and that is 162 children visiting the dentist for check-up. Again, this would not represent the total population of Saudi Arabia since it has been conducted in Riyadh only and included only one public dental care service and a private dental clinic, but still represent part of the Saudi parental attitude toward oral health and reasons for visiting dental care service.

7.3. Pharmaceutical services

In Saudi Arabia, most parents and caregivers seek treatment after the symptoms arise such as: having a dental pain. It appeared that parents seek the intervention of either pharmaceutical services or oral health care services in order to relieve their child's dental pain. This section is going to discuss the pharmaceutical services and highlight the reasons behind using pharmaceutical services as the first point of access for dental pain. I will then

proceed to discuss the way of accessing oral health care services and the related barriers in the next section.

I have provided examples below of two participants who sought the assistance of pharmaceutical services to relieve their child's dental pain.

Yazeed:

"My son had a toothache for a period of time. So, we gave him a medication from the pharmacy and his pain was relieved..... sometimes we say that it is a simple pain and we give him some sedative sprays from the pharmacy, Panadol, salt or other things like this to make the pain go away"

This way of seeking pharmaceutical services or home remedies could be for different reasons. It could be due to health beliefs in previous (Oredugba 2006; Farsi *et al.* 2004) or in my study due to financial difficulties as one of the interviewees explained.

Interviewer:

"Why you did not take your son to visit a dentist?"

Yazeed:

"Sometimes you do not have the money to go to the dentist, you know. I mean we gave him some medications from the pharmacy and painkillers because the least visit to the dentist is going to be a problem"

It appeared that some parents could not afford the cost of dental care at the dental clinics. However, most parents did highlight the cost of the dental treatment as a barrier when searching for oral health care services, which I am going to discuss it in detail later on. In addition, Yazeed is non-Saudi national and he is working in a farm around Al-Madinah, which may indicate that he has low SES. Studies showed that children with disabilities who are from low SES families are less likely to access oral health care services (Mouradian *et al.* 2000; Nelson *et al.* 2011). Furthermore, since he is a non-Saudi national, he has much less choices of free oral health care services than Saudis as

mentioned before in the previous chapter section (6.4.). All of these barriers appeared to exert a lot of pressure on Yazeed, which made him search for pharmaceutical services rather than searching for a dentist and dental treatment.

7.4. Barriers

It appeared that children with disabilities face many barriers when accessing oral health care services, as discussed in the previous chapter. The parental perspectives around access presented barriers that some of them were similar to barriers mentioned by dental professionals and dental students while others were not discussed by the dental professionals. Those barriers are sub-divided into: parental and service related barriers. I will proceed to discuss the parental related barriers at first then I will discuss the service-related barriers.

7.4.1. Parent related barriers

This study showed different barriers that are related to the parents of children with disabilities; primarily behaviour and attitude. Barriers include: attitude toward dentists and oral health, parental oral health literacy and gate-keeping. These barriers emerged as I was interviewing parents (mostly fathers) of children with disabilities.

7.4.1.1. Parents' attitude toward dentists

The interviewed parents of children with disabilities exhibited both positive and negative attitudes toward dentists who treated their children. For example, one parent (Farid) reported a balance of good and bad experiences.

Farid:

"I met so many dentists, some of them were good but other were like butchers"

The interviewee used the "butchers" as an expression to refer to the fact that some dentists were not good and that his son had a negative experience.

Since I am a Saudi citizen and have lived among Saudis since birth, I know that this phrase “Butchers” is said when Saudis refer to a bad dentist who is dealing with his patients without patience and sympathy. In contrast, within the UK I am informed that saying someone is a butcher means he leaves a bloody mess in someone’s mouth and he is rough and uncaring. This negative way of carrying out treatment can act as a psychological barrier preventing further seeking of dental care (Kelly *et al.* 2005). The experience can also have profound impact on parents.

Khadija:

“I do not trust any dentist in this city, so we did not go to a dentist”

Interviewer:

“why you do not trust any dentists?”

Khadija:

“I do not feel that they are capable of treating my son because I felt they do not know how to treat my son and he dealt with my son in a bad way”

These feelings of not trusting a dentist developed because of the feeling that dental professionals are incompetent. It may be due to the insufficient knowledge of the dentist around disability, or particular syndromes and/or the negative way of dealing with children with disabilities, which has been documented among other studies. One study was done in (2010) by Resch and colleagues took place in US through conducting focus groups with a total of 40 parents using purposive sampling. One of their findings was the disrespectful behaviours of some dentists towards children with disabilities. In addition, there was insufficient knowledge and misconceptions about disability among dentists, for example, one of the dentists assumed that a wheelchair user always had an intellectual disability. In my study it appeared that knowledge about disability is an essential part of developing a positive attitude toward treating children with disabilities. Hence, parental attitudes were improved by the presence of favourable dentists’ attitudes toward their children

with disabilities. For example, two of the interviewees demonstrated positive attitudes toward dentists by observing the dentist's positive attitude toward the child. Parents were also grateful that the dentist did not highlight their child as 'different' because of their disability.

Wa'el:

"I think the dentist was good and my son were treated like any other child"

Sary:

"The dentist was good and patient. He worked very fast and gently and my son did like him"

In contrast, another parent displayed a negative attitude toward a dentist who treated her child.

Fatima:

"We went to a public hospital and my son had a very bad experience because the dentist was a very bad man"

Interviewer:

"May I ask, what do you mean by that?"

Fatima:

"I do not mean his skills but his way of dealing with patients and my son, he was very rude, and my son had an emotional trauma over there..... I mean he was nervous and angry. He did not know how to deal with children and cannot tolerate my son's behaviour.... So, I will never return to him again"

The negative attitudes of parents of children with disabilities toward dentists can have an impact on the oral health of their children and may represent a barrier toward seeking oral health care services in the future. A study conducted in India about impact of parental attitudes on the oral health of children by Chhabra and Chhabra in (2012) suggested that negative parental

attitude towards dentists and negative children's experiences within oral health care services represent barriers for seeking dental care. In addition, parental knowledge and literacy can act as a barrier for seeking dental care, which I am going to discuss in the next section.

7.4.1.2. Parental oral health literacy

Many parents do not know the importance of primary teeth. This has been demonstrated by one of the participants when she was asked whether her child visited a dentist or not.

Abrar:

“No, we did not visit any dentist, because his teeth are the small ones and will fall later. So, I think we do not need to go to a dentist these days. But I will take him as soon as his permanent teeth erupt”

This lack of parental oral health awareness about the importance of the primary teeth can act as barrier for seeking oral health care services. Additionally, it can have an impact on the oral health status of children with disabilities and the accessing preventive services (Schultz *et al.* 2001; Oredugba 2007: Chhabra and Chhabra 2012) since parents may not seek oral health care services and act as gate-keepers to care.

7.4.1.3. Parental gate-keeping

Other parents indicated the presence of pain and complaints by their children but did not seek oral health care services for other reasons, such as: lack of time, being busy or the symptoms of pain has been relieved or disappeared. One example from one of the participants hints at the structure of Saudi society and the position of women which can also create a barrier to accessing care.

Abrar:

“His father was busy when he was feeling pain, so we could not go to a dental clinic, but then his pain was disappeared so there was no need to go to a dentist”

In Saudi, women could not drive at the time of the interviews and the families were reliant on the adult male members of the family for transportation. In this case, the mother is unable to reach dental clinics without the father, which can be construed as the father acting as a gate-keeper to care. The full extent of this father's circumstances was unknown, and it would have been socially unacceptable for me to question this mother in depth about her husband. It could also have been that the resources of the father were minimal, and his employer would not allow time away from work, there could have been other family obligations and all of this could have added to the reasons why oral health care was a low priority.

In this next interview, I felt dismayed that the parent focused on the child's behaviour as an obstacle and was unable to offer support by providing the time for his child to be desensitized to dental treatment. The dentist was obviously taking things slowly in an attempt to gain the child's trust and co-operation, but the parent appeared to feel that it was a waste of time, in this instance the parents themselves was a barrier to care. He was obviously dissatisfied with dental services and used the metaphor of war to highlight the impact of attending. When he contrasted this with the dentist who was taking his time to ensure that he reduced the anxiety of the child, it illustrates his lack of insight into the importance of having a child who is unafraid and who can co-operate.

Farid:

“Going to the dentist is like going to war..... you can see all the types of crying, shouting and screaming whenever we want to visit a dentist..... However, once we went to a dentist, he sat with my son and did nothing but talking with him. Then, he did nothing, and the appointment was finished for that day and the same thing happened on the 2nd visit. When I asked the dentist about it, he told me that he needs to make my son trust him to eliminate my son's social phobia and fear. So, all of that time was on the expense of my time and every time we go to the dentist, he does a little work and did not complete the treatment of a single tooth. In the end, I must dedicate my time completely and make myself free to go to the dentist and to be able to do the treatment step by step every other day. I mean, each visit the dentist will do

some treatment till my child trust him and have positive experience. I do not think that I have the time to do that”

The extreme feelings that a visit to the dentist provokes is present in this father's opening statement 'going to the dentist is like going to war'. It implies that the parent has to mentally prepare themselves for the battle ahead. The parent needs to rally his troops, which in this case is his child and convince him to go to the dentist, or 'go to war'. The father's distress during this exercise is palpable. When they reach the dentist this father's experience of going merely transforms into impatience as the dentist then tries to reduce the child's fear and anxiety. The father appears not to understand the positive aspects of reducing fear and is instead focused on the amount of time it takes. This may well have been as a result of pressures at work, but it could also be because of a lack of understanding about the importance of reducing fear and anxiety in his child for the long term.

Fear and anxiety of the dentist and dental clinics have been highlighted among the academic literature as barriers for accessing oral health care services. For example, a study done in Jeddah in 2003 by Farsi and colleagues, where about 3rd of the sample reported fear and anxiety from visiting a dentist as the main reason for not visiting dental clinic. Although fear and anxiety present among children overall including children with disabilities, it is perhaps important that parents should support their children rather than focusing on their fear and using it as an obstacle to access oral health care services. In addition, other barriers have been reported by parents of children with disabilities such as: the cost of the dental treatment in private dental clinics, which will be discussed in the next section.

7.4.2. Service-related barriers

There are barriers that have been reported by parents of children with disabilities and related to the oral health care services provided in Al-Madinah. Since these barriers are related to the service delivery, I used Penchansky and

Thomas' model of access as a lens to highlight sub-themes. Those sub-themes are affordability and availability of the oral health care services.

7.4.2.1. Affordability

Previous studies have indicated that one of the barriers to accessing dental care for children with disabilities is the prohibitive cost (McDermott *et al.* 1986, Kane *et al.* 2008, Loeppky and Sigal 2006). In my study, only one of the dental professionals pointed out the inability of some parents to afford the costs of dental treatment as a barrier to care in section (6.3.2.1.). On the other hand, parents of children with disabilities highlighted this issue as a main barrier. Fourteen out of the sixteen parents whom I interviewed, indicated that for them dental treatment was expensive. Two of the parents highlighted their inability to afford the cost of dental care because it was high. For example, Yazeed chose to go to the pharmaceutical services instead of seeking dental care because of the high cost of dental treatment as mentioned before in section (7.3). In addition, although some parents had medical and dental insurance, they also referred to the high costs of dental care because they were paying a proportion of the fees because the insurance did not cover all of the treatment.

Fatima:

“Although we have insurance, but it does not cover all the cost of dental treatment, we paid a lot with the insurance. So, it was not possible to go to the dentist and pay for every time because the cost is too much. We were paying half of the cost for every dental treatment”

The high cost of dental treatment is highlighted amongst the academic literature as a barrier to accessing oral health care services for many parents of children with disabilities. For example, Edelstein *et al.* (2009) reported that the high cost of dental treatment was the main reason (61% of the participants) for not visiting a dentist. Similar to my study, parents reported that it was because they either they did not have an insurance or because of the high costs of dental care.

In addition, although some families do have dental insurance, they could not eliminate parental perceptions of the high costs of dental treatment, as it has been pointed out by Fatima. This parental perception of cost as barriers has already been reported in the academic literature. A study done by Schultz *et al.* (2001) in the USA retrieved data from the National Health Interview Survey (NHIS) in 1997 and used the child sample, which included information on 14,290 children. The data were used in combination for descriptive analysis and for logistic regression modelling. They concluded that the high costs of dental treatment were perceived as barriers among parents of children with disabilities although most children were eligible to receive Medicaid insurance.

7.4.2.2. Availability of dental appointments

Although the availability of an appointment is a sub-theme within the dental professional perspectives, it is also considered as a sub-theme within the parents' perspectives as well. From the perspectives of parents, the availability of dental appointments is one of the barriers for seeking oral care for children with disabilities. In previous research it has been suggested that structural barriers like the lack of availability of appointments are directly related to a reduction in choice and the inclusion for people with disabilities (Griffiths and Boyle 2005, Kaye *et al.* 2005, Owens 2011, Abdul Rahim *et al.* 2014, Shyama *et al.* 2015). It would appear that this issue also relates to children in Saudi Arabia. In my study, seven out of sixteen parents stated that the appointment would usually be within 2-4 months, but their children were often in pain and needed emergency oral care to relieve the pain:

Jamal:

"We went to a public hospital and they gave us a very far away appointment, which was 4 months away. So, we did not wait and went to a private dental clinic"

This parent was seeking oral care, but whilst trying to access the public oral health care service, he faced a long appointment to see a dentist. His only option was to turn to the private oral health care service and managed to get

a closer appointment in order to gain oral health care provision. Similar results have been found in a study by Prabhu *et al.* (2010) using a sample of patients with disabilities in the UK with an age range of 4-75 years old. They got 113 answered questionnaires and they found that the waiting time to be seen by a general dentist was ranging from 1-2 months while the waiting time to be treated in Secondary dental clinic (dental hospital) was ranging from 1-6 months. However, the 113 answered questionnaires were not completely answered leaving some questions with no answers, which could result in variation in the number of responses for each question.

7.5. Favouritism and access to oral health care services

This section produces further evidence around the use of favouritism and social networks as a way of extending access to oral health care.

Within Saudi Arabia, the health care system offers referrals to services for patients who need further treatment and care and those who need to access secondary and tertiary level of health care services (Saudi Ministry of Health 2014). In chapter 6, dental professionals reported that a referral pathway is used for children with disabilities who need to be treated by specialists or instead they are directly referred for a GA. In this study, I identified that some parents referred to a different way of accessing oral health care services and dental specialists in order for their children to receive oral health care. One parent told me that he has no problem getting an appointment for his disabled son even if it was an emergency because he 'knew' the dentist. Knowing people who can assist you to access services in Saudi Arabia is an accepted part of the care pathway and not unusual.

In chapter 1 (p.22-24), I identified that social capital has three types: bonding, bridging and linking social capital. Furthermore, individuals can use bonding, bridging and linking social capital to facilitate access to oral health care services in different ways.

Within Saudi Arabia the notion of 'wasta', which is loosely translated as favouritism, is a widely known method of gaining access to a variety of resources in Saudi society.

Ma'an:

"I am thinking of having another appointment with the same dentist for my son"

Interviewer:

"What do you mean, could you explain more please?"

Ma'an:

"I mean I can have an appointment whenever I want. I mean I do have a "Wasta" and he is the dentist and my friend and he can arrange an appointment for me. So, the appointment is not going to be far away, and it can be on the same day".

This way of having appointment via using "Wasta", which means the man's social networks and translates literally as favouritism. The term is well known in Saudi Arabia and I have had personal experience of this practice because of my status as a Saudi citizen from birth. Social networks can positively influence accessing various services because they involve the process of advising about or facilitating the access to certain health care provider (Patrick *et al.* 2006; Alam *et al.* 2012). What these studies infer is that social networks are positive because they increase levels of understanding about conditions and can signpost people to different services that are appropriate.

In contrast, what this may mean in my study is that services are not accessed equitably for all because some parents are more connected and therefore can access oral health care services with greater ease because of their social networks, whereas parents with reduced resources and fewer social connections remain unable to access the same levels of oral health care for their children. This is similar to financial resources, which can be distributed unequally in groups throughout societies and an unequal distribution of social

resources merely reinforces oral health inequalities for children with disabilities.

During interviewing parents, one of the parents pointed out to his way of easing the access to oral health care services using *wasta* as a mean to speed up the appointment process, when he stated:

Ma'an:

"I mean I can have an appointment whenever I want. I mean I do have a "Wasta" and he is the dentist is my friend and he can arrange an appointment for me. So, the appointment is not going to be far away, and it can be on the same day".

Although using *wasta* can have a positive impact for this father and his children, it can have detrimental effect on society. The negative impact is caused by creating inequality because other parents of children with disabilities do not have this kind of social network or *wasta* to employ it to ease the access to the needed oral health care services. Nevertheless, Ma'an as a parent did use *wasta* only when he faced a barrier of long waiting appointment to get the needed dental care. So, he used *wasta* to speed up the appointment process to get the needed dental care for his disabled child, as he stated:

Ma'an:

"I can arrange the appointment by talking to a receptionist, but the appointment usually will be after a month at least. It was an emergency and my child was in pain, so I talked to my friend and the appointment was arranged in the same day and my son will be treated"

From this point we can suggest that *wasta* has been used when necessary and it has positive consequences for the child's life. On the other hand, taking this approach to get an appointment means that it may affect other appointments and dental care providers negatively on that day. The consequences of using *wasta* to get an appointment may fall into three case scenarios of which two of them are going to have negative consequences. I

am going to write a short vignette to illustrate the impact of using wasta on dental professionals and other patients.

The vignette

A dental clinic that starts treating patients from 9 a.m. till 5 p.m. provides dental treatment for 10 patients a day with each patient having 45 minutes as a time slot needed for dental treatment. There is a short break of 30 minutes for lunch starting from 12 p.m. to 12:30 p.m. Patient A uses wasta to get a dental appointment on the same day due to emergency. The new patient A is given an appointment and the appointment can be arranged in these two situations:

- An appointment at the beginning or at the middle of the day.
- An appointment at the last of the day.

Each one of those appointment may have different impact on the other patients' appointments or the dental staff team as follows:

- An appointment at the beginning or at the middle of the day is arranged. To create a new time slot for patient A, the dental professionals would squeeze patients' time slots needed for treatment from 45 minutes to 40 or 30 minutes, depending on the time of contact to arrange the new appointment. The new slot is early in the morning or in the afternoon but not the last time slot at the end of the day. If the new appointment is at the beginning of the day, the time slots of the 10 patients would be 40 minutes. If the new patient's appointment is in the middle of the day, the 5 patients' time slots would be shrunk further to 35-30 minutes. This squeezing action on the time slots would result in two things; the first one is delaying all of the other patients' appointments. The second one is exerting more pressure and load on the staff in order to treat all of the other patients. It may even result in shorten the break time of the dental professionals if any of the appointment lasted longer than 40 minutes. In some cases, the last dental appointment is going to be re-arranged on another day if there were no time for treating them. However, if one

of the patients did not show up, there will be extra time for other patients, but this rarely happens.

- An appointment is arranged at the end of the day. The same above scenario could be repeated by squeezing the time slots into 40 minutes, and there is going to be an extra load on the dental professional team to get the last new dental appointment and finish it before the end of the day. Another scenario can happen as a result of no time available, where an extra load is going to be exerted on the dental professionals where they treat the new patient A after their official working time (after 5 p.m.), but the appointment for patient A would never be re-arranged on another day due to the presence of wasta. In addition, this over work may not be rewarded financially but it may be held as favour that shall be returned to other involved dental professionals.

Rarely, some dental clinics and hospitals have certain guidelines where dental professionals are provided with free time slots to be used in case of emergencies and/or treating relatives only, which is usually filled via wasta. In other cases, the dental professional manages to put a free time slot, but these cases rarely happen.

Using wasta to get an appointment has been demonstrated previously in a study done in Kuwait by Shah *et al.* (1994) where they surveyed emergency room (ER) users in health care services in 1993. The study used a questionnaire given 2184 individuals visiting the ER, and it involved asking them about reasons for using ER instead of going to primary health care services. The participants were 1004 Kuwaiti and 1180 non-Kuwaiti nationals. The study found that one major reason was the inaccessibility of the primary health care services in terms of registration procedures. In addition, one of the major reasons for choosing ER instead of going to the primary health care services is the ability to use wasta. Wasta here means the ability to gain access to health care services by using informal social referral through an individual's social network. People used wasta to gain access to health care services are about 18% of the non-national Kuwaitis, which is 212 individuals, while the

Kuwaiti nationals were 8%, which is 82 individuals. The study had limitations in terms of depending on patients to report their accessibility and utilization of health care services. However, the excessive use of ER has negative consequences on the resources and people's health since it lacks the continuity of care where needed in order to provide optimum health care for users.

On the other hand, *wasta* can be used as a form of social network (linking social capital) in a vertical manner to connect health care providers to those people who needed health care. One study by Mason (2016) demonstrated the benefits of using linking social capital between health care providers and members of migrant groups in Spain. Mason reported that little attention was given to refugees and irregular migrants to Europe in terms of services, information and care. To improve health care access among migrants, a strategy was developed involving the use of linking social capital between Nurses and members of migrant groups. Nurses were seen as the most appropriate health care professionals to establish the link based on the reduction of power differentials and mutual respect and trust. However, the strategy was to establish a triage centres to refer patients to access other nongovernmental organizations and charities, which provided health care services. However, there was improvement in terms of accessing to health care services for some individuals, but this strategy had several limitations and gaps. This was because the strategy did not account for cultural and educational differences. In addition, there was a lack for a common language to be used for communication, which was considered to be a major limitation when establishing relationships based on trust.

7.5.1 Observing *wasta* in dental clinics at centre C

When I was doing my observation in one of the four dental clinics, I noticed the act of *wasta* in a case similar to the previous one. This event was not unusual and it went smoothly without disturbing the workplace almost as if it was a routine. I will describe the process as I viewed it:

“A man entered the waiting area; he was wearing thobe (traditional Saudi clothes). He did not talk to the receptionists, but he called someone via mobile and sat waiting. As he was waiting, he did not seem nervous or in pain. One of the receptionists approached him and shook his hands as if he knew the man. The receptionists brought the man while talking to him to the reception area and started taking his details and that of his child. Usually, when the patient goes to the dental clinic, he visits the reception area to talk to the receptionist and the receptionist arranges an appointment for the patient. The appointment can be immediate if the patient is in pain or it can be after some days if the case is not an emergency. The emergency appointment is usually with one of the general dentists or interns (dental student in the last year of his degree). In this particular instance, the patient did not require an emergency treatment, but he got an X-ray and immediate appointment for his child with a consultant. Later that day, I went to the receptionist and asked him why the patient had been seen so quickly when he clearly wasn’t an emergency. The receptionist told me that the man was a friend of his and he did not want him to wait with his child so he contacted the consultant to ease access for his friend and so he did not experience any delay”.

I am a Saudi and have lived in Saudi culture and society for most of my life; I know that this act and what happened is due to the presence of wasta and the man’s social network. In this event, the man used his social connections, which in this case was the receptionist, to gain easier access to an oral health care provider without any barriers, which in this case is the waiting time for an appointment (after a week). He had jumped the queue on the waiting list with his child because of his social connections.

7.6. Summary

It appears that level of care and knowledge about the importance of the teeth of children with disabilities needs to be raised among their parents. Most interviewed parents of children with disabilities only sought care when symptoms appeared and/or after their children complained about their teeth.

In my study, some parents may seek dental care by physically going to a dental clinic while others may seek dental care by going to a pharmacist for medication, which would treat only the symptoms, not the cause.

From the data I can also suggest that some parents of children with disabilities are struggling and face many barriers when seeking and accessing oral health care services for their children. These barriers include structural or service-related barriers such as: the availability of dental appointments and the affordability of dental care. However, sometimes parents of children with disabilities can act as barriers themselves by having low level of awareness and negative assumptions about the importance of teeth, and also acting as gate-keepers for accessing oral health care services. In contrast, some parents showed enthusiasm and high level of motivation for looking after their children's teeth, but barriers still exist and make access to oral health care services difficult.

In contrast, while *wasta* can be seen used by anyone, it appears that it may have both negative implications for the resources, appointment and waiting time for patients who are requiring dental care and positive implications for the patients or parent using *wasta*. It could be argued from a position of equality that access to oral health care services for children with disabilities should be a smooth process and obstacle free because they usually have an increased level of health and oral health needs (Lewis *et al.* 2005). In addition, oral health care services should be appropriate to patients needs and optimised to serve those who are in greatest need. On the other hand, improving access would not diminish the use of *wasta* since it is deeply rooted in Saudi and Arabs' societies.

However, some Saudis use other ways to access oral health care services using their social networks. In terms of access to oral health care, it is acceptable for both patients and practitioners because this is about cultural mores. The use of *wasta* or social networks/ favouritism exists in Saudi society and although it may make access to many health care services easier for some people, in my study, I can suggest that people using their social networks in this way creates inequalities in oral health care for others.

***Chapter 8:
Discussion,
Recommendations
and Conclusion***

8.1. Overview

This thesis explored parent's experience of accessing oral health care services for children with disabilities in Al-Madinah. It adds to the current evidence base because it includes the voices of fathers, it focuses on parent's experiences in Saudi Arabia and in exploring access to oral health care services from different perspectives, it offers a wider understanding about how oral health services operate for children with disabilities in the Kingdom of Saudi Arabia. The thesis highlights different barriers to accessing oral health care and suggests ways of overcoming these barriers whilst taking into account the cultural context in Saudi Arabia.

Chapters 6 and 7 explored different perspectives (including parents of children with disabilities, dental professionals and dental students) around the process of accessing oral health care services for children with disabilities within the Saudi cultural settings. These different perspectives implied that access in Saudi Arabia operates in a slightly different way to western countries. For example, Saudi culture can influence the process of access whether accelerating the process (such as wasta and the referral system) or inhibiting the process and sometimes acting as a barrier (with issues such as reduced parental oral health literacy). In addition, there were other similar barriers to those were described in literatures in western countries (such as affordability, availability of dental professionals and availability of dental appointment) but there were dimensions of associated issues which belonged specifically to the Kingdom.

This chapter summarises the main results of the study. It ends with conclusions and some recommendations for policies and future research areas, which have been drawn from the findings.

Before discussing the main results of this study, it is worth noting that access to oral health care services for children with disabilities is influenced by a variety of factors that can be divided into two main domains: barriers and facilitators. The barriers encountered are divided further into service-related

barriers and socially related barriers. Socially related barriers include parental related barriers, the attitude of oral health care providers and receptionists' attitude.

Facilitators of access to oral health services for children with disabilities include the use of the referral system (service-related facilitator) and the use of wasta (socially related facilitator). These barriers and facilitators are reproduced in diagrammatic form illustrated in figure (17).

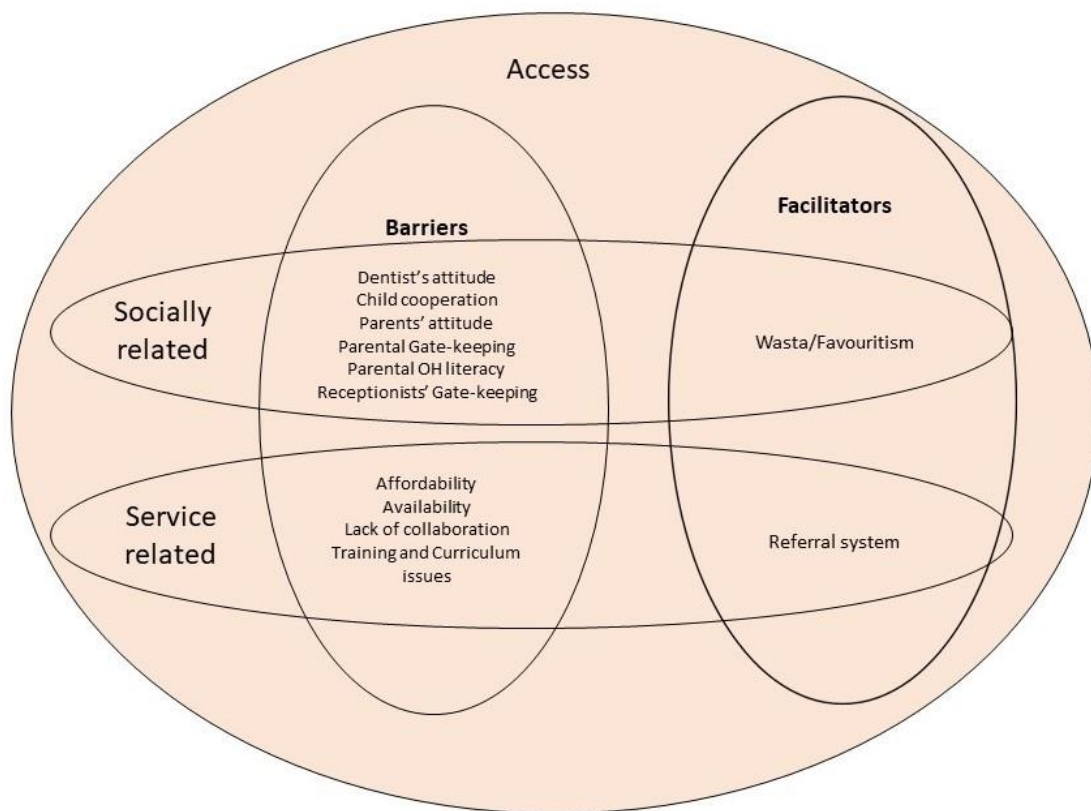


Figure (17). Access' barriers and facilitators

Barriers hinder the process of access to oral health care services for children with disabilities, whereas facilitators overcome those barriers and accelerate the process of access. The experienced barriers and facilitators were obtained from the different experiences of people with different perspectives, which are; parent of children with disabilities, dental professionals and dental students. The original aim of the study was to explore the journey of accessing oral health care services from different perspectives through observing the process

of access within the natural dental setting in Saudi Arabia to provide a deeper and more rounded understanding of the circumstances and events that affected access to oral health care services.

On the other hand, doing a qualitative research in Saudi Arabia is not an easy task because of the many cultural barriers, for example gender segregation and the conservative structure of the society. Additionally, discussing sensitive topics such as disability can pose another obstacle to qualitative research when interviewing participants. For example, during my data collection I was challenged by the low response rate of parents who were unwilling to participate and to be interviewed. Therefore, I used an alternative way to approach parents, which was using telephone interviews. Using telephone to interview participants is considered a valid approach to collect data because in Saudi Arabia disability is a sensitive topic and the participants were also hard to reach (see section 4.5.).

The next section (8.2) proceeds with further discussion around the main findings of this study starting with examining the barriers then the facilitators. It concludes with recommendations for future directions of research and for the Ministry of Health in Saudi Arabia.

8.2. Barriers

This study highlighted that service related and socially related barriers influenced access to oral health. I will begin with socially related barriers and discuss them in more depth.

8.2.1. Socially related

Socially related barriers evidenced within this study were divided into perceptions of parents and oral health literacy. I will begin with parental perceptions and illustrate the link to oral health literacy.

8.2.1.1. Parental Perceptions

One of the key elements that have an impact on whether parents take their child to the dental clinic is parental perception. My study explored access from the perspectives of parents, qualified dental professionals, student dentists and ancillary staff. I will begin with the perspectives of parents of children with disabilities. The interviews with parents of children with disabilities revealed that parental perceptions about dental professionals and dental services could exert a direct impact on attending oral health care services (see section 7.4.1.1.). Negative perceptions have been documented in other papers and represented as a psychological barrier towards utilizing oral health care services (Kelly *et al.* 2005; Resch *et al.* 2010). These negative parental perceptions appear to arise for many reasons. The reasons that emerged during the parental interviews were also present in the focus group discussions with dental students. These included the preconceived and ingrained negative attitudes of the dental professionals towards children with disabilities, the lack of education and training about disability and hands-on experience leading to limited or unskilled dental professionals and limited knowledge. During the focus group discussion, one of the participants pointed out to the reluctant attitude of some dental professionals to accept patient with disabilities. This finding is supported by existing evidence, which pointed out that being reluctant can be due to the dentist feeling uncertain or having limited skills to treat children with disabilities, especially when treating children who exhibit uncooperative behaviour (Stiefel 2002; De Jongh *et al.* 2008). Focusing on child cooperation and disability in this way is the medical model of disability, which sees disability as a barrier and something within the child; so the child is immediately a 'problem'. This perception may result from the dental professionals' limited knowledge and lack of skills to treat children with disabilities, which is one of the findings of this study and is supported by other research in Saudi Arabia (Al-Abulwahab and Al-Gain 2003; Waldman *et al.* 2010).

If we apply another perspective, we can suggest that dental professionals are the ones who need to acquire communication skills and more knowledge to

treat children with disabilities (Shanmugam *et al.* 2014). For example, children both with and without disabilities may not be able to explain their toothache and pain because they may lack the requisite communication skills. Therefore, a required skill on the part of oral health care professionals in order to provide effective oral care should be advanced communication skills. Without advanced communication skills, dental professionals may not notice the presence of toothache until there are behavioural changes, which may then link to oral health problems (Shanmugam *et al.* 2014).

Receptionists' perceptions about disability and about children with disabilities may influence how they deal with them and could be considered an essential part of access to oral health care services because they are in the role of gatekeepers to care. Other research suggests that they sometimes have the ability to decide whether the patient is treated describing them as the '*dragon behind the desk*' (Hammond *et al.* 2013, p.183) and replicated in this study on section (6.3.1.3.). This indicates that more training is needed not only for dentists and dental care professionals but also for ancillary staff and indeed the whole dental team in order to increase knowledge and awareness about disability. This aims towards reducing inequalities for children with disabilities and thereby increasing more effective access to oral health care services.

8.2.1.2. Oral health literacy

This study presented limited and poor parental oral health literacy for some parents, which has been supported by previous papers (Al-Agili *et al.* 2005; Oredugba, 2007; Chhabra and Chhabra, 2012). Furthermore, the findings of this study suggest that some parents have low levels of oral health awareness and need more information about the mouth and teeth of their children in order to increase their awareness about the importance of daily oral care. Other studies argue that parents need to be educated about the importance of visiting the dental clinics for routine check-up especially for children with disabilities since they have higher unmet oral needs compared to their peers (Stella *et al.* 2002; Lai *et al.* 2011).

The findings of this study suggest that parental oral health literacy plays a major role in accessing oral health care services for treatment and routine check-ups, since parents act as gate-keepers. In addition, parental oral health literacy may be said to exert an impact on visiting dental clinics especially for routine check-ups because in this study, some parents ignored visiting the dental clinic when the pain subsided. Shin *et al.* (2014) have supported this finding since the author suggested that one of the reasons for low utilization of dental services and dental anxiety are the poor oral health literacy among parents. In other studies, parental oral health literacy appeared to correlate with the presence of high dental disease among their children due to poor access to oral health care services and deleterious oral health behaviours (Vann *et al.* 2010; Khodadadi *et al.* 2016). Saudi Arabia has a decayed, missing, filled teeth (dmft) rate of 7.34 for children aged 3-7 years and a DMFT of 7.35 for children/adolescents aged 12-19 years (Al Ansari 2014). From this data, it could be inferred that because of poor access to oral health care services this may be the same for children with disabilities.

8.2.2. Service-related barriers

Using Penchansky and Thomas' model of access to analyse the findings helped to identify subthemes. Using their framework of access around quality care enabled examination of different perspectives around service delivery. Service-related barriers included training and curriculum issues, availability, affordability and the lack of collaboration. This section proceeds to explain these issues in more depth.

The findings of this study suggest that dental professionals lack or have limited skills to enable them to treat children with disabilities. Dental students felt that their limited amount of knowledge and contact with children with disabilities had a direct impact on their dental skills and ability to provide treatment for the children. Research in Saudi Arabia in 2010 conducted a telephone interviews with heads of Paediatric dental division of three federal and two private dental schools in Saudi Arabia (Waldman *et al.* 2010). The participants reported that only the postgraduate paediatric residents were exposed to treating children

with disabilities, and they had one or two lectures about treating children with disabilities as part of the medically compromised patients. On the other hand, the undergraduate dental students had no exposure to treating children with disabilities and there were no lectures about treating children with disabilities. This study was nine years ago and my study suggests that there has been limited improvement in the area. Undergraduate dental students still feel they need more practical information around patient management, communication skills and exposure to treating children with disabilities (see section 6.3.2.4.). Some authors suggested that limited teaching for the undergraduate dental students about managing and treating children with disabilities could be due to the shortage in teaching staff and their experiences (Fenton *et al.* 2003; Al-Hadlaq 2008).

Research suggests that most people with disabilities who have special needs can be treated in the general oral health care services (Faulks *et al.* 2012). For example, in the UK, based on the estimates of Joint Advisory Committee for Special Care Dentistry (2003) and Gallagher and Fiske's (2007) research, 9 out of 10 of people with special needs could be treated by general dentists. Therefore, it would appear important to educate and expose undergraduate dentists routinely to children and people with disabilities and focus on management and treatment. The lack of clinical exposure could represent a major barrier to treating children with disabilities because studies report that dentists who have less knowledge and insufficient experience are less likely to treat children and people with disabilities (Smith *et al.* 2006; Rapalo *et al.* 2010; Ahmad *et al.* 2015). Other studies suggest that dentist's lack of knowledge around diversity improved via exposure and this may be one way of reducing oral health inequalities for children with disabilities (Casamassimo *et al.* 2004; Faulks *et al.* 2012). Another example around teaching undergraduate dental students about children and patients with disabilities. It has been reported in the US Commission on Dental Accreditation (2016), which stated that "*Graduates must Be competent to assessing the treatment needs of patients with special needs*" (p.31). In contrast, another study in Saudi Arabia (Alamoudi *et al.* 2017) reported that Saudi dental students have insufficient knowledge and exposure in treating children with disabilities. Alamoudi and

colleagues' study was a cross-sectional study, which used questionnaires to investigate the level of satisfaction among dental practitioners about knowledge along with the level of preparation in their dental education to enable them to treat children with special needs. Two hundred questionnaires were sent out and the study got 108 answered questionnaires with response rate of 54%. The study found that oral health care professionals have low confidence in treating children and patient with special health care needs. In addition, the study suggested a relationship between the quality of dental education received and the dentists' perception of their patient care. However, dental care professionals were willing to attain educational activities to enhance their knowledge and skills. The study concluded that extensive efforts should focus on re-assessing the dental curriculum to include transferable core skills to be adopted through the entire dental curriculum and encourage patient-centred teaching methods.

The presence of dental professionals with insufficient skills and knowledge could ultimately influence the availability of dental professionals who have the ability, skills and knowledge to treat children with disabilities. The lack of knowledge and skills may also influence the willingness of dental professionals to treat children with disabilities and this may further affect the availability of dental appointments and dental professionals. This view has been supported by other evidence (Ahmad *et al.* 2014; Gerreth and Borysewicz-Lewicka 2016; Adyanthaya *et al.* 2017). One particular study in India (Adyanthaya *et al.* 2017) constructed a questionnaire, which was distributed to oral health care providers in Kerala in India. The authors selected 149 oral health care providers randomly and asked them to complete the questionnaire. There was a response rate of 132 answered questionnaires, of which 100 were answered completely and considered valid. The study reported that 57 oral health care professionals perceived their training and knowledge as a major barrier to treating children with disabilities. Therefore, the oral health care professionals were not confident and reluctant to establish any treatment for children with disabilities. In addition, the study reported shortage in amenities and equipment; this meant that availability was also barrier to access oral health care services. About 86 oral health care providers reported the lack of

specialised equipment and materials to treat children with disabilities in Adyanthaya and colleagues' study, which supports the findings of this thesis.

The unavailability of specialised equipment and facilities represented availability as one of the barriers in treating children with disabilities in Al-Madinah, Saudi Arabia. Furthermore, the presence of only one operating room to use GA to treat children with disabilities directly affected the waiting times and increased them. The direct effect of limited facilities and amenities on access to health care services has been supported by other studies (Edward and Merry 2002; Adyanthaya *et al.* 2017; Alumran *et al.* 2018). In addition, Drainoni *et al.* (2006) reported that some parents of children with disabilities find it difficult to find a dentist willing to treat their children and in some cases, the appointment would be anything from 3 months to a year. This indicates that long waiting times for dental care are also the product of a limited number of dental professionals willing and able to treat children with disabilities. The findings of this study indicated that some parents had to travel to other cities in Saudi Arabia such as Riyadh to obtain sooner appointment for their children so they could receive oral care. This may actually widen inequalities because only parents who could afford to travel and stay in Riyadh or other neighbouring cities could access this care. Another way inequality could increase was parents who may seek private dental care for their children in order to obtain care. This increases inequalities because only those who could afford this option could access private dental care.

The high price of treatment for oral health care services has been reported by most of the parents in this study as have reported by other literature, although not for services for disabled children directly (Schultz *et al.* 2001; Edelstein *et al.* 2009; Wallace and MacEntee 2012; Alumran *et al.* 2018). The perceived high costs of dental treatment acted as a barrier to accessing oral health care services for parents of children with disabilities and increased inequalities between those who could afford treatment and those who could not. Some dental professionals appeared to apportion blame to parents who said they could not afford treatment by suggesting that this was the result of low priority and the low level of oral health importance among parents (Wallace and

MacEntee 2012). If a child is disabled, this is not the fault of parents and to apportion blame by claiming their priorities towards oral health are low is perhaps not productive and more equitable suggestions may have been more effective.

My study identified that there was limited collaboration between different sectors, for example hospitals and health care professionals. This hindered the process of access to oral health care services for children with disabilities and led to a lack of continuity of care because of the lack of collaboration at these different levels. For example, the first level is the lack of collaboration between health care providers and the second level is the lack of collaboration between different sectors. These two levels represent two domains of continuity of care as I discussed previously in section (1.8, p.41-44). Continuity of care is essential for children with disabilities in order for services to provide good access and high quality of dental care. Another reason for the lack of continuity of care for children with disabilities is the absence of clear policy and guidance. The unclear mechanisms for coordination between various sectors and health care professionals may be said to be directly related and this includes academic institutions. The lack of collaboration between different health care providers in the general medical literature has been emphasised in the evidence base, but this is the first time it has been illustrated in the dental literature (Barnett *et al.* 2016; Smith and Murray-Thomson 2016; Harnagea *et al.* 2017).

All of the previously mentioned service-related barriers (training and curriculum issues, availability of appointment and resources, inability to afford dental treatment and the lack of collaboration) may be said to exert a negative influence on the quality of care provided for children with disabilities. Drawing on Maxwell's model of quality of care (Maxwell 1992) and its dimensions on section (1.6.), access and equity are ultimately affected by service related barriers found in this study. This may lead to the presence of low quality of care provided for children with disabilities and creates inequalities in their oral health status. The limited number of dental professionals, who are able to treat children with disabilities and lack of collaboration between different

governmental sectors, also has a negative impact on the oral health status of this group. All of these factors contribute towards increasing the inequalities for an already marginalised group.

8.3. Facilitators

This study found that there were two main facilitators involved in accessing oral health care services. These are wasta and referral system. The next section will begin with discussing wasta in more depth and then move on to the referral system.

8.3.1. Wasta

One of the major findings of my study is the act of wasta, which acts as a facilitator for accessing oral health care services for children with disabilities. Wasta is a type of relationship and favour exchange behaviour that used often in Arabian and Middle Eastern countries and communities to get things done (Branine and Bolard 2010). The term “wasta” literally means the middle. It is originated from the Arabic word “waseet”, which means the middleman and the intermediary who intercedes and mediates between two parties (Al-Ramahi 2008; Barnett *et al.* 2013). Wasta has been used in different cultures in various countries via different names such as: “blat” in Russian, “guanxi” in China and “wasta” in Arabic (Al-Ramahi 2008). Wasta has been known as a form of connections, network, contact and nepotism (Hutchings and Weir 2006). This indicates that it can be viewed positively or negatively. Harbi *et al.* (2017) pointed out that wasta can be considered as a form of personal connections that is considered as an integral part of the Arabic societies. Branine and Pollard (2010) used the term “*get things done*” (p.3) to express how wasta works and when it can be useful. It is considered as a tool used to reach certain goals or to speed up certain process (Kropf and Newbury-Smith 2016).

In the Arab culture, *wasta* is a significant power that is central to informational transmission, decision-making and the creation of opportunity (Hutchings and Weir 2006). Furthermore, it is not limited to certain parts of human interactions, as it can be seen in government, academia, other jobs and health sectors. For example, Ezzedein and Sweircz (2001) examined the process of recruitment in one of the largest telecommunication providers in Lebanon. They did a systematic research process where they retrieved the documents and records of the company, distributed an anonymous questionnaire to the employee and interviewed officials. They found that (65%) of the employees (that is 135 out of 225 employee), were hired using *wasta* as a form of personal connections.

Wasta is deeply rooted in the Middle Eastern societies and it has been noted by Spengler (1964) that *wasta* goes back to the 14th century where Ibn Khaldun highlighted the importance of having relationship with the ruler in determining one's profit. In addition, it is considered as a source of prestige especially for the 'waseet' (the middleman) (Barnett *et al.* 2013). In the Middle Eastern countries, *wasta* has been practiced openly and without shame and not seen as a form of corruption, while practicing nepotism and bribery can be taken very seriously and subjected to criminal penalties (Barnett *et al.* 2013). *Wasta* in contrast is considered a vital means of securing many different needs through granting requests and demands (Cunningham and Sarayah 1993). In addition, direct reciprocity is not a requirement for *wasta*. Instead, reciprocity is seen as a form of obligation to assist and returning the favour to the *waseet* himself. So, *wasta* can be portrayed as acting as the hidden hand or force behind society (Cunningham and Sarayah 1993).

Wasta has been highlighted among various disciplines such as: economy (Hutchings and Weir 2006), sociology (Kropf and Newbury-Smith 2016) and political science (Barnett *et al.* 2013), and among Arabic countries such as: Jordan (Al-Ra,ahi 2008), Kuwait (Shah 1996) and Saudi Arabia (Harbi *et al.* 2017), but among general and oral health literatures it has been scarcely documented.

The use of favouritism and social networks has been documented in other countries such as: Bangladesh, South Africa, Burkina Faso and Ghana. For

example, a study done in Burkina Faso by Varenne *et al.* (2006) examined the utilization behaviour of adults using oral health care services. Interviews, using a structured questionnaire, were used to collect the data from participants aged 15 years and older within Ouagadougou, the capital city of Burkina Faso. A total of 3030 participants participated with a 65% response rate. The study showed that 28% of participants used oral health care services while 48% used self-medications and 24% had no treatment. Multivariate analysis revealed that adults who had dental problems and socio-cultural factors had significantly used oral health care services. These factors include: the use of active social networks where active social networks consist of advising about or facilitating access to a certain oral health care provider, but not actually gaining access directly.

From the broad and neutral social capital's definitions in section (1.3.), we can infer that social capital is considered as assets for the society and individual, but it can be used in a positive or negative way. Additionally, social network is considered as the basis of social capital, within these concepts, *wasta* can be included as a form of social network (Kropf and Newbury-Smith 2016). This suggests that social network or *wasta* can act as factors contributing to the presence or the increasing of the inequality among societies since although it can be a facilitator it also has negative impact.

In terms of access, participants discussed *wasta* and I observed it being used to gain entry to oral health services through speedy appointments and in the process obtaining oral health care from suitably qualified and experienced practitioners. *Wasta* creates a smooth pathway that mitigates or reduces barriers. *Wasta* is deeply rooted among Arab communities and it has previously been viewed as having both negative and positive impacts on society (Kropf and Newbury-Smith 2016). This is because it can create inequalities and relies on the strength of social networks and ties for each individual. It is worth noting that although *wasta* been highlighted in Middle Eastern and Arabian economic, industrial and psychosocial science literature (Ezzedeen and Sweircz 2001; Al-Ramahi 2008; Al-Harbi *et al.* 2017; Alwerthan

et al. 2018), it has rarely been addressed among the general and not at all in the dental health care literature.

In terms of access to oral health care services, when we examine *wasta* from health care professional perspectives we can interpret it as the act of offering preference to some patients over others due to the nature of their relationships and social networks. The act of preferring or prioritising some patients over other patients can raise the question of morality, impartiality and equity (Nortvedt *et al.* 2011). Having special circumstances or medical conditions may justify prioritising some patients over another especially if they possess a life-threatening condition. In this situation, morality would take precedence because it could be considered immoral to make a patient with a higher level of need wait for a longer period. In contrast, having a personal relationship and connectedness without having a higher level of need and using that relationship for personal gain does not exhibit the same level of moral relevance because this may affect other patients if an individual 'jumps the queue' (Kropf and Newbury-Smith 2016). The effects on other patients' dental appointments and treatment can range from delaying other patients' appointments to shortening the time slots needed for their treatment and/or the re-arranging of appointments to another day, as this study identifies in section (7.5.). Using *wasta* to obtain an appointment ahead of other patients and jumping queues may also undermine the integrity of the oral health care providers, especially if the patient's circumstances are neither critical nor urgent.

Wasta has deep roots and is considered to be part of Arab and Middle Eastern culture; because it is a part of everyday life it is also viewed as socially acceptable (Al-Ramahi 2008; Alwerthan *et al.* 2018). *Wasta* is a part of Saudi culture and acceptable to both patients and practitioners, it is therefore difficult to eliminate because in doing so a whole culture that is thousands of years old would have to be changed. In this study, the differences between fathers with *wasta* and other fathers without *wasta* to access oral health care services created inequality. This inequality tends to persist until it becomes possible to eliminate the various barriers (e.g., high cost of treatment and the availability

of dental specialists) and establishing clear guidelines and referral pathways to follow when parents of children with disabilities attempt to access oral health care services.

Establishing smooth access for parents of children with disabilities to oral health care services would reduce some of the inequalities because the need for *wasta* and social networks to gain access would be limited, but not diminished because people would still use *wasta* as part of their culture.

8.3.2. Referral system

In section (6.4.), I identified that the oral health care referral system operated differently in practice compared to policy described by the Saudi Ministry of Health in section (2.4.). This study also identified that the referral system is available and free for Saudis, but not non-Saudi nationals, even if the children are disabled. For non-Saudi nationals, oral care and treatment is not free unless the patient was registered with the rehabilitative centre, but further barriers appear because registration follows a complex process and restricted guidelines.

However, establishing clear guidelines for the referral pathway could be an effective way to facilitate this process. One way to step forward with referral process is to refer children with disabilities to be treated using different forms of sedation such as GA, Nitrous Oxide (N₂O) sedation and diazepam. In addition, ensuring all future dentists treat children with disabilities especially if they only have mild dental disease and there was no need for dental specialists via changing the undergraduate curriculum. This is where more effort with oral health promotion could prove beneficial. Changing the undergraduate curriculum for dental students to include teaching students how to manage and treat children with disabilities would potentially increase the number of oral health care providers. The use of education about disability using the social model of disability and focusing on disabling attitudes may assist in shifting negative perceptions, moving them towards the positive concerning children with disabilities. Increasing the numbers of dental professionals to treat

children with disabilities may further enhance the process of referral because it could reduce the need for referral to specialist dentists for all but the most challenging of cases, thereby increasing the number of dentists who are able to treat children with disabilities.

8.4. Access to oral health care services for children with disabilities

From this study, it appears that access to oral health care in Saudi Arabia works in a slightly different way to western countries. In addition, there are some barriers and facilitators that has been highlighted in this research that operate in a different manner than those previously highlighted in literature of western countries such as: referral pathways, parental gate-keeping and pharmaceutical services. What becomes of importance here is that access to oral health care in Saudi Arabia operates in a manner that is defined by cultural norms and expectations.

One example of parental gate-keeping and its cultural relevance is that males were the only ones who were able to drive until recently and women can still only drive with the consent of their guardians. This has an impact on accessibility in terms of physical reaching the dental clinics. Often women use other forms of transportation or drivers with the consent of their male guardian. Even if a mother can now drive, because healthcare services are segregated, she will still be unable to gain access to male only clinics. So, removing one barrier to access does not automatically remove the other barriers forming part of the construction of Saudi society.

In section (1.7.) I discussed various models of access, these all appeared to focus on appeared to be applied a western-centric model of care for western countries and their health and oral health services. Although the health care system of Saudi Arabia is similar in some ways to western countries, there are profound differences such as cultural norms in the shape of *wasta* that modify access to oral health care services in Saudi Arabia. The structure of the services also differs, and this has an impact on access to oral health care.

Another issue that influences access in terms of availability of dentists and their perceptions of and attitudes toward treating children with disabilities, is Saudi dental education, both in terms of teaching and the structure of the undergraduate, this has been supported by studies in other countries (Dao *et al.* 2005; Waldman *et al.* 2010). These studies suggest that attitudes and perceptions of dental students can be enhanced positively via interactive clinical teaching methods, exposure to children with disabilities and lectures about disability that have a social model of disability focus. In addition, including patient management as part of the curriculum with practical tips could assist in developing confidence in dental students to treat disabled children. This suggestion emerged from the focus groups with dental students in section (6.3.2.4.) when they asked for teaching in how to manage the patient rather than teaching them how to manage the tooth. Other studies emphasise direct contact through the clinical teaching to show how to manage and treat children with disabilities instead of only using lectures without actual and direct contact (Al-Abdulwahab and Al-Gain 2003).

This study identifies that a lack of basic knowledge among the undergraduate dental students about children with disabilities and knowledge around patient management leads to fear and uncertainty. Previous studies suggest that this also leads to developing unfavourable attitudes and reduces confidence when treating children with disabilities (Waldman and Perlman 2002). Availability of care and the acceptability of health care professionals, because of the perceptions they have which influence their attitudes towards disability, are important since they have a direct impact on both access and the quality of oral care provided for children with disabilities.

8.5. Strengths of the study

Nature of the study

To date, there is no published qualitative work about access to oral health care services in Saudi Arabia, and more specifically for children with disabilities. In addition, there is a limited body of work exploring barriers to access, which

directly refers to and includes parental perceptions, particularly those of fathers. This study adds to the oral health evidence because firstly it includes the voices of fathers, secondly, it unpicks access to oral health care services in the Kingdom of Saudi Arabia and thirdly it demonstrates barriers to access from different perspectives.

Saudis in general are conservative as a society and the privacy of the family is of importance and fiercely guarded. It was not an easy task to talk to parents and uncover the struggles that hindered access to oral health care services. In addition, disability is sensitive topic that needed to be handled carefully and sensitively, this was so I could gain a deeper understanding from the perspectives of parents during the interviews without causing offence and not appearing to overstep the boundaries of the privacy of families. Furthermore, because I am a male researcher, there are certain social rules I have to conform to in Saudi society when interacting with female participants, making it difficult to interview them, even with their male guardians. Therefore, I have a limited number of female participants, which could make this one of my study limitations. On the other hand, the voices of fathers are absent within the dental literature around access, which makes this work original and a strength of the study. More crucially, it represents hidden voices of Saudi and non-Saudi parents of children with disabilities who are living in Saudi Arabia.

My thesis offers unique insights into the experiences of Saudi fathers' in Madinah and their access to oral health care for children with disabilities.

Methodological approach

Ethnography was the methodological approach and used three different research tools; observation of the dental settings, telephone and face-to-face interviews and focus group discussions. Researchers argue that using multiple methods such as different sources: observations, interviews and focus groups helps to identify issues and understand circumstances, giving the researcher the opportunity to probe and ask questions to clarify and in doing so offer a depth of meaning that quantitative questionnaires fail to capture (Flick 1992). Fetterman (2010) used a holistic ethnographic approach, which describes

religion, politics, economy, environment, cultural and social structure and relationships. Using such method yields benefits when exploring people has lived experiences and their social and cultural backgrounds (Marschan-Piekkari and Welch 2011; Hammersley and Atkinson 2007). My ethnographic approach employs some of these observations when exploring parent's experiences of access to oral health care for children with disabilities.

Data triangulation is considered a major tool which enhances the veracity and genuineness of qualitative research. The use of triangulation with multiple sources is described in section (4.7.). This study employed extensive field notes to enhance descriptions of the cultural surroundings alongside the environment where observations were conducted. Using triangulation of interviews with focus group discussions and field notes from my observation, alongside reflexivity were an attempt to overcome researcher bias (Jakob 2001), and to increase the credibility of the study findings (Patton 1999).

Reflexivity is an important tool within qualitative research (Denzin 1997). This is because it aids with the transparency of the study by revealing any inherent biases on the part of the researcher. As a Saudi male researcher, I was acutely aware of the position of women in Saudi society, but as a dentist, I was also dismayed and felt frustrated with some of the parent's responses. For example, a father preferring a general anaesthetic to save time rather than allowing the dentist to work on reducing the child's anxiety concerning visiting the dentist.

This study is a qualitative and as such cannot generalise the results to other settings, but it can use theoretical generalisability from the findings (Marchman and Rossman 2014). Theoretical generalisation was achieved in this study through a thick and rich description of the environment, participants and their experiences of access to oral health services. Theoretical generalisation is a form of generalisation and it is known as the applicability of the theory generated from research to other groups of similar populations under investigation (Polt and Hungler 1991).

8.6. Limitations of the study

This current study exhibited some limitations, similar to any other study. The limitations are related to the methods employed in terms of using Penchansky and Thomas model of access, recruiting participants and data translation.

Penchansky and Thomas framework of access

Although Penchansky and Thomas' framework of access is used to inform policy makers, it is interconnected and can be misleading and not always applied as it was originally conceptualized (Saurman 2016). Furthermore, making decisions regarding policies based on subjective responses of participants in isolation may be considered unreliable because the response of people is going to be different partially depending on time of the day, their experiences over time and other extrinsic factors (Karikari-Martin 2010). A sixth dimension has also been proposed by Saurman (2016), that is one of awareness because services cannot be effective if they do not '*respond to context or if the intended population does not know it exists*' (p. 38).

Participant recruitment

Due to the cultural barriers in Saudi society, regarding gender segregation and the difficulty in interviewing females, my sample was dominated by males. Although some parental interviews were via telephone, women were either not allowed or preferred not to be interviewed by a man, even on a telephone. This again is cultural because women are the guardians of family honour and doing anything that may be viewed as spoiling that honour marks the whole family. Therefore, most of the recruited participants were males (5 females and 33 males) (see section 4.2.).

The low number of female participants will ultimately limit my insights concerning the barriers and obstacles facing parents in accessing oral health care services for their children, because the mothers constitute a significant part of the family. Additionally, the low response rate and the difficulties that I

had while recruiting participants (see sections 3.6, 4.4, 4.5. and 4.6.) led to my sample being dominated by fathers.

Limitations of method

One of the limitations of this study was that the interviews and the focus group discussions were conducted in Arabic. While translating the data from Arabic to English, I used forward translation, backward translation then compared it to the source to make sure of my translation process to ensure it was as faithful to the original meaning as possible (Maneesriwongul and Dixon 2004; Regmi *et al.* 2010). However, losing or altering some words or meaning of the words in translation did happen to some degree (Emmel 1998) as I highlighted in section (4.10).

Another limitation present within my study is the use of vignettes during the analysis to explain and emphasize on the impact of using *wasta* on access and other patients' appointments (see section 7.5). The main limitation of using vignettes during analysis is the artificiality since vignettes cannot replicate the complexity of the social world, although other researchers would argue that there is no one specific method whereby we can fully capture the complexity of the social world (Barter and Renold 1999). Whereas Corkery (1992), argues that vignettes are able to provide a chance to isolate specific aspects of social issues while assessing and managing the complexity of daily life interactions.

8.7. Study implications

This study represented access to oral health care services for children with disabilities as experienced by parents of children with disabilities. It also included different perspectives, which triangulated with one another to create a rich and varied account (parents, dental professionals and dental students). The study highlighted various factors that acted as barriers or facilitators to hinder or ease the process of access. It appeared that access in Saudi Arabia operates in a slightly different manner than previously examined in Western countries. Some of these factors are related to social and cultural values such

as waste. However, achieving smooth and clear access for children with disabilities is desirable and essential, since their oral needs are higher than their peers as discussed in sections (1.4, 1.5. and 2.7.), and smooth and equitable access to oral health care decreases inequality.

Therefore, tackling those barriers and facilitators may be one way to achieve and reduce the inequalities in oral health status between children with disabilities and their non-disabled peers. In addition, improving oral health status through providing dental treatment for all children with disabilities is an important political and health related issue. This means that regardless of their nationality, severity of disability, gender and age all children should have equitable access to oral health care in Saudi Arabia. The next part of the thesis will introduce some recommendations for policies and future research to improve access to oral health care services for children with disabilities.

8.8. Recommendations for policy

This section includes recommendations in the following areas: oral health inequality, referral process, undergraduate curriculum and teaching methods and raising parental awareness about the importance of oral health for their children with disabilities.

8.8.1. Oral health inequality

The findings of this thesis revealed some variables that contribute to the presence of oral health inequalities among children with disabilities. The findings add to the oral health knowledge base, specifically within the context of Saudi Arabia.

The fees that are paid by non-Saudi nationals for oral health care services act as a barrier to utilization (see section 6.4.2.). Elimination of fees based on nationality, especially for oral health services provided for children with disabilities, may have a positive impact on creating access that is more equitable for children with disabilities and contributing towards reducing oral

health inequalities among various groups within and between the disabled child and adult population in Saudi Arabia.

This thesis focuses on Al-Madinah as a case study and suggests that the Inverse Care Law, as proposed by Julian Tudor Hart (1971), appears to apply to oral health service provision for disabled children (see section 6.3.2.). This means that people most in need of oral health services (disabled children from poorer families) were least likely to access services and experienced more barriers to access. An overview of current service provision within the Kingdom as a whole could assist in providing a more equitable distribution of oral health resources and in providing oral health care services that are more equitable across all cities of Saudi Arabia.

One unique section of this thesis revolved around an area of oral health that has not previously been mentioned and that is the concept of *wasta*. Using *wasta* has been highlighted as a mean of accessing oral health care services for children with disabilities in chapter (7). *Wasta* can contribute to increasing the presence of inequality of access to services for parents of children with disabilities. Eliminating *wasta* is difficult to implement because it is a part of the Saudi culture, being aware of the potential of *wasta* to create oral health inequalities should be considered as part of teaching the undergraduate dental curriculum. It could be that establishing a smoother and more equitable process for accessing oral health care services for parents of children with disabilities may reduce the need for using *wasta* and by default reduce the ensuing inequalities. A recommendation here would be for the Ministry of Health to focus on constructing an equitable pathway of clear and effective access to oral health care services in an attempt to reduce oral health inequalities for children with disabilities, which may then persist across the lifecourse. This may further assist in reducing oral health inequalities between children with disabilities and their non-disabled peers.

8.8.2. Referral process

The findings of this study suggest that children with disabilities in Al-Madinah, Saudi Arabia, are usually referred for a general anaesthetic (GA) immediately. One option here may be to train dentists the appropriate patient behaviour management techniques and the use of sedation such as relative analgesia (Nitrous Oxide) and midazolam. This would provide more options for patients and reduce the tendency to refer to GA, leaving it an option for only the most severe of cases. It would also assist in reducing the long waiting lists for GA in-patient care for dental procedures.

Establishing clear guidelines and process for referring children with disabilities could help both parents of children with disabilities and oral health care providers to follow and implement a more seamless approach to access. For example, excluding nationality as a requirement for referring children with disabilities for dental treatment provision may have a positive impact on the overall oral health status of children with disabilities in Saudi Arabia. Faulks and colleagues suggest that many children with disabilities can be treated by general dental practitioners without the need for referral to specialist care (Faulks *et al.* 2012). This means that practitioners who have skills in behavioural management and who are able to use sedation techniques can actually assist in the referral process because only children who are unable to be treated by any other method will be referred, rather than receive an automatic referral because they have a disabled label.

8.8.3. Undergraduate dental curriculum and teaching methods

The lack of clinical experience and exposure to children with disabilities was apparent and students worried about this aspect of their training because they reported only having teaching and no hands-on experience concerning patient management (section 6.3.2.4.). Teaching undergraduate dental students about people and children with disabilities and enabling exposure to different contexts is highlighted as an important issue in the oral health evidence for a variety of reasons (Faulks *et al.* 2012). One reason is the presence of high oral

health needs among children with disabilities that their needs are said to be higher than their non-disabled peers (Lewis 2009). Another reason is that approximately 90% of people with disabilities requiring special dental care are unable to access general dental clinics and primary care settings, which contain suitably trained, qualified and experienced general dental practitioners and hygienists (Gallagher and Fiske 2007). This is apparent within my study, which focusses on children.

One more reason which emerged as one of the findings of this study is the presence of unfavourable attitudes of some of the dental practitioners and low levels of confidence of some of the dental students in treating children with disabilities. Therefore, to develop positive attitudes and increase the levels of confidence of the dental students, a change in the dental curriculum should be established as has been discussed previously. Increasing levels of confidence and developing positive attitudes towards disability among dental graduates could lead to an increase in the number of dentists that are both able and willing to treat children with disabilities. Increasing the number of oral health care professionals who are able and willing to treat children with disabilities may in turn enhance the availability of dentists, which could improve overall access to oral health care services for children with disabilities.

8.8.4. Raising parental awareness

Within this study, parents were sometimes themselves represented as a barrier to access (see section 7.4.1.). One example was given of a parent who refused to allow the dentist time to reduce anxiety in the child and instead demanded a GA for speed and convenience. This illustrated a lack of awareness about the dangers of GA for what is essentially a non-communicable disease. Lack of awareness itself may create inequalities and prioritizing children with disabilities, developing legislation or controls to prevent routine referral, increasing oral health promotion to reduce dental decay, improving accessibility of services for oral health promotion from birth and enabling community action around the area may assist in raising

awareness about children with disabilities, their oral health needs and the oral care services provided for them.

Within Saudi Arabia there could be some structural changes to the environment regarding education around food and a reduction of availability of foods with high sugar contents. Oral health care managers could also focus on raising parental awareness about the importance of the oral health and availability of services provided for children with disabilities. Informing the parents about the referral process and how it works is essentially important and central to making oral health care services more accessible. Heightened awareness about the different oral care services provided and the importance of oral health for children with disabilities among their parents may help maintain good oral health status for their children and reduce waiting time for unnecessary or inappropriate oral services. This in turn could free up resources, which could then be used to enhance utilization of needed services such as preventive oral care services.

8.9. Recommendations for future research

This study has identified areas for future exploration. A national survey is needed to estimate the number of adults and children with disabilities in Saudi Arabia. The survey also needs to be stratified by type of disability and severity in order to estimate the numbers of individuals in groups that could be classified as high risk. Furthermore, there is a need to estimate the prevalence and the incidence of the different types of oral disease among adults and children with disabilities. This would more accurately represent the oral health needs of children with disabilities in order to configure services and ensure they are appropriate and acceptable in relation to need. This could further assist commissioners of services in providing more effective oral health care services for adults and children with disabilities.

More research is also needed to highlight access to oral health care services in other cities in the Kingdom of Saudi Arabia from different perspectives in order to further understand the differences in access and whether one

configuration of service provision works better than another. This is because financial resources, workforce and the cultural environment differ from one city to another. For example, Al-Madinah differs from Jeddah or Riyadh, because it is far more conservative and possesses fewer resources. This creates structural inequity and adds to oral health and indeed general health inequalities.

Further studies are also needed which assess the quality of oral health provision for children with disabilities. This could entail regular audits to address appropriateness and acceptability of services provided.

Policy for oral health service provision guidance for adults and children with disabilities does not currently exist in a formal sense. The Ministry of Health in Saudi Arabia could implement and lead in constructing formal oral health policy, which may assist with developing more focused guidelines, which could then be used to guide, regulate and assess services.

Dental schools' curriculums could be reviewed, and clinical teaching around groups of adults and children with special needs could become more focused and of greater value. One area which could be improved is enabling dental undergraduates to gain more exposure to treating and interacting with children with disabilities. This may develop greater levels of confidence for the students alongside more awareness and insight around diversity within and between children with disabilities as a marginalised group. The outcomes could be a reduction in oral health inequalities because structural changes have been implemented.

8.10. Conclusion

This thesis examined the process of access to oral health care services for parents of children with disabilities, using Penchansky and Thomas's model of access as a lens to identify and gain deeper understanding. The model is an older model and although newer models have been constructed, none of them provides the level of clarity and focus derived from that of Penchansky and

Thomas. The research was an ethnographic case study, which took place within the natural dental setting in Al-Madinah, Saudi Arabia. The perspectives included those of parents, oral care professionals and dental students. One main objective was to critically explore different perspectives around the provision of oral health care services for children with disabilities. One other aim was to enable the voices of Saudi parents of children with disabilities to be heard in oral health research whilst, to exploring the various factors that influence the process and dimensions of access.

The observed dental clinics were public dental clinics and they were accessible in terms of the presence of lifts, parking spaces and ramps. However, the dental clinics could not accommodate the needs of children with disabilities because they were either were picked up and transferred to the dental chair or were treated on their wheelchair. In addition, there were a clear limitation of the resources and the workforce because there was only one GA operating room in Al-Madinah for one day per week available to treat both adults and children with disabilities. The length of waiting lists meant that parents of children with disabilities, who had resources, travelled to other cities to obtain oral health care for their child, which avoided the long waiting list for treatment under GA.

This thesis highlighted that the attitudes of some dental professionals and dental students towards treating children with disabilities were negative and associated with low level of confidence among dental students in treating children with disabilities. The negative attitude and the low level of confidence appeared to be the result of having little knowledge about children with disabilities, coupled with no hands-on clinical experience.

Furthermore, the research in this thesis highlighted the role of Saudi culture, specifically the role of *wasta*, which influenced access for children with disabilities. *Wasta* appeared to have a significant role in easing the process and experience of access for parents of children with disabilities, but there was also the potential for it to increase inequalities.

Overall, the findings of this thesis suggest that access to oral health care services for children with disabilities in Saudi Arabia exhibits some similarities but there are also differences to access compared to those described in the evidence base in western countries. Moreover, there was evidence of inequalities in terms of access to oral health services and oral health care. These inequalities were compounded by the lack of oral health policy and guidance for children with disabilities, the limited opportunities for the education of dental professionals around disability and oral health, cultural perspectives around oral health, the lack of equitable oral health service provision within the Saudi community and structural barriers for service commissioning in the Kingdom of Saudi Arabia.

Papers to be written from this thesis:

1. Marghalani, A., Deery, C. and Owens, J., Father's experiences of access to dental services in the Kingdom of Saudi Arabia for of children with disabilities. *International Dental Journal*
2. Marghalani, A., Deery, C. and Owens, J., Wasta, morality, impartiality and equity in dental care. *Community Dentistry and Oral Epidemiology*
3. Marghalani, A., Deery, C. and Owens, J., Pathways of access to OHC services for children with disabilities in the Kingdom of Saudi Arabia. *Internal Journal of Paediatric Dentistry.*

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Appendices

Appendix (1). Literature review.

Searching for relevant literature:

Before starting the search for the relevant literature, I initiated a book log to keep track of my search terms, books, journals, search engines and documents acquired. Then, I separated the relevant data sources into lists as follows:

Journals.

Computer data bases.

Search engines.

Books.

Governmental documents.

Dissertations and thesis.

Conferences.

Libraries that could be accessed.

Journals accessed

Saudi Medical Journal

Saudi Dental Journal

Journal of Taibah University Medical Science

European Journal of General Dentistry

Community Dental Health

Journal of Disability and Oral Health

Tropical Dental Journal

Journal of Humanities and Social Science

Eastern Mediterranean Health Journal

Journal of Dental Education

BioMed Central Oral Health

Journal of Nursing Scholarship

Journal of Applied Research in Intellectual Disabilities

Clinical Oral Investigations.

Special Care Dentistry Association and Wiley Periodicals Inc.

British Dental Journal

British Medical Journal

Health and Place Journal

Developmental Disability Research Reviews

Medical Care

I accessed these journals in a systematic manner using the library electronic journal service to look for articles that were relevant to access to oral health care services for children with disabilities. I scanned articles and identified which appeared to be useful then listed them with the journal reference. Articles that appeared to be important and could be used in my literature were downloaded and filed in terms of themes.

Computer databases

I accessed the following databases through the university library:

Web of Science (Web of Knowledge)

MEDLINE via OvidSP

MEDLINE via PubMed

I encountered a slight problem regarding the different terms that can be used in the numerous studies that referred to disability. Disability is considered to be an umbrella term and different terms have evolved over time, but they all refer to disability. For example, learning disability has evolved from idiocy or cretinism and has had many associated terms such as mental deficiency, mental retardation, mental sub-normality, developmentally delayed, intellectual difficulties, learning difficulty, educationally sub-normal and a host of other terms that refer to learning disability.

A preliminary search for “disability and oral health” using Web of Knowledge revealed “2909 hits”. Going and reading each hit would have been extremely time consuming, therefore I decided to link the term ‘disability’ with other search terms. Inclusion and exclusion criteria were established to narrow the searching process and to be more systematic, concise and focused. The

inclusion criteria were; articles published from 1960-2017; articles about oral health; articles about children; articles about mother's and father's experiences OR perceptions; articles about access. The term disability was expanded to include intellectual disability, learning disability and learning difficulties. The exclusion criteria included studies that were not in an English language and studies that were not about or related to the general and/or oral health.

The terms that I used to search for disability were:

Disabilit*	Impairment*	Mental retardation
Mentally retarded	Autism	Down syndrome
Cerebral palsy	Developmental delay	Intellectual difficult*
Intellectual disabilit*	Mental disabilit*	Cognitive
impairment*	Cognitive disability*	Special needs
Developmental disorder	Developmental difficult*	Hemiplegia
Developmental disability*	Special care needs	Blind*Physical
Handicap	Mentally handicapped	disabilit*
Quadriplegia	Hearing disability	Learning difficulty*
Learning disability*		

Search engines

It is known that Google Scholar is the easiest and fastest search engine in the World-Wide-Web. It provides a simple way to broadly search for the scholarly literature, because it provides a simple access to different sources: books, articles, abstracts and opinions from academic publishers, universities and other websites. It also provides a way to explore relevant authors, citations and publications. The terms used were: "Disability" and "access" and "oral health", the terms were joint with and/or and sometimes they were used alone. Each searching term when used, either used separately or were joint, there were over thousands of hits. I went through the first ten pages to look for relevant articles, books and studies. Some of those papers and books were useful and others were not relevant to my work.

Books

I read some books about people with disabilities because of previous research. In addition, my supervisor suggested some books to read and I got others that were most cited by authors from the University library.

I looked for books about different methodologies and accessed books about mixed methods, because I was intending to use mixed methodology but then after more reading and discussion with my supervisors and other staff members, I decided to use ethnography in isolation. I then accessed a range of books on qualitative methods, ethnography, and qualitative interviewing. I also read a variety of journals that focused on qualitative methodologies to expand my knowledge and thinking in the area.

Governmental documents

Governmental documents that were related to children with disabilities, health services and health systems were accessed from the UK and USA. The Ministry of Health of Saudi Arabia was accessed to retrieve any updated policies or documents regarding health system and health care services, which were readily available.

Dissertation and thesis:

Searching for other thesis and dissertations that were similar to my thesis was essential, because I wanted to see what had been done already and in which countries. This was done via the university libraries.

Libraries that could be accessed

The library and databases of the University of Sheffield were the most used ones because they are extensive, convenient and provide easy access to various journals, articles and theses. I also accessed Taibah University's libraries to get more information about the health system within Saudi Arabia and the health care services provided to gain more local and contextual knowledge.

Writing the literature review

The process of organizing, linking and analysing the search was a major task. At first, I read through articles and book chapters to look for gaps and issues that were not addressed in the literatures. This process increased my thought processes and expanded my knowledge about the issues facing people with disabilities and their families. I found the whole process extremely sobering, mainly because I am a father of a child and could identify with some of the challenges. I used the terms children and young adults to make my search more precise and focused. Identifying issues encountered by children with disabilities and their parents led me to search for ways of accessing oral health care services and I used the terms below and linked them with the previously used terms:

Access	Barriers	Perceptions
Experiences	Perspectives	

After that, I focused more on issues related to accessing oral health care services for children with disabilities and their parents. So, I used the terms below and link it to my search:

Oral health	Oral health care	Oral health care services
Dental health	Dental health care	Dental health care services
Oral	Dental	Dentistry

The challenges were in analysing the studies and weighing up the evidence and some papers were difficult to read because of their complexity. In addition, some papers were irrelevant to my area of interest. Constructing the literature review was a difficult task and I had to re-write it several times to get the structure, meaning and clarity. After the literature review, establishing contact and accessing the field was the next step to my thesis.

Appendix (2). Information sheet



The
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Participant Information Sheet

Access to oral health services for children with disabilities in the Kingdom of Saudi Arabia

We would like to invite you to take part in a research to develop our oral health services for children with disabilities. Before you decide to take part you need to understand why we are doing this research and what it would involve. Please take your time to read the following information carefully. Please feel free to ask questions if anything you read is not clear or would like more information. Take your time to decide whether or not to take part. Thank you for reading this.

What is the purpose of this research?

The purpose of this research is to explore the access to oral health services for children with disabilities. Oral health services provide oral care for all children in the society. Gaining an understanding about the different obstacles that are experienced by children with disabilities and their parents when accessing oral health care will help us to understand and try to overcome those obstacles. It may also help us provide more effective oral health care.

Why did we choose you?

We are asking different people to take part because they have knowledge of the ways that children with disabilities access oral health services. They are:

- Parents of children with disabilities.
- Dental professionals who are treating or have previously treated children with disabilities.
- Dental students of Dental School in Taibah University.

Do you have to take part?

It is up to you to decide whether or not to take part in this research. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can still withdraw at any time without giving any reasons.

What is going to happen?

If you decide to take part of this research, please read this information sheet and sign the attached consent form. I will contact you to arrange a meeting with you, where the interview will be recorded with small audio recording machine. This should take about an hour. After that, our conversation will be transcribed and uploaded onto a password-protected laptop; the interview will then be deleted, I will then analyze the conversation.

What are the possible risks for you?

There will be no risk for you because no one will know your name. The interview will be kept strictly confidential and you will not be identified in any reports or publications. Instead you will be given a false name and any identifiable details will be altered. If you do not wish to discuss something in particular, you can ask the interviewer not to talk about it and that would not affect you.

What are the possible benefits for you?

There are no immediate benefits for those who are taking part. However, the interview may help future generations and families who have children with disabilities.

What will happen if the research is stopped earlier than expected?

If the research is stopped for any reason, you will be contacted and asked what you wish to do with the recorded interview and the data.

What if something goes wrong?

We hope that there is no need to raise a complaint but if you needed to raise one, you can contact the following team members:

Name and details	Name and Details
<p>Dr. Janine Owens Lecturer in disability and health, Academic Unit in Dental Public Health School of Clinical Dentistry University of Sheffield 19 Claremont Crescent Sheffield, S10 2TA Telephone: +44 (0)1142717891 Email: jan.owens@sheffield.ac.uk</p>	<p>Professor Chris Deery Professor of Paediatric Dentistry Dean of School of Clinical Dentistry Editor-in-Chief International Journal of Paediatric Dentistry School of Clinical Dentsitry University of Sheffield 19 Claremont Crescent Sheffield, S10 2TA Telephone: +44(0)1142717803 Email: c.deery@sheffield.ac.uk</p>
<p>Dr. Ahmed Alnezawi Dean of School of Clinical Dentistry Assistant Professor of Prosthodontics Dentistry School of Clinical Dentistry Taibah University King Abdulaziz Road Almadinah Almonawara, Saudi Arabia Email: alnazzawi@gmail.com</p>	<p>Dr. Badr Othman Assistant Professor Chairman of Oral and Clinical Basic Sciences Department Chairman of Preventive Dental Sciences Department School of Clinical Dentistry Taibah University King Abdulaziz Road Almadinah Almonawara, Saudi Arabia Email: dr.badr.othman@gmail.com</p>

What is going to happen to the recorded conversation?

Our conversation is going to be analyzed and the issues that you raised will be used to highlight different obstacles and barriers. If you wish, once I have

transcribed the recording into writing I will delete the tape. Please let me know what you wish when we speak. In the future, I will be writing article and other researchers could find my work useful to answer future questions. I would like to ask you for your clear consent to share your transcribed and anonymised data in this way and will make sure that your data cannot be traced back to you.

Who is organizing and funding this study?

The study is organized under the supervision of the School of Dentistry academic members of the University of Sheffield at UK. The Saudi Cultural Bureau and Taibah University at Saudi Arabia are funding the study.

Who is ethically review the study?

The study has been ethically approved by the University of Sheffield ethics committee and the Taibah University ethics committee.

Who can I contact for further information?

In case you wish to obtain more information or have questions about the study. You can contact the following people:

Name and details	Name and details
<p>Dr. Ahmed Marghalani Teaching assistant of Dental Public Health School of Clinical Dentistry Taibah University King Abdulaziz Road Almadinah Almonawara, Saudi Arabia Saudi Mobile: +966 (0) 562341500 UK Mobile: +44(0) 7459622966 Email:</p>	<p>Dr. Janine Owens Lecturer in disability and health, Academic Unit of Dental Public Health School of Clinical Dentistry University of Sheffield 19 Claremont Crescent Sheffield, S10 2TA Telephone: +44 (0)1142717891 Email: jan.owens@sheffield.ac.uk</p>

amarghalani1@sheffield.ac.uk

Appendix (3). Consent form



The University
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Participant Consent Form

Title of Research Project: **Access to Oral Health Care Services for Children with Disabilities in Kingdom of Saudi Arabia.**

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understood the information sheet explaining the above research project and I was giving enough time to ask questions about the research.

2. I understand that my participation is completely voluntary and that I am free to withdraw at any time without giving any reason and there will be no negative consequences to me.

3. I understand that my interview will be kept anonymous and my participation will be kept strictly confidential. I give permission for the members of this research to access my anonymous interview.

4. I agree for my interview to be used in future research by keeping it anonymous.

5. I agree to take part in the above research project.

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

To be signed and dated in presence of the participant

Copies:

Once all parties have signed this, the participant should receive a copy of the signed and dated participant consent form, the letter of information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project folder, which is kept in the main office on oral health and development.

Appendix (4). Interview topic guide for parents



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Topic Guide for Parents

Introduction

I would like to thank you for participating in this research. My name is Ahmed Marghalani and I would like to talk to you about your son, his mouth health and your experience in treating his mouth and teeth. Particularly, one of the components of our project is that we will be assessing your experiences of getting dental treatment for your son.

The interview should take less than an hour. I will be taking some notes during this interview and audio-recording it.

All responses will be kept confidential and anonymous. This means that we will ensure that any information we include in our report does not identify you as the respondent. Please remember that you don't have to talk about anything that you don't want to and you have the right to end this interview at any time.

Questions

General questions:

1. Can you tell me about your child, disability etc.?
2. Where do you live?
3. Who is helping in raising and caring for the child?

Oral health question:

4. How do you see your child's mouth and teeth?
5. When was the last time your son visited a dentist? Why?
6. Where do you usually go for treating your child's teeth?

7. How did you find the dentist and dental clinics?

Attitude questions:

8. Was the dental team friendly while treating your child's teeth?

9. Did the dentist take the time to explain to you about your child's oral health and diseases?

10. Did the dentist explain to you how to care for your child's teeth?

Availability and accessibility questions:

11. How far is the dental clinic from your home?

12. Was it hard to find a dental appointment for your child? Explain please.

13. Did you find the dental clinic easy and prepared to treat your child's teeth?

Affordability questions:

14. Can you tell me if your child has insurance and what it includes?

15. Is the dental treatment expensive? Please explain?

Acceptability question:

16. Are you satisfied with your child's dental treatment? Please explain?

17. Is there anything you would like to add?

Continuity of care:

18. Do the dental staff know your child and his/her condition?

19. Do the dental staff keep in contact with their other medical colleague to know about your child's condition and disability?

Conclusion question:

20. Do you have anything that you would like to add?

Thank you for taking the time to participate in this study

Appendix (5). Interview topic guide for dental professionals



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Topic guide for Dental professionals

Introduction

I would like to thank you for participating in this research. My name is Dr. Ahmed Marghalani and I would like to talk to you about your patients with disabilities, their oral health and your experience in treating their oral diseases and complications. Particularly, one of the components of our project is that we will be assessing your experiences of treating your patients with disabilities.

The interview should take less than an hour. I will be taking some notes during this interview and audio-recording the interview.

All responses will be kept confidential and anonymous. This means that we will ensure that any information we include in our report does not identify you as the respondent. Please remember that you don't have to talk about anything that you don't want to and you have the right to end this interview at any time.

Questions

General questions:

1. Can you tell me how many patients with disabilities you are treating within a month?
2. How often do you treat children with disabilities?
3. What sort of training have you had to treat children with disabilities?

Attitude question:

4. Were you anxious when treated patients with mild, moderate or profound disabilities?

5. Do you prefer treating children with disabilities more than others?
Why?

Accessibility and accommodation questions:

6. Is the type of dental treatment and precautions for children with disabilities differ according to the severity of their disability? Please explain?
7. How do you see your dental clinic in terms of disability friendly?
Please explain?
8. Can any dentist treat disabled child teeth? Could you explain?

Acceptability questions:

9. How do you see the overall dental care for people and children with disabilities? Please explain?
10. Do you think the parents know about their child's oral health? Explain please?

Continuity of care:

11. Do you know the patients before they attend the clinic?
12. Have you been contacted by other colleagues about one of you disabled patient's condition? Why?
13. Did you contacted any physician, dentist or nurse to inform them about one of you disabled patient's conditions? Why?
14. Do you think it is important to keep in touch with other colleagues about you disabled patient's conditions?

Conclusion questions:

15. What should be done to increase the access for people with disabilities in dental clinic?
16. Do you anything that you would like to add?

Thanks for taking the time to participate in the study

Appendix (6). Focus group topic guide for dental students



The
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Topic Guide for Dental Students

Introduction

I would like to thank you for participating in this research. My name is Dr. Ahmed Marghalani and I would like to talk to you about children with disabilities, their oral health and your experience and knowledge about treating their oral diseases. Particularly, one of the components of our project is that we will be assessing your knowledge and experiences around treating children with disabilities.

The interview should take less than a half hour. I will be taking some notes during this interview and audio-recording it.

All responses will be kept confidential and anonymous. This means that we will ensure that any information we include in our report does not identify you as the respondent. Please remember that you don't have to talk about anything that you don't want to and you have the right to end this interview at any time.

Questions

Curriculum questions:

1. Did you learn about the oral health of children with disabilities?
Explain?
2. Did you ever have the chance to treat a child with disability?
3. Do you think that you are able to treat children with disabilities?

Attitude questions:

4. Who is supposed to treat children with disabilities? Please explain?

5. What should have been done to make students able to treat children with disabilities?


Conclusion question:

6. Anyone would like to add?

Thank you for taking the time to participate in this study

Appendix (7). Unconditional ethical approval letter from Taibah University:

Kingdom of Saudi Arabia
Ministry of Education
Taibah University
College of Dentistry
Research Ethics
Committee
TUCD-REC



المملكة العربية السعودية
وزارة التعليم
جامعة طيبة
كلية طب الأسنان
لجنة أخلاقيات البحث

09/11/2017 - 20/02/1439 Study Reference No.: TUCDREC/20170120/Marghalani

Subject: Approval of the study entitled "Access to oral health care services for children with disabilities in the Kingdom of Saudi Arabia" by the Ethics Committee

Dear Ahmed Marghalani,

Please be advised that Taibah University, College of Dentistry Research Ethics Committee (TUCDREC) has reviewed and discussed your application to conduct the research mentioned above with yourself as the Principal Investigator.

TUCDREC has decided the following for your protocol:

Unconditional Approved Conditional Approved
 Deferred Rejected

The TUCDREC expects to be informed regarding the progress of the study and any serious adverse events occurring during the study, any amendment/addendum in the protocol and patient information/informed consent. You may *not* initiate any changes in the approved research protocol without the prior TUCDREC review and approval except when it is necessary to eliminate imminent and apparent hazards to study subjects.

While The TUCDREC has provided this decision. The committee, however, takes this occasion to draw to your attention that this document is purely ethical and in no shape or form, is it to be understood to mean the conduction of or the end of the search to be conducted.

Comments to the investigators:

Since it is a good practice to involve the parent of a child in the decision-making and to keep their confidence. It is also as good to assess that the person providing the consent (parent or guardian) is in a position capable of taking and making that particular decision, i.e., competent, for the consent form to be valid.

This TUCDREC is organized and operated according to the Saudi National Regulation of the National Bioethics Committee, the Guidelines of the Declaration of Helsinki, the International Conference of Harmonization ICH, and the United States Codes of Federal Regulations. The TUCDREC is registered in the Office of the Human Research Protection under the IORG #: IORG0008371 which Expires on: 13th January 2019, and FWA00023781, which Expires on 13th January 2021, IRB# 00010037.

Coordinator of TUCD-REC **Chairman of TUCD-REC**
Vice Dean for Postgraduate Studies & Research

Dr. AbdelRahman M. Ramadan
Associate Prof.

Dr. Sary S. Borzangy
Assistant Prof.

Appendix (8). Ethical approval letter from the University of Sheffield



Downloaded: 30/10/2017
Approved: 29/10/2017

Ahmed Marghalani
Registration number: 150258096
School of Clinical Dentistry
Programme: Dental Public Health PhD

Dear Ahmed

PROJECT TITLE: Access to oral health care services for children with disabilities in the Kingdom of Saudi Arabia

APPLICATION: Reference Number 014541

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 29/10/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 014541 (dated 11/10/2017).
- Participant information sheet 1035896 version 2 (11/10/2017).
- Participant consent form 1035897 version 2 (11/10/2017).

The following optional amendments were suggested:

Approved with suggested amendments: - I am happy that the parents and children to be observed are given the chance to participate or withdraw, but I'm not sure how consent for this part of the project will be obtained nor how this may effect the observation. Is information going to be provided generally to all at the clinic and then people will given the option to withdraw? I can imagine that the use of specific forms at this juncture may effect behaviour, and thus what is observed, however I do think some information needs to be provided. - inclusion criteria refined - sample size justified - approach to sampling described

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Janine Owens
Ethics Administrator
School of Clinical Dentistry