



## “The poor have no memories”

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Oral histories of women with oral cancer in Pakistan

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## Summary

This thesis explores how women with oral cancer in Pakistan make sense of their experiences. The social context of Pakistan is seen as integral to people's meanings and experiences because it is intimately connected. Oral history interviews were conducted with fifteen women diagnosed with oral cancer receiving treatment at the Foundation University College of Dentistry, Pakistan. The findings suggested that the pathways to diagnosis with oral cancer could be direct or circuitous. These variations reflected the interplay of the social determinants of health, which included socioeconomic status, gender, beliefs in alternative medicine and religious influences. Socioeconomic status mediated access to diagnosis with some participants reporting extensive consultations with spiritual healers before accessing medical services. This contributed to late presentation for diagnosis. The diagnosis often left participants feeling that God had decided they would develop cancer. Cancer was interpreted as a death sentence and in some cases as a personal punishment. Participants also tended to resort to home remedies and alternative medicines before accessing dental professionals. Gender acted as a determinant by promoting the isolation of women from social participation in education and health. Participants interpreted the use of naswar, areca nut, chillum, bleeding gums, boils/ulcers and past sins as the main causes of oral cancer. Some women reported having to go through their husbands and complex private networks in order to secure diagnosis. This meant that they would often present late, which has implications for disease progression. The social position of women also affected how they made sense of their disease through their faith and talking more about its impact on their family. The findings of this thesis suggest that oral cancer diagnosis in the context of Pakistan develops within complex individual cosmologies and pathways, determined by the perplex interplay of the social determinants of health.

## **Dedication**

This thesis is dedicated to the participants of my research study.

Dear Ameena Mehboob, Zahida Kalsoom, Muzammil Bibi, Razia Begum, Shehnaz Bibi, Imtiaz Bibi, Maqsood Akhtar, Nasreen Akhtar, Rukhsana Begum, Sabra Bibi, Shamim Akhtar, Sughran Bibi, Wazira Khatoon, and Nisbah Shaheen, your voices will never be forgotten.

## Acknowledgments

Little did I know when I first came to the U.K. for Masters in Dental Public Health that I would embark on this ever-challenging PhD journey. Challenging in a good way, of course. With limited finances to cover a three-year PhD, I vowed to complete it in less than three years. But oh well, God has His plans. After 2 years, I got the David Locker scholarship from The University of Sheffield. This scholarship was established in 2016 as a permanent endowment (thanks to a generous legacy from the estate of the Late Professor David Locker), to support international students seeking to do social science research in the field of oral health and dental public health. It helped fund the remaining of my course. My interest in documenting the life stories of people with oral cancer and the meaning they attributed to them has brought out some really powerful and heart breaking narratives. I regard it as a big responsibility on my shoulders in delivering the stories of the participants as eloquently as possible so that their voices are heard.

I thank my Allah for giving me the opportunity to be able to carry out this research study in good faith and with sincere intentions.

I am indebted to my supervisors – Barry Gibson, Janine Owens and Michelle Winslow for their constant support, feedbacks and patience. Barry, I am grateful for the trust you put in me for carrying out this research and the confidence you gave me every time I encountered any challenge. To me it never felt like a usual ‘student – supervisor’ relationship. I was never afraid to ask questions and you never failed to satisfy my inquiries. I could not have asked for a better supervisor. Jan, thank you for never getting annoyed at my questions. You were always the quickest to give a useful feedback. I appreciate how every time you replied to emails beyond light speed even out of your working hours. Michelle, your thorough knowledge of oral history was always impressive to me. Thank you for conducting the interview training sessions with me before I started data collection. They really helped me in the interview settings. I am also grateful to you for providing me with extremely useful reading material always.

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## Conferences

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## List of abbreviations

ICD	International Classification of Disease
WHO	World Health Organization
IARC	International Agency for Research on Cancer
NICE	National Institute of Health and Clinical Excellence
CSDH	Commission on Social Determinants of Health
SES	Socio Economic Status
SLT	Smokeless Tobacco
OR	Odds Ratio
RR	Relative Risk
NCI	National Cancer Institute
HPV	Human Papilloma Virus
PHCA	Primary Health Care Approach
CAM	Complimentary and Alternative Medicine
TM	Traditional Medicine
PDHS	Pakistan Demographic and Health survey
OSMF	Oral Submucous Fibrosis

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# Chapter 1. Introduction

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## Chapter 1. Introduction

Oral cancer is among the leading causes of death in South Asia (Pakistan, India, Sri Lanka and Taiwan) and has a high prevalence worldwide. It is a major public health problem due to its increasing incidence and mortality rates (Gupta et al. 2016). It is the 16<sup>th</sup> most common cancer in the world with 354, 864 new cases in 2018 (World Cancer Research Fund 2018). In the UK, oral cancer is amongst the twenty most common occurring cancers (Cancer Research Fund UK 2018). In contrast, oral cancer is the second most common cancer in Pakistan after breast cancer (Tariq et al. 2005). There were around 18, 881 (12.72%) new cases (both sexes) of oral cancer diagnosed in 2018 in Pakistan (GLOBACAN 2018). Furthermore, oral cancer now affects younger people without the well-known risk factors of smoking and chewing tobacco. It affects low socioeconomic groups more.

Most of the funding for oral cancer research is concentrated in Western countries where it is less prevalent. In countries where the incidence is the highest, research and treatment remains drastically under funded and poorly understood. Due to the lack of research funding in Pakistan, there is minimal robust data about the barriers to access, late diagnosis and social determinants of the disease. This is important because resources could otherwise be directed for therapeutic benefit. Furthermore, there is limited patient centred data to assess the needs and views of people with oral cancer in Pakistan. Very little is known about barriers to diagnosis from the patient's point of view. This is urgent because there is an increasing mortality rate of 13.07 % (GLOBACAN 2018) associated with oral cancer. The voices of people with oral cancer in Pakistan remain ignored.

The focus of this thesis is on how people with oral cancer in Pakistan make sense of their experience.

In order to address this focus, this thesis uses oral history as a method of qualitative interview that accentuates the perspectives of the participants. My methodological approach offers the participants with an opportunity to share their life stories and express in their own words, the experience of oral cancer. By sharing these

experiences, the participants are contributing to the paucity of knowledge from the point of view of patients with oral cancer and adding to our understanding of the social determinants of oral cancer in Pakistan.

### **Thesis structure**

This thesis is divided into eight major chapters. This chapter one of the thesis introduces the research project, the focus of the study and structure of the thesis.

Chapter two – *Literature review* begins with identifying oral cancer as a public health problem based on the criterion of Sheiham (1996) followed by global epidemiology and an overview of the research on the risk factors of oral cancer. A section on Pakistan will detail its sociodemographic profile, healthcare systems, the status of women and the subsequent inequalities in health and oral health. This will be followed by a critique of the current interventions to address oral cancer, an introduction to the framework of social determinants of oral health inequalities and how far the research on oral cancer has addressed these determinants. The final part of the literature review will focus on the lay perspectives on cancer especially oral cancer, including the various types of alternative health therapies that people employ.

Chapter three – the *methodology* begins with why oral history was chosen as the most appropriate strategy to address the research focus. Oral history and its key methodological aspects are also discussed. The final part of this chapter details my reflexive position in this study.

Chapter four – the *materials and methods* explores how the data for my oral history project was collected, analysed and interpreted. The first section starts with a consideration of the study in general terms, the preparation that went into the study, including the ethical considerations. A reflexive approach has been adopted throughout this chapter as well. The data collection process (including descriptions of setting, access and recruitment of the participants and the interview process) and data analysis is discussed staying as transparent as possible.

The findings and discussion have been divided into three chapters:

Chapter five – *The participants* – introduces and describes the demographics and social background of the participants;

Chapter six – *Making sense of oral cancer: giving a voice to women with oral cancer*- describes how participants remembered and made sense of the reasons for their oral cancer, its diagnosis and treatment. It also explores how religious beliefs in terms of belief in the power of prayers and fatalism; use of alternative and complimentary medicine in terms of home remedies and consultations with spiritual and traditional healers influenced their health seeking behaviours;

Chapter seven – *Women's lived experiences of oral cancer* – describes the social attitudes toward oral cancer and women's internalised beliefs about the disease. It also details how women in the study experienced depression/anxiety leading to oral cancer diagnosis, how they addressed the fear of death and uncertain consequences of oral cancer, faced seclusion and identity crisis after the oral cancer diagnosis. This chapter shows how lonely and difficult oral cancer journey be for the patients.

Chapter eight – in *Discussion and conclusion* I argue that there are several implications of the findings of this study in oral cancer research. The chapter also highlights the contribution of my study to previous research and literature. The implications of the study findings suggest the inclusion of the voices of women in health care research. I also argue for the inclusion of spiritual healers in the health care system to target early diagnosis in rural communities. The incorporation of patient's religious beliefs and influences in the treatment is also recommended. The limitations in terms of sample recruitment, settings, transcription and generalisability are considered. Recommendations and proposition for future work are also detailed.

## Chapter 2. Literature review

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## Chapter 2. Literature review

### Summary of the structure of the chapter

This chapter begins with the review of oral cancer as a public health problem, its global epidemiology and an overview of the research on the risk factors of oral cancer. A section on the settings of this research study - Pakistan, its sociodemographic profile, healthcare systems, the status of women and the subsequent disparities in health will follow this. This will be followed by a critique of the current interventions to address oral cancer, an introduction to the framework of social determinants of oral health inequalities and how far the research on oral cancer has addressed these determinants. The final part of the literature review will focus on the, lay perspectives on cancer especially oral cancer, including the various types of alternative health therapies that people employ. The chapter will end with a rationale including aim and objectives for this study.

### 2.1 Oral cancer as a public health problem<sup>1</sup>

Oral diseases are important public health problems. It is imperative to identify priority areas so that the available resources can be effectively directed at them. This is important because the demands on the health care system worldwide are increasing and the resources are limited (Daly et al. 2013). Sheiham (1996) devised criteria to determine if a condition is a public health problem. The first aspect of the criteria refers to the prevalence of the disease. For instance, is the disease widespread? Is the prevalence increasing or decreasing? How much of the population is affected? And which parts of the community the disease is most prevalent in. The second aspect is concerned with the impact of the disease at an individual level – do people suffer from pain, loss of function and discomfort or die? Are they able to carry out their normal social roles? The third aspect relates to the effects of the disease. Are there any costs to the health services for treating the

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<sup>1</sup> All the figures reported in this section have been taken from the latest edition of GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries in 2018. All rates are per 100, 000 population.

disease? What impact the disease has on the 'performance and productivity' of the country? Finally, it is important to consider if the disease can be treated, is preventable and there are strategies to stop its progression (Sheiham 1996).

It shall be noted in the subsequent sections of this chapter that because of its increasing incidence worldwide (354,864 new cases in 2018), diagnostic delay, significant impact on the society and the individuals, high mortality rate (177,384 deaths in 2018), morbidity and the presence of preventive activities, oral cancer can be regarded as a major public health problem.

### **2.1.1 Oral cancer definition**

Defining oral cancer remains a challenge for both researchers and clinicians (Moor et al. 2000). Unlike the rest of the body, the oral cavity and oropharynx are not clearly demarcated and hence defining oral cancer poses a difficult task. A PubMed search in 2011 retrieved eleven different terms used to report data on oral cancer. This variability in the nomenclature also hinders the ability of the researchers to retrieve the literature on oral cancer for comparative purposes (Tapia and Goldberg 2011).

For the purpose of this thesis, the term 'oral cancer' will incorporate any malignant neoplasm of the lip, tongue, buccal mucosa or any other part of the oral cavity or oropharynx in accordance with the "International Classification of Disease 10<sup>th</sup> revision- (ICD – 10)" by the World Health Organization (WHO) (2004).

### **2.1.2 Common sites**

Buccal cancers are more common among Asian populations while tongue is the most common site for the development of oral cancer among US and European populations (Warnakulasuriya 2009). Other intra oral sites may include palate, gingivae and floor of the mouth (Table 1).

Table 2.1 Anatomical subsites for sites related to oral cancer based on the International Classification of Diseases 10<sup>th</sup> revision\*

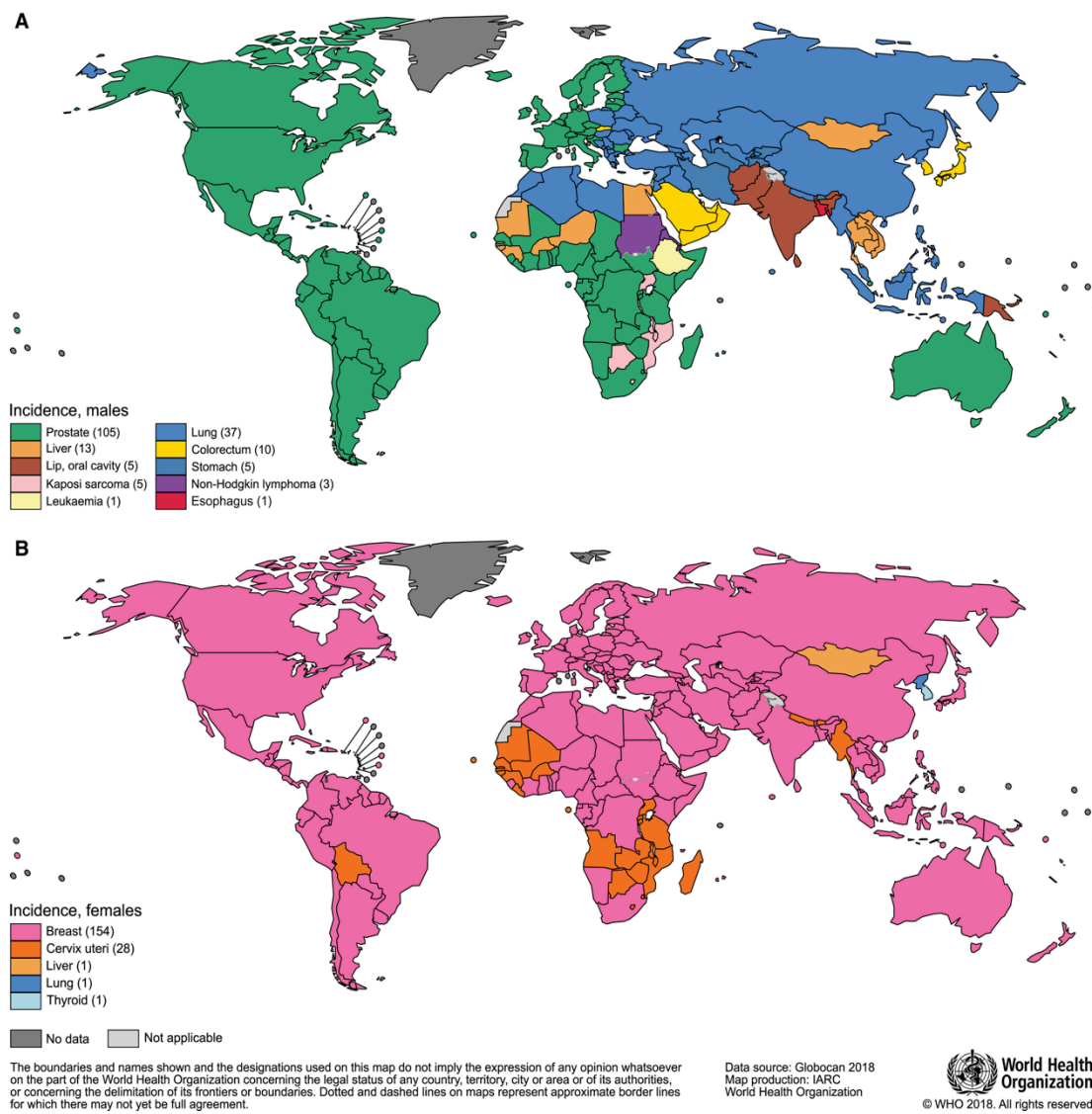
ICD – 10 code	Anatomical sites
C00	Squamous cell carcinoma of the lip
C01/02	Base of tongue/ other and unspecified parts of tongue
C03	Gum
C04	Floor of mouth
C05	Palate
C06	Other and unspecified parts of the mouth
C09	Tonsil
C10	Oropharynx
C13	Hypo pharynx
C14	Other ill – defined sites in the lip, oral cavity and pharynx

\*Data source: Khan (2016; p. 6)

### 2.1.3 Global Epidemiology of oral cancer

Oral cancer is highly prevalent in Southern Asia (Pakistan, Sri Lanka and India) and the Pacific Islands (Papua New Guinea) and contributes to almost one fourth of all new cases of cancer (Gupta and Johnson 2014; Gupta et al. 2016). Figure 2.1 shows the global maps presenting the most common types of cancer mortality by country in 2018 among (A) Men and (B) Women. It can be noted that highest mortality for lip and oral cavity cancer is concentrated in South Asian region with the highest incidence of oral cancer among men in Sri Lanka. Figure 2.2 shows the number of new cases of cancer diagnosed in Pakistan in 2018 with oral cancer.

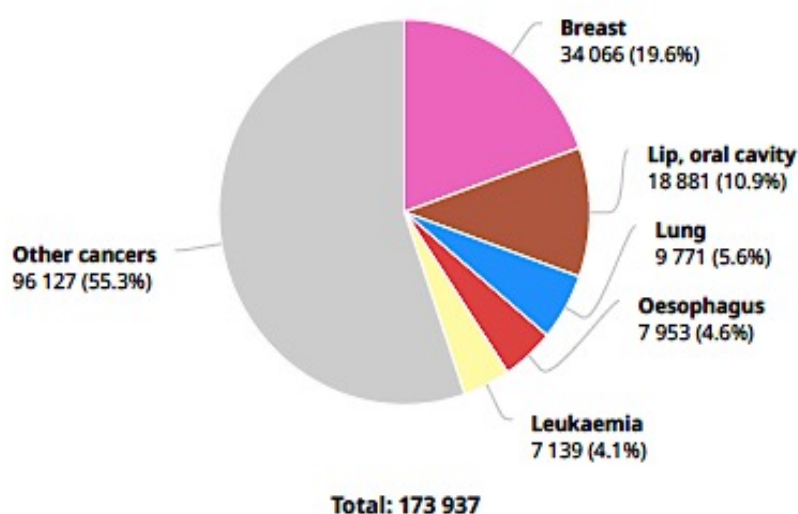
Figure 2.1 Global maps presenting the most common type of cancer incidence in 2018 in each country among (A) Men and (B) Women\*



\* Data Source: GLOBOCAN 2018



Figure 2.2 Number of new cases for all cancers in Pakistan\*



\*Data Source: GLOBOCAN 2018

The highest incidence of oral cancer is frequently cited in India, with 20 per 100,000 population affected by oral cancer (Gupta et al. 2014). In some reports by International Agency for Research on cancer (IARC), Karachi Pakistan has been recognised having the highest incidence of oral cancer (Warnakulasuriya 2009). The incidence of oral cancer increases with age in all countries. For example, in the global west where the incidence is comparatively low, 98% of oral cancer cases are people over the age of forty. However, in the areas where oral cancer incidence is high, oral cancer occurs prior to the age of thirty-five (Warnakulasuriya 2009). In industrialised countries, men are twice more susceptible to oral cancer than women mainly due to increased consumption of tobacco and alcohol. In India however, the incidence of oral cancer is more in women because of their smokeless tobacco chewing habits (Johnson 2001). It has also been observed that oral cancer rates are the highest in disadvantaged communities (Warnakulasuriya 2009).

Lack of appropriate health care and effective national preventive programmes especially for low socio economic groups lead to a sizeable social gradient – ‘the individuals at the top of social hierarchy tend to enjoy better health as compared to those immediately below them’ (Marmot 2010). The social scale thus indicates that the positive health outcomes deteriorate in a ‘step wise’ and ‘consistent graded fashion’. The gradient is continuous and does not have a threshold (Sheiham 2000). Although the major advancements in surgical procedures for oral cancer and technology have improved patient’s quality of life, little improvement has been seen in survival rates. The treatment of oral cancer is expensive and the physiological and psychological impacts of the disease on individuals are considerable (Daly et al. 2013). According to Cancer Research UK (2018), almost 4000 people died of oral cancer in the UK in 2016. The overall five – year survival rate for most of the countries is 50%, however, for the cancer of the lip, 90% of the cases survive the disease for five years. The survival rate for hypopharyngeal tumours is the lowest. The prognosis becomes worse with increasing inaccessibility to the tumour – the further back in the mouth, the poorer the diagnosis (Warnakulasuriya 2009). Survival is better in affluent groups while people from most disadvantaged groups dying sooner (Coleman et al. 1999). For example, deaths from oral cancer in England are concentrated in deprived socioeconomic groups (Cancer Research UK 2018). This social gradient is not only present in Britain but in both high and low/middle income countries across the globe (Victoria et al. 2003). A clear social gradient exists not only across countries but also within developed and developing countries. This means that health inequalities affect everyone (WHO 2008).

Due to uncontrolled social determinants, the risk factors for oral cancer such as tobacco, alcohol use and smokeless tobacco consumption are likely to be increased in the low-income communities. These determinants include the place where we grow up, the quality of our early childhood experiences, the level of education we attain, the work we do, the income we generate and the environment that surrounds us (Daly et al. 2013). As we shall see in the following section, the focus of global research is largely on the etiology of oral cancer and not on the social

determinants.

## 2.2 What is known about oral cancer?

The clear geographical and demographic variations in the incidence and mortality rates of oral cancer suggest a differential exposure of population groups to certain risk factors. The table below (Table 2.2) shows the risk factors for oral cancer.

Table 2.2 Commonly attributed risk factors for oral cancer

Risk factors	Description	Health effects
<b>Tobacco</b>	Includes smoking cigarettes, bidi, cigars, hookah, chillum and shisha, chewing (smokeless tobacco), or sniffed through nose.	<ul style="list-style-type: none"> <li>• Leads to cancers like lung cancer, cancers of stomach, oesophagus, liver, kidney, ureter, urinary bladder, bone marrow and cervix, tobacco also causes cancers of oral cavity, larynx and pharynx.</li> <li>• Oral health risks of tobacco include periodontal disease, oral mucosal disorders, tooth loss, delayed healing, implant failure, pre malignant lesions and oral cancer (Napier and Speight 2008).</li> </ul>
<b>Smokeless tobacco</b>	<p>Smokeless tobacco can be consumed orally by placing it in the mouth, lip or cheeks and then sucked continuously or sniffed without burning the leaves (Boffetta et al. 2008).</p> <p>Several smokeless tobacco products such as Mishri, Mawa, Kiwam, Khaini, Gutkha, Naswar and Zarda are readily available in South Asia. They are usually consumed in</p>	<ul style="list-style-type: none"> <li>• It is reported that more than 30 cancer-causing agents are present in smokeless tobacco (Boffetta et al. 2008).</li> <li>• It can cause pre malignant lesions which if aggravated lead to the development of oral cancer or squamous cell carcinoma.</li> <li>• It has also been established that since smokeless tobacco is usually placed adjacent to buccal mucosa or sniffed, it is likely to cause pre malignant lesions in the</li> </ul>

	combination with areca nut in form of betel quid.	mouth, pharynx and larynx. A white patch known as Leukoplakia is normally seen on the buccal mucosa and people who are snuff users.
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### 2.2.1 Use of tobacco

It is estimated that around the world, approximately 43% of cancer mortality is because of sedentary lifestyles, unhealthy nutrition, infection, alcohol consumption and tobacco use (Ullrich et al. 2004). The research on oral cancer has largely ignored the social determinants of health whereby the literature has characteristically focused on discussions of risk factor epidemiology. Use of tobacco is the single most important yet preventable risk factor for the development of oral cancer (Warnakulasuriya 2009). Worldwide, nearly 1.3 billion adults over the age of 15 smoke daily which includes 10% of women and 48% of men (Guindon and Boisclair 2003). It is also reported that the annual deaths caused by smoking related diseases are approximately 5.4 million potentially rising to 8 million by the year 2030. In industrialized countries, smoking is estimated to be a risk factor implicated in 85% of the oral cancer deaths.

The relationship between smoking tobacco and oral cancer has been described repeatedly for decades. For instance, a Swedish study in 1937 reported that people with mandibular cancers especially buccal and gingival were those who had a habit of snuffing and chewing tobacco more frequently than people diagnosed with other types of cancers (Ahlbom 1997). Similarly, in late 1950's, reports of increasing diagnoses of oral cancer in the United States were amongst those who snuffed and chewed tobacco (Wynder et al. 1957a). This was the first modern epidemiological study that explored the effects of smokeless tobacco and concluded that it had significant association with the development of buccal and gingival cancer.

Oral cancer incidence is higher in countries where tobacco usage is common. A recent meta-analysis of 12 observational studies from India, China, Italy, USA, Uruguay, Sweden, Taiwan and Korea has determined the relative risk for oral cancer

in current smokers to be 3.43 (95% CI: 2.37-4.94) as compared to non – smokers (Gandini et al. 2008). In this meta - analysis, an Italian study reported that smoking was a risk factor implicated in 87% of oral cancers in men and 42- 47 % in women (Negri 1993). It was suggested that the risk of developing oral cancer increased with more frequent usage of tobacco. Therefore, both the intensity and duration of smoking are of prime importance when calculating the risks associated with oral cancer. Furthermore, studies from the US and Europe demonstrated that the risk of oral cancer was comparable for those engaged in cigarette and cigar smoking. However, the risk of smoking bidi (which is a hand rolled cigarette made of flaked tobacco in temburni leaf) was found to be three times higher than cigarette smoking. The findings are consistent with the results of a nested control study conducted in India, which found increased risk of oral cancers for smokers of bidi alone with an OR of 1.9 (95% CI, 1.1 - 3.2)(Muwange et al. 2008). Duration of bidi smoking also had an impact on the risk of developing oral cancer. A meta-analysis of 12 studies identified an rise in oral cancer risk by three – fold in bidi smokers as compared to non – smokers with an OR of 3.1 (95% CI, 0.7 - 1.8) (Rahman et al. 2003). More recently, Chang et al. (2015) have reported increased mortality ratios of 4.0 to 7.9 for oral cancer when people had the habit of smoking cigar.

Similarly, a meta-analysis of 15 case – control studies reported an odds ratio of 4.6 (95% CI, 3.1 - 6.7) for smokers as compared to non-smokers (Sadri and Mahjub 2007). Likewise, a study in Italy highlighted the role tobacco plays in the development of oral cancer with an increased risk found in individuals who smoked for longer durations of time and used a greater number of cigarettes (Franceschi 1990; La Vecchia et al. 1997). Cigar or pipe smokers reportedly had a greater risk of developing oral or pharyngeal cancers. This finding however is not consistent with Mashberg et al. (1993), which suggests that a combination of smoking and alcohol increased the risk of developing the majority of oral cancers.

Whilst these studies focus on behaviours such as smoking as a risk factor, they fail to consider any other factors such as social deprivation or inequalities and we could argue that they do not provide us with a comprehensive picture of oral cancer.

### **2.2.2 Smoking tobacco and alcohol consumption**

For many decades, the association between smoking and alcohol consumption with an increased risk of oral cancer has been highlighted. It is noted that most people using more than the weekly-recommended intake of alcohol of 14 units per week (almost 80%) are also cigarette smokers and implicated in 70% of all oral cancer cases in the world (Radoi and Luce 2013).

A meta-analysis identified 16 studies reporting that compared to non – users, the long-term alcohol users were at a five times greater risk of oral cancer (mRR = 4.6, 95% CI, 3.1 – 6.7) (Jayasekara et al. 2015). Never - users of tobacco who consumed three or more drinks per day had almost twice the risk of developing oral cancers than those who never drank. In cancer sub sites, never smokers who drank one or two drink per day were at a risk of developing pharyngeal cancer, while there was increased risk for laryngeal cancer in those who drank five or more drinks each day (Hashibe et al. 2007). Furthermore, a high risk of laryngeal cancer has been observed in subjects who were exposed to both alcohol and smoking in Europe. In addition the prolonged use of tobacco and alcohol supplements the occurrence of secondary primary tumours (Do 2003). It has also been argued that independent effect of drinking reduced and was not associated with the development of head and neck cancers. In contrast whilst the independent effect of smoking also decreased, it remained associated with disease occurrence. The combined effect of cigarette smoking and alcohol drinking were significantly associated with oral cancer (Ferreira Antunes et al. 2013).

The risk of head and neck cancer decreased in people who had stopped smoking 1-4 years previously while the decreased risk of head and neck cancer in people who had stopped smoking for more than 20 years, was equal to that of never smokers. However, both former and current smokers had an increased risk of developing laryngeal cancer rather than oral or pharyngeal cancer (Marron et al. 2010).

In order to determine the separate effects of cigarette smoking and alcohol consumption on the development of head and neck cancer, a pooled analysis of data

from 15 case control studies was conducted (Hashibe et al. 2007). Seven out of fifteen studies found that cigarette smoking was associated with a significantly high risk of head and neck cancer in never drinkers. In case of cancer sub sites, there was increased risk of developing laryngeal cancer among the never drinkers. Likewise, slightly stronger association between cigarette smoking and head and neck cancer in never drinkers was seen in women as compared to men. European and South American studies report higher risks of head and neck cancers with cigarette smoking among never drinkers compared to studies from North America, Sudan and India (Hashibe et al. 2007).

From these studies it appears that although behaviours involving the use of tobacco and alcohol increased the risk of developing oral cancer, the evidence in some areas appears contradictory and unclear. The constant focus on behaviours as risk factors has a tendency to ignore other determinants of oral cancer.

### **2.2.3 Use of Smokeless tobacco (SLT)**

Tobacco is mostly smoked in a cigarette but can be used in a variety of other ways. In some parts of the world, smokeless tobacco is also very common. Smokeless tobacco can be snuffed or chewed, sucked, inhaled, or dipped (Cogliano et al. 2004). It is used with leaves or mixed with other ingredients to enhance its taste and for the active ingredients to absorb more quickly into the blood stream (Gupta et al. 1996).

According to National Cancer Institute (NCI), smokeless tobacco use is prevalent all over the world with almost 300 million people using SLT products regularly in 70 countries (NCI 2014). In the developing world, almost 90% of SLT burden lies in South Asia in countries like Pakistan, India and Bangladesh (Siddiqi 2015). In developed countries the use of SLT is the highest in America and Sweden (Boffetta 2008). The prevalence of various smokeless tobacco products by region is described in the table 2.3.

Table 2.3 Prevalence of SLT products by region\*

Habit	Ingredients	Global prevalence
Pan/paan/betel quid	Areca nut, betel leaf/ inflorescence, slaked lime, catechu, condiments, with or without tobacco.	Indian subcontinent, Central Asia, Southeast Asia, Papua New Guinea, part of South America
Gutkha	Commercially manufactured version of Paan/betel quid, which is not perishable.	United Kingdom, Southeast Asia
Khaini	Tobacco and Lime	Bihar (India)
Mishri	Burned tobacco	Maharashtra (India)
Zarda	Boiled tobacco	India and Arab countries
Gadakhu	Tobacco and molasses	Central India
Mawa	Tobacco, lime and areca	Bhavnagar (India)
Nass	Tobacco, ash, cotton or sesame oil	Central Asia, Iran, Afghanistan, Pakistan
Naswar/Niswar	Tobacco, lime, indigo, cardamom, oil, menthol, etc.	Central Asia, Iran, Afghanistan, Pakistan
Shammah	Tobacco, ash, and lime	Saudi Arabia
Toombak	Tobacco and sodium bicarbonate	Sudan

\*Data source: Niaz et al. (2017)

Daftary et al. (1991) and Gupta et al. (1992) have covered the evidence on the carcinogenicity of these mixtures extensively. A case control study conducted in Sudan identifies that the form of smokeless tobacco used in Sudan, called Toombak contains high levels of tobacco specific nitrosamines (TSNs), which is associated with increased risk of oral cancer (Idris et al. 1995). Likewise, chewing betel quid with tobacco is associated with high risk of oral cancer in the Indian subcontinent. This combination carries a higher risk than smoking because of the enhanced topical effects of nitrosamines present in it as compared to tobacco smoke (Johnson and Warnakulasuriya 1993). All of these substances (in the table above) have reported evidence regarding their carcinogenicity in India and Pakistan (Warnakulasuriya



2010) with high rates of oral cancer associated with prolonged use of these products. Smokeless tobacco has also been identified as a major cause of pre malignant lesions such as leukoplakia. Similarly, the studies conducted in Sweden, Norway and Hungary suggest that tobacco is a major risk factor for pre-malignant lesions and oral cancer (Napier and Speight 2008). It is noteworthy, however, that after the discontinuation of smokeless tobacco, oral lesions usually disappear (Martin et al. 1999).

In a comprehensive review of smokeless tobacco and health in India and South Asia, it was argued that about one third of all cancers in India, Pakistan, Bangladesh and Sri Lanka are tobacco related (Gupta and Ray 2003). It was also suggested that among the 700 000 – 900 000 new cancers diagnosed every year in India, approximately 250 000 are tobacco related cancers. In recognition of commonly used smokeless tobacco in South Asia, the incidence of oral cancer is very high. The IARC Working Group (2007) evaluated tobacco-chewing habits (consuming betel quid containing tobacco or tobacco combined with slaked lime) in relation to an increased risk of oral cancer and concluded that the risks for consumers were significantly higher than non-consumers. Other studies support this position, arguing that in six out of nine studies reviewed, the relative risk of people who were non-chewers compared with those who were in a habit of chewing pan with tobacco varied from 1.8 to 5.8. Similarly, relative risk (RR) in women varied from 30.4 to 45.9 (Gupta and Ray 2003).

Smokeless tobacco is used commonly in Pakistan but unlike alcohol; it is widely available in public markets. Tobacco and its related products (bidis, hookah and smokeless tobacco in the form of naswar) are consumed by 54% of men and 20% of women in Pakistan (Zakiullah et al. 2012). The use of smokeless tobacco is a culturally and socially acceptable habit in Pakistan (Bile et al. 2010) and even after knowing the harmful effects; the majority of the population still continues with its use (Riaz et al. 2015). Its social acceptability means that it is not considered a taboo or stigmatised and is used widely among people of all age groups irrespective of

gender in South Asia. It has been reported that women in South Asia tend to disapprove of smoking; yet interestingly, smokeless tobacco use is popular amongst them (Kakde et al. 2012).

Studies from Pakistan observe that the risk of developing oral cancer in people who had ever chewed betel with tobacco was 8.4 times and 9.9 times without tobacco greater than those who never consumed betel quid (Merchant 2000). Research from Bangladesh suggests that the site where betel quid was mostly exposed corresponded to the site of origin of oral cancer and duration of use; i.e., the buccal mucosa (Sein 1992; Ghosh 1996). These findings are replicated in Taiwan; habits such as cigarette smoking, betel quid chewing and alcohol drinking primarily increased the risk of developing oral cancer (Yc et al. 1995). Chewing betel quid with tobacco has been strongly associated with buccal and labia cancers (Sankaranarayanan et al. 1990).

Similarly, Khan et al. (2014) conducted a systematic review and meta - analysis to explore the association of oral cancer with different forms of smokeless tobacco in South Asia. The results of this review suggested a strong association between oral cancer and various tobacco products. The data revealed that betel quid with tobacco consumers were at a seven-fold higher risk of developing oral cancer as compared to the non-consumers OR 7.1 (CI 4.5 -11.1). It was also found that for frequency and duration of use, there was a significant exposure -response between smokeless tobacco (and related products) with the development of oral cancer (Khan et al. 2014). A linear response was shown in case of chewing tobacco while a non-linear response is depicted in case of betel quid. These findings were inconsistent with reviews from North America and Europe, where no exposure response relationship was identified (Weitkunat and Lee 2007; Lee 2011). This may be due to the differences in prevalence of oral cancer and the type of smokeless tobacco used in North America and Europe as compared to South Asia. Other differences might include ethnicity, environmental issues as well as socioeconomic status. Furthermore, reviews from North America and Europe reported comparatively

smaller effect sizes to the studies included in this review. It was interesting to note in these studies that as compared to men, women were at a higher risk of developing oral cancer from smokeless tobacco. The possible reason could be that the women's oral mucosa is more susceptible to the negative effects of tobacco and its related products (Balaram et al. 2002). Poverty and lack of education can also add to the already aggravated situation for women (Gupta and Ray 2003). It is worth noting that there was a very high inconsistency in the effect estimates of the case-control and cohort studies. The problem may be that researchers may have underestimated the effect in women (Khan et al. 2014). Confounding factors, selection and recall bias, under or over reporting of exposure status and retrospective exposure assessment are included in the limitations of the review. Moreover, the findings were generated only from publications issued in India and Pakistan and this may have influenced the findings (Khan et al. 2014).

#### **2.2.4 Use of Betel quid**

Betel quid is the most important commercial crop grown in Southeast Asia and is approximately consumed by 10% of the world's population (Joshi et al. 2014) comprising mostly of low socioeconomic groups (Williams 2002). This also indicates that after tobacco, alcohol and caffeine, betel nut is the fourth most commonly used addictive substance (Zdrojewicz 2015). It is regarded as one of the oldest known psychoactive mixtures in history. Antonio Pigafetta (1521) first described the custom of betel quid chewing in Philippines in 'The First Voyage Round the World':

*"These people regularly chew a fruit they call areca, which looks like a pear. They cut it into four parts and each part is wrapped in a leaf from a tree called betre (i.e. betel), very similar to a laurel leaf. They stick this in their mouth and after having duly masticated it, they spit it out, their mouth becomes completely red. All these people take this fruit in order to lift up their spirits. If they didn't they would die."*

(Pigafetta 1969, p. 32)

Pigafetta describes the process of wrapping and chewing betel quid; a habit adopted by nearly 600 million residents of Southeast Asia and Pacific Islands. From occasional uses to habitual usage, betel quid has gradually become a part of Asian culture and

traditions (Petti 2009). The justification for using betel quid employed by people in South East Asia was in reference to high alertness and increased capacities to withstand harsh environmental conditions such as cyclic monsoons and storms. The prevalence of betel quid usage is high among Asian adults and amongst South Asian migrants to western countries.

Areca nut, which is one of the important ingredients of betel quid, has been reported for its carcinogenicity (Van Wyk et al. 1996). Likewise, a strong correlation between areca nut and pre-malignant lesions like oral submucous fibrosis (OSMF) (a precancerous condition characterised by 'inflammation and progressive fibrosis of the submucosal tissues' resulting in marked rigidity and trismus) has also been identified (Sinor et al. 1990; Murti et al. 1995; Zain 2001).

A review of betel quid chewing conducted in China revealed 22 studies that looked at the association between chewing and potentially malignant oral diseases (Zhang and Reichart 2007). It was suggested that betel quid was a major risk factor of oral submucous fibrosis. Similarly, oral leukoplakia (a white patch or plaque on oral mucosa that cannot be characterised or histologically identified as any other disease) was reported more prevalent in betel quid chewers who had sub-mucous fibrosis than ones without. In contrast, oral cancer prevalence in betel quid chewers with oral sub-mucous fibrosis in Mainland China was low as compared to data from South East Asian countries (Zhang and Reichart 2007). This inconsistency can perhaps be explained by the difference in the composition of betel quid in Hunan province, but needs further in depth exploration.

Although, there has been comparatively more data from Asia - Pacific supporting the augmented risk of developing oral cancer in betel quid chewers compared to non-chewers, researchers have failed to distinguish between betel quid with and without tobacco (Zain 2001). Betel quid with or without added tobacco is a risk factor in the development of oral cancer (IARC 2004). A recent meta-analysis of 50 studies conducted to assess the relationship between oral and oropharyngeal cancer and chewing betel quid (with or without added tobacco) supports this classification by

IARC. The review found that the risk of developing oral cancer was high in Taiwan, China (mRR, 10.98) for chewing betel quid without tobacco as compared to the Indian subcontinent (Guha et al. 2014). This difference was not only due to dissimilarities in the preparation and type of areca nut but also due to a large quantity of betel quid chewed in a day in Taiwan, China. A large number of inconsistencies were identified in the studies; however, the results clearly allude that an exposure – response relationship exists between increased risk of oral cancer and betel quid (Guha et al. 2014).

A systematic review and meta-analysis of the association between smokeless tobacco and betel quid with tobacco with incidence of oral cancer in South Asia was conducted (Gupta and Johnson 2014). A total of fifteen case control studies reported a positively significant association between consumption of betel quid without tobacco and incidence of oral cancer. It suggested that although the studies from Pakistan, India and Papua New Guinea reported a higher incidence of oral cancer with increasing betel nut chewing habits, the association of betel quid chewing and oral cancer in Taiwan is much higher than the Indian subcontinent. This might be due to the higher number, type of areca nut chewed per day and type of slaked lime added in Taiwan. One of the studies included in the review reported that slaked lime from amongst all other components of betel quid had the most significant effect on development of oral cancer in Thailand (Loyha 2012). Similarly, a few other studies conducted in Taiwan demonstrated that the people who chewed betel quid without tobacco were 24 times more at the risk of developing oral cancer than the people who consumed betel quid with tobacco (Ko 1995; Mack 2001; Gupta 2002; Lin 2005; Yen 2007).

After tobacco, betel quid is the second most commonly consumed carcinogen in the Indian subcontinent. Reports from South Asian countries such as India, Pakistan and Nepal suggest that the prevalence of betel nut products has increased considerably in the past three decades and almost 20- 40% of the adults use it regularly. After India, Pakistan is the second highest consumer of betel quid (Niaz et al. 2017). It is

widely used in Karachi, Pakistan because of its low price and ease of access. A study from Karachi, one of the largest metropolitan cities of Pakistan showed that 40% of the population (mostly men) consumes betel nut on a regular basis (Khawaja 2005). Furthermore, Shah et al. (2002) has identified that more than 74% of school going children in Karachi use chewable products like betel nut.

The results of a systematic review demonstrated a strong link between tobacco and its related products with the incidence of oral cancer, where individuals consuming tobacco with betel quid had a seven-fold higher risk of developing oral cancer in comparison to non-consumers (Khan et al. 2014). A possible reason for this could be that paan is prepared using areca nut that exhibits significant carcinogenic properties which when combined with the carcinogenicity of smokeless tobacco can generate increased negative effects.

Betel leaf with areca nut (paan in Urdu –the national language of Pakistan), with or without tobacco, was assessed for its association with oral cancer (mediated by OSMF), in a case control study, which collected data from three hospitals based in Karachi (Merchant and Pitiphat 2014). The study consisted of 79 cases of oral cancer and 143 controls. Out of them, only 56 had OSMF and 166 did not. It was reported that paan, used with or without tobacco, caused increased risk of oral cancer. However, the risk of developing oral cancer was higher in people consuming paan with tobacco. The study however failed to demonstrate any association or interaction between paan use and OSMF. The reason may be attributed to a small sample size because the results included wide confidence intervals showing no association. Also, the study design used was case control, which may have introduced a recall and selection bias.

In order to understand the knowledge, attitudes and practices of those who chew betel quid in Pakistan, a cross sectional study was conducted in two areas of Karachi, Pakistan (Khan et al. 2013). Saddar (a low socioeconomic area) and Defence (a comparatively affluent area) were chosen using purposive sampling. The study sample was 370, with a total of 185 participants from each area. It was interesting to

find that the study identified the same percentage approximately (40%) of betel nut chewers among the age group of 21 to 40 years from both Saddar and Defence. This was alarming because 40% is quite a high percentage of the working population to be involved in this habit. Participants (N = 112) had been chewing betel nut for more than ten years and only a small proportion (N = 30) reported that they had started less than 12 months ago. Similarly, it was found that 78% of the sample consumed betel quid daily and only 27% reported that they consumed in once every four weeks. Furthermore, 20% admitted that they chewed more than ten packs while 43% consumed 1-5 packs on a daily basis. The majority of the participants from both areas recognised betel quid chewing as a bad habit. Every three out of four participants acknowledged that betel nut chewing could be implicated in causing oral or throat cancer. This awareness was noted more in residents of Defence because they were educated and had read articles on the risk factors associated with betel quid. Awareness regarding the injurious effects of oral tobacco use has also been reported by Dhanani et al. (2011), where almost one third of the individuals did not consider oral tobacco as detrimental to health. However, it was found that people living in Saddar were more eager and had attempted to quit betel nut chewing compared to those from Defence. Almost 60 percent of the sample from Saddar had previously tried to quit the habit but failed. Peers and friends are an important factor in an individual's decision to start using oral tobacco especially when they are young.

Advertisements were the second most common reason to consume betel nut (Khan et al. 2013). It was alarming to find that two in every three residents reported that their peers and friends introduced them to betel nut. Dhanani et al. (2011) found similar patterns in that friends often inspired participants to start using oral tobacco and argued that young people are excessively conscious of their image among their friends and want to look 'cool' and 'charming' like models. This is mostly portrayed on television and social media. For example, betel nut in the form of 'paan masala' has been advertised as 'mouth freshener' in India (Garg et al. 2014). In addition, almost half of the participants reported that their family members consumed betel

nut as well and for most of them it was a part of their family tradition (Khan et al. 2013). This was found more in Saddar as compared to Defence. Likewise, the amount of money spent on betel nut also varied. For instance, 12 % of the participants reported that they spent 1000 Pakistani rupees (approximately £6) on betel nut every month. This is inexpensive compared to other products and may not be considered a high financial outlay for residents in higher socio-economic areas. It was also reported that even participants from low socioeconomic areas spent a good amount of their income on betel quid. The cheap price at which betel nut is purchased is probably one of the main reasons for its high prevalence in low socioeconomic areas. Furthermore, the practice differs in lower income areas with research demonstrating that participants often have the habit of keeping betel nut in their mouths for a longer period and consuming more tobacco-related betel products. These factors invariably lead to increased chance of oral cancer. There was a reported difference in how people consumed betel quid (Khan et al. 2013). For instance, people living in Saddar (76%) purchased it at a cheap price from nearby shops whilst friend and peer influences were more prevalent in residents of Defence. This finding was consistent with another study (Shah 2008) in which 88% of the participants purchased betel nut from shops.

More recently a cross sectional study analysed the prevalence of areca nut chewing in the school going children in Malir, Karachi, Pakistan (Leghari et al. 2016). Malir is a remote place in Karachi with sub-standard healthcare facilities because of a lack of basic infrastructure facilities people are involved in low paid jobs. The age range of the children included in the study was from 4 years to 8 years. A total of 285 children (Boys = 214, girls =71) were surveyed after seeking informed consent from the parents. It was found that 222 participants were regular users of areca nut and its products. More than 74% of the users had oral lesions. The frequency of use was higher in boys as compared to girls. The majority of the children's parents themselves were users of areca nut and its products like Gutka. The most surprising finding was that the increasing frequency of areca nut usage was during school time. The results of this study are comparable with another study conducted in 2002 in



Karachi Pakistan, which reported that majority of the school going children in the sample (74.2%) under the age of 12 years and attending school regularly were habitual users of areca nut. These findings are particularly poignant and fit calls for policy makers to place a ban on supplying areca nut and its related products to young children who remain a high target group for manufacturers in Pakistan (Leghari et al. 2016).

### **2.2.5 Use of Gutka (Betel quid with tobacco)**

Gutka is a form of smokeless tobacco, which is available as a mixture of powdered tobacco, slaked lime and areca nut along with an occasional addition of sandalwood and musk ketones. Gutka is readily available at a low price and glittery packaging in markets and is one of the major risk factors for oral cancer in Pakistan. Unlike tobacco, gutka is commercially sold without any health warnings (Javed et al. 2010). It is not restricted from use in Pakistan and a recent study reported that almost 46% of the residents in Karachi consume gutka habitually (Javed 2008). Khan et al. (2012) found that 30 % of their sample (N = 170) that had oral cancer was habitual users of Gutka in Karachi, Pakistan.

In order to assess the prevalence of betel nut, pan and gutka usage in school children of Karachi, a cross sectional study was conducted in March, 2013 by (Uqaili et al. 2014). A total of 462 school children were recruited from the three districts Thatta, Jamshoro and Hyderabad of Sindh, which is one of the largest provinces of Pakistan. It was found that almost 66% of children reported consuming at least one of the following betel nut, paan and gutka, where in Thatta 76% of children consumed either, 54% in Jamshoro and 69.5% in Hyderabad (Uqaili et al. 2014). Moreover, 100% of the sample consumed betel nut, while pan was eaten by 53% of the children. Gutka was consumed by 19%. The knowledge of the side effects was generally poor with only 40% children aware in Jamshoro, 25% in Thatta and 72% in Hyderabad. Children were aware of side effects such as dental caries, teeth staining, mouth ulcers and sore throats. The study also revealed that 92% of children at least brushed their teeth once a day. When they were questioned about oral cancer, only

34% had heard of the word oral cancer (in the Sindhi language). This clearly shows the lack of awareness of oral diseases among the population (Uqaili et al. 2014). An interesting finding of this study was the misconception that school children had regarding the side effects of consuming betel nut and paan and gutka. They were of the opinion that the most harmful effect was dental caries. This not only reflects the lack of awareness on children's part but also on part of the teachers who seemed less aware themselves. The fact that 100% of the children were involved in the consumption of any of the substances in question shows that, in Pakistan, users tend to start consuming betel nut and its related products from a very early age. The lack of awareness, low cost and ready and cheap availability in nearby markets aggravates this harmful practice (Uqaili et al. 2014).

In Karachi, Pakistan it was found that out of 408 participants, almost 80 percent regularly consumed gutka. Most of the sample population included males. The prevalence of smokeless tobacco was higher in workers coming from a low socioeconomic status and who had comparatively less educational attainment. The habit of gutka consumption was more prevalent, and had a longer duration of use in people belonging to low socioeconomic status as compared to high (Patoli et al. 2015).

The data from the studies allude towards the importance of placing a ban on the sale of Gutka to children as well as teasing out patterns of consumption within low socioeconomic groups.

### **2.2.6 Use of Naswar**

Naswar is a form of smokeless tobacco, which was historically used in Afghanistan, the northern parts of Pakistan and in Central Asia. However, it is now becoming popular in other parts of the world as well (Mackay 2002). According to National Cancer Institute, it contains one of the highest amounts of Tobacco – Specific Nitrosamine content and alkalinity among the SLT products used in South Asia (NCI 2014). In Khyber Pakhtunkhwa, Pakistan, more than 60 % of oral cancer occurrence is associated with the use of naswar (Khan 2016).

In order to assess the toxicity profile of naswar as a risk factor for oral cancer in Pakistan, a study was conducted that tested 30 different brands of naswar for their constituents and pH (Zakiullah et al. 2012). The results of this study clearly showed that the average amount of toxins used in naswar is above the allowable limits, which increases the health risk for consumers.

Similarly, the results of other work suggested that the risk of developing oral cancer was four times greater in people who use naswar regularly. This could be because naswar is the most frequently used form of smokeless tobacco in Pakistan (Riaz et al. 2015). There has not been any policy or public health measure to reduce its usage as well as create public awareness regarding its ill effects.

### **2.2.7 Role of oral hygiene in oral cancer**

Poor oral hygiene has been proposed as a risk factor for oral cancer (Hashim et al. 2016). However, because of limited evidence, it remains a controversial (Warnakulasuriya 2009). A large multicentre case control study from Europe claimed that poor oral hygiene contributed towards tripled risk OR 2.8 (95% CI 1.7 - 4.8) of oral cancer (Guha et al. 2007). Similarly a meta-analysis to explore the association between tooth brushing and the risk of head and neck cancer found that effective tooth brushing (both day and night) might contribute towards prevention of oral cancer (Zeng et al. 2015). What these studies do not consider are any social inequalities that people may experience and therefore the evidence may be said to be biased and unreliable.

In many low-income countries, alternate methods to tooth brushing are used. For instance, in Nigeria, people belonging to low socioeconomic status groups, with little or no education, use chewing sticks to clean their teeth. These sticks are made of fibrous logs, branches or roots of certain trees and shrubs. The sticks can contain essential oils, fluorides, silicates, tannins and cathadines which have anti - cariogenic, antibacterial and haemolytic properties (Malik et al. 2014). The sticks are used in up and down movements to clean the teeth. Similarly, a 5-year prospective study to explore the role of poor oral hygiene in causing oral cancer was conducted in Nigeria

(Oji and Chukwuneke 2012). It was found that infrequent use of chewing sticks like toothbrushes can be a risk factor for oral cancer. The study also demonstrated that all the cases presented late to the hospitals because they consulted prayer houses, “quacks<sup>2</sup>” and herbalists before eventually consulting medical professionals. Likewise, a study from Brazil reported increased risk of oral cancer with advanced stages of periodontal disease resulting from poor oral hygiene with an OR =3.1 (95% CI 1.2-7.9) (Marques et al. 2008).

In contrast Marshall et al. (1992) and Talamini et al. (2000) observed a very weak correlation between poor oral health and oral cancer. Other confounding factors like smoking, alcohol consumption, and smokeless tobacco usage were mentioned as the strongest risk factors for oral cancer.

In some epidemiological studies, poor oral hygiene, ill - fitting dentures, faulty restorations and sharp teeth have been cited as risk factors, it remains unclear whether confounding factors like alcohol and tobacco have been accounted for. In a high-risk individual, chronic irritation from a denture may cause exposure to carcinogens that the individual may encounter on a daily basis (Warnakulasuriya 2009). There is also a need to explore the socioeconomic determinants such as education, poverty, diet and nutrition as contributory factors for poor oral hygiene.

### **2.2.8 Role of Human Papilloma Virus (HPV) in oral cancer**

The incidence of oral cancer seems to be on the rise in tandem with the diagnosis of other factors like viruses (Mehanna et al. 2010; Sharma et al. 2010). A 32% increase in the prevalence of HPV was noted among oropharyngeal cancer cases in the studies conducted before the year 2000 and the studies between the years 2000 to 2009 (Mehanna et al. 2013). The HPV 16 and 18 subtypes mainly cause oral cancer. These viruses were found in approximately 25% of cases in India to 85.7% in Taiwan (Nagpal et al. 2002; Chen et al. 2002). Similarly in Taiwan, even after adjusting for

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<sup>2</sup> Quack is a “fraudulent or ignorant pretender to medical skill” or a person who pretends, professionally or publicly, to have skill, knowledge, qualification or credentials they do not possess (Collins English Dictionary).

age, gender, smoking habits, the high risk HPV (subtypes 16 and 18) appeared as independent risk factors for oral cancer (Chen et al. 2002).

Although evidence from industrialised countries acknowledges a link between HPV and oral cancer, this is far from conclusive and having the HPV virus does not mean it causes oral cancer because some people have the HPV virus but do not go on to develop oral cancer (Campisi et al. 2007). Therefore, more research is needed globally to draw firm conclusions (Khan et al. 2014).

As highlighted in the beginning of this chapter, oral cancer is the most common cancer affecting the population in Pakistan but due to lack of research funding, the patterns of social gradient remain poorly understood. For the purpose of introducing the settings of this research, it is therefore, imperative to have an insight into the social and cultural profile of Pakistan. The following section of the literature review will provide an overview of the demographics of Pakistan including the social profile of the population and oral health challenges faced by the country followed by a review of literature on oral cancer in Pakistan.

### **2.3 Pakistan – an overview of the setting of this research**

Seventy-two years since independence from British rule in 1947, Pakistan remains among one of the developing countries having to confront serious health problems. There are often chronic energy crises, the political influence of the military and a lack of conscience from powerful stakeholders. The latter tend to regard the issue of health as something of minor significance and this casual approach has left the country with several preventable health challenges, which include the incidence of oral cancer. The following sections will briefly introduce the demographics of Pakistan, its state of economy, health systems and major challenges in health and oral health - especially oral cancer.

#### **2.3.1 Geography and population**

The Islamic Republic of Pakistan is located in South Asia (Fig. 2.3) bordering India on the east, China on the north and the Arabian Sea and between Iran and Afghanistan on the west. It is divided into three major geographic areas: the Baluchistan plateaus

in the south and west, Indus River plain in the centre and east and the northern highlands. With a population of about 208 million, Pakistan is regarded as the seventh most populous country in the world (The World Fact book 2018). Almost 40% of the total population lives in urban areas of Pakistan, which are Islamabad, Karachi, Lahore, Rawalpindi, Faisalabad, Gujranwala and Multan.

Figure 2.3 Map of Pakistan



### 2.3.2 Governance

Pakistan has a federal parliamentary government with Islamabad as its capital and four administrative divisions such as Punjab, Sindh, Khyber Pakhtunkhwa and Baluchistan.

### 2.3.3 Religions and ethnic groups

Pakistan is a multicultural society with a rich social and cultural diversity. The main religion practiced and followed in Pakistan is Islam. Christian and Hindu minorities occupy 3.6% of the total population (2010 est.). There are a number of other smaller religious minority groups like Ahmadis, Parsis, Buddhists and Sikhs for which there

are no statistics and little reliable information (Malik 2002). The ethnic groups present are:

Table 2.4 Ethnic groups in Pakistan\*

<b>Ethnic groups</b>	<b>Percentage population</b>
Punjabi	44%
Pathan	15.4%,
Sindhi	14.1%
Saraiki	8.38%
Muhajirs	7.5%
Balochi	3.57%
others	6.28%

\*Data source: The world fact book (2019): <https://www.cia.gov/library/publications/the-world-factbook/geos/pk.html>

### **2.3.4 Family system**

The Pakistani family system is 'patriarchal, patrilineal and patrilocal'. Joint and extended family living arrangement is typical with 6 to 7 people living in one accommodation on average (Tovey et al. 2005). However, some affluent families now also prefer to live independently. Older people in the family are the cornerstone of the house holding an authoritative position where they are treated with respect and reverence (Itrat et al. 2007). Pakistanis also have an obligation outside their immediate families' commonly known as the 'biraderi<sup>3</sup>' system meaning brotherhood (the word 'biradar' means brother). This system is very influential in rural areas of Pakistan whereby the main decisions of marriage, health seeking, and education are usually made with the consent of biraderi (Chaudhry and Ahmed

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<sup>3</sup> Biraderi - It is literally translated as 'patrilineage' referring to network of individuals sharing the same ancestors.

2014). Until marriage, women belong to the biraderi of their father after which they become a part of their husband’s biraderi.

### **2.3.5 The state of the economy**

Decades of domestic political disparity and a reduced level of foreign financial support have led to wide spread underdevelopment in Pakistan. A continuous energy crisis, flood and rains, poor law and order and its recent war with terrorism have seriously undermined its economy. Nevertheless, despite these setbacks, Pakistan has been able to revive its economy and is now experiencing a period of sustained growth. According to the Annual Pakistan Economic Survey for the fiscal year 2018, gross domestic product rate (GDP) has grown by 5.8% after staying at 4.7% for the last three years. This was due to strong growth in Agriculture (the main contributor of GDP in Pakistan) and the Services sector. There remains, however, the issue of the reliability of the Governmental data. Pakistan Economic survey (2017-2018) also suggests that the initiations of China - Pakistan Economic corridor (CPEC), infrastructure and energy projects are the major driving forces behind Pakistan’s accelerating growth. As a result, financial, industrial and service sectors are expected to steadily grow which may lead to thousands of job opportunities and improved economic prospects (adding up to 2.5 %) to the growth rate of the country.

## **2.4 Pakistan at the cross - roads for health**

### **2.4.1 General health profile**

The general health profile of people of Pakistan is influenced by several social, physical and environmental determinants. The table 2.5 shows the key indicators of health in Pakistan, India and the UK.

Table 2.5 Determinants of health in Pakistan, India and United Kingdom\*

<b>No</b>	<b>Determinant</b>	<b>Pakistan</b>	<b>India</b>	<b>UK</b>
1	GDP- Real growth rate	5.8%	6.7%	1.7%
2	Annual population growth rate	1.41%	1.14%	0.51%



3	Population below poverty line	29.5%	21.9% (2011 est)	15% (2013 est)
4	Literacy rate (Age 15 and over who can read and write)	57.9% M = 69.5% F = 45.8%	71.2% M = 81.3% F = 60.6%	99%
5	Unemployment rate (Youth 15-24)	6.6 % (per annum)	10.1%	13%
6	Health expenditure (% of GDP)	2.6 %	4.7%	9.1%
7	Education expenditure (% of GDP)	2.8%	3.8% (2013 est)	5.6% (2015 est)
8	Average life expectancy at birth	68.4 years	69.1 years	80.9 years
9	Infant mortality rate (per 1000 live births)	50 deaths	38	04
9	Maternal mortality rate (per 100 000 live births)	178	174	09 (2015 est)
10	Annual sugar consumption per person	26kg	-	68.4
11	Proportion of population using improved sanitation facilities	45%	39.6%	99.2%
12	Population malnourished (Underweight children under the age of 5)	31.6%	35.7%	-
13	Physicians to population ratio (Per 1000 population)	0.98	0.76	2.83
14	Hospital bed to population ratio (Per 1000 population)	0.6	0.7	2.8
15	Population to dentist ratio	16,854:1	-	-

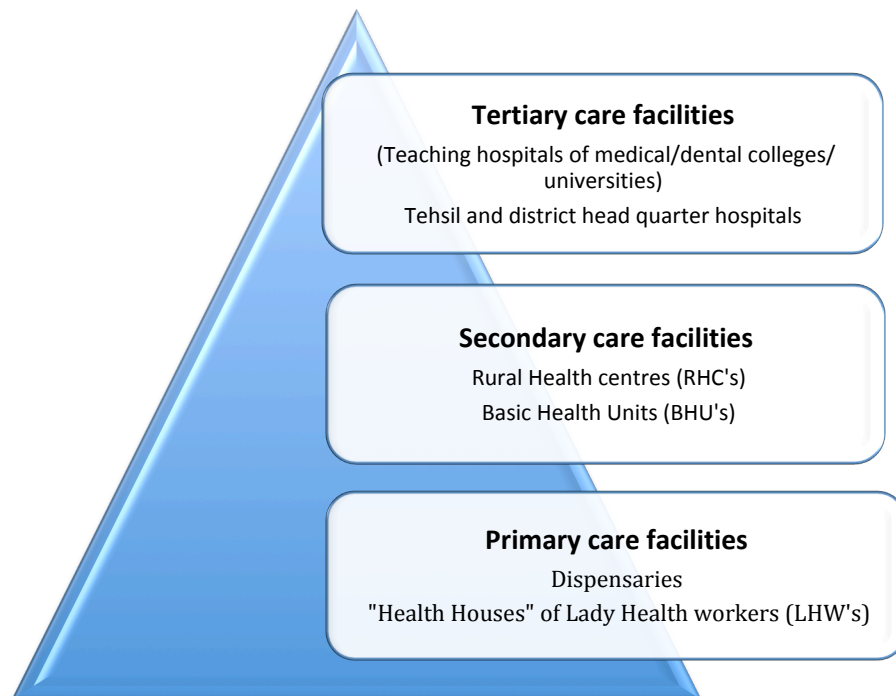
\*Data source: The World Fact book (2018)

#### 2.4.2 The health system in Pakistan

Pakistan has a mixed health care system comprising of government infrastructure, private sector, para – statal health services and philanthropic contributors (Ahmad and Shaikh 2011). The infrastructure of the health care system in Pakistan is based on the framework of the Primary Health Care Approach (PHCA) (Sabih et al. 2010).

Figure 2.4 shows the hierarchy of public health facilities. The first point of contact between the population and health care system is at the primary and secondary level. The lady health worker programme in Pakistan is the most popular and has gained trust from the communities. More than 100, 000 lady health workers and community midwives deliver outreach primary health care and have been immensely successful (Hafeez 2011). Complimentary and alternative medicine (CAM) and traditional healing are also very common in Pakistan (Niaz et al. 2013). The informal structures provide alternative medicine in the form of ‘Tibb - Yunnani’ (Greek Medicine), homeopathy, Ayurveda (herbal medicine), and Chinese medicine/acupuncture.

Figure 2.4 Hierarchy of public health facilities in the health care system of Pakistan



Annually, Pakistan spends less than 0.6% of its GDP on health. Most of which is allocated to secondary and tertiary care leaving very little (merely 15%) for preventive and primary health care. The public sector lacks a skilled workforce for effective and equitable distribution of health services. The public health system is also affected by low performance and lack of accountability within the government.

The private sector consists of comparatively modern hospitals and clinics with state of the art diagnostic and therapeutic facilities (Niaz et al. 2013). The private sector is expensive and contributes least towards prevention and health promoting services. Pakistan has improved in access to health care but despite having primary, secondary and tertiary systems in place, the out of pocket expenditure is still around 70% (Shaikh and Hatcher 2005).

### **2.4.3 Major Challenges to health**

The population of Pakistan has been subjected to a double burden of diseases: both communicable and non-communicable. A geographic disparity exists between provinces, with rural and urban areas and the less affluent areas facing low health outcomes. The expenses for health care seem to affect the less well-off sections of Pakistan more than their counterparts. Access to health care is comparatively better in urban areas although the quality of services is questionable. Belonging to comparatively less affluent sections of society are often forced to seek help from ‘quacks’, who are not qualified and can add to worsening health conditions.

According to the Pakistan National Health Vision (2016 - 2025), the burden of disease is higher in the low socioeconomic areas; many diseases can be effectively controlled using low cost interventions and best practice. The increasing rates of communicable diseases, maternal mortality, infant mortality, underweight children, diarrhoea, respiratory illnesses contribute to just half of the total burden. Polio, hepatitis B and C (7.6% effected individuals) are still endemic in Pakistan. It also carries the 5<sup>th</sup> highest burden of tuberculosis in the world (WHO 2014). Pakistan has some focal areas where malaria and HIV/AIDS is endemic among certain high-risk groups (UNAIDS 2014).

Non-communicable diseases including mental health issues are on the rise. This means there are more people with life altering impairments and early deaths occur among the younger generation (WHO 2014). Poverty is compounded by less or no education, unemployment, gender discrimination and a rise in mental health problems in the recent years. Moreover, the Pakistani print media have published

countless stories where people were forced to commit crimes such as theft and robbery and even took their own lives just because they could not afford the most basic standards of living. The statistical data consistently shows that the majority of the population lives very close to the poverty line while the stakeholders of Pakistan continue formulating policies that result in more poverty (Hafeez 2014).

In Pakistani households taking care of the sick is common and regarded as an important family duty. This means that frequently home treatments are provided to the sick, but when the sickness gets prolonged, more extended family members get involved. Similarly, friends, neighbours and other relatives may well come up with different remedies to cure an ailment. This practice is more common in rural areas of Pakistan where health services are sparse. Women are responsible for taking care of the sick and share different remedies such as what foods to consume and which ones to avoid. In case of men, they share their health problems with their male friends or women in the house. On the other hand, in urban areas, where health services are more accessible, and people are comparatively more able to access care the tendency is for people to know more about illness and disease from a biomedical perspective. So they will frequently know the names of the diseases and common medications (Tovey et al. 2005). Coupled with this is the commonly held belief in 'hot' or 'cold' food in Pakistan. Sick people in the house are often given a balanced diet of food with 'cold' and 'hot' effects to create good health.

#### **2.4.4 Role of gender in health disparities in Pakistan**

The United Nations Millennium Development Goals report in 2011 has highlighted the promotion of women, empowerment and gender equality but countries in South Asia especially Pakistan are far from reaching these targets (Nasrullah and Bhatti 2012). Pakistan also carries a heavy burden of gender inequalities where there is a widening gap between men and women despite all the efforts to curb it.

The status of women is not homogenous in Pakistan and links with several other forms of exclusion in society. A significant diversity in status exists across different levels of the social classes, regions and urban/rural areas. This may be attributed to

uneven socioeconomic growth and the influence of feudal, tribal and capitalist social formations on the lives of women. The deeply embedded gender roles and patriarchal values have placed women in 'reproductive roles' as mothers and wives limited within while men are in a bread-winning role (Asian Development Bank 2000). Home is considered to be 'the legitimate, ideological and physical space' for women, while men rule the world outside the home (Moheyuddin 2005; p. 8). The consequences of such a divide in gender roles has led to low level of monetary investment in women both by the family and the state. Restrictions on women's mobility in certain areas of Pakistan, cultural practices, negative social biases and concepts of honour linked only with women have formed the basis of gender discrimination in Pakistan. Most of the gender related issues in Pakistan are because of the same underlying factors such as preference for sons (Atif et al. 2016), increasing demands of dowry in many regions (Makino 2014) and marginalization of women to agriculture (Drucza and Peveri 2018). This also alludes towards the issue that women are not regarded as economic utility but a burden. The increasing costs of having a daughter and keeping up with the societal demands go hand in hand with forcing families to invest less in their wellbeing. Society also undervalues women and has created a vicious circle in preventing them from adding to the depleting resources; creating the view that they are a drain on society (Fikree and Pasha 2004). If there were more opportunities for women within Pakistani society, rather than being tied to the home, then perhaps perceptions of women would change as they became economic contributors.

Forced marriages are another challenge for women living in some rural areas of Pakistan. Their views are not sought or considered necessary, as the elders in the family are considered to be a better judge of their lives ahead. If a woman in the house tries to protest or raise her voice/exercise her free will, she is considered a 'Kari'- eligible to be put to death by the biraderi (Shameem and Ara 2011).

Professor Kazi (2007)<sup>4</sup>, in the article 'Gender discrimination and the role of women in Pakistan' describes the central idea of this situation as:

*"As soon as a girl grows up to be a teenager, her parents worries start taking shape. How soon she gets married. Will her marriage be a successful one? These are followed by things like the visits of complete strangers to have a look at her and consider her as worthy of getting married to; the tea trolley that she pushes into the drawing room for strangers to have a look at her. The joy of her parents and a girl herself knows no bound when the boy's family says that they want the girl to get married into their family."*

(Kazi 2007)

Shamim and Ara also describes that once married, the daughters are often told:

*"Daughter, now your husband's house is your real house and you should not step out while living."*

(Shamim and Ara 2011, p. 103)

The control of family and society over women is not just limited to their mobility, sexuality, marriage decision and economic dependence on men but also on their access to health services (Qadir et al. 2011). For women, there are high levels of illiteracy; low socioeconomic conditions; early marriages in certain geographic areas; excessive child bearing; and a total lack of control about their lives and bodies, leading to adverse effects on their health. Their inferior position means that women often experience high levels of nutritional deprivation in low-income households. The health indicators of women in Pakistan are amongst the worst in the world with their life expectancy lower than that of men. Alarming low levels of literacy in the rural areas of Pakistan have kept the grips of patriarchy strong on society (Shameem and Ara 2011). For a society like Pakistan, research is not seen as necessary about the status of women. Going through the daily newspapers reveals numerous stories on a daily basis of gender discrimination and sexual abuse. On the other hand, women from higher social classes in Pakistan have greater control of their lives; a comparatively greater access to resources, education, and have better chances of

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<sup>4</sup> Kazi, Shahida (2007). Unfair to the fair sex, Daily Dawn, Karachi.

getting employed (Fikree and Pasha 2004). Issues with women’s health and nutrition status are outlined in the table:

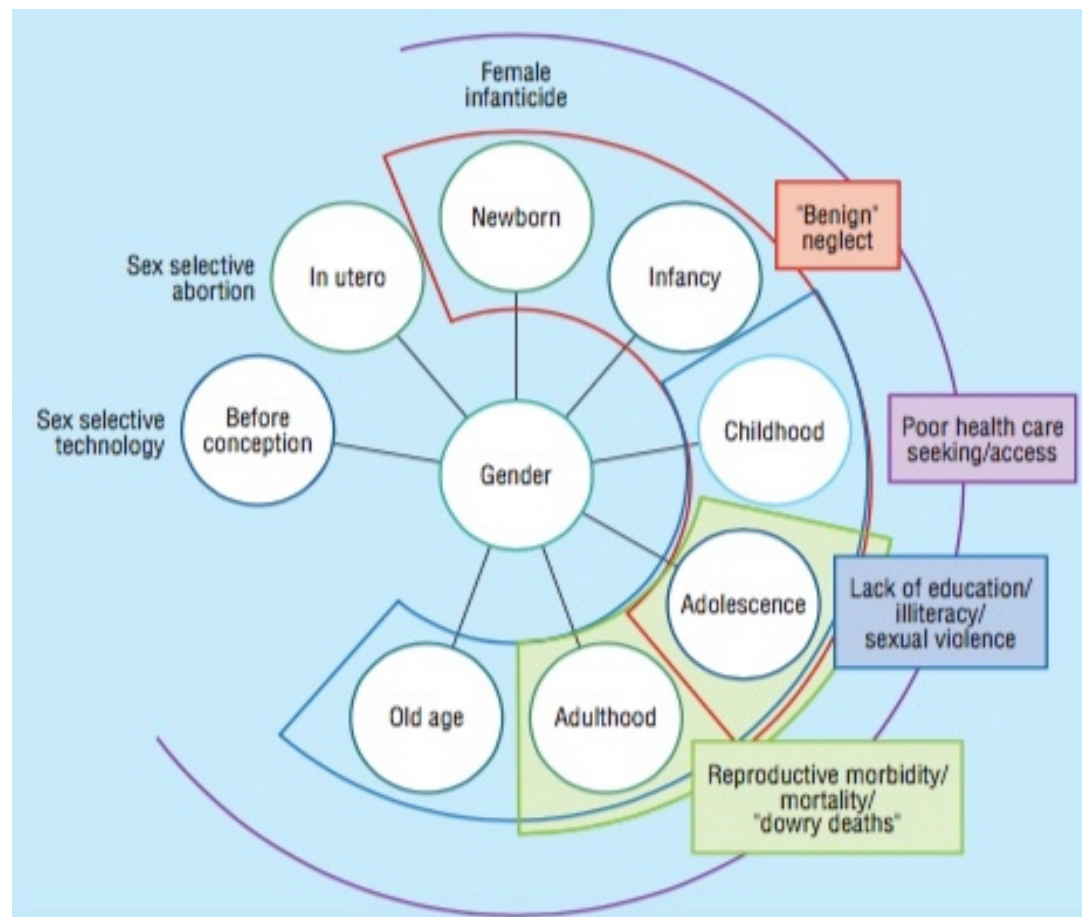
Table 2.6 Problems with women’s health and nutrition status in Pakistan\*

<b>Issues/problems in women’s health and nutrition status</b>	
<b>Immediate</b>	<ul style="list-style-type: none"> <li>• Lack of health services and poor quality of care</li> <li>• Distant and inappropriate location of health services</li> <li>• Inadequate community outreach</li> <li>• Non availability of medicine</li> <li>• High infant mortality rate among women children</li> <li>• Low health and nutritional status of women</li> <li>• Higher incidence of diseases among women</li> <li>• High maternal mortality rate</li> <li>• Lack of women service providers</li> <li>• Weak supervision and monitoring</li> <li>• Illegal and unsafe abortions</li> <li>• Absenteeism of health personnel at service facilities in rural areas</li> <li>• Shortage of competent doctors and nurses especially in rural areas</li> </ul>
<b>Underlying</b>	<ul style="list-style-type: none"> <li>• Poverty</li> <li>• Inconsistent health policies</li> <li>• Restricted budget for the health sector</li> <li>• Early marriages</li> <li>• Low social and economic status of women</li> <li>• Son preference</li> <li>• Overburdening of women with roles</li> <li>• Violence against women</li> <li>• Illiteracy</li> <li>• Restriction over women’s mobility</li> <li>• Lack of women’s access to information</li> <li>• Lack of access to clean water</li> <li>• Limited decision making power in marital relationships</li> <li>• Cultural barriers to discussing sexual issues within and outside marriage</li> <li>• Frequent pregnancies</li> <li>• Patriarchal control over women’s sexuality</li> <li>• No wage incentive for doctors to work in underserved areas</li> </ul>

\*Data source: Asian development Bank (2000, p. 7)

According to Fikree and Pasha (2004), gender discrimination at each step of the women's life cycle adds to this adverse situation, which starts even before conception. An interesting life cycle of gender discrimination in South Asian countries (Fikree and Pasha 2004) and the reasons are being presented in figure 2.5.

Figure 2.5 Life cycle of gender discrimination and health\*



\*Source: Fikree and Pasha (2004; p. 824)

An unsettling aspect of prenatal selection of male embryos is that even educated women who have exposures to the outside world are seeking selective abortion for the sex of the child (Singh 2000; Bindra 2003). This is a common practice in certain communities in India along with female infanticide.

Girls of all ages in South Asia are subjected to a benign form of neglect, which is comparatively less notorious than infanticide. According to World Bank policy



research paper No 1867, this has led to gender based health inequalities especially in the population under 5 years of age. For example, in India or Pakistan, a girl under 5 years of age has a 30 to 50% higher chance of dying than a boy of same age. This neglect ultimately leads to poor health outcomes for girls, attributed to a lack of good nutrition, immunisation and access to preventive (Abbasi et al. 1997; Hassan and Khanum 2000; Pandey et al. 2002). As a result of this neglect in childhood, they experience poor health outcomes in their adult lives as well.

In the South Asian region, early marriages and pregnancy, sexual violence, anaemia, poor nutrition, compounded with limited educational opportunities lead to ill health among young women (Fikree and Pasha 2004). Also, worldwide, women adolescents are increasingly being diagnosed with HIV, are vulnerable to motor vehicle accidents, suicide and drug use (Barker 2000). Suicide among young women is common in South Asia. They also have to bear the burden of the dowry and are at high risk of spousal, family and societal violence (Kumar 2003).

Furthermore, women are more vulnerable to reproductive health hazards. With child marriages seen as the norm in some areas, South Asian mothers are often too young, get minimal pre-birth care and are anaemic and malnourished during pregnancy (Fikree and Pasha 2004). At the national level, registration systems do not accurately reflect maternal mortality particularly well. This is caused, by sepsis, eclampsia, unsafe abortions, and deliveries done at home (often by unskilled attendants). Therefore, the issue fails to be addressed. Women also cite economic conditions and familial opposition as the main reasons for delivery at home as husbands and elders in the family are the main decision maker regarding women's health (Barua and Kurz 2001; Bloom et al. 2001).

Women are often prevented from seeking appropriate health care, yet their burden of disease, maternal mortality and morbidity, and the quality of care they receive is not well documented. As the women in Pakistan age, they experience comparatively more illnesses and loss of daily functions (Kabir et al. 2003). This is often because of

a lack of education, unemployment or dependency on others they become even more vulnerable with age (Prakash 1997).

The patriarchal system reproduces itself and is made stronger through an amalgamation of social customs, practices with religious concepts taught in the home, schools and madrasas, reinforcing its dominance. The whole system is so intricately woven that it is difficult to challenge (Shameem and Ara 2011). Women are asked not to raise their voices and if they do, they are given examples from the Quran and Ahadiths that they shall be burnt in hell fire if they defy or question the will of their fathers or husbands. It is noteworthy that the presented text from Quran is often cited without revealing its true context; this has the effect of keeping the women subjugated (Shameem and Ara 2011). The most worrisome aspect of this is that women learn these roles and passively wait for their destiny, accepting discrimination, unequal treatment and injustice as the norm. Pakistan has numerous generations of such women who have learned to be silent over the course of their lives. They also pass the same learning on to their daughters:

*“The lesson is learned so well, it is hard to unlearn.”*

(Shameem and Ara 2011, 103)

Social gradient also exists and contributes towards the oral health disparities in Pakistan. The following section will describe the situation of oral health in Pakistan with an emphasis on research on oral cancer.

#### **2.4.5 Oral health situation in Pakistan**

As mentioned previously, Pakistan spends 0.6% of its GDP on health including oral health services. According to the latest United Nation estimates, the population of Pakistan is about 200 million with only 15000 registered dental surgeons giving a ratio of 1 dentist to 13000 people (Qureshi and Inayat 2018). Almost 62% of the total registered dental surgeons are women, who either do not practice in long term or do not prefer to work in rural areas of Pakistan. Furthermore, Pakistan has no oral health policy at national or provincial level (Saeed 2015). There have been no vacancies for dentists on the health policy-making bodies in the previous years with

no future oral health proposals. Even in the ‘Vision 2030’ document by the Planning Commission of Pakistan issued in 2016, there is a separate chapter on health but oral health remains ignored. Also, there are no national statistics on oral health status. Nevertheless, small-scale studies on oral health problems in Pakistan suggest that there is high prevalence of caries (Dawani 2012) and periodontal disease (Sufia et al. 2011; Haseeb et al. 2012). People only tend to visit the dentist when their teeth have become grossly carious (Saeed 2015).

The data in Table 2.7 shows various oral health determinants in Pakistani population (Niaz 2013) based on the last oral health situation analysis (Khan 2004) conducted in 2004. This pathfinder survey states the prevalence, severity, geographical and age wise distribution of the common oral conditions in Pakistan.

Table 2. 7 Oral health determinants of Pakistan

No.	Oral condition	Indicator	Value
1.	Caries	Mean DMFT score (12 year olds)	1.38
2.	Periodontal disease	% Population with healthy gums	<28.1%
3.	Malocclusion	Prevalence rate	25%
4.	Oral Cancer	Annual incidence	>4000
5.	Dental Fluorosis	Prevalence rate	31%
6.	Need for prostheses	% Of 35-44 years old wearing denture.	5%
		% Of 35-44 years old requiring dentures but not wearing it.	30%

Although the data in the table appears to show that Pakistan has a low prevalence of caries, it should be kept in mind again that these inferences are not made on a very high quality data (Niaz 2013). The increasing incidence of oral cancer makes it one of the central issues in the public health domain. Oral cancer has become the most

common cancer in men and the second common disease after breast cancer in women (Khan 2015; GLOBOCAN 2018). Around 18, 881 new cases of oral cancer were diagnosed in 2018 with a mortality rate of 13.07% (GLOBOCAN 2018). The data for these estimates has been provided by Punjab Cancer Registry Pakistan. In the absence of a national cancer registry, no proper mortality data are available and these figures are just based on national incidence estimates.

The oral health situation in Pakistan not only demands a focus on oral cancer as a public health problem but also on its prevention and early detection. A clear need exists for formulation of a far-reaching public health strategy to tackle the underlying causes of oral cancer. It is for this reason that it is important to explore the current global interventions that are employed to address oral cancer.

## **2.5 A critique of the current global interventions to address oral cancer**

The predominant approach in dental research to oral cancer is 'biomedical' with a focus on chair side clinical methods and giving advice to patients. The downstream approach to prevention has become dominant (Watt et al. 2015). New generations of dentists are also becoming tied to this approach because historically dentistry was considered interventionist in nature e.g. applying fissure sealants or providing toothpastes. The promotion of oral hygiene products such as toothpastes and mouthwashes act in the interest of influential international companies that have a great hold over the preventive methods employed by the dental team (Watt et al. 2015). Also, the biomedical model follows a reductionist approach focusing on the disease and eliminating the etiological factors at the individual patient level.

Traditional preventive strategies tend to focus on individuals, their lifestyles, their dietary habits, and their choices about health. It has also been considered important to change behaviours in order to lessen widening oral health inequalities (Towner 1993). The basis of this lifestyle approach is that once the individuals acquire necessary skills and knowledge, they are better able to change their habits and behaviours and maintain good oral health (Watt 2005).

The suggested causes of oral cancer appear frequently in the clinical literature with claims that many cases can be prevented if appropriate measures are taken on time. According to Cancer Research UK (2018), almost three quarters of the oral cancers can be prevented if tobacco and alcohol consumption can be curtailed. Globally, screening and patient counselling have been frequently cited in the literature to tackle oral cancer, but little is known about their effectiveness in reducing its incidence, providing early diagnosis and reducing inequalities.

### **2.5.1 Screening**

Screening of oral cancer is defined as “the application of a test to people who are apparently free of disease to identify those who may have oral cancer and to distinguish them from those who may not” (Wilson and Jungner 1968). Identification of patients through mass screening programmes has received a lot of attention but oral cancer does not qualify for many of the criteria required for screening to achieve maximum public health gains in a cost effective manner and is therefore not recommended in the UK (Speight et al. 1993). Only one trial conducted in Kerala, India demonstrated the benefits of screening on mortality and down staging of oral cancers (Sankaranarayanan et al. 2005). However, a systematic review by Brocklehurst et al. (2013) suggested uncertainties in the findings of the Kerala study in providing sufficient evidence to justify the implementation of the screening programme.

A meta – analysis to identify patients with potentially malignant lesions through visual examination demonstrated insufficient evidence to either support or disprove screening (Downer et al. 2004). Similarly, a Cochrane review demonstrated that there is limited data available on tests, such as brush biopsy, toluidine blue or fluorescence to detect oral potentially malignant disorders and insufficient evidence on the specificity and sensitivity of oral cancer screening in primary care (Walsh et al. 2013). Based on these findings, population screening of oral cancer has not been advised. Nevertheless, opportunistic screening of high - risk groups attending dental practices can be employed and may be cost effective (Mulrow 1994; Speight et al.

2006; Subramanian et al. 2009). A major drawback to this approach however, is that high - risk individuals may not be attending dental practices on routine basis (Netuveli et al. 2006). Also, high - risk screening may fit well within a clinical approach to prevention of oral cancer, but it is considered a palliative approach, which does not address the underlying determinants of the disease (Sheiham and Joffe 1992; Batchelor and Sheiham 2002).

### **2.5.2 Patient counselling in tobacco cessation and adopting healthy lifestyles**

The predominant focus of research on the prevention of oral cancer globally has focussed on chair side prevention. In this perspective, the dental team has an important role to play whereby they proactively advise and support their patients to adopt healthy choices. The World Health Organisation (WHO) recommends the adoption of routine brief opportunistic interventions by all health professionals (Raw et al. 2002). In the literature, health professionals are regarded as a credible source of information and therefore important to deliver tobacco cessation advice to their patients (Butler et al. 1998; Rikard - Bell et al. 2003). Dentists and clinical teams are obligated to help their patients in preventing; controlling and managing their oral health and the advice should be tailored to the need and circumstances of each patient (Daly et al. 2013). According to the National Institute of Health and Clinical Excellence (NICE) in the United Kingdom (2006), brief interventions for smoking are time and cost effective, therefore all patients who smoke should be referred to intensive support services.

It is essential that the advice given to the patients be based on scientific evidence in order to ensure maximum patient benefit. Good evidence exists for the effectiveness of smoking cessation (NICE 2006). In a systematic review of physician's advice, Stead et al. (2008) found that a brief intervention increases the quit rate by 1-3 %. On an individual level, it could be regarded as a modest impact, if conducted widely it may help to motivate enough smokers to quit. Evidence from randomised controlled trials also supports the effectiveness of smoking cessation and counselling in adults. For instance, Cohen et al. (1989) and Little et al. (1992) have suggested that there is

comparable effectiveness of smoking cessation in dental practice settings. In these studies, counselling by health care providers including physicians, nurses, dentist and dental hygienist have been shown to increase smoking cessation rates over a period of 6 to 12 months. Case controlled studies have also indicated decreased risk of oral cancer associated with smoking cessation (Blot et al. 1988; Kabat et al. 1994; Macfarlane et al. 1995) whereby after 10 years of cessation, odds ratio for ex – smokers became equal to non – smokers. A 10 year follow – up study in India attributed the anti – tobacco education programme for a reduction in incidence of precancerous lesions in the intervention group as compared to the control group (Gupta et al. 1992).

In terms of prevention of oral cancer, after a comprehensive medical history, and detailed oral examination, three key messages are stressed to patients; they are advised to stop smoking, limit their alcohol usage and eat at least five portions of fresh fruits and vegetables a day (Warnakulasuriya 2009; Daly et al. 2013). It should be noted however that smoking is an addictive behaviour and is difficult to stop. Despite this authors have concluded that advice, help and encouragement from trained dental professionals may have a significant impact on those who want to quit. It is imperative for the dental team to initiate smoking cessation activity within their practice through the framework of 5As - ASK (smoking status of the patients should be established and evaluated at a regular basis), ADVISE (tobacco smokers and chewers are advised on the value of quitting and on the consequences of continuing), ASSESS (evaluate patients motivation to quit), ASSIST (help the patients set achievable targets, give them self-help literature, discard cigarettes in order to prepare the environment and review the past quitting experiences) and ARRANGE ( follow – up visit is arranged, congratulated if successful in quitting and reviewed periodically, if lapsed, asked for recommitment) (Daly et al. 2013). As we can see, these findings have at best questionable relevance to oral cancer in Pakistan where the status of organised dentistry is very different.

The model of 5As is based on delivering a brief intervention to the patient at every consultation (PHS 2008). Although the model is becoming increasingly popular, it can

be time consuming. Also, health professionals routinely report a lack of expertise and time to be the major barriers in delivering smoking cessation interventions (Richmond et al. 2005). Trotter and Worcester (2003) found that in Australia, although the dentists were keen to ask and advise about smoking, they were less interested in giving assistance or following up and were not systematic in their approach to prevention. Similarly, lack of protocol and guidelines for best practice has also been cited as another barrier to provide brief interventions (Edwards et al. 2006). In Canada, patient's resistance and dentist's self-confidence was cited as the main barrier to deliver smoking cessation advice in the dental setting (Campbell et al. 1999).

The dental team may also be able to target young people (11 to 14 year olds) and advise them not to experiment with the cigarettes, as they are vulnerable to getting addicted to nicotine after the first few cigarettes. The dental team therefore is in a unique position to influence this age group and educate them regarding the immediate halitosis and stained teeth which may be a concern for young people and an appealing factor to quit (Daly et al. 2013).

Although these positive changes improve access to preventive dental services and have formed the basis of many oral health preventive programmes, they frequently produce only short-term benefits for patients and fail to make a sustainable improvement or reduce oral health inequalities. It should be kept in mind that although oral cancer can be addressed effectively through primary prevention strategies, changing habits and lifestyle is difficult and slow (Speight et al. 2010).

Focusing solely on behavioural and life style change risks being considered 'victim blaming' (Watt 2007) implying that individuals freely choose their 'health damaging behaviours' and are subsequently responsible for the emergence of the disease (Daly et al. 2013). This implies that individuals are accountable for their own oral health while the social and economic aspects of the occurrence of disease remain unaccounted for (Blane et al. 1996).



Sabbah et al. (2009) in a cross sectional study suggested that changing health behaviours does not in any way explain the existence of oral health inequalities in the United States despite increasing health literacy. The data from an old survey conducted in 1988 – 1994 was used for analysis. Since, it was a cross sectional study, the results could not be used to draw causal conclusions. An absence of data on specific oral health behaviours such as tooth brushing also accounted for the limitations in the analysis. However, the overall conclusions of the study implied that the determinants of oral health inequalities were more complicated than simply changing health related behaviours, such changes, it was argued, were unlikely to abolish oral health disparities.

In a cross sectional survey analysis on a large Australian population, Sanders et al. (2006) reported a lack of significant effect of behaviour change on oral health inequalities. They found that neither dental attendance nor dental self-care behaviours had any affect on reducing inequalities in oral health. The findings from this study suggested that a focus on and understanding factors other than behavioural change in individuals was needed in order to reduce social inequalities. In a similar way, Sheiham (2000) demonstrated that life style is usually considered a 'consciously chosen personal behaviour', leading us to victim blame people if they had failed to adopt health-enhancing behaviours, which is unacceptable. For instance, people respond to stress or poor social circumstances by drinking, smoking and indulging in risk taking and poor diet. Therefore, awareness and knowledge about health are seldom of any value when resources and opportunities to change are non-existent. Personal behaviours are fundamentally determined by socio economic and environmental conditions (Graham 1998). Focusing on changing behaviours distracts from paying attention to the 'causes of the causes' (Sheiham 2000). Behaviours and lifestyle do have some impact on health, but it is crucial to understand the broader context that determines those behaviours. Behaviours cannot be easily changed without probing larger socioeconomic changes (Dahlgren and Whitehead 1993).

It is now accepted that for health services to deliver prevention and treatment effectively, there is dire need for health professionals to understand the factors that influence patients' health, their choices and actions (Daley et al. 2013). The following section will detail social determinants of health based on the Commission on Social Determinants of Health (CSDH) introduced by the WHO (2008).

### **2.5.3 Understanding social determinants of health inequalities**

In order to appreciate the presence of the social gradient and oral health inequalities, it is imperative to understand the determinants of health as pointed out in the beginning of this section. These factors include the place where we grow up, the quality of our early childhood experiences, the level of education we attain, the work we do, the income we generate and the environment that surrounds us. These factors are known as the social determinants of health (Daly et al. 2013). The WHO (2008) defines social determinants as:

*“The structural determinants and conditions of daily life responsible for a major part of health inequalities between and within countries.”*

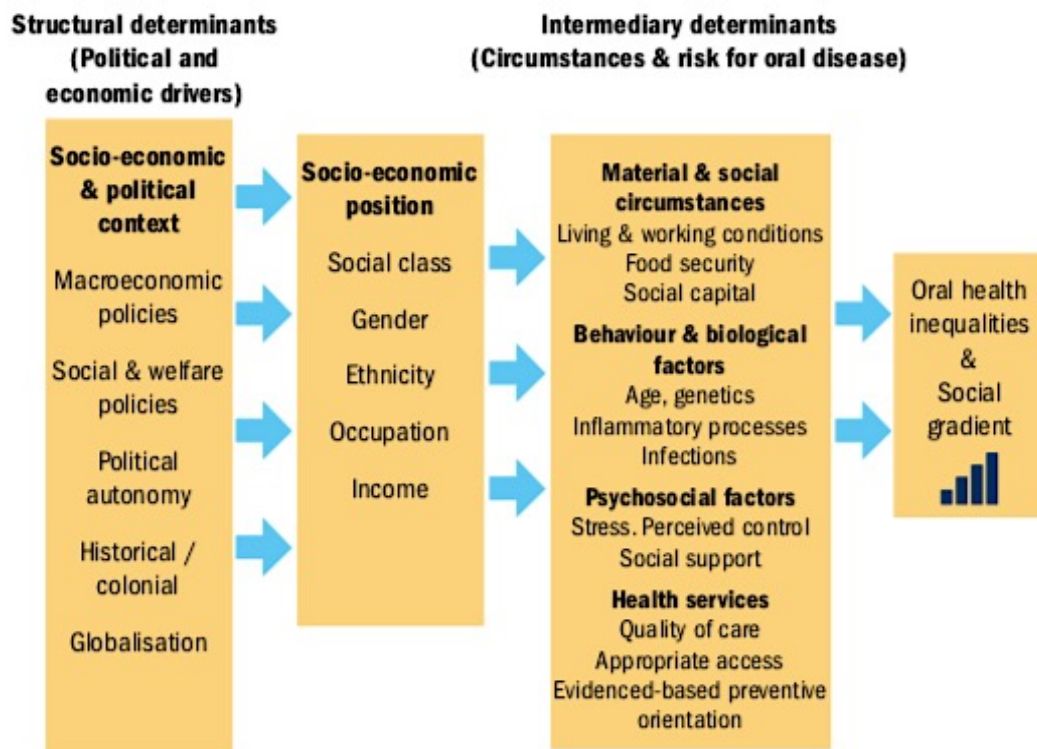
To which Marmot 2007 added:

*“The causes of the causes, the ‘fundamental structures of social hierarchy and the socially determined conditions these create in which people grow, live, work and age.”*

(Marmot 2007, p. 1153)

In a drive to reduce inequalities in health the WHO (2008) led a global public health policy and introduced a Commission on the Social Determinants of Health (CSDH). It identified the fundamental social determinants, including how they relate to each other in creating health inequalities. The key components of the framework include the structural determinants and intermediary determinants. An adapted version (Figure 2.6) for oral health inequalities devised by Watt and Sheiham (2012) will be used to provide a theoretical framework for the purpose of this thesis:

Figure 2.6 Conceptual framework for social determinants of oral health inequalities\*



\*Reproduced from Watt RG, Sheiham A. (2012; p. 293)

### i. Structural determinants

The first key component of CSDH framework (see figure 2.6), ‘the structural determinants’, places emphasis on the socioeconomic and political context, which generate social stratification and socioeconomic positioning of individuals. This term refers to a range of components including all the political and social mechanism that produce, underpin and support social hierarchies incorporating macroeconomic strategy, work markets, fiscal policy, welfare and wellbeing frameworks (Watt and Sheiham 2012). These factors cannot be measured directly at an individual level in society but which nonetheless have a determinant effect on health (CSDH 2007).

Population health researchers acknowledge that the social determinants of health determine the health of individuals and society, but less attention is given on the policies that the government adopts when in power as well as policies that drive those determinants (CSDH 2007). The policies, as Raphael (2006) emphasizes are

reflected in: active employment policies, family friendly labour policies, the endowment of social safety networks and the level of availability of health and social resources for citizens. Good governance, transparency, accountability and political autonomy can help in shaping policy development and its implementation in order to achieve societal benefit (Watt and Sheiham 2012). For instance, the 'global sugar trade' sets an excellent example of how influential and interconnected socioeconomic and political factors are (Mintz 1985). These comprehensive factors lead to class distributions that ultimately identify an individual's socioeconomic position within the 'hierarchies of power, prestige and access to essential resources', fundamentally determining health disparities (Solar and Irwin 2010). The socioeconomic positioning of the individual is a reflection of their social class, educational attainment and their income level. It is also related to the degree of power an individual possesses, their prestige as well as their level of access to support and resources (Watt and Sheiham 2012).

It is argued that health policies directed at the structural determinants of oral health inequalities will pave ways to reduce the social gradient (Strand et al. 2009). How this will work in practice remains to be seen.

## **ii. The Intermediary determinants**

The second and final component of the CSDH framework is intermediary determinants of health. The 'socioeconomic position' tends to influence health through more specific intermediary factors such as: Material and social circumstances including neighbourhood, working and housing conditions; behavioural and psychological factors such as age, genetics, stress and social support. Social position also determines the opportunities and access to formal education, employment, job security and income, working and living conditions, access to the social world, material environment at home, neighbourhood and work place (Graham 2004). People from deprived socioeconomic groups are 'born, live and age' in less favourable environments and therefore experience to comparatively more health damaging behaviours as compared to the more affluent counterparts

(Watt and Sheiham 2012). Educational attainment, income and occupation contribute towards the association between oral cancer and socioeconomic status (SES). Education tends to play a major role because it has a direct causal relationship not only with the individual's childhood experiences but also with their position in society in later life. Education also exerts an effect on occupation, income, development of cognitive skills, decision-making, building and maintaining social relationships, access to health care and awareness of one's own health. Social class positioning not only increases or decreases the chances of unemployment, shorter or longer periods of employment but may also expose people of lower social class to adverse environmental conditions and agents, which can lead to oral cancer or increase the risk of acquiring the disease. The work stress associated that is bundled with lower social class occupations may also increase an individual's susceptibility to oral cancer. Moreover, household income also has a direct effect on health because it influences housing and the environment inside the house. It also determines individuals' diet, access to good quality food, social as well as health services (Conway et al. 2008).

Health care (see figure 2.6) is also regarded as a social determinant of health because of its role in creating inequalities. Benzeval et al. (1995) recognises three ways by which health services can create greater health equity; by ensuring that all the resources are distributed according to the needs of the different groups in the community, by responding aptly to the health care needs of the various social groups and by taking an initiative in the establishment of a strategic public health policy at both local and national levels.

The majority of global disease burden and causes of health inequalities stem from the conditions in which people are born, live and grow old. Therefore it is imperative to address the underlying factors of the disease to curtail inequalities and attain sustainable improvements in health (Sheiham et al. 2011). Governments and health professionals around the world are now recognising the importance of addressing the social determinants of health inequalities (WHO 2008; Petersen and Kwan 2011). The concept of social determinants is not new but constantly evolving similar to the

conditions in which an individual's life is controlled by a wider set of forces, which are inclusive of social, economic and political policies. The literature pertaining to the role of social environment on health is relatively scarce in terms of social inequalities in health and oral health.

## **2.6 How far does research on oral cancer addresses the social determinants of health?**

According to Solar and Irwin (2010), "inequalities in health are determined by patterns of social stratification arising from the systematic unequal distribution of power, prestige and resources among groups in society". The framework of social determinants of health focuses on how socioeconomic status (SES), environmental and political factors determine oral diseases and patterns of health inequalities. Oral cancer like many other chronic conditions may also be said to exhibit a social gradient. Yet the independent role of socioeconomic conditions is often ignored in the literature, perhaps because the predominant model in the literature is a medical model?

A systematic review of the evidence and meta-analysis explored the association between socioeconomic inequalities and oral cancer risk (Conway et al. 2008). Forty-one case control studies were included. Twenty-four of these were from high-income countries and seventeen were from low – income countries. The study concluded that socioeconomic inequalities were implicated in a higher risk of developing oral cancer. Confounding factors including area of residence, poor diet, HPV infection, tobacco and alcohol consumption were not accounted for in the review. Conway et al. (2008) suggested greater consideration of the confounding factors when undertaking research that assesses the association between socioeconomic status and oral cancer.

In order to assess the combined effect of individual and neighbourhood SES on the risk of oral cancer mortality, Lee et al. (2012) conducted a population based follow up study. They found that patients below the age of 65 of low individual SES, living in in disadvantaged neighbourhoods had a higher risk of death compared to their

affluent counterparts. This may be because oral cancer patients living in disadvantaged neighbourhoods sought treatment from local hospitals which were not well resourced (Wang 2001). Also, the main centres for surgery, chemotherapy and radiotherapy are often located in neighbourhoods with higher levels of resources. The access and use of advanced cancer care is not possible for people living in disadvantaged areas and thus forms the basis of inequality in health care provision. People living in less affluent areas also have comorbidities such as depression, occupational stress, and social isolation. These conditions makes it difficult for them to reach out to friends and family for support. Poor treatment compliance has been reported for patients in deprived areas (Peters et al. 2010). However, the mechanisms that are involved in non-compliance; lower levels of education, health literacy, access to transport, food, healthcare, health insurance have not been fully explored (Jin et al. 2008). People with more resources; money, power and connections, and possibly living in more affluent areas may use these resources to access specialized care and improve their prognosis.

The next sections explore how socio economic position (in terms of education, occupation and income) as intermediary social determinants of oral cancer has been researched. Only major research studies have been added to this review of the literature.

### **2.6.1 The role of educational achievement in oral cancer**

Education level has been broadly used as an indicator of socioeconomic status in research. A search on available literature identified that the individuals who acquired only up to middle school education and adopted habits like smoking and drinking alcohol were more likely to be at a risk of developing oral cancer. Literature from South Asian populations like Pakistan, India and Turkey clearly reveal that people with no education (Balaram et al. 2002; Subapriya et al. 2007; Muwonge et al. 2008); those with lower levels of educational qualifications (Guner et al. 2005); and those who had never attended school, or had any formal education (Merchant et al. 2000) were more susceptible to developing oral cancer. In comparison, individuals who

acquired higher education were at a significantly lower risk of developing pre-cancerous lesions (Rao and Roberts 2013).

The risk of oral cancer in Tamil Nadu, India was associated with higher levels of illiteracy. Majority of the sample composed of illiterate people who were at an advanced stage of oral cancer and diagnosed. This might have been due to a lack of understanding and knowledge about the symptoms of oral cancer as well as problems accessing health care facilities (Ganesh et al. 2013). Similarly, work conducted in Turkey demonstrated that oral cavity cancer was directly related to educational achievement where people with little education levels exhibited higher levels of oral cancer incidence compared to well educated counterparts (Güneri et al. 2005).

Low educational attainment was also associated with a reduced quality of life found one year after surgery in people with tongue cancer (Yang et al. 2010). More recently, it has been found that the risk of developing head and neck cancer increases twofold (even after smoking, tobacco and other factors are adjusted) for people with the lowest levels of educational attainment. However, this association was greater for laryngeal and hypo-pharyngeal cancers compared to other oral cancers (Conway et al. 2015).

Work exploring the socio economic determinants of tobacco use in Rawalpindi, Pakistan has found a positive association between tobacco use and residing in a rural area. Low educational status was also regarded as a proxy for low awareness regarding tobacco related health issues (Alam et al. 2008). The study was a cross sectional survey and included one person from each household through random sampling technique. This was done to increase the total number of households being included in the survey. This is important because these methodological approaches may have induced selection bias and therefore the results, should be interpreted with caution.

The studies identified in the literature search have shown that education and socioeconomic status are entangled. For example, Johnson et al. (2012) identified



that people from high socioeconomic status groups tend to be more aware of and are screened for oral cancer. They also had higher levels of educational attainment. This confounding makes it challenging to make definite links between education and oral cancer.

### **2.6.2 Role of occupational status in oral cancer**

Occupation is an important indicator of socioeconomic status. It is commonly believed that unemployment or unstable employment gives rise to anxiety, depression and adoption of unhealthy habits such as alcohol consumption (Popovici and French 2013) and smoking to relieve stress (Jarvis and Waddle 1999). Stress might also add to the situation and further deteriorate health conditions but this is frequently underplayed or fails to be recognised (Moreno-Smith et al. 2010). Unemployment also limits individual's access to health services, their attentiveness to the signs and symptoms of oral cancer and thus leads to poor health outcomes. We have already discussed that socio-economic status is associated with an elevated risk of developing oral cancer and persistent long-term unemployment fits into the category of low SES. This is consistent with studies suggesting that unemployment or discontinuity of employment might be detrimental with regard to oral cancer (Greenberg et al. 2016).

Studies from India suggest that people belonging to low paid occupations were at an increased risk of developing oral cancer (Dhar et al. 2000; Balaram et al. 2002; Muwonge et al. 2008). Similarly tea estate workers in Sri Lanka were regarded a high-risk population (Ariyawardana et al. 2007). Low socioeconomic groups with employment in fishing, agriculture and forestry industries are considered susceptible to oral cancer in Karachi South, Pakistan (Bhurgrri 2005). It should be kept in mind that these studies were conducted in South Asia where there are other socio-economic drivers for health inequalities, which can also influence the development of oral cancer. These include socio economic status in terms of income and education.

### **2.6.3 Role of income in oral cancer**

Household income is one of the main variables on which health outcomes are dependant (Auluck et al. 2016). Most of the survival studies involving head and neck cancer employ house income as the only variable to measure socioeconomic status (Booth et al. 2010; Hwang et al. 2013; McDonald et al. 2014). In terms of pre malignant oral lesions, cost of house was inversely proportional to oral sub-mucous fibrosis and oral leukoplakia; the most expensive house type had the lowest risk of oral leukoplakia and erythroplakia (Hashibe et al. 2003). People from deprived groups were more likely to develop premalignant lesions such as leukoplakia, erythroplakia and sub-mucous fibrosis. Individuals with low incomes tend to smoke cigarettes, consume tobacco and drink alcohol more often as well as consumed less fruits and vegetables, had a reduced were more likely to eat less fruits and vegetables and had a reduced Body Mass Index (BMI) compared to people from higher socioeconomic status (Hashibe et al. 2003).

In Asian countries where more than 40% of the population live below the poverty line, studies suggest that this population experiences the highest prevalence of oral cancer (Bhurgri 2005). This again would link with social determinants exerting an effect on health and the development of diseases like oral cancer. Yet as we can see there are precious few studies from these countries. We could argue that the multidimensionality of socioeconomic status (SES) fails to be captured in many of the studies, which leads to false assumptions about cancer as well as other illnesses/diseases.

We can see that considerable research attention has been paid to identify the risk factors of oral cancer with a little focus on the social determinants of oral cancer and the resultant inequalities. It can be argued that lay perspectives on oral cancer can be useful to provide the patient's understanding of their disease and health inequalities.

## **2.7 Lay perceptions of cancer**

Lay perspectives often differ from those of health researchers and professionals yet are legitimate and add value to the research (Entwistle et al. 1998). The patients may be able to identify the things that they value, or cause problems, or are important to them, which researchers may overlook. They may also be able to raise concerns regarding a particular health care intervention and assist in enhancing the understanding of health technology (Irwin 1995).

It is argued that because lay people do not have formal medical knowledge or are unfamiliar with scientific approaches, they can seldom add value to research decisions. However, in terms of research, each individual brings their own set of skills and lay participants may provide valuable insights. Moreover, participants who have a specific experience of a disease are more valuable than the organisation with a generic health interest. Some researchers argue that the selection of lay people should be done cautiously because of the potential for varying consumer groups with conflicting views for some health conditions (Entwistle et al. 1998).

### **2.7.1 Cultural perceptions about cancer in Pakistan**

The importance of cultural beliefs and values are becoming increasingly recognised as important to understanding health seeking behaviours, prevention as well as the psychological outcomes of post - cancer diagnosis and treatment (Kreuter 2006). Other researchers suggest that it is important to address the beliefs and stigmas related to cancer that have silencing effects in order to more effectively control and prevent (Ling 2006). Even the media have become involved; an article in The Wall Street Journal (Lucette - Lagndo 2008) raised an important concern about why certain ethnic minorities had increased mortality with cancer than the rest of the population. She noticed that although diverse, ethnic groups shared strong beliefs regarding silence around a cancer diagnosis. Some wanted to keep it as a secret from public knowledge or their loved ones, some were reluctant to seek medical advice while some even refused to say the word 'cancer'.

Yet we know very little about how people experience cancer in Pakistan. This is

important because Pakistan has a different social and political context to the West. As a result perceptions about health and disease may also differ. The social and demographic profile of Pakistan may also significantly shape how people react towards advice on screening cancer, diagnosis and strategies to cope with disease. Socioeconomic status and literacy levels may also have an impact on dealing with cancer in a society that tends to believe in myths around certain diseases. For instance, there are various cultural and social myths around cancer; cancer being a punishment from God; cancer being a social stigma, a taboo alongside other diseases such as diabetes and epilepsy (Nisar et al. 2007; Shafiq et al. 2007). Because breast cancer is the most common cancer in Pakistan, majority of the research to explore the lay perspectives and lived experiences of cancer in Pakistan has been conducted on women with breast cancer. The research exploring their lay perspectives has revealed negative perceptions accounting for certain social and cultural factors.

#### **2.7.1.2 The fear of death and stigmatisation associated with cancer**

Cancer signifies death for the majority of people in Pakistan because it is considered an absolutely fatal disease and this belief is transmitted to Pakistani's who have become naturalised in other countries (Leader et al. 2017). This may largely be because of reflections derived from their culture and religious beliefs or most importantly because this is the widely held experience of people from Pakistan and India.

Another prominent aspect related to the perception of cancer is how it is stigmatising and how this can have additional effects on women in particular. The growing cancer burden worldwide, especially in low and middle-income countries has pronounced effects on women because of gender discrimination, cultural taboos and stigma. All these aspects limit women's access to health care (Story et al. 2012). For instance, women in Pakistan do not tend to discuss breast cancer even among their female friends. They also experience grief and anxiety fearing the reaction of their families to the disease. For many women, the diagnosis of cancer brings fear of social isolation from both friends and family because it is regarded as contagious

(Kumar et al. 2010; Sarwar et al. 2015). It is also possible that feelings of isolation could lead to increased anxiety, which in turn may also impact, on survival rates. The fear of transmitting the disease to the future generations can be compounded with poor emotional and physical reactions to chemotherapy leading to a worsening of the personal experience of cancer (Banning 2014).

The stigma of breast cancer in Pakistan is also related to stigma around the breast as an organ. Young girls/women are advised right from their childhood that this organ has to be kept secret. Therefore, any felt condition in the breast is not talked about openly even with friends or parents and as a result disease can remain hidden. Breast disease especially breast cancer has also implications for potential problems in marriage (Leader et al. 2017). In Asian cultures, especially Pakistan, where marriages are typically arranged and family lineage holds importance, if cancer is found in the family, the reputation of the family is tarnished. Also, people worry about children getting cancer (Leader et al. 2017). If diagnosed at an early stage, breast cancer is treatable, but a lack of awareness regarding the breast puts women in danger of being diagnosed at an advanced stage (Naqvi et al. 2018). This is probably one of the reasons that breast cancer tends to be diagnosed very late in Pakistan, leading some researchers to argue that the stigma and shyness around the word 'breast' needs to be addressed (Gupta 2015).

Many of the patients also do not disclose their diagnosis or seek help when they have symptoms because they are unsure about what sort of support they would get from their families and the community around them (Leader et al. 2017). This is important because similar beliefs may exist in people with oral cancer in Pakistan leading to delayed diagnosis and treatment.

### **2.7.1.3 The financial and emotional burden of cancer diagnosis**

The diagnosis of cancer is not only devastating news because of the nature of the disease but also because of its constant monetary strain. Research from Canada reveals that despite state support, the patients and their families have to bear a

significant financial burden (Longo et al. 2006). In the UK, although the NHS offers free treatment for people with cancer, Macmillan reports that 83% of people diagnosed are £570 a month worse off when living with the disease (Macmillan Cancer Support 2013).

In countries like Pakistan, the majority of households still depend on the income of one family member, which is typically the male member of the family. There is a lack of assistance from the government and entire treatment costs (including direct and indirect costs) are borne by patients and their families. Low-income families are often unable to afford cancer treatment (Zaidi et al. 2012). For example, almost 73% of participants in a study on recently diagnosed head and neck cancer and breast cancer revealed that the cost of their treatment was much more than they had anticipated (Zaidi et al. 2012). The situation often became difficult in case of breast cancer especially where women rely on the male members for financial assistance. Likewise, if a male member who is the sole earner is diagnosed with cancer, then financial support becomes very difficult (Zaidi et al. 2012).

Research also reveals that cancer patients in Pakistan tend to hide their health issues for as long as they become apparent. There could be various reasons for delaying seeking help: may be due to the fear of cancer at large, chemotherapy and its side effects, lack of understanding or mistrust in the medical system and doctors. They also avoid diagnosis because they wish to avoid becoming a financial or emotional burden on the family (Malik and Qureshi 1997).

The families of the cancer patients also pose a challenge for physicians, because they may wish to keep the diagnosis and prognosis hidden from patients. This results in the patient being unaware of their diagnosis at the time of presentation to the oncologist. Children do not tell their parents of the cancer diagnosis, conversely, parents do not disclose diagnosis to their children (Leader et al. 2017). It is also believed that information about cancer is mentally torturing for the patient and can make their quality of life worse as they are already fighting with their deteriorating health. There is a belief that letting the patient know of their cancer diagnosis will

hasten death (Malik and Qureshi 1997).

### **2.7.2 Role of religious beliefs and Islamic healing in cancer**

Religion can play an important role in the experience of health and disease. This is particularly relevant in this instance because when individuals are faced with serious or life-limiting diseases such as cancer, they tend to turn towards God or religion as a way of coping (Thune-Boyle et al. 2006). Tix and Fraser (1998) define religious coping as “ the use of cognitive and behavioural techniques in the face of stressful life events, that arise out of one’s religion or spirituality”. Traditionally religious coping was considered as a way to deal with the negative emotions; however (Thune-Boyle et al. (2006) suggests that it has cognitive (such as appraising disease as a part of God’s will) and behavioural (such as praying) components. It is the most commonly reported coping strategy opted for by patients and their families (Pargament 1997). A growing body of research is exploring the effects of religiosity in cancer. For instance, studies have found that religiosity and regular religious attendance has a protective effect against cancer, being associated with increased physical health and longevity (Mytko and Knight 1999; Gartner et al. 1991). Religiosity is also positively associated with health related behaviours (George et al. 2002). It has been demonstrated that with high levels of spiritual well being, the levels of depression, hopelessness and wishing for early death are greatly reduced in palliative care consultations (Hills et al. 2005). In interviews with 100 newly diagnosed advanced lung cancer patients and 257 medical oncologists, faith in God was demonstrated as the second major factor when deciding between different treatment options after recommendations from the oncologist (Silvestri 2003). Physicians, however, felt that faith in God should be the least of the patient’s priority. It could be argued that all those patients who rated fate highly were less educated. Alternatively, it may be that they did not understand the technical aspects of the cancer treatment and that the best way for them to cope was to resort to religion. All patients belonged to the same geographic location, which was known for strong religious beliefs and this was maybe a major limitation of the study.

Islam is the main religion practiced in Pakistan and is an integral part of everyday life. Islamic practice is guided by the Quran and Sunnah which both place emphasis on having a good health. In the Quran it is stated: “And when I am ill, it is (Allah) who cures me” (26:80). Therefore, like all other affairs of life, people turn to Allah (God) and Quran to seek cure for diseases as well. It is taken into consideration when deciding between consultation with medical doctors or spiritual healers (Tovey et al. 2005). In semi-structured interviews conducted with 30 breast cancer patients in Pakistan, belief in Allah and prayer were among the most popular coping strategies (Banning et al. 2009). Women used their belief in Allah to cope with the diagnosis. It was also considered as an essential source of strength for treatment, reduced their fear and anxiety and gave them hope for the future. The majority of women in the sample resorted to praying as a means of gaining strength and support from Allah. They recited Surahs from the Holy Quran repeatedly to strengthen themselves in the face of disease. They had the belief that cancer was from Allah and only ‘He’ would cure it (Banning et al. 2009). It is not unusual for Muslim women to gain emotional support for the cancer and its treatment through prayers and reading verses from the Quran. Women in Iran (Taleghani et al. 2006) and Malaysia (Shah et al. 2017) have shown comparable positive attitudes towards breast cancer and its treatment because of their strong belief in Allah and prayers.

Similarly, in a questionnaire based study on the influence of cultural practices and religious beliefs on decision making in 241 cancer patients in Pakistan, it was found that almost 60% of the sample believed that by performing certain religious rituals, they will be able to get rid of cancer (Kumar et al. et al. 2010). Of those that responded, 5.7% regarded cancer as an infliction that had resulted from past sins, as a punishment from God or not believing in a higher power. Negative beliefs like God’s curse, not following religious practices well, ill wishes, the evil eye and immoral behaviours were also regarded as causes of cancer. It was also found that women participants were more influenced by such beliefs and this means that they may well be predisposed to the use of alternative therapies.



### **2.7.3 Use of alternative therapies for treatment of cancer in Pakistan**

Definitions of 'traditional' (TM) and 'complementary' or 'alternative' medicine (CAM) are hotly debated. There is often no set idea as to what constitutes these practices. They are frequently agenda - driven and political with much historical and cultural variation (Frank and Stollberg 2004). For the purpose of the context of this thesis, CAM practices will be referred to health care practices not offered as biomedical treatments in Western nations (Zollman and Vickers 2009). As I have already discussed (see section 2.4.2 The health system in Pakistan), Pakistan relies on many religious, traditional and professional sources of health care from local 'quacks' to modern hospitals and clinics with highly qualified doctors and dentists. According to the WHO (2017), almost 70 % of the Pakistani population especially those from rural areas use traditional and CAM medicine. Yunnani Tibb and Hikmat (traditional healing) and spiritual healing are the most popular in Pakistan. In the case of cancer, particularly, these methods are used before receiving any medical treatment because they are regarded as non-toxic and inexpensive by the patients (Malik et al. 2000).

#### **2.7.3.1 Use of Yunnani Tibb**

Yunnani Tibb is a traditional system of medicine practiced among Muslims mainly in South Asian countries. The word Yunnani means 'Greek'. The Yunnani medicine is based on the concept of humoral theory of illness and so involves a number of minerals and herbs. The practitioner of this medicine is usually known as 'Hakeem' (Shaikh and Hatcher 2005). Hakeems are trained through a process of apprenticeship (Tovey et al. 2005). There are some well-established institutions for this practice in Pakistan and the adoption of this method generally runs in the family. These institutions are under the direct control of the Ministry of Health of Pakistan, in order to regulate and maintain standards of health and education. Approximately, 51, 600 registered Yunnani medical practitioners serve the nation in both rural and urban areas of Pakistan (WHO 2017). A structured survey on the use of TM and CAM practices of 362 cancer patients (with breast cancer, throat cancer, haematological

malignancies, cancer of the uterus and cancer of abdomen) was conducted in four different hospitals in Punjab Pakistan. The findings demonstrated that 84% of the cancer patients had used one or more form of TM or CAM including spiritual healing, Hikmat and homeopathy. Among them, Hikmat was opted by 35% of the patients. A distinct relationship between level of education and use of Hikmat was also exhibited. The higher the level of education, the less likely patients were to utilize Hikmat. As this study was done in only four hospitals of Lahore, Pakistan, there may be a possibility that cancer patients living in remote areas of a Pakistan could not be accessed in this survey. These results may also differ if a nationwide survey is conducted.

Similarly, work involving 158 cancer patients in Pakistan, found that almost 70% of the patients were aware of their diagnosis of cancer and 48% had used some form of traditional therapy (Malik and Qureshi 1997). Hikmat and homeopathy were the most commonly used before visiting the doctor. It was noteworthy that socioeconomic or educational status was not associated with the use of alternative methods. This means that cultural practices and their beliefs are so widespread and important to people that even getting higher education or living well does not change their perception. However, family size also had a significant effect on the choice of alternative methods attributable to different opinions and suggestions. The length of time that was spent on obtaining the alternative therapies was 6.6 months, which might be responsible for late presentation and diagnosis of cancer in developing countries

There is no reported data on the effects of this therapy on oral cancer patients in Pakistan.

### **2.7.3.2 Spiritual therapy**

Spiritual healing is the second most common method of treatment delivered by holy men known as 'Piirs', providing spiritual therapy either personally or through a designee (Tovey et al. 2005). Ciftci et al. (2012) reports that low socioeconomic

groups in Pakistan do not report to medical services because they take illness as a blessing or punishment from God and instead of availing medical therapies, they get involved in setting their deed right and contacting faith leaders. From mental health issues to fertility issues, the first point of contact is faith healers who have a tremendous psychological influence on patients as well as their families (Saeed et al. 2000). Majority of the clients of these faith healers are uneducated women. This finding is consistent with the findings of Farooq (2006) who found that most of the traditional faith healing was employed by the women in the sample who were uneducated, under privileged and vulnerable. Similarly, Qidwai (2003) conducted a study on 387 mental health patients in Karachi and found that 45% of the total sample had visited the faith healers, mainly because of family recommendations, belief in spiritual healing and the belief that medical physicians are unable to cure them. Mirza et al. (2006) also suggest that traditional faith healing is the most popular choice for people with mental health problems in Pakistan.

In terms of curing physical ailments like cancer, people in Pakistan often visit the shrines and tombs of piirs. Most of these people are of the view that cancer is a disease caused by some spirit or 'jinn', who have cast a shadow on the person. It is believed that only 'Piirs' can manage this situation via amulets or by reciting holy verses and blowing on the patient. Some cancer patients even have to undergo physical torture as treatment. For example, red-hot iron bars are placed on the patient's chest or abdomen as a part of the treatment. The patient apparently does not feel any pain (Tovey et al. 2005).

People living in the remote areas of Pakistan mostly use spiritual and faith healing instead of conventional medical therapies because of their cheap availability, closeness to where they live, family pressure and affordable fee (Shaikh and Hatcher 2005). It can be argued that although a lot of time is wasted in consulting the local healers and homeopathic treatments, which are comparatively cheaper and affordable, if people living in remote areas of Pakistan are to access proper cancer treatment centres then there needs to be more resources, attention paid to the

infrastructure of the country, and more focus on supporting people who are unable to afford healthcare.

Currently, there is only basic data available on the use of alternative practices in terms of oral cancer in Pakistan. No existing work aims to explore or understand the underlying decision making process. Also, the effectiveness of Hikmat and spiritual therapies in oral cancer has not been the subject of research. It may be because there is an underlying reluctance to question or test anything that has a spiritual or religious element. Nevertheless, there is a need for explicit studies for low and middle-income countries like Pakistan to explore the patterns of complementary and alternative therapies in the social context.

The summary of the main conclusions from the literature review and rationale for this research study will be described in the section below.

## **2.8 Rationale – aims and objectives**

As we can see from the literature review, the current approaches to understanding the experience oral cancer are predominantly conducted in countries where the incidence of oral cancer is relatively low. There are no studies exploring the meaning of oral cancer from the perspectives of people living within countries where the incidence of oral cancer is relatively high. We therefore know very little about oral cancer from the point of view of those who experience the condition especially from populations in the Global South. We also know very little about the social context of oral cancer from within countries where the prevalence of oral cancer is relatively high. In addition, most current research is from the perspective of a social epidemiology that focuses on behavioural habits and life-style risk factors including the use of tobacco, smokeless tobacco such as betel quid and naswar. There is very little focus on the social determinants of health. Where research does exist that focuses specifically on countries like Pakistan the focus is once more on risk factors. Only a handful of studies have explored the attitudes, awareness and knowledge of smokeless tobacco users. There is therefore very limited evidence concerning the complex interplay between gender, socioeconomic status, religious practices and

health.

This is important because people from low socioeconomic groups with strong religious beliefs experience the highest rates of oral cancer. Yet the voices of people with the disease are largely missing, this includes the voices of women in particular. In the absence of a national cancer registry, there is limited data to influence health policy in Pakistan and there is a need to develop an approach that is much more sensitive to the needs and views of people with the disease. It has been demonstrated that sustainable improvements in the health of the population can be achieved by addressing the 'causes of the causes' (Sheiham and Watt 2000). If this is to be achieved with respect to oral cancer we really need to start understanding what these might be within Pakistan.

The aim of this thesis therefore is to explore how people make sense of their experience with oral cancer from within the social context of Pakistan.

The objectives of this thesis are:

1. To recruit a sample of people with oral cancer in order to get a sense of what oral cancer means to them.
2. To collect data using a well-defined methodological tradition
3. To subsequently conduct detailed analysis of these results whilst making sense of how people experience oral cancer from within Pakistan, including how these findings might relate to the social determinants of oral cancer, from their perspective.

## Chapter 3. Methodology

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## Chapter 3. Methodology

### Summary of structure of the chapter

The first part of the chapter begins with a detailed discussion of oral history as the chosen research method to address my research question. The key methodological aspects of oral history important for my study will also be reviewed. The final part of this chapter will detail my reflexive position as a dentist who grew up in Pakistan.

Oral History promised to both document and present the in depth narratives of people with oral cancer; a process that has rarely occurred throughout the history of Pakistan.

### 3.1 Oral history – method of choice

This study uses oral history methods and techniques to involve people with oral cancer in Pakistan with the aim of understanding their life histories, including their disease experience. It was imperative for me to employ a method that focused on the participant's perspectives and was more than just uncovering facts about their lives and past. It was also important to choose a method that sought out the inclusion of individuals or groups that are silenced, marginalised or had their experiences and point of views left out of the historical record. It was also necessary to choose a method that was able to provide me with the intended in depth data appropriate for my research question, within the specific time frame for my PhD study.

Oral history was chosen as a research method because it addressed the aim and research question of this study in the best manner. Oral history is different from other forms of qualitative research in its ability to learn about participants lives in a holistic manner from their own perspectives, how they form meaning, their feelings and emotions, what they deem as important, the relationship between different periods in their lives, their perspectives and “their own voice on their own life experiences” (Hesse-Biber and Leavy 2011).

According to the Oral History Association (2018), oral history can be defined as:

*“A field of study and a method of gathering, preserving and interpreting the voices and memories of people, communities and participants in past events.”*

(<https://www.oralhistory.org/about/do-oral-history/>)

Oral history was ‘the first kind of history’, according to Paul Thompson (1978) in ‘The Voice of the Past’, a key publication in oral history. He insists that all history ultimately depends upon its social purpose. Thompson states that through reflecting on history, ordinary people appreciate and comprehend the changes, which they experience in their lives. Oral history can “give back to people who made and experienced history, through their own words, a central place” (Thompson 2008, p. 3). His original work was published in 1978, which helped in making oral history widely acceptable as a methodology.

Oral history is a method of qualitative research that emphasizes participant’s perspectives and follows an open-ended interview model, which involves story telling: the researcher guides the process and the participant narrates their story (Leavy 2011). The participants are the ‘knowing parties’ with important knowledge to share. Oral history as a method of research helps the researcher to explore major social shifts by understanding how individuals make sense of the experiences and the meaning they attach to them. It relies on memory whilst acknowledging that memory can be partial and unreliable (Ritchie 2015). The qualitative approach utilised by oral history enables the researcher to get close to the subjective experiences and the views of the participants and gain insights into how and why things happened (Roberts 2002). Oral history as a research method compels us to make sense of many hidden meanings and interpretation of what is residing within the confines of people’s memories. It also helps in understanding how participants make sense of difficult events in their lives through the process of remembering. Whilst memory can change over time, oral history is an important tool to understand the way memory is constructed (Clark 2002). The researcher prompts the participant to remember their life experiences and through this process a narrative is generated.



The information about the past that is uncovered in the interview is interpreted as far as possible from the perspective of the participant. The interactive process between the interviewer and the participants makes oral history a peculiar historical practice, different from other approaches (Abrams 2010). This collaboration and the process to sought out meaning is a fundamental aspect of oral history interviewing (Leavy 2011).

### 3.1.1 How is oral history different?

In order to illustrate the distinctiveness of oral history interviews, it is important to contrast these with other interview approaches such as the biographic narrative interpretive method, in-depth interviews and structured interviews. The table (Table 3.1) below provides a summary of the distinguishing features of these methods:

Table 3.1 Summary of comparisons of interview methods\*

<b>Interview methods</b>	<b>Distinguishing feature</b>
Minimalist biography interview	Open-ended, employs minimal passive interviewing technique, on-going interpretive process, minimum of two interview sessions, begins with one open “narrative” inducing question.
In – depth interview	Topic is focused, one interview session per participant, interview guides; continuum of structure, depth is valued over breadth.
Structured interview	Larger pool of participants, breadth is valued over depth, high levels of comparison.
Oral history interview	Open-ended, taps into processes, micro– macro links, comprehensive understanding, bearing witness/filling in the historical record, participant– researcher collaboration, emphasizes participants’ points of view.

\*Source: Leavy (2011; p. 21)

The biographic narrative interpretive method is considered the most open – ended type of qualitative interview (Jones 2003). It has been in use for over twenty years

theorised by Tom Wengraf. A minimum of two interviews with one participant is required (lasting from 45 to 60 minutes). The first interview session involves a 'minimal passive interviewing technique' whereby the researcher opens with an open and 'narrative inducing' question and then allows the participant to tell their story without any interruption (Wengraf 2001). Rapport building is essential for this kind of interview, which is essentially maintained by visual cues such as nodding and eye contact. This approach to interviews is based on the notions that "pre conceived ideas or questions may 'obscure' parts of data that are 'nested' within something else" (Jones 2003, p. 61). Analysis is done after the first interview session. In the second interview, follow-up questions are asked followed by another analysis. If needed, a third interview may be conducted. Jones (2003) notes that by using a non-interruptive approach, integrity of 'gestalt' (the constructed shape of a story, through theme, motif and/or various agendas – hidden or otherwise (p. 62)) is retained. He also suggests that traditional interview practices may reduce the 'essence' of the story.

Another approach involves in - depth interviews which are mainly focussed on the topic. In-depth interviews are usually employed to explore the shared understanding of a particular group in which participants are fairly homogenous and share similarities (Kuzel 1999). One interview per participant is conducted lasting from 45 to 75 minutes. These interviews generally consist of open-ended questions with a lot of latitude for the participants to answer. In - depth interviews are conducted with a larger sample of participants as compared to oral history interviews (Leavy 2011). Typically, the researchers prepare interview guides that may include topics, themes and specific questions to be asked from participants. The extent to which the researcher structures the interview guides may vary dependent on how (un) structured the interview will be. It is dependent on how much length and breadth is sought from each participant. It may be useful to see what comparisons are intended amongst participants. Additionally, the researcher may use an interview guide that follows up on the cues given by participants; hence, it is the participants that provide most of the structure to the interview (Fox 2009).

In case of structured interviews, a large pool of participants are involved. Strict interview guides are followed which contain highly structured questions. Same questions in a similar order are asked from participants. The questions may be open ended and if a participant deviates, the interviewer guides them back to the questions on the guide. In many structured interviews, the answers or possible choice of answers are also set in advance (Fox 2009). Structured interviews are more focussed on the breadth of the topic rather than depth and so mostly generate quantitative data. This data can often be directly entered in the computer for analysis thus reducing time for coding and content analysis. However, a high level of comparison can be made between participants in structured interviews (Leavy 2011).

In comparison, for oral history the data is usually generated through open ended and extensive interviews, with the focus of providing a complete understanding of certain experiences (Leavy 2011). Oral historians may conduct several interviews with each participant allowing the participants to feel free to construct their own narrative (Ritchie and Lewis 2003). Roberts (2002) stresses that oral history provides the individual with the authority and freedom to share what they see as important in daily life and how they interpret their past. The interviewing techniques embedded within qualitative research strengthen the oral history process. For instance, rapport building fosters trust between the interviewer and participants. Recounting and remembering personal experiences can be extremely cathartic for participants (Lowes and Gill 2005) because they are given an opportunity to talk and reflect at length with a non-judgmental and empathetic interviewer. Oral historians tend to spend comparatively less time with their subjects as 'observers' but may devote more time with each participant over the course of several interviews. Oral history therefore depends on the skill of the interviewer as well as how long participants can spend time giving interviews (Meyer and Crothers 2007). Extensive interviews along with gradual construction of the questions are underpinned by a thematic approach. A participant may give surface level initial responses, but follow up questions obtain a deeper and rich interpretation of feelings, reasons, opinions, and meaning (Batty

2009). Also the face-to-face experience in the oral history interview may facilitate and enable both the researcher and participant to generate an interactive environment (Ritchie and Lewis 2003). Rapport building may also help produce greater depth in narratives and a holistic understanding of the participant's experiences (Leavy 2011).

The use of oral history has a number of positive implications for my research of which the most important is that it gives a voice to groups that are otherwise 'hidden from history' (Thompson 2000). Oral history is also capable of empowering marginalized groups of society (Hesse - Biber and Leavy 2011) and thus suitable for addressing my research question. Oral history proved appropriate for the current study because the voices of people with oral cancer are unknown to the wider population. Acknowledging the fact that oral history is about real people, Abram (2010) insists that the uniqueness of oral history gathers around communication with living breathing human beings (no other history method does that). Another strength of oral history is that it enables the researcher to study the process (Hesse - Biber and Leavy 2011) for example, in the current study, oral history will not only help me understand what are the feeling and perspectives of people with oral cancer at present but also the 'process' that led them there. Further, oral history can place emphasis on critical experiences in participants' lives, how and why those experiences are critical, and what meaning is associated with them (Patel 2005). This was important for my study, as the participants may have experienced certain critical periods in their lives that shaped their current social realities e.g. financial problems in childhood, loss of parents, marriage, and disease in adulthood. My study seeks to explore what meaning they attach to those critical experiences? What was their daily life like before these critical periods? How it changed after including how participant's interpersonal relationships were subsequently impacted?

Smith and Bornat (1999) suggest that since oral history recognises the way people's lives are interconnected, it is a suitable approach for medical practice. In relation to the patients, oral historians and the historians of medicine have increasingly become interested in the patient's story as Roy Porter (1985) identified:

*“ We have histories of disease, but not of health, biographies of doctors, but not of the sick.”*

(Winslow and Smith, p. 377)

The patient’s story has been an important part of the history of medicine. Oral history studies began to address the invisibility of the patients and included stories of people who experienced certain diseases and treatments. The notable examples cited by Winslow and Smith (2011) in *The Oxford Handbook of Oral History* are: Sanjiv Kakar (1996) who studied the leprosy sufferers in British colonial India, Claudia Malacrida (2006) recorded testimonies of the people affected by disability policies and practices in Alberta, Canada and Kerry Davies (2001) who worked on people with a history of mental illness and found how they were silenced by their ‘objectification’ as the ‘patient’. The Oxford Centre for Diabetes, Endocrinology and Metabolism (OCDEM), UK, has also used oral history whereby participants shared how diabetes affected their quality of life in terms of work, family and friends. They vividly recollected and explained their encounters with health services and clinicians and reflected on how these experiences changed over time (Diabetes stories 2005). Similarly, an oral history project called ‘Nurse’s Voices’ was conducted in London hospitals in 2015, highlighting the experiences of midwives and nurses. Over 300 interviews with nurses and midwives were recorded who had received training at one of St George’s Hospital, Guy’s and St Thomas’ Hospital or St Bartholomew’s Hospital. The aims of the project were to compare and contrast the experiences of the nurses at these hospitals during great social change and subsequently create an archive of their memories. This was an initiative to empower the voices of nurses and to view the way they absorbed changes and developments at these London teaching hospitals, with oral history used to understand these processes.

In terms of cancer, oral history has been used to explore how the family members of a child with cancer manage the illness at home (Misko and Bouso 2007). In this study, oral history was used as a methodology to record experiences of people in the context of their social life. Similarly, a childhood cancer sibling’s oral history has also been recorded in order to explore how cancer alters lives of family members (Lehna

1998). Because of the ability of oral history to give a voice to the patients and record experiences with disease, oral history is deemed to be a suitable method for my research - to record the experiences of the people with oral cancer in Pakistan.

Furthermore, since 2007 oral history has been used to record and archive the voices of patients at the Sheffield Macmillan Unit for Palliative Care (Northern General Hospital) thus enabling them to produce an audio recording of their unique life experiences. These recordings capture the voices of individuals and enable them to recall and enjoy talking about their lives (Winslow et al. 2009). The process of recall appreciates their sense of identity, can raise self-esteem and serve as a legacy for families. Health care professionals can acquire a deeper insight into the condition of their patients while health care research teams gain information on how life-limiting diseases affect people differently (Winslow et al. 2009). Oral history helps clinicians to understand the perspectives of the patients regarding a disease, the impact it has on patients, treatments at home and hospital, and relationships between the patient, family and the hospital (Winslow et al. 2009). It is evident that oral history can be used as a method to understand the perspectives of patients, including how they perceive their lives and their disease in a social context. These oral histories may be used to inform and develop a sensitive oral health care system in Pakistan.

Finally it is important to review the potential benefits that patients involved in the oral history may experience. It is argued that oral history helps raise self worth and esteem because patients have an opportunity to create their own narratives, they are the authors of their own stories (Winslow et al. 2011). The experience of sharing their life stories, thoughts and feelings may be validating and rewarding. Oral history may also highlight meaning in life experiences whilst creating a family history and a legacy. It also provides participants with a chance to reflect as they construct their story (Patel 2005) leading to a greater understanding and making sense of themselves.

The following section will detail how oral history has developed as a research method and how these developments have led to the key approaches within the method and thus aided in my PhD study.

### 3.2 Oral history and its key methodological aspects

#### 3.2.1 Variation in the definition of oral history

Oral history has been defined in many ways. Table 3.2 demonstrates these variations.

Table 3.2 Varying definitions of oral history

Grele 1973	“The interviewing of eye witness participants in the events of the past for the purposes of historical reconstruction.”
(Thompson 2008, p. 22)	“Oral history is as old as history itself. It was the first kind of history.”
(Abrams 2010, p. 3)	<p>“It is the process of conducting and recording interviews with people in order to elicit information from them about the past.”</p> <p>And;</p> <p>“Oral history refers to both the research methodology (a means of conducting an investigation) and the result of the research process; in other words, it is both the act of recording and the record that is produced.”</p>
(Hesse-Biber and Leavy 2011, p. 133)	<p>“It is a kind of intensive biography interview...and a collaborative process of narrative building.”</p> <p>“Oral history is a methodology that allows us to get at the valuable knowledge and rich life experience of marginalized persons and groups that would otherwise remain untapped, and, specifically, offers a way of accessing subjugated voices.”</p>

(Yow 2014)	“ A process of recording personal testimony delivered in oral form.”
(Ritchie 2015, p. 1)	“ A process of collected memories and personal commentaries of historical significance through recorded interviews.”

It can be noted in the definitions that oral history has changed its focus from the ‘eye witness’ approach towards the subjectivity of the narrator. Taking Grele’s definition for instance, interviewing (through recording, transcribing and archiving) and historical reconstruction (in order to interpret and represent past) are still an important part of oral history methodology. However, the oral history of today is less concerned with the objective eyewitness accounts and concentrated more towards experience, subjectivity and historical imagination (Summerfield 2016). This is useful because as a methodology oral history would enable us to explore how people with oral cancer use their historical imagination to make sense of the disease as they live within their particular social context. Bearing in mind there is nothing from their point of view in current perspectives on oral cancer.

The shift to the study of subjectivity is attributed to the transformation of oral history in recent years. Accordingly oral history has undergone four major paradigm shifts in theory and practice; from the post war renaissance in the use of memory as a source of ‘peoples history’, post positivist approaches to memory and subjectivity, the shift from objectivity of the oral historians to subjectivity of oral history relationships and lastly the digital revolution in the late 1900s and early 2000s (Thomson 2007). These developments have led to several important approaches within the method that have become central to oral history. As we shall see, the aspects of memory, subjectivity and intersubjectivity of oral history can help us better explore the social and cultural context of oral cancer from the perspective of those who experience it. These key aspects remained prominent in my research and will be demonstrated throughout the thesis. I will now provide a brief summary of these key developments:



### **3.2.2 Use of memory as a source of people's history and the inclusion of the ordinary**

A key development in the practice and theory of oral history was to understand memory as central to research methodology (Thomson 2007). As mentioned earlier, one of the paramount interests of oral history has been to give voice to those that have been 'hidden from history'. Perks and Thomson (2006) regarded this as the first paradigm in the advancement of oral history. Through oral history, these non-authoritative marginalised voices can contribute by 'inscribing' their experiences on the historical record, offering their own interpretations of the processes (Kothari and Hulme 2003). This may add heterogeneity to more traditional data collection methods and allow evidence from a new direction. As mentioned previously, for participants of oral histories, it may be the first time that anyone has ever taken an interest in their lives and seen value in their opinions and perspectives, therefore oral historians 'empower' their interviewees by encouraging them to take the lead in the conversation. This power as High (2009) notes can be derived from 'being there and telling it like it was'. Nonetheless, power imbalances exist between oral historians and their interviewees and will be discussed in detail in the subsequent sections.

In the US, Allan Nevins at Columbia University in the 1940's focussed his work on the lives of the 'elite' and their contributions towards political, professional and social life (Thompson 2000). All oral history projects focused on people of stature, key figures, politicians, senators, publishers, cabinet members, civic leaders, business executives, moments and eras of social and political importance (Young 2006). The experiences of people who were considered ordinary by historians were excluded. The excluded groups included working class, the poor, non – whites, women, non – heterosexuals and people from minority groups (Young 2006). Later in 1960s and 1970s, with the widening of the scope of oral history in the USA the 'no elites' were also interviewed and so were racial groups, ethnic, women, blue-collar workers and ordinary political workers (Ritchie 2015). In contrast to the 'great men' approach in the US, the oral history projects in the UK and Europe incorporated the social

histories that targeted the everyday lives and experiences of common people (Ritchie 2015). For instance, George Ewart Evans, the UK pioneer of oral history in the 1940's and 50's, gathered memories of life and work in Suffolk Villages, where 'the old survivors were walking books'. These collections were first published in 'Ask the Fellows Who Cut the Hay' in 1956 (Thompson 2000). Similarly, in Scotland, oral history projects focussed Scottish culture and history. The history workshop movement also helped in recording the voices of the 'less powerful' (Smith 2008). Influenced by the labour historians in the 1960's and 70's, oral historians began to collect 'history from below' in order to preserve and acknowledge the change brought in the society by the non - elites. This is important because it encouraged a wider involvement in history making (Smith 2008). Furthermore, in 1969, Ronald Blythe's *Akenfield*, focused on the oral testimonies of rural villagers about their experiences of a swift change in the lifestyles over the previous half century. Similarly, Paul Thomson's account of early twentieth century social change, 'The Edwardians' was drawn from Britain's first national oral history project (Ritchie 2015). The debate regarding the value of 'elite' against 'non-elite' interviewing encouraged oral historians to widen their scope and be more inclusive. This also came with the realisation that not one group could be targeted to extract the historical details. There was growing recognition that projects could be more representative of differing experience/background.

### **3.2.3 The role of memory and subjectivity in oral history**

The focus on memory and the challenge of subjectivity represents a key development in oral history. This development occurred in reaction to positivist critics who targeted memory, claiming that it was unreliable. This became a major criticism of oral history in the early 1970's and resulted in a focus on how memory deteriorated over time, its fallibility and its ability to be 'infected' by external influences. Critics like Cutler (1970) raised major concerns regarding reliability and validity of oral histories with particular reference to memory. Likewise Patrick O 'Farrell (1982) wrote that oral history was moving:

*“Into the world of image, selective memory, later overlays and utter subjectivity...And where will it lead us? Not into history, but into myth.”*

(O’Farrell 1982 p. 3)

In the light of such criticism, to evaluate the reliability of memory, oral historians established their standard procedures. These guidelines became useful for understanding memory and relating it to the events in the past by combining them with other resources of historical importance (Thomson 2007).

In response, during the late 1970’s oral historians reinforced the argument that memory has in fact its own characteristics and the so-called ‘un – reliability’ of memory was actually its strength. It had the ability to give meaning to the historical experience as well as specify the relationship between individual and collective memory. For instance, Luisa Passerini in her study of Italian memories of interwar fascism suggested how experiences were remembered consciously and unconsciously and how the influences of culture and ideology on individual memories becomes evident in the silences, idiosyncrasies and discrepancies of personal stories (Passerini 1979). Similarly, Frisch (1990) argued against the notion that oral history delivered ‘a pure sense of how it really was’ and emphasized that oral history could be:

*“A powerful tool for discovering, exploring, and evaluating the nature of the process of historical memory-how people make sense of their past, how they connect individual experience and its social context, how the past becomes part of the present, and how people use it to interpret their lives and the world around them.”*

(Frisch 1990, p. 188)

Memory became a central theme for oral historians and they began to use different analytical approaches (linguistics, narrative, cultural and ethnographic) for analysis as well as interviews (Thomson 2007). For instance, with respect to chronic illness a landmark study by Jocelyn Cornwall (1984) used oral history methods and techniques to explore the health care experiences of men and women belonging to Bethnal Green in the East End of London. Bethnal Green was a place notorious for its

deplorable living conditions. All the participants of Cornwell's study were working class. She noticed that her participants often spoke in two different 'voices'. At first unsure of their relationship with Cornwell, people gave 'public' accounts of family and health care, which were stereotypical, and predictable. Those also reflected collective norms and presented the community in a positive way (Cornwell 1984). However, in their second interviews, when people gained more confidence, more 'private' narratives emerged, which were critical of doctors and mostly questioning other health professionals. Both the voices were important- public accounts revealed what a person thought the world would like to hear while the private ones exhibited what they actually felt (Gesler and Kearns 2002).

The fallibility and the ability of memory to weaken with time was seen as an 'opportunity' for the oral historians rather than a problem as they appreciate memory with all its imperfections, weaknesses, and mutability. They want to know what takes up spaces in people's memory and the reasons behind this, they also want to know why they tend to remember some things and forget others, the distortions and mistakes they make (Portelli 2000). Similarly, Perks and Thomson (2006) recognize that "oral history can be a very effective and powerful tool for exploring, discovering and evaluating the process of memory; how people make sense of their past, how they interpret individual experiences and generalize it in a social context; how people try to understand their lives and the world around them." It is not hard to see then that oral history presents as a strong method for the examination of the experience of oral cancer and subjectivity within a particular social and cultural context. Perks and Thomson (2006) go on to emphasise that oral history is about strengthening the forgotten voices of ordinary individuals and groups through the process of remembering (Perks and Thomson 2006). This was particularly important for my study, as I wanted to bring the people with oral cancer into attention and give them a voice.

Socialists also criticized oral history. On one hand they were against the notion that oral history was democratic and radical – and encouraged the 'oppressed' to 'speak for themselves' but on the other did not consider how dominant cultural histories

influenced memory (Passerini 1979). The Popular Memory Group<sup>5</sup> however argued that oral history could be significantly contributing towards giving people the opportunity to tell stories that were silenced because they did not match dominant cultural memories (Thomson 2007). Abrams (2010) also argues that memory for oral historians is not an abstract concept but is active. Memory exists within a field of memory work that is going on many levels – it is not just about the individual but also about the collective memory of family as well as community.

Despite these criticisms, Smith (1998) noted that these issues have helped in the development of oral history. These problems have become important methodological considerations and have helped develop strategies that have transformed these weaknesses into strengths. Further, oral historians do not claim that their work is ‘historical truth’:

*“ Oral histories are credible but with a different credibility; their importance lies in departure from fact, as ‘imagination, symbolism and desire’. The historical significance of oral history does not lie in its ability to preserve the past but in its capacity to convey the changes wrought by memory; changes which reveal the narrators’ efforts to ‘make sense of the past and to give a form to their lives...”*

(Portelli 2016, p. 49)

Oral historians acknowledge that memories are constructed in order to support one’s identity (Thomson 1990). Because oral history relies on memory as its source, which may weaken or change over time, it can be argued that a skilled interviewer can explore ambiguous answers and guide the interview into areas of concern and interest. Thompson (2000) argues that memory depends on an a person’s specific interest and therefore, reliability of oral history partly depends on whether the question or subject is on participant’s interest.

Selective memory also helps one to be comfortable with who they are and how the others perceive them:

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<sup>5</sup> According to the group, ‘the public representations of the past (popular memory) are used as an aid in the constant process of making sense of personal experiences, offering forms and general interpretative categories by means of which people can locate their own experience in terms of wider social patterns.’ (Thomson 2011, p. 87)

*“We compose our memories so that they will fit with what is publicly acceptable, or, if we have been excluded from general public acceptance, we seek out particular publics which affirm our identities and the way we remember our lives.”*

(Thomson 1990, p. 25)

This is similar to how Cornwell (1984) described her participant’s accounts. She observed that the public accounts often started with phrases like “ well, they that...” reflecting the legitimacy of knowledge. She argued that researchers encounter such accounts in formal interviews whereby the participants are putting up a performance. These accounts also depict ‘what people think’ or ‘what people believe’, assuming and thus offering the researcher what the participants assume they expect to hear. This is extremely relatable to my study, which highlights how the process of collating thoughts into a secure and comfortable narrative plays a role in rejecting difficult memories related to adverse socioeconomic conditions in childhood in order to come to terms with their past. I can also expect to see collective or public accounts of oral cancer related to aspects of religion and cultural circumstances in my study. In short, oral history, through the challenge of memory, can provide us with the tools to grasp in detail how participants make sense of their social and cultural circumstances and how these relate to their experience of having oral cancer.

People’s memories may also be prompted by trauma such as death, natural disasters, disease, murders, genocides or wars (Abrams 2010). Oral historians involved in conducting interviews with survivors of trauma believe that the first-hand accounts not only depict an ‘authentic’ picture of the event – how they remembered and made sense of it, but self-reflection may also help the participants in recovering. There is a general consensus between oral historians that traumatic events are remembered differently from everyday life experiences. However, disagreement exists about the association between trauma and memory (Abrams 2010). For instance in my study, some of the participants were able to recall their early childhood experiences of adverse social conditions vividly while for the others

it was difficult to provide details or to form a consistent narrative. Cultural constraints may be a contributing factor towards silencing those memories.

### **3.2.4 Subjectivity and intersubjectivity in oral history**

In response to the criticism by postmodern anthropologists, feminist theorists, sociologists as well as oral historians another critical development took place in the 'objective' approach to oral history interviews in the relationship between the narrator and the interviewer (Thomson 2007). Oral historians were criticised for 'swallowing' the stories that participants narrated by social historian who had the belief that a genuine 'people's history' should be established on objective data and statistical analysis and rather than on stories (Ritchie 2015). Thompson (1978) admits that there may be some defects in oral history but he negates any superiority of written documents and statistics, which may be equally vague and distorted. Portelli (1997) stated, "tell us not what people did, but what they wanted to do, what they believed they were doing, what they now think they did." He faced immense criticism for his 'passivity' and 'unsystematic' stance. Sceptics like AJP Taylor regard oral history as "old men drooling about their youth." Such sceptics construct oral history as an unreliable source of information. They want to look beyond any biases or personal prejudices and seek objectivity - under any condition the evidence should remain the same even if their interpretations change over time (Ritchie 2015).

From the late 1980's, Valerie Yow (1997) argues that the new paradigm created awareness and use of the interactive process of the narrator and the interviewer and subsequently the interviewer and the content. Oral history practitioners gradually started to become aware of the significance of subjectivity in the fabrication of memory stories:

*"This process is a dialogic (or interactive two – way) process, the outcome of a relationship between two people, and drawing upon a wide range of discursive formulations and positions."*

(Abrams 2010, p. 55)

It was also recognised that there was no such thing as a narrative that is a pure or transparent oral representation of the past experience. Therefore in an interview process, just like an interviewer forms an impression of the narrator, the narrator may also be conscious of the audience they may be speaking to which can influence what is said and how it is said (Abrams 2010). Memory stories tend to be influenced by environment in which the interview is being conducted as well as the words, agenda, intentions, mood of the interviewer as well as the interaction between the interviewer and interviewee. In the same way, the interviewee's responses such as the words they use, their tone and the emotions they express is determined by the interview context. External influences such as the number of years between the experience and the interview, the ability to recall and re - tell them and the events taking places hours and days prior to the interview may also affect the content of the interview.

The oral history document becomes a result of three - way process (dialogue) with the presence of subjectivity and intersubjectivity (Abrams 2010): the narrator with themselves, between the interviewer and the narrator and between the narrator and the cultural discourse. Therefore it is possible that different stories are formulated for different audiences. The story that is told is shaped by the intersubjective relationships present at the time of the interview (Abrams 2010). It is also considered imperative for the historian to be aware of their own position by being reflexive about themselves as researchers.

Feminists have engaged extensively with issues around subjectivity and intersubjectivity in women's oral history. They have embraced the potential of oral history to liberate women's experiences from the patriarchal structures and language as well as recover the dimmed voices of ordinary women. One of the pioneers, Sherna Gluck (1977) remarked:

*" It is the creation of a new type of material on women; it is the validation of women's experiences; it is the communication among women of different generations; it is the discovery of our own roots*



*and the development of a community that has been denied us in traditional historical accounts.”*

(Gluck 1977, p. 5)

It was initially thought that the project to recover women's voices would be relatively easy but it turned out to be rather complex. Two important issues were: the difficulties experienced by women to express their realistic thoughts and feelings and the possible power imbalance in the interview.

In 'Interpreting Women's Lives', Maynes and Garner (1989) noticed that the research method employed by the feminists always rejected any 'pretence at objectivity' and was encouraged by the ideology that sought to explain and understand women's inferiority in order to liberate women in the present. Initially, feminist researchers also regarded oral history as a way of hearing the silenced voices of the women. But very soon oral history interviews was regarded as an imperfect method for emancipating women's voices and assessing subjectivity for several reasons. First, it was argued that women's voices had less validity in a community that oppressed them and that the stories they narrated were an expression of the overriding or patriarchal discourses rather than a true reflection of their own feelings. Anderson and Jack (1991) points out that the language women use should be appreciated as it informs their cultural context, 'one that has historically demeaned women's activities'. Women have this inherent ability to restrain their own experiences as they do not fit in the normal societal pillars and may also not be as significant as the experiences of men. For instance, early interviews with women settlers in USA revealed less about women's experiences as they mediated their stories through their men counterparts because 'they believe that history was made by men' (Armitage and Gluck 1998). Second, it was observed that women would show reluctance in narrating their life stories because they are not used to speaking in public (Anderson and Jack 1991). A particular feature of this is that they would not adopt a 'performative mode'. Writing on the 'muted channel of women's subjectivity', Anderson and Jack (1991) also noted that women often dominate their own feelings in an interview while privileging activities. For example, in the case of illness, they

regard other activities and family as more important than their own feelings. Third, the 'honest' voices of women were harder to hear because they were silenced for not matching with the expected women's behaviour (Anderson and Jack 1991). The description of a 'gender based communication system' by Minister (1991) highlights a system in which women have less power than men and whereby men use speech in varied forms to assert authority in contrast with women who use communication as a method for determining intimacy and equality. It was also thought that women found it difficult to 'turn themselves into narrative subjects' (Summerfield 1998). Finally, it was argued that the interview itself was not deemed fit of liberating women's voices (Oakley 1981). Anderson and Jack (1991) also argued that most of the times women struggle separating their own subjective experiences from the 'façade of the acceptable woman role'. The role of feminist oral historians therefore, was to establish an interview setting in which the women can be themselves and express their honest thoughts and feelings (Abrams 2010). The proposed solution to this was to minimise the perceived power imbalance between the interviewer and the interviewee. This was also proposed to facilitate the production of a narrative that focused on the inner self rather than external social self -giving women a free space to speak as well as acknowledge their narrative on their own terms rather than drawing from the social models (Chanfrault-Duchet 1991). Minister (1991) was in favour of women interviewing women because it would give them a common ground of a shared socioeconomic subculture and they understand how to talk with other women. Drawing from my own experience, being a woman helped me to build a strong rapport with my participants.

All the above arguments are consistent with the feminist's objectives of producing an alternative history that gives equal weight to women's experiences and interpretation of those experiences (Abrams 2010). The strategies to cater for this included: treating the interview as a shared experience or a conversation, dressing differently, adapting the language with that of the participant and allowing them to question the interviewer. Similarly in Minister's (1991) view, women's subjectivity

could be unlocked through alteration of the 'communication frame' rather than trying to change the woman herself.

Where these suggestions could raise some important debates, it should be kept in mind that with the advancements in media sectors in the western culture, it has become normal to talk about one's private life and therefore power imbalance during the interview are no longer so pressing for women in the West. However, in most of the developing countries, like Pakistan, talking about one's private life with a 'stranger' is considered 'inappropriate'. Therefore, rapport building as a part of the oral history interviewing process can yield trust between the researcher and the participants.

In order to fully understand the reason behind my approach to this research, it is essential to provide an account of myself as a researcher in this study.

### **3.3 A reflexive view of my personal position**

*"All knowledge is affected by the social conditions under which it is produced; it is grounded in both the social location and the social biography of the observer and the observed."*

(Mann and Kelly 1997, p. 392)

Reflexivity is important as Ruby (1980) suggests that to be reflexive is to be accountable for: the producer, process and product, three important components of the communicative process.

As a 28 year old, healthy looking Pakistani female dentist, belonging to a comparatively high social class (with reference to the social classes in Pakistan), studying abroad, I had to be mindful of my position in the Pakistani society and any biases that may or may not influence my research.

My point of connection with the participants was my profession as a dentist and interest in oral cancer – the disease they were all diagnosed with and I was always scared of. The interaction with fearful patients on occasional basis during Oral Surgery rotation in my dental school in Pakistan made me genuinely interested in

knowing the experience of oral cancer and the general fear around its diagnosis. I would notice that most of them were anxious about oral cancer and were scared of the uncertain consequences of the diagnosis. Some could not afford treatment at all. Some presented very late in the disease process and were sent home. My Masters degree in Dental Public Health had also brought a change in shifting my focus from chair side techniques to having a broader population health perspective. Recognising that oral cancer was a major public health problem; I was interested to know how social position impacted the experience of the disease in Pakistan. Nevertheless, the fear instilled in me during those years at my dental school and a disturbing silence about cancer in general in Pakistan was my main motivating factor for engaging in this research.

Likewise, the process of oral history interviews demanded that I should be aware of my position in the research process. Even before meeting my participants, I may have displayed traits of my subjective self to the potential participants for my study, which may have contributed to how they perceived me and also how they formulated their stories. The participants may have read the information sheet with my name and mention of a university from abroad in different ways depending on their own subjective positions. It could have been read as a sign of official legitimacy, credibility or existing academic difference between us. Similarly on the face-to-face meetings, my name, age, my clothes, way of dressing, my accent, ethnic background, my first language and even gender may have influenced the relationship I had with the participants. Similarly, in the interview itself, I also noticed the participant's accent, their age, their dressing as well as body language. I was aware that I was interviewing the participants who could tell me what I wanted to know for my study. Furthermore, the interview process completely relied on the relationships that developed between my study participants and myself. The respect I gave to all the participants regardless of the age difference came back many folds. I was younger than all of the participants so I had to be particularly conscious when interviewing elderly women because it is considered important in Pakistani culture to be immensely respectful towards elders. I did not objectify them as 'old people' and

they could recognize it by the importance they felt they were receiving.

Similarly, there were times when I could relate to the women in my sample when they were narrating how they were not allowed to wear makeup or dress up, other than on Eid and weddings, before marriage because of the cultural restraints. I had observed this happening when I was growing up in Pakistan, as there are certain unwritten rules, regulations and societal expectations for women to comply with in order to be regarded as a 'respectful' member of society. The silence that many women displayed around cancer and the way they put the needs of their families ahead of their own as a part of cultural conditioning was also something I could deeply relate to. I had seen my mother and grandmother doing the same when they became ill. These experiences did not seem strange to me because such conditioning is passed on through generations. It made me realize that my own voice had also been lost over the years. Being able to give a voice to the participants in my sample in the form of translating and turning the spoken word into an account helped me find my voice as well. Many of the participants regarded the interviews as conversations with a loved one or between friends. They said that they were able to confide in me about the things they would only tell their close friends or a family member. The openness of some of the participants was rather unsettling for me because the exchange of information was not reciprocal despite it contributing greatly towards my research. I do believe that being of the same gender, sharing a common language (Urdu) and a shared wider Pakistani cultural background may have influenced their 'trust' on me. Perhaps, my gender was also the reason why none of the male patients showed any interest in getting involved in the research process.

Nevertheless, the reflexive process made me conscious of not only my position in the current research study and society but also how my own beliefs could influence the way I portrayed my participants. However, I have endeavoured to analyse and interpret the stories of my participants staying faithful to the original content and in a way that reflects my participant's perspectives completely.

My relationship with the participants of this study and the methodological considerations in oral history interviews conducted with them will be further explored in the next chapter.

## Chapter 4. Material and Methods

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## Chapter 4. Material and Methods

### Summary of the structure of the chapter

This chapter will explore how the data for my oral history project was collected, analysed and interpreted. Rather than beginning with recruitment and sampling this section starts with a consideration of the study in general terms, the preparation that went into the study, including the ethical considerations. The data collection process (including descriptions of the setting, access and recruitment of the participants and the interview process) and data analysis will be discussed in the subsequent sections of this chapter.

### 4.1 The oral history project

This study uses the techniques and insights of oral history to explore the perspectives of those with oral cancer. Oral history is a valuable tool to understand the past. In terms of this research study, the value of oral history is implicated in its ability to encourage the participants to tell their stories in their own words. It provides people with oral cancer, who as we have seen, have previously been overlooked in oral and dental research, with an opportunity to contribute to the field of dentistry as well as medicine in general. It gives a way of accessing memory and through this, of understanding how people make sense of their social circumstances.

The challenge however was that a successful interview required skill and practice. I needed to prepare properly for the study before starting in earnest. A few months before I went to Pakistan to collect data, I had made sure to practice conducting interviews with a few people to develop my skills. I recorded their stories and discussed the recordings and content with my supervisors in order to identify how to improve my approach. This practice not only gave me confidence, but also taught me the importance of listening to the others without interrupting or presenting my own point of view. I strived to adopt the qualities Paul Thompson had suggested in “The Voice of the Past”:



*“There are some essential qualities which the successful interviewer must possess: an interest and respect for people as individuals, and flexibility in response to them; an ability to show understanding and sympathy for their point of view; and, above all, a willingness to sit quiet and listen.”*

(Thompson 2008, p. 222)

Because of several readings on the methodological considerations in oral history method, I was aware of my responsibilities as a researcher and of the potential relationship between the participants and myself. Therefore, when I went to Pakistan to collect the data, I was prepared for any challenges, excited and looking forward to conducting the interviews. Being a dental graduate from Pakistan, I had prior knowledge about oral cancer and the disease course but had never conversed with an actual oral cancer patient. The background reading during the literature review helped me to understand how oral cancer affects people.

I was nervous that maybe the potential participants would refuse to talk to me or because they are so unwell, they would just refuse completely. I prepared a list of semi structured interview questions following the literature available on oral history methodology and the sample questions suggested by Thompson (2008) and Ritchie (2015). However, as I developed as an interviewer, my approach changed whereby I started referring to the list of questions only as a means to break the ice and to obtain information regarding their place of birth, description of the area of residence, early childhood memories and family makeup. From here on, I would let the participants take the lead and then build my follow-up questions regarding oral cancer from within the conversation. The participants were aware that I was interested in knowing their experiences of oral cancer. Nonetheless, oral cancer was a major part of their lives so every participant brought it in their narration without me having to probe much (as a part of my own research agenda). As a result the list of questions from each participant varied depending on what they chose to share with me. This gave the participants some flexibility to determine the content of the interview (Leavy 2011). It also helped the interview to reveal processes and link individual experiences within the wider context in which those experiences took

place.

## **4.2 Ethical considerations**

John A Barnes (1979) defines ethical issues as “the problems we try to solve not in terms of expediency or gain but in terms of morality, of standards of right or wrong.” The resolution of these ethical problems according to Yow (2005) is through a strong understanding of professional guidelines and the ability of the researcher to critique their own behaviours and reflect on them.

Before the research project began, in order to make sure that the proposed study was acceptable to the participants and passed ethical approval, there were a number of preparatory steps that needed to be taken according to the Oral History Society Ethical Guidelines (2012). I started with a thorough literature review to understand what had already been said about oral cancer in Pakistan. Pakistan’s social and cultural history as researched in the literature review was also taken into account. I attended specialized training courses conducted by the Oral History Society to conduct interviews in best possible standard. The General Data Protection Regulation guidance (2017) and later the revised version (GDPR 2018) was also consulted as a supplement. My supervisors and I had agreed on the future use of the interview recordings for research as well as educational purposes and for them to be archived at the University of Sheffield’s library. A comprehensive information sheet was formulated in both English and Urdu for the understanding of participants, collaborators and potential users in Pakistan.

### **4.2.1 Ethical approval**

As this study involved human participants (terminally ill in some cases), ethical approval was needed. Ethical approval from Foundation University College of Dentistry, Pakistan and the University of Sheffield Research Ethics Committee (UK) was sought. The ethics application from both the institutions were similar yet very detailed and covered important areas such as the project description, participants, access and recruitment of the participants, personal safety of the participants and

myself, any potential dangers or risks involved in the research (See Appendix 1 and Appendix 2). The application was approved from both the institutions.

#### **4.2.2 Information sheet and consent forms**

It is imperative for the oral historians to honestly tell participants about the objectives of the project, the phases of the research process, the way their data will be used or archived (Yow 2005). It is regarded as a form of respect that the researcher can give to their participants by informing them of their research agendas.

My first contact with the participants in my study was through phone calls and in some cases face to face. In any case, they were provided with information about the purpose and nature of the project and what it meant to give consent for this particular study. In case, any participant was unable to read, I read the information sheet and consent form in Urdu to them. In this way I made sure that all the participants understood the purpose of the study. All participants were given ample time to read, understand and question anything that raised any ambiguity for them. In this way, it was established that the participant understands the purpose of research, my objectives and their role in my study. According to Yow (1994):

*“The rule of thumb in the ethical in-depth interviewing is: Don’t carry out a project in which the narrators, if they knew the truth about your objectives, would not reveal themselves.”*

(Yow 1994, p. 91)

Consent forms, participant information sheet and legal release forms were given to all the participants willing to participate in this study (see Appendix 3, 4 and 5). They were advised to thoroughly read the participant information sheet, legal release form and then make an informed decision whether to take part or not. If they agreed, they were asked to sign or have their thumb impression. The consent form sought permission for their inclusion in the study, for their interviews to be audio recorded, transcribed and archived. I also advised that they could choose a pseudo

name for themselves if they did not wish for their original name to be included. Participants were reassured that they were free to withdraw at any point during the interview and they did not even have to give any reasons. Their participation was voluntary (Yow 2005) and it was made sure that they did not feel pressurised to take part in the study. In case some participant or relative did not wish to publicise some personal details or happenings, they were given an option to anonymize themselves or use a false name. Only one of the participants in the whole sample chose a pseudonym for herself. By signing the consent forms, the participants certified that all the procedures were fully explained to them and they had a free will to consent.

Informed consent can sometimes become problematic. This is because at the start of the project, it is not known where the project may lead to and therefore, some qualitative researchers consider informed consent as 'an acknowledgement of the willingness to participate and permission to begin' (Yow 2005). It does not guarantee where the study might end up and this is where care needs to be taken. As a consequence it has been advised to check with the participants during the interview if they are still happy to proceed. I found that this could make the participants cautious and conscious of something 'incorrect with their train of thought' and their concentration may break. During my initial conversation with the participants, I got a fair idea that they did not have a 'voice' and too much checking with them could have fractured their story and undermined their ability to contribute. To the best of my knowledge, it was their first ever interview for such a wide audience. They were a bit reluctant initially but after my explanations about the study and their potential contributions, they consented and were pleased to be a part of it.

#### **4.2.3 The setting**

The participants were happy for the interviews to be conducted at the hospital. Therefore, a sound proof room at the hospital was chosen for the interviews to take place. Because the interviews were taking place in the hospital environment, it was possible that the participants were worried that they may be treated differently.

Some of the participants got concerned about the negative consequences of their care and relationships with their health professional of their non - participation. Therefore, I made a conscious effort to dissociate myself from the clinical team by contacting them every time through my personal phone number, which had been acquired purely for the use in the study and always meeting them in a room away from where they were usually receiving the treatment. I also reassured participants before, during and after the interview that my research was independent of the hospital and that no care related relationship existed between the two.

#### **4.2.4 Dealing with any potential harms**

There were no potential harms involved in this study, however, some minor/major inconveniences were anticipated as the participants were talking about cancer and their experience with taboos related to it. In order to avoid participant's distress at the time of interviewing, I made sure that they were fully informed before hand and felt confident in participating in the research project. It has also been advised to spend some extra time with the participants after the interview in case they feel upset (Yow 2005). For instance, at one point during an interview with a participant, I felt that it was getting difficult for her to continue because she was crying, I offered to turn the recording off so she could take her time and feel better. I also proposed to reschedule the interview. The participant however, chose to pause the recording and continue after a break. In cases where the participants still did not feel better, they were referred to a clinical colleague for support and reassurance. In other cases, they were also referred to the mental health department at the hospital for counselling services (the contact details were provided to the participants).

Yow (2005) also alludes towards the potential distress that can result from the publication of the research. There were a couple of instances in the interviews where I recognised that the interview contained sensitive information or 'special category data' (GDPR 2018) such as voicing strong religious or political beliefs, or naming government institutions or stakeholders that could cause the participant's

distress or harm after it is published (in terms of location or identification). Although all the participants except one had given consent to use their original names, those specific passages will be embargoed and muted before public access (GDPR 2018). Winslow and Smith (2010) suggest that in oral history interviews in palliative care, it is imperative to have a discussion of the interview with the participant in order to omit any information that may be potentially harmful for the listener. In my sample, there were only two participants who were in palliative care and I made sure that they heard their recording as soon as it ended. They were happy with what they had narrated and did not want any part of their interview to be edited.

#### **4.2.5 Intersubjectivity: Interpersonal relationships with participants**

As we have seen from the methodology section oral history is regarded as a collaborative process (Hesse Biber and Leavy 2011), but the power between the narrator and the researcher is not equal. Subtle ethical issues exist in the interpersonal relationships (Yow 2005) whereby the power lies with the researcher: they take the information from the participants; use the information to get a degree and even a better job. Therefore, it is essential for the participants to be able to trust us in order to share their intimate life stories, still they are not aware how their information will be used and how will they be described in the actual account of their narrative. While we as researchers have the advantage of knowing what we intend to do (Yow 2005). Daphne Patai (1987) describes this situation as:

*“ We ask of the people we interview the kind of revelation of their inner life that normally occurs in situations of great intimacy and within the private realm. Yet these revelations are to be made within the context of the public sphere— which is where, in an obvious sense, we situate ourselves when we appear with our tape recorders and note pads eager to work on our “projects.” The asymmetries are marked, further, by the different disclosure that our interviewees make and that we are willing or expected to make—this goes back to the fundamental rules of the interviewing game. While shyly curious, interviewees never, to my knowledge, make a reciprocal exchange a condition of the inter- view. And researchers almost always are much less frank than they hope their subjects will be.”*

(Patai 1987, p. 6)

I realized the imbalance and the nature of intersubjectivity between the participant and me in that on one side, it was me, a healthy interviewer – having a lifestyle, living abroad, independent of any clinical needs, and on the other side a participant – with an illness that is life limiting, whose lifestyle has thoroughly changed from the pre illness situations, and is facing uncertainty in almost every aspect of life. For instance, in my study one the participants who was diagnosed just two days prior to the interview, was eloquent about her childhood experiences and her family life. She seemed lively and happily shared the events that led to diagnosis and was hopeful that she would recover soon. She had not undergone the experience of oral cancer and its treatment yet. The third interview conducted with the same participant while she was undergoing the rounds of chemotherapy, was totally different. She was frustrated, depressed and angry because she was not able to bear the effects of chemotherapy on her body. The interview reflected what she was going through in the previous days prior to the interview. The content of the interview and her presence affected me a great deal as well because unconsciously I had built a relationship with her. It was difficult to see her in so much pain and anger. I was wary of her emotional state and was cautious about asking her any questions that would instil a sense of fear or hopelessness in her life.

Furthermore, building a rapport in the initial meetings helped not to intimidate the participants in anyway or make them feel inferior in any respect. The participants, who informed me that they had access to Internet or laptops at home, were given a copy of their recorded interview. The other participants, who were not educated, neither had access to Internet or storage devices did not ask for the copy of their interview and were also happy for their names to be included in the research study and for it to be printed. As Portelli (1997) suggests:

*“The real service I think we provide to communities, movements, or individuals, is to amplify their voices by taking them outside, to break their sense of isolation and powerlessness by allowing their discourse to reach other people and communities.”*

The best way I can acknowledge their participation and contribution towards my study is to recognize their help in my thesis and the potential publications that arise

from it.

Moreover, on oral history interviews, both the narrators and interviewers can be changed in some way (Yow 2005). For instance, oral history gives the narrator an opportunity to tell their life story to another person (the researcher) who considers the story as true to the narrator and something important to them. This way, the narrator achieves validation that they are worth listening to. Such validation, as Yow (2005) observes is important for the marginalised population of the society such as women, working class people, the elderly and the minorities. The interviewing process also gives the narrators a chance to learn about themselves that they may have not known before and give their life a meaning. The sense of importance and drama, which a casual conversation is incapable of giving, often thrills the narrator in an oral history interview (Yow 2005). In terms of my research project, all of the participants were grateful for being given a chance to narrate their life stories and the experience of oral cancer. One of the participants responded in the following way on being asked about her experience of the interviews:

Ameena:

*“ I cannot thank you enough Mariam for these interviews and for giving me chance to describe my feelings...I know I will fight this cancer and when I recover, I will help you in your venture to raise awareness of oral cancer. I will write in the newspapers for the government to take necessary steps regarding its diagnosis...believe me, I have never shared my life in such detail with anybody. Now at this time in life when I have just been diagnosed, you are the only one I turn to and can make sense of what is happening with me and of my current situation. I cannot share this with my children...they are too young to be shared such misery with”*

Likewise, some even told me that they reflected on the interview after they went back home and that they felt valued. Yow (2005) encourages a non-critical/judgmental listening of the narrator in order to reap rich data and is of extreme importance for the self-esteem of the narrator.

I was also aware of the transference that was taking place between my participants and me. As emphasized by Roper (2003), during the interviews the researchers tend



to encourage their participants to take them along their journey into their pasts and make them feel a part of what the participants had gone through. Such an intimate interaction often triggers emotions. Likewise the emotions captured in the recordings and the transcripts affect the interpretation of the data as well as those who were not even present at the time of the interview (Godfrey et al. 2004). Such is the nature of transference. Many times during the interviews, I had a strong realization of uncanny resemblance of the participant's experiences with my own as if they were speaking my mind especially when talking about the loss of both parents.

#### **4.2.6 The problem of representation**

Oral history interviews may also raise issues of representation. For instance, in an oral history interview, the data collection in the research process is collaborative. The participants narrate their stories; the researcher facilitates the interview, transcribes and may also add memo notes to the transcripts including certain important aspects of the interview and their own feelings. Therefore a collaborative process allows both the researcher and the narrator to produce a life history (Hesse Biber and Leavy 2011). Schneider (2002) emphasises the importance of the responsibility of the researcher in retelling the story by remaining true to the original intent of its telling. Yow (2005) argues that correct representation of the narratives demand attention to words, which may include checking the transcripts with the oral sources –the participants. However there may be instances when the inevitable interpretative conflict arises. Kirsch (1999) argues that in such situations both interpretations (of the researcher and the participant) must be presented. However, regardless of this, the narratives should be presented correctly. For my research study, I analysed and interpreted the stories as 'whole'.

### **4.3 Data Collection Process**

#### **4.3.1 Setting**

Initially I planned to interview people diagnosed with oral cancer in different hospitals in Punjab, Pakistan but the huge distances and associated costs prevented

me from doing do. As a compromise, the interviews were restricted to Rawalpindi/Islamabad only. Because the aim of the study is to understand perspectives of people with oral cancer in Pakistan in their social context, it was ideal to choose the subjects from a hospital setting that caters for people from a range of socioeconomic status groups. Therefore, the participants in this study were recruited from Foundation University College of Dentistry (FUCD), located in the heart of the twin cities Rawalpindi/Islamabad, Pakistan. As stated previously, at FUCD the wives; sons (up to the age of 18 years) and daughters (until they are married) of ex - servicemen (Junior Commanding Officers (JCO's) and soldiers) are entitled for a free treatment.

According to the Government of UK foreign travel advice, Rawalpindi, (where FUCD is situated) is a comparatively safe zone and has no particular out of bounds areas. Also, there were no risks of working with potentially threatening people. Still to ensure my safety in Pakistan interviews were not conducted at the participant's home in any case. The participants themselves were also happy for the interviews to be conducted in the hospital as they were coming from far off areas. The interviews were conducted at the Oral and Maxillofacial department, Foundation University College of Dentistry during hospital hours i.e. from 0800 AM to 1500 PM. A friend from the same department used to call or visit me at a set time during the interview to ensure my well - being. Both my immediate family residing in Pakistan and supervisors were aware of my stay in Pakistan for research purposes.

All the interviews were held in a separate room allotted for interviews, at the FUCD, with a comfortable seating arrangement and temperature. It was important for smooth recording without disruptions and people around. Good external microphones were crucial since built in microphones may pick up the machine and the recorder might not sit close enough to record a soft speaker (Ritchie 2015). The recording equipment were set in a way that they do not distract the participant or make them conscious in any way. Water and tissue boxes were also placed in case they were needed.

#### **4.3.2 Access and recruitment of the participants**

After receiving approval from the head of Oral and Maxillofacial department at FUCD, a list of potential interviewees was prepared. The list provided me with twenty possible participants along with their contact details and files. Initially, the potential participants were contacted through telephone a week before their appointment and requested to visit the hospital for a follow up. I introduced myself to them as a PhD student from The University of Sheffield looking at the impact oral cancer has on the lives of people living in Pakistan. At this point, they were informed that on their visit, they would be requested to take part in a research study looking at understanding how a range of people live their lives, their experience of oral cancer and how they made sense of it. They were also informed that they could talk about anything they wanted to and that it will be a great opportunity for them to express talk about themselves, their families and oral cancer with no time limit and crucially with no medical agenda. The topics and subjects to be covered were discussed allowing them to share as much as they would like to share. These preliminary calls greatly helped me in building a rapport with potential participants and strengthened my relationship with them (Ritchie 2015). The participants were reassured that their participation was voluntary and their non - participation would have no consequences on their treatment.

In order to make the process easy and comfortable for participants, I suggested that they could choose a date and time of their choice for the interview. All participants agreed on the spot and were ready to give the interview after small discussions with their family members and me. Some of the participants came to the hospital for a check-up from far off places and it was not possible for them to visit again during the same week or even month. Therefore, they agreed for the interview to be conducted on the same day. While the others took the consent form and legal release form with them and promised to inform me of their decision. Fortunately, all of them returned and set a time and date for the interview.

The first round of interviewing took place from January 2017 to March 2017 in which I was able to recruit and interview only four participants. While the second round of interviewing took place from July 2017 to September 2017 in which I recruited and interviewed 14 participants.

#### **4.3.3 Brief description of the sample**

I interviewed a total of eighteen participants out of which only fifteen of the interviews were deemed fit for the purpose of this study. The three excluded interviews were very short and the participants refused to talk about any aspect of their lives and ended up stopping the interview. It could be that they were not particularly well on the day of the interview or simply did not want to take part in the study. Ethically, I thought it was best to thank them and stop the interview rather than probing them and making them uncomfortable. Later, while discussing their reluctance to take part in the study, one of the participants told me that she did not find her story 'worthy' of getting included in a research and that she did not want to participate because of some personal issues. Her honest and frank reply did teach me a lot. I made sure that I focus on the participant's contribution towards this research more and let them know how they were potentially going to benefit others and my PhD.

All of the participants whose interviews were entered into the study were women. The youngest participant was 29 years old and the oldest was 80 years of age. They were all born and raised in Pakistan and identified themselves as Muslims. I am not related to any of them. All of the participants in this research excluding one were married and had Pakistani spouses. All were diagnosed with oral cancer and receiving treatment at different stages at FUCD. All the participants entered the study voluntarily and written consent was obtained from them for the oral history interviews to be audio recorded, transcribed and subsequently archived. They were allowed to quit the study at any point in time without giving any explanation to me. Also, they were not promised any compensations or benefits for their participation or non - participation in the study.

All the participants that I interviewed were keen in taking part in the research study and shared many personal stories and experiences. As Seidman explains:

*“At the heart of interviewing research is an interest in other individual’s stories because they are of worth.”*

(Seidman 2013, p. 9)

The characteristics of the participants detailed in (Chapter 5. Introducing the participants) ensure that social determinants had a complex role in their journey to diagnosis of oral cancer. The first interview was conducted in January 2017, and the participant agreed to give the interview just two weeks after her diagnosis. It was a difficult time for her and she needed to share her worries with somebody and I was present. I am honoured that the participants chose to share their life histories and personal experiences with me.

#### **4.3.4 The interviewing process**

##### **4.3.4.1 Before the interview**

From the preliminary meeting till the end of the interview, I followed and adapted where necessary, the advice on interviewing techniques and strategies by Valerie Yow (2014) in the ‘The Oral History Reader’ published in 2015. It is understood that it takes more than one interview ‘to break the ice’ (Ritchie 2015). In order to gain maximum profit from the interview bearing in mind the physical state of the people with oral cancer, it was best to meet the subjects in person at least once before the interview. However, I have to be honest it was not possible with all participants in my sample because of the long distances they had to travel as well as the challenge of the journey through oral cancer diagnosis and treatment. There were only two participants with whom I conducted more than two interviews on different days lasting for 50 to 90 minutes. The rest of the interviews lasted for 45 to 70 minutes. As stated earlier, at the preliminary meeting, I made an effort to get to know participants and explained to them about the process of recording interviews. This strengthened the initial rapport building between the participants and myself. I also informed them why it was essential to choose a noise free environment because the

recorder picks up on the background noises, hence a room separate from the departments in the hospital. Participants' files and information regarding their treatment stages was also consulted prior to the interviews for detailed background information of their disease and treatment experience.

Prior to turning on the recorder, I explained them the purpose of my research study, how I got involved in this research and why was it important for me to conduct this interview with them. It is important for the participants to feel appreciated and valued for the time they are serving towards the research study (Yow 2005). They were also reassured that they were in no way obliged to answer all my questions. I wanted the participants to feel safe and valued in my presence. After the initial chat, the participants were advised to wear the microphones and get settled for the interview to begin.

#### **4.3.4.2 During the interview**

After the recordings began, the first questions always related to their name, age, place of birth, their early childhood and adolescent memories, their home structure, relationship with the family members and their parents. I found this really helpful as it set the tone to the interview and seemed to make participants comfortable. I would occasionally choose a question or two from the prepared list of questions, but would mostly let the interview take its own course. Sometimes, I was so engrossed in listening to them and following their thought process that I would forget about the list completely. This approach worked well for me as the conversations continued beautifully and often led to narration of experiences which would have otherwise not developed if I had followed strict semi-structured format.

I also engaged into active listening and maintained eye contact. Following the participant's thought process greatly helped in formulating the follow up questions and also may have reassured the participants that they were getting heard. To understand my participant's interpretation of their lives, I would ask them what they meant by a certain word. For instance, one of the participants used the word 'ghareeb khana' (poor place) to describe her home in childhood. Upon asking I was

told that it was a way of telling that her home was simple and destitute of all the luxurious things that are desirable or might naturally be expected. Non-verbal responses such as a smile, a nod and shaking of head means that the researcher is following their responses (Yow 2005). I took notes during the interviews as well. I noticed the pauses, silences, laughter, facial expressions, hand gestures, tone of the voice, raising and lowering of the voice and so forth. Hesse – Biber and Leavy (2011) recognize this step as essential to know about the nuances in the way an individual narrates their story – their narrative style. Given that Pakistan is a patriarchal society, it was useful to pay attention to how the women in the sample opted different narrative styles. I noticed how gender, social class, education and belief system affected the way my participants narrated their stories. Schatzman and Strauss (1973) consider it an important step in thinking about all the possible ways to analyse data. While it helped me to know where my participants placed meaning and how they were feeling at a particular point in the interview, it was noticed that none of the participants recognised gender as a cause of inequalities in health, making me think about the potential role of social norms and conditioning that encouraged a culture of silence.

The burst of emotions on topics like social background, painful childhood memories, loss of family members and the present disease experience alluded towards the emotional importance of these memories for participants. One of the participants in my sample broke down into tears several times during the initial stages of the interview and chose to ignore topics like childhood, parents and marriage, perhaps as a defence mechanism, it is disappointing that I was not able to arrange follow-up interviews in these cases. All I could do was to give my participants complete freedom to deal with their emotional reactions towards sensitive questions. In this case the participant discussed such topics in detail later in the interview as she became more comfortable with her emotions.

It was not hard to see how oral history was giving the participants a chance to remember the specific stories of their past and how the narration of those events was intricately woven in their memories. My study was conducted with the

participants when they were experiencing the disease or had just gone into remission so some of the participants were not able to produce a coherent narrative, rather their stories were powerfully emotional, disjointed and disturbing for both myself and them. There were also many instances when the participants broke into tears recalling the memories of their deceased parents, or spouse. One of the elderly women in my sample shared that even at the age of 80; she had not come to terms with the death of her parents. She still carried hurt and because she had never discussed her feelings with anyone else, the interview itself made her relive those painful memories and get some sort of closure. Having lost both of my parents when I was young, I could relate to what the participants felt while talking about their loss. It was always a difficult question to pose regarding what memories did they have of their parents. Unconsciously, I used to remember my own parents (which I would otherwise never do because it brought pain) and it would often bring tears to my eyes during the interviews. However, as I relived my own memories and heard the participants talking about their parents gave me some relief and made me happy to be able to recall good memories of my childhood. So the interview process was not just cathartic for the participants but for me as the interviewer as well.

I gave my participants a chance to talk more so they are aware that the interview was about them and what was important to them. Although oral historians like Abram (2010) regard oral history as a dialogue I argue that it is not a conversation in the real sense because both the participants and the researcher are aware that the participant's story is important and more importantly that it is being recorded. However, if participants want to hear the researchers point of view or story, then they should tell it (Yow 2005). One of the participants wanted me to tell her if she will be okay and if I knew what her physicians thought about her oral cancer. Because I had already consulted her file prior to the interview, I was able to reassure her that her physicians were planning to run some more tests in order to declare her completely free of cancer. This reveals just how much interpersonal pressure can be brought to bear in these exchanges and is obviously a product of my role as a dentist researcher.



Anderson and Jack (1991) suggest that researchers should be wary of their internal conversation as well and listen to themselves during the interview too- what they are feeling, confusions and any questions. There may be thoughts and feelings that require elaboration or clarification. When such instances occurred, I made sure I was not interrupting their stories and refrained from commenting or passing judgments on what they were telling me. Instead, when a pause or a prolonged silence arose, I clarified my thoughts and feelings with the participants. I was conscious of their position and how it was a big step for them to open up to me. Alston and Bowles (2003) regard this understanding and compassion an important step towards building a rapport and relationship between the interviewer and the participant. It is no doubt essential for the participants to feel comfortable in opening up honestly about their thoughts and feelings. It is also important when marginalised groups are speaking because the researcher can accidentally call into question the narrative being provided. I had to be aware of these pressures throughout the interview process.

Acknowledging their health limitations of speaking for long periods of time, the participants were allowed to have breaks or sip water in between. They were reassured that they could signal me to end the interview whenever they liked. There were only two or three occasions when the participants asked me to take a break. The reason was mostly because they got so emotional; they could not continue to talk and needed a break to settle down. I also made sure that, like the others, elderly participants were not forced to give information or try to share what they may have forgotten.

As a part of the oral history interviewing skills, probing was only used when I thought the participants could give me a more detailed answer. Probing, according to DiLuzio and Hiller (2004) forced their narrator to 'think more deeply... perhaps even to admit things he had never verbalized before to another person'. Therefore in respecting the integrity and privacy of participants, none were probed for more than they could tell. There was an interesting instance when, after talking through the details of the study, a participant's husband wanted to sit with her during the interview. He had

reservations regarding the separate room in which the interview was to be taken place. The presence of another in the room usually changes the interview and presence of one often constrains the performance of another (Yow 2005). Therefore, he eventually agreed to leave her with me after a 20 - minute discussion regarding her safety and the content of the interview. But before leaving the room, he advised his wife to only speak well of the hospital and the team to which she politely agreed. I was taken aback, because even during the interview, she was not comfortable sharing her personal details or opening up about the pain she was in. Nonetheless, as the interview progressed, after frequent and polite probing, she became a bit more vocal of her experiences. This was the most difficult interview for me to conduct because I could see that she wanted to share a lot, but she was scared to do so. I gave her the opportunity to withdraw if it was uncomfortable for her, but she insisted on telling her story.

#### **4.3.4.3 After the interview**

At the end of each interview recording, every participant was thanked on tape. They were given a chance to add anything they had either omitted earlier or thought was important to them. I reiterated my stance for being interested in their stories and in giving them a voice regarding any aspect of their life especially oral cancer. This time period gave the participants and myself a chance to think of something that could have been added to their narratives. McMahan (2013) suggests that at this time, “the interviewer and the narrator now have a history together on which they can build.”

Soon after the recording was turned off, I explained the process from that point forward to them. They were made aware that I would be contacting them again once the transcription was complete and they would be provided a copy and if they wished to make any changes, they could. The participants were offered to listen to the audio recording soon after the interview if they wished to. The participants and I would often chat and engage in an informal conversation toward the end of the meeting. I thanked each of the participants for their contribution towards the study

and above all for trusting me with their personal stories. As Thompson (1988) advises that after the interview:

*“You need to stay, to give a little of yourself, and show warmth and appreciation in return for what has been given to you.”*

(Thompson 1988, p. 211)

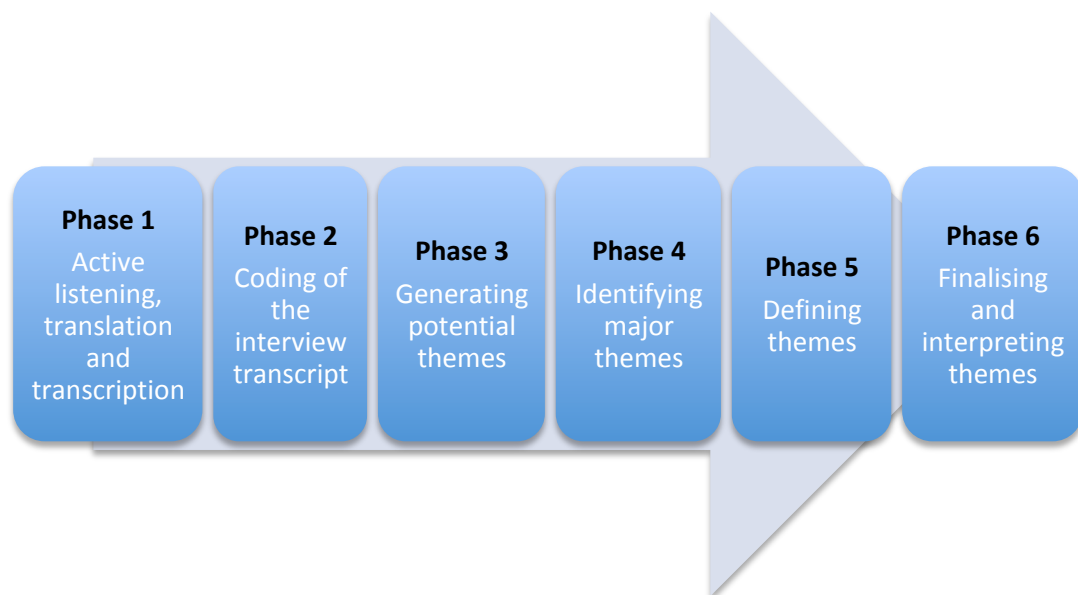
It was noted that during this post interview conversations, the participants seemed more relaxed and often gave more insights into their lives. Such events were included as an addendum to the actual transcripts after permission from the participants. It was also noted that all the participants were thankful for being given a chance to voice their opinions and feelings. One of the elderly even kissed my hand for she felt so emotional and grateful. I am forever indebted to their contributions and the trust they put in me with their valuable stories.

After the end of each interview, the interview recordings were downloaded directly to my laptop, which was password, protected. A copy of the interview was also made in an encrypted external storage device (Model: SRD0NF1). My supervisors and I could access the interviews only.

#### **4.4 Data analysis**

The figure below shows process by which the oral history interviews in my study were analysed:

Figure 4.1 Steps in data analysis for my project



#### **4.4.1 Phase one – Active listening, translation and transcription**

The principle of intersubjectivity in oral history meant that the analysis of data began during the interviewing process. Active listening and field notes were considered the preparatory steps for a comprehensive data analysis. In addition phase one of data analysis also involved further active listening, translating and transcribing the interviews one by one.

##### **4.4.1.1 Active listening and summarising**

The first stage of analysis comprised of listening to the recorded oral history interviews and making memos. It is considered fundamental for the researcher to get immersed in the data fully in order to be familiarised with the interview content (Braun and Clarke 2006). Therefore it was best to listen the data repeatedly and actively. Active listening refers to finding the meanings and patterns within the data. This also comprises of hearing the stories that have been narrated by participants in the research and experiencing their emotions (Kleinman and Copp 1993). After each interview, characteristics of the participants, scene, setting, body language, my reflections and field notes were summarised. Taking field notes about the time, setting and the emotional climate is fruitful for interpretation (Anderson and Jack

1991). At this point a short summary of the whole interview was also prepared. Notes about how each interview started, unfolded and then ended was a beneficial exercise to hint at the ways in participants narrated their stories (Plummer 2001). It was also useful to refer to my field notes and explore how it felt to listen to the story, what and how emotions were experienced before, during and after the interview as well as what main theme arose from it.

#### **4.4.1.2 Translation of the interviews**

It was of paramount importance that for the ease of the participants and myself, the interviews were conducted in Punjabi/Urdu (Pakistan's national language). Consequently, the need for translation did arise. Because the participants and I spoke the same language, there were no language differences in data collection process. However, since this research was going to be presented to a wider global research community, all interviews were translated directly into English and transcribed by myself. Translating interviews can raise interpretive challenges. Qualitative research seeks to understand how language and subjective experiences relate: language is employed to express meaning but in turn meaning is also influenced by language (Van Nes et al. 2010). Chapman (2006) states that social reality is experienced differently in one's own language and therefore may perceive the world in a different way. Polkinghorne (2007) argues that the "validity of qualitative research exists in the closeness between the meaning as experienced by the participant and the meaning as interpreted in the findings." Likewise, Bassnet (2013) has argued for the value of understanding a person's experience and story "if they have been translated out of their original language."

All of this is really important for this study. I argue that as a native speaker of Urdu/Punjabi, I was able to pick the subtleties of language, understand them and use these for the benefit of the study. Since English is a common language, I have spoken it since childhood; I was able to identify the commonalities in both the languages. Rich descriptions with the use of quotes were made in the findings and special attention was given to instances where participants used metaphors. The process of

translation added another level of reflection to this study because it involves looking very closely to the meaning of what was said, whilst trying to convey this meaning in another language. Although this process is by no means easy it does mean that there is an added layer of complexity in the analyses of these stories.

Temple (2008) argues that the translation of quotes into another language can lose their essence. During the analysis phase, repeatedly went back to the original codes and preliminary findings made in Urdu, to make sure they were getting translated staying true to their essence in the original language. Van Nes et al. (2010) also recommend the use of professional translator even if the researcher and participants share the same native language but due to the financial limitations for this project, a professional translator could not be afforded. Therefore, I took the responsibility to translate and transcribe all the interviews. I was aware of the bias I could introduce while translating, knowing that even with minute changes of punctuation and the structure of sentences during translation, the researcher can change how the interviews are heard, understood and read. Although translating each interview from Urdu/Punjabi to English was a lengthy task, every effort was made to stay as close to the spoken interview as possible in order to sustain the essence of the original story.

#### **4.4.1.3 Transcription of the interviews**

Translation therefore resulted in transcription of the interviews. Transcription of the interviews is extremely important however; it is a very tedious and time-consuming task (Leavy 2011). Professional transcription services or commercial online transcribing software was not used for transcription for this study due to the language challenges and financial limitations. It took me almost six to eight hours to transcribe one hour of an interview. This process however, helped me in revisiting the data and also getting a deep insight into the stories that were narrated by the participants. It also saved time and energy from not having to brief other transcriptionists about the participants, time, settings and emotional distress they were going through. I made sure that the testimonies of people with oral cancer in

Pakistan were transcribed remaining faithful as far as possible to their original speech.

Transcription is regarded as the first step towards understanding the interview (Riessman 1993). It is also considered to be an 'interpretative act' where meanings are created, rather than mechanically putting words on paper (Lapadat and Lindsay 1999). Transcription of the interviews also aids the researcher in quickly comprehending the voices and assessing the relevance of the interview. However, it should be kept in mind that not every minute detail is recorded in the transcription such as the highs and lows of the voice, facial expressions, hand gestures or the emotions expressed in words. According to Abrams (2010), a non-native speaker is usually not able to accurately or precisely translate speech into text. It can be argued that because I am a native Urdu speaker, I managed to reflect the participant's rhythm of speech, dialect and linguistic idiosyncrasies very well. Other scholars and researchers can later use these documents as well instead of listening to the audio recordings (Ritchie 2015).

The goal of transcription is not to pick up all the background noises or utterance but to create a transcript that is readable and comprehensive to the reader. Oral historians differ in their opinions regarding what to include in a transcript (Whitman 2004). Some argue that there should be no editing of the interview other than adding punctuation marks, or first names or dates (carefully in brackets so that it is known that it has been edited by the interviewer), and should be completely verbatim. While the others argue that the narrator should work closely with the interviewer while transcribing in order to check facts, omit or correct details and restructure any sentences for better understanding and accurate account of the narrator (Whitman 2004). For my study, it was plausible to include all the false starts, uhms, and grammatically incorrect sentences for the first and full account of each interview in order to see and understand the narrative in its entirety. Initially, I transcribed the interviews verbatim and later edited them to clarify the instances where certain emotions were shown, the tone of the voice changed or prominent hand gestures made. When denoting tone, emotions and gestures, italics were used.

This is important to distinguish and clarify the formatting because quotes and excerpts from transcripts will be used in the discussion and findings chapter of this thesis.

It is also advised to get the transcripts reviewed by the narrator once the transcription process is complete (Ritchie 2015), therefore edited versions of the transcripts were run through the participants to make sure that all the facts were correct. The participants had already once listened to their audio recordings after each of their interviews. Transcripts/ audio recordings were made available to all the participants who requested them.

#### **4.4.2 Phase two – coding of the interview transcripts**

After familiarising myself with the data and transcribing it into written word format, phase two began with generating the specificities of each transcript (Fraser 2004). There is not one format for analysing qualitative data it is more about the interpretation of the data and finding the meaning people give to their experiences rather than the numbers (Alston and Bowles 2003). This stage involved identifying the similarities and contradictions in the stories of participants. Initial codes in the data were generated. These codes represented the main theme of a particular segment of the data. It should be kept in mind that these initial codes were different from the broader themes (which were identified in later stages of the analysis).

Alston and Bowles (2003) have pointed out that qualitative data analysis usually occurs simultaneously to the data collection process. This was also the case in my study whereby; throughout the data collection process I was developing themes, making notes. I found it useful to refer to the field notes that I wrote in the beginning of my research project in order to compare how and if what was being said aligns with how it was said during the interview. It was also useful to make notes of how the setting and mood of participants on the day of the interview influenced the content of the interview. The narrative styles of participants were also referred to. William (2001) emphasises focusing on the 'narratology' or the



narrative structure of the story in order to deduce important data about participants.

It was worthwhile to work systematically during this phase of analysis in order to carefully code the entire narrative while paying equal attention to each segment. Interesting aspects of the data were identified which formed the basis of repeated themes across the whole narrative such as role of gender and socioeconomic status. Braun and Clarke (2006) suggest the use of highlighters or colour pens when manually coding the data and even writing notes on the text, which is being analysed. Using 'post it' notes can identify the potential patterns and data segments. It is important to code all the data extracts, which can later be organised together under each code. As I chose to code the data manually, it was fruitful to copy extracts of data from each transcript or photocopy the extracts of printed data and then collate them in separate computer files. I coded for as many potential themes and extracts as possible and as suggested by Bryman (2001) inclusively – keeping a little of the surrounding data in order to provide context.

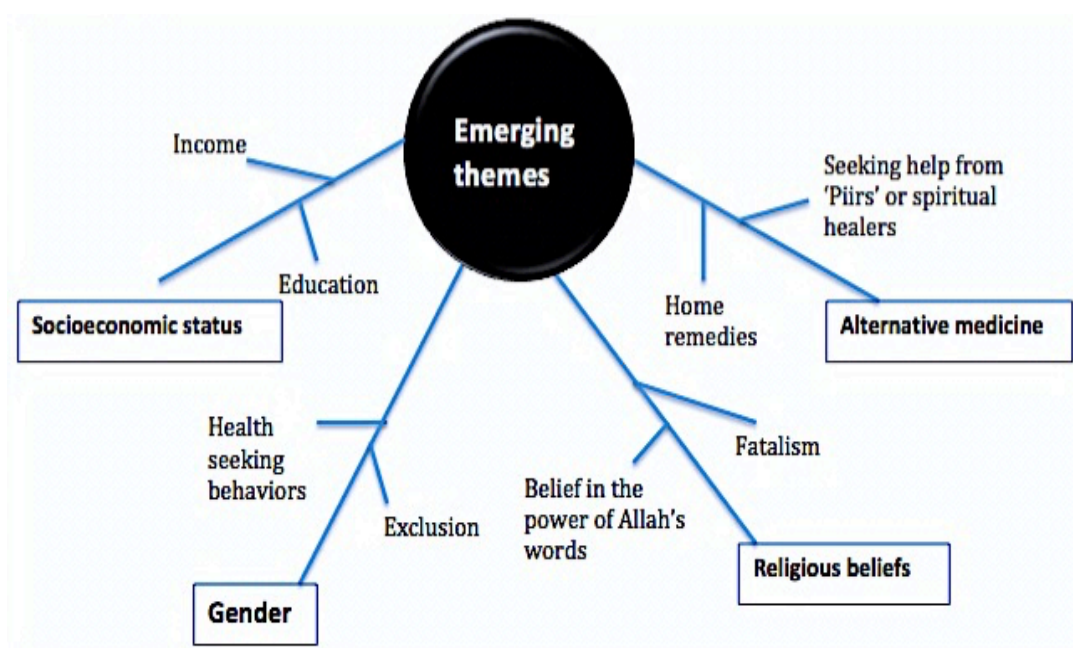
Although it was plausible to use computer software programme to assist in coding (Ritchie 2015), it is argued that there is a concern that the researcher may become isolated from their data (Hesse - Biber and Leavy 2011). With a sample size of fifteen participants, I did not find manually coding of the data much of a task.

One of the main challenges of this phase was to separate extensive chunks of the transcript into explicit themes. It may be difficult because at some points stories can 'ebb' easily into others, because the narrator can shift from one subject to the other. Fraser (2004) proposed that one way in which this can be handled is by dividing the narrative into ideas and scenes in which the story unfolds. While Chanfrault- Duchet (1991) suggest scanning the narrative in a chronological order. In the case of this study, for a couple of participants, chronological order was not straightforward and it was a little challenging to decipher the beginning, middle and end of their story.

#### 4.4.3 Phase three – Generating potential themes

In this phase of data analysis, the initially coded and collated data comprised of a list of codes identified, which eventually formed the basis of broader themes. The codes were divided into possible themes and all the important coded extracts were collated under the themes. It started to become clear how various codes might be pooled to form an all-encompassing theme. Visual representation proved fruitful. Mind maps (shown in figure 4.2) were used to construct the emerging themes related to the participants.

Figure 4.2 Mind map for emerging themes



The relationship between codes, between themes and between different levels of themes started becoming more prominent. It was also noticed that some themes formed 'subthemes', while others formed major themes. A list of 'miscellaneous' codes was also generated containing codes that did not fit anywhere. A collection of major themes, subthemes and all the data that had coded was available by the end of this phase.

The way a person tells a story shapes how we interpret it (Riessman 1993). However it can be argued that our own knowledge, beliefs and experiences cause us to interpret narratives in certain ways. Deliberate attention was given to popular

discourses such as when the participants' spoke of 'recovery' and the 'aftermath' while narrating their stories of cancer experience. The use of any metaphors to describe their experience was also noted. Likewise, any attempts to use humour, irony, puns, and sarcasm were also noted. Identifying these was interesting as it directed my attention towards understanding the role of time; gender, place and the cultural setting the participants dwelled in.

#### **4.4.4 Phase four – Identifying major themes**

At this phase, the transcripts were examined for commonalities and differences among the participants. Just like individual transcripts were worked on. In this phase, all data was compared and contrasted for tone, style and content. Common patterns were unveiled. It was interesting to find how different themes; plots, settings and temporal orderings were expressed and whether the material conditions in which participants were living had any influence on their experience.

In this phase, the major themes were refined. Any particular theme, which did not have enough data to support it, was eliminated. It was important to make sure that the data within the themes was coherent and there were clear and identifiable differences between themes. There were instances where the data was deemed to fit under more than one theme. Careful discussion with the supervisors helped me with refining them. Coding was stopped when after reviewing and refinement, nothing substantial was being added. At the end of this phase, I had a very clear idea of what the major themes of my study were, how they fit together and what overall story they were telling.

Because my research is interested in the experiences of people with oral cancer in Pakistan, I could relate the narratives linking back to how the participants constructed their memory. I kept asking myself: What stories are emerging from the data? What the public and private accounts of my participants were telling me about their temporal, cultural and social issues that may be influencing participants' experiences? What are the main determinants of the experiences of my participants? Thinking about these questions helped me interpret my data as well as

linking the experiences of the participants with the social processes going on in the background.

#### **4.4.5 Phase five – Defining themes**

This phase involved defining and naming themes- essence of each theme and what it comprised of was identified. Braun and Clarke (2006) warn that it should be kept in mind not to try and get too expressive or diverse regarding naming a specific theme.

A detailed analysis of each theme along with the data extracts was written.

Although, it was useful to identify the story each theme tells, it was of equal importance to consider how it fit into the overall story of the data or my research question. Sub themes were not ignored, as they were considered to be essential in giving a structure to the narrative. By the end of this phase, the themes were clearly defined and the scope declared. I found it useful to give concise and comprehensive names to each of the theme.

#### **4.4.6 Phase six – Finalising and interpreting themes**

Paul Thompson (2000) claims that oral history can be best put together as a collection of stories if one wants to do a historical interpretation, however, it was argued by Shopes (2013) that oral history research has started to focus more on the meaning embedded under the narrators words rather than on what was said:

*“Interpreting oral history as narrative means looking for underlying patterns of meaning within the interview.”*

(Shopes 2013, p. 135)

Interviews were not just treated as recordings of acts and action but also a search for meaning. The approaches to the interpretation of my oral history interviews focused on the silences in an interview, the experiences of the participants through language and the personal understanding of their past. Any blind spot that may have developed and undermined the veracity of the claims was also taken into consideration. Literature on the major themes was reviewed which helped in guiding interpretation. The findings were compared and contrasted making sure that the

findings of this study were novel and contributed to the existing literature on the perspectives of people with oral cancer. Arguments that were repetitive were edited if necessary. It was made sure that the analysis and interpretation remained relevant to the research question and the interpretations made were fair. The write up also included enough data extracts to support the prevalence of a certain theme. Clear examples from the transcripts were chosen to capture the essence of the point that needed to be demonstrated in a very simple way. A careful discussion of the themes was written in a respectful (not apologetic) manner and presented to the supervisors to check for consistency and coherence. I made sure that the write up in the form of findings and discussion was more than just stating the facts and data but tell a compelling story of the data embedded in an analytical narrative.

The themes worked out in earlier phases of the analyses were able to state a coherent, crisp, logical, interesting and non-repetitive account of the data through writing. The participants of my study did not contribute in the interpretation of the data.

This chapter reviewed oral history as a methodology suitable for my research question. It also considered several debates and methodological considerations that were accounted for during the research. My methodological reflections have also been interwoven in the chapter where needed. The next chapters will comprise of findings and discussion of the current study.

## Chapter 5-7. Findings and Discussion

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## **Chapter 5-7. Findings and Discussion**

Oral cancer remains the second most common cancer in Pakistan after breast cancer (GLOBOCAN 2018). The social and cultural background of Pakistan is different from Western countries; therefore the difference in opinions, attitudes, behaviour and response to health and disease varies. Geographical areas of Pakistan are also diverse socio culturally, for instance, people from tribal and northern areas of Pakistan believe that vaccination will make them infertile and vaccinations for Polio and Hepatitis B are not opted for, even amongst well-off families (Khan and Sahibzada 2016). These strong norms and myths mean that Polio is still endemic in Pakistan. In the light of a common cultural background with the Arabs, Persians and Turkish, believing in myths and stories is central to the people of Pakistan and something that remain undervalued by researchers. The strong influences of the myths influence the lives of people including their health seeking behaviours during an illness period (Rai and Kishore 2009). Likewise, diabetes is also considered contagious in Pakistan and people seek spiritual treatment to combat it (Nisar et al. 2007). Research around cancer and epilepsy has identified similar cultural and social myths (Shafiq et al. 2007).

In the literature review, I highlighted that the majority of studies conducted in Pakistan appear to confine themselves to descriptive studies of oral cancer with simple histopathological findings. This does not add to the existing knowledge base nor does it help in addressing the challenges of oral cancer in Pakistan.

My study involved interviewing women with oral cancer using an 'oral history' approach whereby they were given an opportunity to share their life stories and experiences of oral cancer. By exploring their life experiences I was given a greater level of insight into how they encountered and made sense of the various social determinants of oral cancer, including how these worked along their lives and in particular influencing their pathways to diagnosis.

### **Summary of the structure of this section**

The findings and discussion have been divided into three chapters:

#### Chapter 5:

The participants – will introduce and describe the social background of the participants;

#### Chapter 6:

Making sense of oral cancer: giving a voice to women with oral cancer – will describe how participants remembered and made sense of the reasons for their oral cancer, its diagnosis and treatment. It also explores how religious beliefs in terms of belief in the power of prayers and fatalism; use of alternative and complimentary medicine in terms of home remedies and consultations with spiritual and traditional healers influenced their health seeking behaviours;

#### Chapter 7:

Women's lived experiences of oral cancer – will describe the social attitudes toward oral cancer and women's internalised beliefs about the disease. It will also detail how women in the study experienced depression/anxiety leading to oral cancer diagnosis, how they addressed the fear of death and uncertain consequences of oral cancer, faced seclusion and identity crisis after the oral cancer diagnosis. This chapter shows how lonely and difficult oral cancer journey can be for the patients.



## Chapter 5. Introducing the participants

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## Chapter 5. Introducing the participants

### Summary of structure of the chapter

The chapter begins with a brief overview of the participants in the study and will then proceed to describe individual participants. It should be noted that the descriptions provided in this section are derived from the interviews and the field notes written after each interview. The data for each participant may differ according to what they chose to disclose. The chapter will then provide an account of what is known about the social position of participants.

### 5.1 Introduction

I recruited the participants in this study from Foundation University College of Dentistry, located in the heart of the twin cities Rawalpindi/Islamabad, Pakistan. This hospital serves the wives; sons (up to the age of 18 years) and daughters (until they are married) of ex- servicemen (Junior Commanding Officers (JCO's) and soldiers) free of cost. All the participants were women. The youngest participant being 29 years old and the oldest was 80 years of age. They were all born and raised in Pakistan and identified themselves as Muslims. All participants in this research, excluding one, were married and had Pakistani spouses. Foundation hospital college of Dentistry is located in Rawalpindi/Islamabad; therefore 80% of the participants came from the nearby villages and districts. Table 5.1 shows the individual demographics of the participants.

Table 5.1 Demographics of the participants

No	Name	Age	Gender	Location	Socio-economic status	Level of education
1.	Nisbah Shaheen	29	Female	Chakwal	Low	No education
2.	Ameena Mehboob	34	Female	Sadiqabad	Lower Middle class	Masters
3.	Shamim Akhtar	39	Female	Mansehra	Low	Intermediate (Year 12)

4.	Rukhsana Begum	44	Female	Arang Kel	High	No education
5.	Shafeen Bibi	54	Female	Sohawa	High	No education
6.	Maqsood Akhtar	54	Female	Chakwal	Low	No education
7.	Shehnaz Bibi	54	Female	Gujrat	Low	Primary (till year 5)
8.	Sughran Bibi	54	Female	Jhang	Middle class	Primary (till year 5)
9.	Zahida Kalsoom	55	Female	Chakwal	Low	Primary (till year 5)
10.	Sabra Bibi	55	Female	Gujar Khan	Low	No education
11.	Nasreen Akhtar	55	Female	Kallar Syedan	Low	No education
12.	Imtiaz Bibi	56	Female	Mithial	Low	No education
13.	Wazira Khatoon	57	Female	Mianwali	Low	No education
14.	Razia Begum	65	Female	Gujar Khan	Lower Middle class	Primary (till year 5)
15.	Muzammil Bibi	80	Female	Faisalabad	Low	No education

In order to better understand the participants in this study, it is important to provide some background information in order to enable a better appreciation of the characteristics of culture and place that they belonged. The Appendix 6 provides a brief overview of this information. It should be noted that due to the non - availability of the data regarding many of the locations, just basic information is stated. Most of the data regarding the cities in Pakistan has been taken from Wikipedia and Britannica and a little from blog posts. The population figures for specific cities, however, have been taken from the Population Census of 1998 and 2017 where needed. Although this information is useful in providing context for the

reader it should be pointed out that what matters is what the participants think about their experience of oral cancer in the context within which they live.

The following section will describe individual characteristics of the participants and my experience with them, derived from their interviews and my field notes. This will potentially help the readers understand and relate the findings and quotes from the participants effortlessly.

## **5.2 The participants**

### **1. Ameena Mehboob**

Ameena Mehboob was born in Sadiqabad, in the Punjab province of Pakistan, approximately 16 kilometres from the border with India. She grew up in a large and spacious house with plenty of room for her and her siblings. Ameena had a loving childhood, which was shared with her sister and brother. She remembers her childhood as being carefree, with plenty of freedom to explore with her siblings and reported that she did not have much interest in education and studying. From a very young age Ameena used to help her father at his medical store and felt that was the reason she did not focus on her own education. She was 17 years old when she got married. At that time she was completing her intermediate studies ('A' levels). Later she got her bachelors degree and studied further for her master's degree.

I met Ameena in early January 2017. A colleague at Fauji Foundation Hospital introduced me to her just after she had been diagnosed with oral cancer (cancer of the tongue). I remember her being very anxious and I registered the worry on the face of the person who was accompanying her. It was my very first interview so I was a bit anxious myself as to how to approach people. When I began to talk to her, the anxiety swept away because she was so open and willing to discuss her life with me. Ameena had a gentle and kind disposition, a serene face and at 36 years old she was young to be diagnosed with oral cancer. She had two daughters, one son and was a widow because her husband had died of blood cancer a few years previously. We had a chat about how things were and if she would like to tell me her life story and her experiences of oral cancer. She agreed without any hesitation and was very

supportive. The person accompanying her, whom I later discovered was her cousin, had reservations about her participating in an interview. But after I explained everything to him about the research and the potential benefit for future generations, he agreed. Initially, he wanted to come and sit by her during the interview for support but after our initial discussion, Ameena herself reassured him, telling him there was nothing to worry about and requested that he leave us to discuss what was important to her. Ameena and I developed a connection, which built through the process of developing mutual understanding and trust as the interviews progressed. She was very keen to tell her life story and about the cancer and her openness and generosity with things she shared helped to reduce my anxiety as a researcher. During the course of the first interview, Ameena also pledged to write about her cancer in the newspaper and was keen to create awareness about the pre – cancerous lesions.

The Ameena I met during her chemotherapy treatment was a totally different person from the serene individual I had first encountered. She was crying with pain and exhibiting strong emotions of anger and frustration with the doctors. She was worried and frightened. At one stage she held my hand and asked me; “ Have you interviewed any other person who has survived tongue cancer?”. I responded, “Yes, I have. And there is always hope.” I re-assured her because I had recently interviewed a participant who was in complete remission. I comforted her and asked if she wanted me to continue to record her experiences. She indicated that she wanted people to hear what she had to say.

She began by telling me that in the evening it was her youngest sons’ wedding and that she was getting him married because she wanted someone to take care of him after she was gone. This abandonment of hope was clearly not the same Ameena I had met a few months previously. She was in constant pain and felt let down and disappointed with the doctors and life as a whole. She still wanted to have her voice heard and I was there to listen and record her story.

Ameena died in June 2017 during the course of her treatment.

## **2. Razia Begum**

Razia Begum was born in a village near Gujar Khan. She described her home as 'ghareeb khana' (a poor household) that is a very humble way of describing a house, which consists of everything you need but with no luxuries. She was the youngest of four and had a sister and two brothers. They were very close to each other. Razia experienced a loving and warm childhood; filled with memories of long days playing with her siblings and felt loved by everyone in the family. Her mother was viewed by all as a very wise woman and people from the village used to come to her for consultation and prayers. Razia and her sister did not receive any formal education, which followed local traditions. She studied until year 2 and then later Razia and her sister studied in secret from their brothers' course books because it was not seen as appropriate for women to receive formal academic education. Instead, they received religious instruction and the sisters were taught the Quran regularly. Razia was married to a very pious man who treated her with love and respect, holding her in the highest regard. He was a landlord and they were comfortable financially.

I met Razia Begum when she was 80 years of age and on one of her annual visits to The Foundation Hospital, College of Dentistry. She arrived at the hospital in a wheel chair because she could no longer walk unaided. Her eldest daughter accompanied her. Although her daughter had informed me earlier that Razia would not be able to give a long interview because of her illness and age, Razia was very keen to talk to me. She told me she might forget stuff in between to which I reassured her that this would not be a problem and that she was to take, as much time as she felt was necessary.

Razia looked very tired later in the course of the interview and I remembered her daughter's words so I asked if I could end the interview to which Razia politely agreed. In subsequent discussions, I was amazed by the depth and details of her childhood that she described. She said that she had summarized her whole life to me. The one she could remember.

### **3. Shehnaz Bibi**

Shehnaz Bibi was born in a village near Gujrat, Pakistan. She and her two siblings grew up in a 3-bedroom house made of mud. Her father was an agricultural labourer who used to work on the land. He died when Shehnaz was only 6 months old. Their mother brought them up alone. Despite not having a father (that she could remember), she recalled having a loving childhood describing herself as 'beautiful' because she used to eat pure butter and drink milk produced from their own cows. She did not remember a lot of detail about her childhood, apart from being naughty, and because she was the youngest she felt that their mother loved her the most. Her brother died in childhood leaving only herself and another sister. They just went to primary school compared to their brother who completed ten years of education. Shehnaz married when she was 17 years old and her husband treated her well. She was diagnosed with oral cancer at the age of 54 after experiencing persistent ulcers in her mouth. She had no history of using paan, Chalia or tobacco in any form. For her, the word cancer was a terrible one and she did not even want to say its name. She was frightened, anxious; worried and uncertain about her future and hope of survival.

I met Shehnaz a couple of weeks before her operation and she appeared depressed and worried, but wanted people to hear what she had to say and was happy to participate in the study.

### **4. Muzammil Bibi**

Muzammil Bibi was born in Faisalabad. She had five sisters and four brothers. Their father was a very hardworking man but his money went on food and clothes for his children and there was nothing left over to pay for education. He worked on a few acres of land that he had inherited from his father. They are a very close-knit family and she describes the immense love and respect they have for each other.

Muzammil Bibi remembered being very obedient as a child. Along with her siblings, she received a Quranic education. Muzammil Bibi got married at fourteen and had many sons and daughters. Her faith in Allah acted as her guide for her life and anything that happened was for her because Allah had willed it.

When I met Muzammil, she had been diagnosed with 4<sup>th</sup> stage oral cancer. The lateness of the diagnosis meant that surgery was not possible and she had been referred to palliative care. I felt upset that this 65-year-old lady was lying on the bed of a ward that was still under construction and apparently a chemotherapy ward, which also doubled as a palliative care ward. There were two other beds on which two other women were resting and waiting for the nurse to get their injections. I felt this extremely unacceptable to place three extremely unwell women in the same room with no privacy with workers entering and leaving every now and then. As I entered, the three of them stared at me with surprise because nobody other than the doctor or nurse could enter that room. I introduced myself to Muzammil Bibi and sat by her side. The construction workers kept on working so I had to ask them if they could pause the work for a few minutes so I could introduce myself to her. They were not very happy about it and told me that I could only have 3 to 4 minutes. The construction noise was continuous, vibrating and the drilling noise was of high intensity. I found this unbearable and struggled to think. I wondered about the effect this had on patients who were unwell and in the terminal stages of cancer.

Muzammil Bibi had covered her face with a veil and looked so frail. She was in the last stages of her life. Her face was swollen and immensely disfigured and the cancer had left a deep hole in her cheek. The doctors and her family chose not to tell her about the seriousness of her disease to protect her. Muzammil Bibi was happy to share her story with me. She had a lot to say, and I was there to listen.

### **5. Imtiaz Bibi**

Imtiaz Bibi was born in Mithial. She had five sisters and one brother. When she was a child she recalled that they used to live in a village that had lots of fields around it and that she enjoyed living in that environment because of the peace and feeling of freedom. They lived in a large house with their parents. Her father was a labourer and mother was a housewife; they were a very closely-knit family. She married early in life. Imtiaz Bibi did not share the details of her marriage and husband.



Imtiaz Bibi was diagnosed with oral cancer in 2015 and told me that the doctors said this was because of her chillum and hookah use. The cancer had grown and she presented late at the hospital in August 2017, where I met her. When she arrived, her lymphatic system was involved and her whole face was swollen. She was only worried about her children. She thought that she would be able to afford her treatment with her husband's help. Imtiaz Bibi talked for a very short time with me, as she was very anxious about being diagnosed with oral cancer at a later stage. Imtiaz Bibi was scheduled for operation later in September 2017.

#### **6. Maqsood Akhtar**

Maqsood Akhtar was born in a village near Chakwal. She was the only child in the family because her twin had died not long after birth and her brother had died at the age of sixteen. Her father was a farmer and her mother was a housewife. Maqsood lived in her paternal aunt's house, because they did not have a house of their own. Maqsood Akhtar felt she had been deprived of material things and luxuries when she was a child, but as an only child had undivided attention and love from her parents and extended family. Similar to the other women in this study, she did not go to school after completing her primary education but she received an Islamic education at home. Although Maqsood was fond of reading and writing, her grandmother did not approve of the education of girls and insisted that she was guided to help her mother with the household chores. Every aspect of her life was controlled and even using toothpaste before marriage was forbidden in her family. She got married at the age of fifteen, but had no children so her husband married another two wives to give him the family he wanted.

Maqsood Akhtar was diagnosed with oral cancer after having gum disease and tooth trauma in 2016. When I met Maqsood Akhtar in July 2017, she told me she was 54 years old, frightened, worried and very reluctant to talk about her disease but she still agreed to an interview about her life. Having oral cancer had disrupted her life and she appeared in low spirits. When I left to return to the UK, I called in on her and felt that she was recovering well after treatment.

## **7. Nasreen Akhtar**

Nasreen Akhtar was born in Kallar Syedan. Her father was a servant in the army and later retired as an army man, with a pension, her mother was a housewife. She had two sisters and one brother. They all enjoyed a good relationship with each other. Nasreen's family used to live in a 2-bedroom house, which was not made of bricks or stones but of mud. She started using naswar from an early age. It was a norm in their households. This 55-year-old woman was diagnosed with cancer in 2016 but was in remission. She was of the opinion that cancer had taken the best of her and there was no point in discussing the disease because she did not want it to take any more from her.

I felt that this particular interview was the most difficult interview for me to conduct. Initially, when a fellow colleague introduced me to Nasreen and her husband, they appeared reluctant to talk to me. I talked them through the details of my study and they agreed that they wanted to participate. Nasreen's husband wanted to sit in the interview, saying that he was concerned about his wife giving the interview in a separate room. I told him that it was not possible for me to talk to his wife in his presence because it was her story that she was going to tell me. He eventually agreed to her being alone with me after a 20-minute discussion regarding the content of the interview. Before leaving the room, he instructed his wife to 'talk good' about the hospital and the treatment and refused to leave until she had indicated compliance with his request.

At the beginning of the interview, Nasreen looked calm, would either stare at me, remain silent; respond with a single word or short sentence after what seemed to be an interminable pause. She did manage to talk about her disease experience and her life in general. As we built a relationship of trust she began to open up, becoming more forthcoming and allowing me to probe her responses in more depth. I felt that her participation in the research was extremely important mainly because of her position as a woman in a traditional Pakistani household, whereby women have no voice of their own. She had a voice and was not scared to raise it.

## **8. Rukhsana Begum**

Rukhsana Begum was born in Azad Kashmir. Rukhsana's father used to work in England. When she was seven years old, her mother, along with her two younger sisters, moved to England leaving Rukhsana with a paternal uncle in Pakistan. It was not a happy time for a seven year old but her uncle was kind and took care of her as if she was his own daughter. Rukhsana did not receive any formal education, but like many of the women in this study, received a Quranic education. Financially she never wanted for anything throughout her childhood. Her father supported her living costs and her subsistence. Although her parents kept visiting her from time to time, they never took her to England with them. Rukhsana never complained but felt lonely and abandoned. She was married at 15 years of age and had four sons and three daughters. She started using naswar when she got married, copying the behaviours of her mother-in-law. She used it for 3 to 4 years and then quit it completely. It made her choke and left her breathless and scared. Rukhsana was diagnosed with oral cancer in 2016.

I met Rukhsana, who was 44 at the time, in July 2017 at one of her visits to the hospital. Rukhsana was the first participant in my research project who did not want her real name to be included. Therefore, a pseudo name is being used. She said she was happy to talk about her life but she was unwilling for her real name to be published. I agreed to her request, but was still curious as to why she wanted anonymity. She told me that as I was going to go back to England and write a thesis there, her relatives in England might recognize her name and story. I could then understand why she was reluctant because of the issue of disclosing her private life and illness and stigma in the family. Rukhsana Begum was very supportive throughout the interview. She was an excellent storyteller; very detailed and animated, talking in such a way that drew me in and made me even more intrigued about her and her story.

When I last saw Rukhsana before I returned to the UK, I could see that she was recovering well after surgery and regularly attending her follow up sessions at the hospital.

## **9. Sabra Bibi**

Sabra Bibi was born in Gujjar Khan. She had one brother and four sisters. They lived in a house big enough for all of them to live peacefully. She enjoyed a happy childhood. Their father was not of a conservative mind and regarded his daughters as 'sons' and was proud that he had five daughters. He was a religious man but never strict with the children and took care of them in every way. Sabra did not receive any formal education, because girls were not allowed access to education; similar to other participants in the study. Their father regarded education for girls as forbidden in the religion. Her brother did go to school though. The girls received an Islamic education instead. According to Sabra, she never consumed naswar or paan but was a regular user of chillum. She started using chillum after her husband passed away of a cardiac arrest. She felt depressed and resorted to chillum. After the loss of her husband, Sabra faced major financial difficulties in feeding and looking after her children. She would earn enough to feed herself and her children. Sabra suspected something wrong when she started feeling a sharp pain on the left side of her tongue whenever she would eat or drink. The local doctors at the village recommended some medicines to treat what they said was her infection but all in vain. A dentist later took a biopsy of her tongue. She was referred to Fauji foundation hospital and diagnosed with oral cancer in 2016.

I met and interviewed Sabra Bibi at a follow up visit in 2017. She looked calm and happy but was worried about her monthly evaluation reports.

## **10. Shafeen Bibi**

Shafeen Bibi was born in Sohawa, Jhelum, Pakistan. She had 5 brothers and one sister. She spent a very playful and carefree childhood. Their father used to work in London, England. The family never faced any hardships or financial issues. Shafeen felt that she was a very naughty child. The girls in her family were loved and pampered and everyone took special care of them. She was close to both her parents and missed them a lot after they passed away. She did not receive any formal education because her maternal uncle did not allow girls from the family to attend school. Shafeen was fond of reading and writing but due to strictness at

home, she never went to school. Later she got married in a well off family and enjoyed a great relationship with her husband who took care of her by all means. She had 5 daughters and three sons and all were well settled in their lives. She was diagnosed with oral cancer in 2017, which started as a small boil in her mouth with an unknown etiology.

I met Shafeen Bibi in August 2017, at one of her routine follow up sessions at the hospital. She had covered her face with her shawl and the scars from the surgery were still apparent on her face. She agreed to share her experience of oral cancer and her life story just after a short discussion about my research. She was recovering well after the surgery.

### **11. Shamim Akhtar**

Shamim Akhtar was born in Mansehra, Pakistan. She grew up in a very poor household. Shamim had spent a very stressful childhood. Her father was an ordinary driver and they used to live in a rented house, which was not big enough for all the children. She had 4 brothers and two sisters. The circumstances only started to get better when she and her sisters grew up and started teaching. None of her brothers were interested in studying. They would play truant instead of going to school. Shamim struggled to study but was able to study till year 12 when her mother sold all the utensils she had. She studied till grade 12, after which her father refused permission for her to continue. Her father was against the idea of colleges and of the opinion that colleges are not good places for girls and that the environment is not safe. Although many people in the family continually told him that his daughters were academic and that he should let them study for longer, he stubbornly refused. He was okay with them studying privately at home and tutoring children from the neighbourhood but they were not allowed to go out and work. Shamim was ambitious but then she got married at the age of 17. She could not develop an understanding with her husband who was a drug addict and lived in an unhappy marriage for several years, after which she sought a separation from her husband. Even after 10 years of separation, she took care of the children. Although the

children did not live with her, she managed their finances and their schooling because she started working as a receptionist at the Fauji foundation Hospital. Although the journey was not very pleasant; the job helped her develop as an individual. As a result her confidence increased and she felt stronger.

Shamim was diagnosed with tongue cancer in 2016 and felt it was because of her habitual usage of 'Sapari'. She made it to the hospital fairly quickly for her initial check-up because she was working in the hospital as a receptionist. Shamim's supervisor advised her to get the check-up done at the dental hospital and surgery if needed. Shamim was diagnosed and operated at an early stage. She did not receive any chemo or radiotherapy.

I met and interviewed Shamim on one of her follow up visits to the Fauji Foundation Hospital in August 2017. Initially during the interview, Shamim was very emotional and I had to pause the interview for her to recover and feel okay to continue again. As the interview went on, I found Shamim getting more vocal and confident in what she was telling me. The transition from an emotional Shamim initially to a more confident one was plausible as she could make sense of her life in a far better way after the interview. She thanked me many times for providing her with an opportunity to rethink about her life in a different way in front of a stranger. On a follow up call to her, I was told that Shamim was in complete remission and living well.

## **12. Sughran Bibi**

Sughran Bibi was born in Jhang. She spent a happy childhood and her family did not face any financial hardship during her early childhood. She lived in a small city but her house was big and spacious and had all the necessities. She had two sisters and four brothers. Sughran was very timid and shy as a child. Her relationship with her parents and siblings was based on mutual love and care for each other. She studied till grade 5 only, because her city, Jhang, did not have a high school or college for girls at that time. Sughran Bibi received religious education. She married at the age of 15, as it was the norm in her family to marry their daughters young. Her husband

and father-in-law were very keen for her to pursue her studies but she preferred learning from her husband at home. She lived a very happy marital life and had 8 sons and 4 daughters. All of them were educated and well settled in their lives. Sughran Bibi had a great lifestyle even after her marriage. She was diagnosed with oral cancer in 2016 and according to Sughran she faced all the challenges of the disease very bravely. Unlike a few other participants in the study, Sughran's treatment was not a burden on the family because they were financially capable to afford it.

I met Sughran Bibi in August 2017. She had a certain grace to her personality and was keen to share her life story and about her experiences of oral cancer. She looked confident and happy by the way she narrated her childhood experiences. On the follow up call to her, I was informed that Sughran Bibi was recovering well after her treatment and visiting the hospital regularly for her routine monthly follow up sessions.

### **13. Wazira Khatoon**

Wazira Khatoon was born in Mianwali, Pakistan. She had 4 younger siblings. The house they lived in was not spacious enough for five children to live comfortably. Her father who used to be a landowner, died when she was very young. After her father passed away, her mother brought them up and faced many difficulties. She used to sew clothes for people in the village and save money to feed her children. Wazira Khatoon did not spend a happy childhood as she and her family struggled financially and she was aware of their impoverished situation. Wazira and her siblings did not receive any formal education, because their mother's main concern was to feed them. Education was a luxury they could ill afford. Wazira did however receive a Quranic education. She married early and had three sons and four daughters. When her eldest daughter was 6 months old, Wazira started using naswar. Nobody in her family except her father-in-law used naswar.

I met and interviewed Wazira Khatoon in January 2017. She was one of my first participants. She looked frail and wore the traditional Pakistani dress 'Shalwar

Kameez' and a veil to hide her face. At first, similar to the other participants, she was very anxious about the interview and sharing her life story. Right from the beginning of the interview, I could sense stress building in her. Later, she seemed eager to tell the details of her life and shared the most personal happenings. Wazira managed to talk about her life including what she felt was the miserable disease experience. After the interview, Wazira told me that she felt a lot better about herself and the life she has spent. She was supportive of such opportunities to talk.

#### **14. Zahida Kalsoom**

Zahida Kalsoom was born in Chakwal. She has two brothers. Being the only daughter she was loved by everyone in the family. She went to school till grade four, because from grade 5, male teachers taught children. She had studied the Quran and was very proud of it. Zahida shared that her childhood was a sad one as her family faced immense financial difficulties. She loved her parents and missed having a sister and told me that it was not possible for her to remember more details from her childhood because the poor did not have memories. So I respected her position and did not probe, instead I let her take the lead. When Zahida married, she had no children of her own so her husband married again. Zahida felt very lonely because she had no one from the family to take care of her or share her problems with. She often used to visit her nephew, who would sometime support her financially. Zahida started using naswar because it was a norm in her village. She told me that according to the doctors, she had developed oral cancer because of her habitual naswar usage. Zahida was diagnosed with oral cancer in 2015.

Zahida Kalsoom aged 50 years came to Fauji foundation for her routine monthly check up where I met her in February 2017. A colleague introduced me to the lady. Zahida was operated a year and a half ago and was on a regular follow up every two months. She had an extensive surgery and grafts were placed on one side of her face.

Zahida agreed to share her story soon after I explained her the purpose of my research. She wanted to talk to someone about her loneliness and her disease



experience and it was fortuitous that I was there. Zahida was in complete remission after her surgery two years previously, but was becoming weak and frail because of her lack of proper diet and resources. Her teeth were removed during her treatment so she could only eat a soft diet. She shared with me her love of food and how much she missed eating properly. My interview with Zahida will remain close to my heart because it not only taught me the value of small things that I took for granted but also to be grateful for the things I already have. On a follow up call to the hospital after I came back to UK, I was informed that Zahida was facing issues with the bone grafts placed in her jaw (possibly radio necrosis) and was receiving more treatment.

### **15. Nisbah Shaheen**

Nisbah Shaheen was born in Changa Meran, Chakwal, Pakistan. She lived in a house, spacious enough for all of her family members to live peacefully. Her mother died when she was very young. Her father was an educated man and worked at in a bank. Later he joined the army and became a junior commanding officer. After her mother's demise, Nisbah's elder sister who was married took up the responsibility and moved in to take care of them. Her sister brought them all up. Her relationship with her father was good but she missed her mother a lot. She said she used to be very naughty as a child. Nisbah was not fond of studying and did not attend any school or college, but her brothers studied until grade 5. She was very feisty and had a strong will power; deciding not to marry, because she wanted to take care of her father. Nisbah developed oral cancer in 2016 and really struggled with her treatment and post-treatment while people in her family secluded her inside her home. Her sister-in-law would not let her wash dishes or let their children come near her. Nisbah felt that this was unfair. She would often cry herself to sleep and wondered if disease was within her control.

I met Nisbah at one of her routine monthly check-ups after radiation. She seemed vibrant and full of life. She agreed to tell her story after a short discussion of the research and was happy to share her experiences with the disease. Her stories were heart breaking. Although she got very emotional during the interview, she felt that

the discussion was very therapeutic and made her realize what a gift health was. On a follow up call to Nisbah, she told me that she was well and happy.

### **5.3. Commentary on the social background of participants**

#### **5.3.1 Socioeconomic groups**

Social class in Pakistan is measured on the basis of income (see below for more details on what this means). A complicating factor is that socio-economic factors such as social class and education combine to place women at special disadvantage. Pakistan is a patriarchal society and majority of the women are dependent on their fathers and other male members of the house for income, which ultimately defines their social class. Socioeconomic status is an important social determinant but it was interesting to find that none of the participants in my study explicitly declared or recognised low/high socioeconomic status in relation to their disease. Whilst participants belonged to a range of socioeconomic backgrounds, more than half of the sample belonged to a comparatively low social class while others belonged to comparatively higher but middle class families. However, socioeconomic status always worked as a determinant throughout their lives in terms of access to basic necessities, education, health care, as well as wider social participation and in their pathway to the diagnosis of oral cancer.

According to the latest Pakistan Social and Living Measurement (PSLM) survey conducted for the Pakistan Bureau of Statistics in 2016, the average monthly household income for the population residing in rural areas of Pakistan is 26,452 PKR (£165.92). Most of the participants from my sample belonged to what could be described as a low social class. The class categorized as 'low' in Pakistan live 'hand to mouth' lives with minimum access to basic necessities of life like clean water, housing, education and health services. Wazira Khatoon belonged to a low social class and when asked about her memories of childhood and the house she lived in, she said:

Wazira:

*“Poor we were. And the poor have no memories. There are no memories of the poor (starts crying)...poverty is a curse...people who have got money and luxuries in life only they have good lives, what about the poor? They have nothing. My husband served in army, only that’s why we could afford this disease treatment otherwise how would have we? Nobody does it.”*

The link Wazira has made between being poor and her memory is noteworthy; she is saying that only rich people get to make good memories. She clearly articulates her views about lack of money and calls it a ‘curse’ to be poor. Wazira makes an interesting contrast between the poor and rich, that only people who are well off can afford a good life. If it were not her husband’s job as a serviceman in the army, they would have never afforded the treatment. Although Wazira acknowledges her sadness in the beginning of her interview, it is the sentiment that was largely present in the remainder of her interview as well. In this study therefore memory itself becomes something denied to the poor and only allowed to the rich. Only the rich have memories worth having. It is important to note that only Wazira had this perspective on her social context. Others related to poverty in different ways.

Similarly, Zahida Kalsoom, who belonged to a low class and was living alone in a village in Chakwal, shared her experience with poverty as:

Zahida:

*“My nephew gives me some money, which I try my best not to spend lavishly, I just cook one thing and then put it in neighbours fridge and use it for three days, I cant eat much anyway since the operation, my stomach cannot digest hard stuff, then just a quarter of the roti (bread), one time tea only, and then nothing the whole day, in winters I do feel the need to have more of warm food but I cant afford the milk packs, so I just tolerate my cravings [chuckles], and my clothes, my nephew sometimes gives it to me, or somebody from the village like my relatives if they give me some money I get my clothes sewn once a year, for example this suit that I am wearing, it cost me 1300 rupees, (approximately £13) I normally buy them on my own every season...”*

Zahida, who was mainly dependent on her nephew for monthly income shared how she would control her craving for certain food and curb it in order to save the money. She eats the same food for three days. Zahida was also dependent on her distant relatives for money so she could buy clothes once every season. The other women in the sample from a low social class chose not to express their views on low social class and how and if it affected their childhood or present experiences.

Participants belonging to the lower middle classes resided in comparatively well off (urban) areas and were earning or in possession of enough money to fulfil the basic needs of their children and family. For instance, Ameena was from a lower middle class family, earning a fair amount of money, but education was one of their main priorities. Although Ameena got married at the age of 17, after her intermediate schooling, she completed her bachelors and masters after her marriage. Later she managed to get a job at a Government institution alongside her husband. She also educated all her children, even after the death of her husband continued to work towards their education and sustenance. The population residing in urban areas in Pakistan have a monthly household income of 38, 923 PKR (£ 244.15) (Pakistan Bureau of statistics 2016). Also, the lower middle class tends to be most economically deprived because they have to maintain a minimum standard of living, including providing education for their children and paying utility bills.

Only one participant belonged to the middle classes. Sughran Bibi who was a housewife belonged to a middle class family. All her children and grandchildren were doctors and professionals in different areas. Compared to the other participants she appeared to have had a more comfortable lifestyle financially. Professional degrees such as Medicine, Economics and Law promise a variable but higher monthly income compared to more manual jobs.

Two out of the fifteen participants were of a high social class. Rukhsana Begum and Shafeen Bibi were not earning money themselves but belonged to very rich families who could afford to pay for treatment privately at the hospital. Their children were receiving an academic education and were financially well supported. The average

monthly household income for a typical high-class family in Pakistan could range from one million to 100 million PKR (£6272.55 to £627255.00).

From many perspectives, women from Pakistan find themselves in an inferior position and are socially, economically and culturally dependent on men (Narayan et al. 2000). As discussed earlier, they are not only ignored from decision-making, but have limited access to their personal income and resources. Gender roles are clearly defined and male preference is deeply embedded in Pakistan (Fikree and Pasha 2004). Men are considered to be the breadwinner, family name carrier and carer for their parents in old age. Therefore they are 'entitled' to enjoy more care and attention and family resources. They are considered to be an economic and religious utility whereas women are regarded as an economic liability (Arnold et al. 1998). Compared to women of the same age, they are also given better nutrition and health care access (Nasrullah and Bhatti 2012). Women compared to men are at a disadvantage right from their birth and subjected to bias and discrimination along the life course. This sheer neglect continues to be reflected in their childhood as well as adolescence because as compared to 49% of men, only 25% of women in Pakistan are able to complete their primary education (Qadir et al. 2011).

### **5.3.2 Education status of the participants**

According to UNESCO 2012 factsheet, Pakistan has the second highest number of children out of school; approximately 5.1 million. Two thirds of this number (about 3 million) is comprised of women. The majority of the women in my sample belonged to the rural areas of the province of Punjab where according to the UNESCO statistics of 2007, at least 17% of children had never gone to school. Women belonging to poorer areas were the most disadvantaged in terms of education. The policy documents of Pakistan also ignore the issue of gender equity. For instance, the target for Universal Primary Enrolment (UPE) in the year 2000 for boys and girls was 5 years and 10 years respectively. It can be argued that educational disadvantage for women in Pakistan is taken for granted and instead of working more on filling the gender gap, the gap is maintained (Shaukat 2009). However it should be kept in mind

that because of their age, the schooling years for most of my participants (in 1940s and 1950s) were way before the introduction of educational reforms in Pakistan. While there may have been fewer schools for girls in those times, it may be possible that the women in my study remained uneducated because of cultural or religious reasons. My study findings are still consistent with the education statistics of Pakistan because the majority of the women in my sample were completely illiterate. Only 1 participant received education until grade 12 and another participant acquired a Masters degree.

Brint (2006) observes that for most of the population, the experience of schooling is associated with youthful experiences and identity formation. Similarly, I was aware that by asking my participants about their schooling, I was expecting them to return to a very particular type of identity that is formed at a very crucial stage of life and is central for self-understanding. On one hand, there are universal experiences of being a student, which are familiar and experienced widely. On the other hand, the story one tells about being a student tells a lot about who they are individually, how they developed and grew as young adults and the relationships they formed (Brint 2006). My aim to ask about the education of my participants was to know what was remembered and how that experience was recounted and woven in a story. The question regarding schooling and education was among the first questions asked from the participants after their childhood memories. Although, for most of the participants it was difficult to remember the exact details or particular events, a little probing led to the recollections of how they remembered not being allowed to attend school in those days. Across the interviews, there were a few past – present comparisons of girls not being able to receive education previously as compared to the present times.

Now fifty-five, Sabra Bibi remembered that she was not allowed to go to school and laughed at her experiences at home where her brothers were sent to school in accordance with the 'Islamic Sharia':

Sabra:

*"I remember my father used to say that 'Dear, it is not allowed in Sharia (Islamic Law) for girls to study' (laughs) Brothers were allowed though that makes me laugh. But I never revolted against him because he was the elder in the family and I used to respect his views. But we did receive Islamic education."*

Sabra clearly expressed obedience and acceptance of her father's decision to not allow her to attend school while her brothers had no restrictions. Note in particular how these gendered experiences are narrated as a private experience in contrast to her experience of a religious education, which is presented as a 'public' or shared memory. Like the other participants in the sample, Sabra received an Islamic education within the boundaries of her home. Sabra may have chosen not to disobey her parents as a part of strong cultural ethos in a Muslim Pakistani household. Similarly, Shafeen Bibi did not attend school because when she was younger, girls could only study up to year 5:

Shafeen:

*"No during our times, girls weren't supposed to go to school. My brothers did but we did not. But I wanted to go to school..."*

Shafeen did want to go to school like her brothers and her statement illustrates a shared public narrative about what boys and girls should do and therefore highlights societal expectations related to gender. Later in life, she made sure that her daughters received an education, which reflects the comparative change in the perception of education in the present:

Shafeen:

*"Yes I wanted to get education but we were not allowed. My maternal uncle (mamu) was very strict. He used to say that daughter should not be sent to school. It was thought shameful (laughs). My mother was scared of him so she said no. Although the males in the family did go to school. Now times are good and everyone sends their children to school. I, too sent my daughters to school and all of them have passed their year ten."*

These public accounts relate closely to what others have found. Jamal (2016), found that families are reluctant to send their daughters to school over concern for their safety and honour. Religious and cultural beliefs also tend to play a major role. Similarly, Moheyuddin (2005) argues that there are two separate worlds for men and women in Pakistan. Men (usually the elder brother or father) are the head of the family and are the sole decision maker. They rule the outside world. Women on the other hand are confined to the four walls of the home as their 'legitimate ideological and physical space' (Moheyuddin 2005). This often leads to little or no power in decision - making as well as in wider social participation. The role of 'producer and provider' is usually associated with men and is denied to women. Parents also tend to spend money on their sons education in order to prepare and equip them with the skills required to 'compete for resources' and to provide support when the parents get old. In contrast, the daughters are taught domestic skills because it is expected that their domain will be the home. This means that women experience double discrimination because they are affected by both lack of resources and shame.

Maqsood Akhtar shared a similar experience where her grandmother forbade the girls in the house to attend school. Instead she insisted that they stayed at home and helped their mother with the household chores. When asked about why she did not have formal schooling, she said:

Maqsood:

*"Umm. I don't know but it was the norm in those days, there was nobody who got an education at a school in our family, I remember my grandmother saying that daughters and sisters should not be educated, But you know what I secretly wanted to study always, I always wanted to read and write, I was so fond of it. So I studied in my village up until 5<sup>th</sup> grade but inside the house, but they didn't let me study ahead, although my brother used to go to school every day and I used to go as well, but then as I grew up they said whose going to help a mother in the kitchen and other household chores, who is going to take care of the herd, so you stay at home. You won't believe how I*



*completed the Quran, going from person to person and completing and trying to read parts of it, that's how I read Quran, otherwise, that was impossible."*

Like many other participants in the study, Maqsood was also not allowed to attend school because of cultural norms at the time when she was young. Her opinion, wish or decision to get education did not matter nor was it significant enough for her to receive the education of her choice. She received Islamic education at home. Again, Maqsood has shared a public knowledge about the status of women in a typical Pakistani household. It is important to note that Scambler (2018) in 'Sociology, Health and the Fractured Society' argues that gender relationships pre - date the economic relationships of capitalism. So it should not be surprising to find that patriarchy is more dominant than class or socioeconomic relationships.

According to the Pakistan Integrated Household Survey 2015-2016, there is a positive correlation between household income and attendance of children at school. The higher the income, the more the parents prioritize their children's education. However, uniforms, tuition fees, textbooks and other school supplies can be a massive burden depending on the number of school children going in each household. Wazira Khatoon who belonged to a low socio-economic group could not afford education. She shared her experience:

Wazira:

*"I didn't go to school, but I learnt how to read Quran and how to pray. We were so little when father died, who would have afforded our education? Nobody! It was such a small village we didn't go to any school. But mother used to worry about feeding us only. She was not worried about education at that time. It was sustenance that was an issue. We couldn't afford education."*

Wazira stated that for her mother, feeding the children was more important than education. On being asked if she herself ever wished to go to school, Wazira made an interesting observation regarding education linking it to a great life and said:

Wazira:

*“Of course yes, my heart always wished to get education but now when I see the educated people and their children getting education, I see how much great life they are spending and how much facilitated they are. My husband did get some education and got in army, at least because of that our children are well fed and living a good life...”*

Wazira’s narrative highlights that sustenance is the main focus in poor and lower middle class households. In Pakistan, the most marginalised group comprises of poor women of illiterate parents living in rural areas (Shaukat 2009). The struggle to survive is very real and education becomes a luxury. Ironically, the way of helping lift people out of poverty is through education and the provision of a skilled workforce, something that these segregated gender roles fail to acknowledge. This then becomes a cycle that repeats itself.

Similarly, Rukhsana Begum who belonged to a high class did not receive any education as her parents ‘stranded’ her with a relative. She was expected to help her aunt in household chores rather than go to school. She said:

Rukhsana:

*“I always wanted to study, but then my uncle asked me to take the responsibility, so he used drop her at school and pick her from school and had to manage his work too. But my auntie said she cannot take my responsibility and she will only do that for her own daughter. She said she would be happy to teach me the household chores and Quran. I said okay, I didn’t fight with them, but of course I loved going to school and I wanted to get education.”*

This affirms the idea that acquiring education was not dependent on money, but it was influenced by the mind-set regarding educating women. A woman’s place revolved around the home, looking after children and fulfilling domestic responsibilities. Although Rukhsana had been denied a formal education, she made sure that her children, including her daughters, received a formal academic education:

Rukhsana:

*“All my children are well educated. One of them is going to college. One of the sons studied till 14 grades later he went to England. My other sons have studied till grade ten too. One of my sons studied till grade ten and wanted to study more but we got him married. He still wants to get higher education. We wont stop him. He can. All my daughters are good in studies. One of my daughters never went to school though. She is a bit mentally challenged. They even got Quranic education. My grand children are studying in English schools too. They have great minds.”*

However, the above quote points out on a very important aspect of education in Pakistan where children with intellectual or physical disabilities are treated differently from the rest. It further underlines the lack of inclusion within Pakistani education.

On the other hand, Nisbah did not attend school and said she had never wished to study:

Nisbah:

*“I never wanted to study. I don’t know I was never fond of studying. Neither any one at my home. What different would we have done had we studied. This dukh (sadness) has killed me already. This disease, doctor. What difference education would have made doctor?”*

Nisbah has clearly voiced her view regarding education and did not see any good in getting education now that she has cancer. For Nisbah, discussion of school and education prompted reflection on her disease as well. For her, education would not have made any difference to her disease. What is interesting is that education was not important for her family because nobody in her family was educated. Illiterate parents can however cultivate literacy if they are supported by the education system (Farris and Denner 1991), but this does not appear to have been possible for many in this cohort.

Muzammil Bibi, Nasreen Akhtar and Imtiaz Bibi did not provide any detail other than mentioning that they did not receive any education. The data from this sample

shows an interesting mix of views regarding education from the participants who were prevented from accessing formal academic education. Instead, they were encouraged to pray and read the Quran at home.

The four participants who went to school but dropped out before completing their primary education appeared to accept their lot because they did not question the decisions of their elders. It was presented in their memory as a socially accepted way of being and they all reported that during their childhood, girls were not allowed to attend school beyond primary. Zahida Kalsoom expanded on the reasoning and explained that women were prevented from attending classes past year 5 so they were not exposed to 'male' teachers who they were not related to:

Zahida:

*"Yes dear, I left school when I was in grade 4. It was not about my heart dear, in those times, no body use to study that much, only till 5, the teachers were so nice, in those days there were less women teachers like they are now, in those days more were males, so we were not allowed to go beyond class 5."*

This reflects cultural mores for women in Pakistan who in some cases may not be allowed in the company of a male who is not their father, brother, or husband.

In contrast, Sughran Bibi was more comfortable in learning from her husband at home:

Sughran:

*"In our times we could only go to primary school...so I completed my primary school. We did not have a middle or high school in our city for girls. But at home, I kept learning from my husband. Alhamdulillah..."*

What is interesting here is that Sughran's husband wishes her to be literate and to become more educated. In order for this to occur he has taken it upon himself to educate her. It would have been interesting to explore the reasons why he felt that

this was important but unfortunately because of the limitations of the study we could not meet again for a second interview.

Razia Begum praised her intelligence but belief in the ultimate fatality of life can also be observed when she commented:

Razia:

*“My elder sister learnt all my brothers books secretly...they didn’t use to study in front of us...so she got admitted in 4<sup>th</sup> grade because of that she had finished all the course books (laugh) we all were very good at brains...they used to teach me too but it is different in schools and what we are taught at home...so whatever was in my fate I got it...thank God...”*

Razia offers a fatalistic account of why she had a lower level of formal education; because God did not will it. This exemplifies how women do not challenge and merely accept their position and whatever happens to them because of their belief system.

Shehnaz Bibi while discussing her childhood and giving a public account of the norm in those days told me that she completed her primary education while her brother continued till year 10:

Shehnaz:

*“Yes I did study, but it was just till primary. My brother did get education though. He studied till year 10. In those times, girls were not allowed to study beyond year 5 in our village.”*

The findings from my study support Shaukat (2009) that there is a widening female dropout rate from school compared to males in Pakistan. According to the participants in my study, they dropped out or were not allowed to attend school beyond primary school so that they could help their mothers at home, look after their younger siblings, fetch water from far off places and help with the household

chores. These factors explain why women in my sample with little or no education did not seem to be in complete control of their decisions regarding their health.

The findings of my study are similar to Zahid et al. (2014) who explored the help seeking behaviours of people belonging to low socioeconomic status groups with oral cancer in Pakistan. In that study, the majority of participants were males (N = 117) compared to women (N = 71), and irrespective of gender, did not pursue their education beyond grade 5 and only 10 participants continued their education further than grade 10. This had a huge impact on their levels of knowledge regarding oral cancer and greatly hampered their help seeking behaviours.

The Planning Commission (2009) states that only 30 % of students continue their education after primary level in Pakistan. Although there is an extensive network of government primary schools in rural areas that provide free education and textbooks, it can be argued that the majority of the villages in Pakistan do not have any middle or high schools for boys and girls to independently complete their education. In my study, Shamim Akhtar was one of the two participants who managed to study beyond primary school. She was allowed to attend school till grade 10 after which she was tutored privately for her Intermediate studies. She did not belong to a rich family and her father was an ordinary driver. Shamim was able to study because of her mother:

Shamim:

*“My father was just an ordinary driver...he used to drive a car. And we were seven children and it was so difficult to fulfil our needs. So...Even our house was a rented one...we never owned a house...there was no happiness at all...we struggled so hard to study a little...and that too when my mother sold all her things. It was so difficult...”*

Women usually come to a marriage with a dowry and this can be in the form of jewellery or household items. Shamim’s mother obviously thought the sacrifice was worth it. She also remembered her father’s strict rules for the daughters and pointed out towards her father’s ‘allergy’ to college and said:

Shamim:

*“I did study till year 12...and college...our father did not let us go to college. It was done privately...I just went to school till year ten...then stayed at home and gave the exams privately. All three of us. My father was kind of allergic to college. He used to think very ill of colleges. He was of the opinion that colleges are not good places for girls. The environment is not good...(Laughs) he was of a primitive school of thought.”*

[...]

*“My father said I could do whatever at home...study and even tutor other children but can't go to college...so he didn't let me...(sighs)”*

[...]

*“I get so happy and thank God that at least my children are studying well and getting education...my own life is messed up but at least they are on the right track.”*

Shamim was able to make informed decisions in her life after she got married. In contrasting her life with that of her children, Shamim was grateful to Allah that she had the chance to get her children educated. Shamim got separated from her husband but her children's education remained her first priority. What she could not enjoy in her childhood, she wanted her children to get that opportunity.

Dantas et al. (2016) reported similar findings in a sample from Brazil. The majority of the participants with oral cancer had dropped out of school before completing their primary education. Less education appeared to affect access to information regarding oral cancer and its treatment. What we can also see that within families there was a private process of negotiation with perceived risks to women in particular at school.

The role of educational attainment is prominent and cannot be overlooked in terms of the diagnosis of oral cancer. For instance, a study in India suggests that the risk of oral cancer decreases with increase in educational attainment and socioeconomic

status (Pawar et al. 2014). Similarly, oral cancer in Tamil Nadu, India was associated with higher levels of illiteracy. Majority of the recruited sample comprised of illiterate having late diagnosis. This might have been due to lack of understanding and knowledge about oral cancer and access to health care facilities (Ganesh et al. 2013).

Sociodemographic characteristics including education remain important. It is noteworthy that research in South Asian populations reveals that people with no education (Muwonge et al. 2008), those with lesser level educational qualification (Guneri et al. 2005) and those who had never attended school (Merchant et al. 2000) have a greater risk of developing oral cancer. Educational attainment is associated with better health (including oral health) throughout life. It remains one of the key indicators of socioeconomic position along with occupation and income (Galoberdes et al. 2006).

Every step up the socioeconomic ladder is complemented by increases in health. However, there is an array of other variables that influence health, alongside education, that determine the absence or presence of disease. The findings from Baker et al. (2018) suggest that structural determinants such as social, economic and political should be considered fundamental in relation to oral health. It is imperative to understand that these determinants interact and the influence of one may be dependent on the mediation of another. The social environment one belongs to may trigger certain biological and behavioural responses that may otherwise remain dormant (WHO 2010). Although the CSDH framework (see section 2.5.3) calls out for attention on the structural determinants of health inequalities, they remain understudied. The focus on the household based and individual risk factors have made us the 'prisoners of the proximate' (Baker and Gibson 2014). We can see from the data in my study that how a lack of, or limited economic resources hindered participants from securing education, which later as we will see in the next chapters, prevented them from accessing dental care and treatment in the early stages of oral cancer. The findings also indicate that gender is deeply entangled with social inequalities, which the oral epidemiological studies fail to tease out. However, from



the point of view of the participants in my study, they are confronting structural determinants and inequalities and how they cohere and interact in detailed ways in their biographies. They do not recognise them but they clearly identify the challenges and struggles they have.

This section of the thesis has sought to describe the participants in detail and cover the major aspects of their lives derived from the interviews and field notes. Their stories are heart breaking yet very powerful. It was no more than an honour to analyse and make sense of them. The following chapter will begin to discuss the findings from the interviews in more detail. The chapter will also highlight that these women from Pakistan had a voice and they wanted to share their experiences of oral cancer with the world in the hope of making the health care more sensitive to the needs of the patients.

## Chapter 6. Making sense of oral cancer in Pakistan: Giving voice to women

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## Chapter 6. Making sense of oral cancer in Pakistan: Giving voice to women

### Summary of the structure of the chapter

The first part of the chapter will describe the participant's interpretation of the reasons for their oral cancer followed by sections on how faith as a part of religious beliefs, spiritual healing, home remedies and alternative medicine influenced the health seeking behaviours of the participants of this study. Often these factors combined leading to late presentation for diagnosis and treatment of oral cancer.

### 6.1 Introduction

Pakistan is a patriarchal society; this patriarchy predates development and is the central reason for gender inequality. Patriarchy is defined as:

*“The sum of institutional mechanisms that serve to limit women's economic autonomy relative to men's or as ‘a set’ of social relations with a material base that enables men to dominate women.”*

(Cain 1979, p. 406)

Patriarchy is conditioned and reinforced by various economic, social, legal and religious institutions all of which emphasize and contribute towards the view that women are subordinate to men (World Bank 2005). In Pakistan, gender roles are constructed from traditional beliefs and social values which dominate the lives of women, with culture and religion being used to reinforce socialisation (Zaman et al. 2006, Qureshi and Shaikh 2007). Women are expected to submit to men both inside and outside the household, which often leads to their exclusion from key decisions (Rizvi et al. 2014). Being treated as a subordinate means that women are more vulnerable and likely to experience discrimination in areas such as education, employment and health care (Government of Pakistan 2004, 2005, Planning Commission of Pakistan 2013). Gender inequalities impact greatly on women's autonomy, rights and health status (Saleem and Bobak 2005; Ali et al. 2011). Indeed, gender inequalities, reinforced and reproduced by the structure of Pakistani society disempowers women and a lack of investment into their education and health

alongside qualified male staff in health care increases the negative impact on women's health (Rizvi and Nishtar 2008; Shaikh et al. 2008).

Findings from my study suggest that men influence women's participation in society. Women were restricted to and within the boundaries of their homes and were not allowed to dress up or visit relatives other than on special occasions like Eid. They were not allowed to put lipstick on when they were young for fear of earning retribution and anger from the male members of their family. Muzammil Bibi narrates:

*"Maa (mother) used to tell us off from a certain thing, we all used to obey and sit quietly unlike the children of today, we did not use to do that. Maa used to scare us that do not put lipstick on your lips or else your father will be angry so we used to listen to her but whatever maa used to say we used to act on it"*

Muzammil gives a public account of how validation from men in the family cannot only be seen inside the house but also be observed in role of men influencing women's decision outside the four walls of the house. She also provides a contrast with the children of today. Not being able to have a say in the house has significant implications for women's help seeking behaviour and subsequently their health.

In one of my field notes from the interview with Nasreen Akhtar, I wrote:

*"This interview was the most difficult interview for me to conduct. Initially when a fellow colleague introduced me to Nasreen and her husband. They were a bit reluctant to talk to me. I talked them through the details of my study and then they agreed. The husband wanted to sit in the interview, as he was very much concerned about her wife giving the interview in a separate room. But I told him it was not possible for me to talk to his wife in his presence. He agreed after a 20-minute discussion regarding the content of the interview. He strictly told his wife to talk good about the hospital and the treatment to which she agreed."*

This observation of the interactions between husband and wife reflects the position of women in a Pakistani society where they are dependent on the 'approval' of men

not only about way they look or dress up but also in order to seek treatment and voice their opinions regarding the treatment. Consequently, women may be said to suffer in silence and do not report to health services because the illness threshold set by society is very high for them that they tend to endure the pain and discomfort in order to keep the household intact. It also reflects that in Pakistan, one is conditioned from childhood to be silent about pain. From pain that girls feel around the time they are menstruating to the pain of delivering a baby, it is expected of Pakistani women to 'suffer' silently and endure.

In the literature review I suggested that cancer researchers tend to spend their time working through complex numbers, incidences and statistics. They also focus on 'objectively' and 'subjectively' applying tools to measure specific dimensions of the experience of cancer. However, there is a risk that they remain safely insulated from being entangled in the human dimension of oral cancer. In the western world, cancer is becoming less the whisper it once was (Sontag 1978) and is talked about openly in documentaries, blogs; self-help literature and artwork. In Pakistan, it is still a part of a 'silent-culture'. However, the oral history approach used in this study, seeks to give my participants an opportunity to make sense of their experience of oral cancer. It was noted that the majority of the participants wanted to talk about their disease more than anything else. For many of them, oral cancer could be seen as a turning point in their lives. None of the participants mentioned oral cancer as being a turning point; instead they were left with a feeling that disease had robbed them of everything they had in their lives. The participants gave private accounts of their disease experience. None of them focussed solely on the public notion of oral cancer; rather each of them had their own individual experience to narrate and to make sense of. I also observed that because of the medical conditioning they had received over the years, they blamed themselves (their habits etc.) for developing oral cancer.

## 6.2 Participant's interpretation of the reasons of oral cancer

In the literature review, risk factors such as naswar and betel quid, were cited as major risk factors for oral cancer in Pakistan, but the social determinants that encourage people to use these substances have not been sufficiently probed. While the direct causes of oral cancer are numerous, the following section will explore how the participants of this study made sense of the reasons for the development of their oral cancer. In their narratives, most of the participants did not focus on why they developed oral cancer while some explicitly made sense and stated their interpretation of the reasons for oral cancer. It should be borne in mind that my focus during the interviews was not to know the risk factors for their oral cancer but how they made sense of the diagnosis and what meaning they attributed to it. The table below summarises participants' interpretations:

Table 6.1 Causes of oral cancer according to the patients

No.	Participant name	Participants interpretation of the causes
1.	Ameena Mehboob	Unknown
3.	Razia Begum	Unknown
4.	Shehnaz Bibi	Unknown
5.	Muzammil Bibi	Past sins
6.	Imtiaz Bibi	Chillum/Hookah
7.	Maqsood Akhtar	Unknown
8.	Nasreen Akhtar	Naswar consumption
9.	Rukhsana Begum	Naswar consumption
10.	Sabra Bibi	Chillum
11.	Shafeen Bibi	Boils/ulcers
12.	Shamim Akhtar	Sapari/areca/betel nut
13.	Sughran Bibi	Unknown
14.	Wazira Khatoon	Naswar consumption
15.	Zahida Kalsoom	Naswar consumption
16.	Nisbah Shaheen	Unknown

### i. Use of Chillum- smoking tobacco in a clay pipe

Sabra Bibi while sharing her personal story of oral cancer became embarrassed about mentioning the cause of her cancer:

Sabra:

*“Dear, I am so ashamed to tell you about why it all started. I hated naswar and cigarettes, but to be honest now, I used to take Chillum, but I took it for a very small period of time but I don’t do it anymore. It’s been ages now but those were great tobacco leaves.”*

Sabra Bibi started using ‘chillum’ after her husband’s death as a stress reliever and a pleasurable activity along with other women in the house. Although she despised the use of ‘naswar’ and ‘tobacco’, she found solace in using chillum. She felt that due to a prolonged use of chillum, she developed oral cancer:

Sabra:

*“I did not take it for very long. Their (the children’s) father died and I was depressed and stressed because the children were very young at that time. I was young too and when he died I did not know how to tackle it myself. My daughter was in 5<sup>th</sup> grade, you tell me how stressful that was you couldn’t imagine (sobs)...I don’t know how to explain it is getting difficult. If there is no husband then the children suffer too, I can’t remember for how much time I took chillum for...But I hate naswar. I wonder how can people place it in their mouths, the smell is disgusting and it makes me puke when I smell it near anybody. So I just took chillum because it smelled less bad (laughs) I just found it very nice and soothing. One other thing I noticed while taking chillum was that as long as I was taking it I used to urinate only after taking it I would take it and eat food and then urinate in the toilet, otherwise for days I won’t urinate if I didn’t take it. That was strange. I took it as means of leisure at first for instance, we all girls would sit so we decided to smoke it...because the elders were doing the same, then we started too.”*

Sabra started using chillum as an antidote to her stress and depression after her husband passed away. She became emotional while telling how difficult it was for her to run the family without any support. She also stated that because of chillum she was able to urinate regularly. It was a norm for the adults in Sabra’s family to smoke chillum and so she and the other young girls started smoking as well.

Similarly, Nisar et al. (2005) reported that the women in Pakistan who suffered from financial difficulties would often resort to using chillum or hookah to address their

anxiety and depression. Sabra lived under the conditions of deprivation, her husband had died young and she was on her own.

Similarly, Imtiaz Bibi was a heavy user of chillum and Hookah but she stopped using it right after her diagnosis. She remembered:

Imtiaz:

*“Not naswar or paan, but yes I was a heavy user of chillum and hookah. I would use it as many times as I would like it during the day. I have left it now though. It has been two years ever since I got diagnosed...”*

[...]

*“No I did not know it could cause cancer. I was just using it... My doctors told me that it was chillum that caused this cancer.”*

Imtiaz was not aware that the regular and consistent use of chillum could be a risk factor for oral cancer until the doctors at the hospital confirmed. Out of fear, she stopped using it. It can be noted that the doctors were blaming her for her disease, which conditioned her into thinking that it was her own habit that caused her disease.

Twenty one percent of women in Pakistan use tobacco in some form on a daily basis but this remains under-reported because of cultural prohibitions for the use of tobacco by women (Nisar et al. 2005). The women residing in rural areas of Pakistan mainly use chillum. The literature shows that women of low socioeconomic status tend to smoke chillum/huqa more than the women residing in urban areas that are generally of a higher educational level (Sufia et al. 2003). In the Friday Times, which is Pakistan's first weekly newspaper, Amtul Jamil (2012) writes that women residing in the rural areas of Pakistan smoke chillum to aid digestion because there is not much mobility in their routine. Chillum smoking women have an air of respect in villages. It is a norm for people to gather after dinner and smoke chillum as a means of winding down.



According to the national health survey findings of 1998, seven percent of women aged between 25 and 64, smoked chillum or hookah. Also, the women who were illiterate and belonged to a low socioeconomic status tend to use chillum more than their affluent counterparts. This research supports work by Nisar et al. (2005) who identified a strong pattern of smoking habits in adult women above 18 years of age belonging to Karachi, Pakistan. They found that 79% of the women from low socioeconomic backgrounds used chillum/hookah regularly. The findings of my study are consistent in that both Sabra and Imtiaz belonged to low socioeconomic status groups and were not educated.

## ii. Use of naswar

In my sample, Nasreen Akhtar was a habitual user of naswar and very sure that this was the cause of her oral cancer:

Nasreen:

*“It was naswar. I am so sure about it. I don’t remember how many times I used to take it but it was a lot that I took each day. Yeah.”*

[...]

*“What should I tell you now? Umm, my father used to take it, my mother used to take it, my khala used to take it. It was very normal in our household.”*

[...]

*“For very long. Maybe 12 or 13 years. Maybe more than that.”*

[...]

*“Umm...what could have I done? (Loud) I just left naswar because I had no teeth left in my jaw after the operation. Of course I left naswar. There are no teeth... [Laughs]”*

Nasreen did not provide details on why was it a norm in her house to use it but clearly her memory is that this was the case. She used it consistently for more than twelve to thirteen years and stopped consuming naswar after her diagnosis of oral cancer. Here again the doctors confirmed to her that naswar might have caused her oral cancer. Zakiullah et al. (2011) argue that the naswar available in Pakistan has a

higher concentration of carcinogens like lead nitrate, nitrite, cadmium, chromium, nickel, arsenic, and beryllium, which may cause oral cancer. Also it contains highest free form nicotine content (70%) creating a toxic environment for oral cancer development (Stanfill et al. 2011).

Rukhsana initially did not disclose to me why she thought she developed oral cancer. After a little probing, she disclosed that she used naswar for three to four years at length when she was young and a mother of two children:

Rukhsana:

*“ I never used any addictive substance...”*

[...]

*“Naswar, yes I did use it when I was relatively younger and had 2 children. That’s it. I did it for 3 to 4 years. That’s is the truth, Doctor. And now I am being very honest. I did naswar for 4 years. Then left it because I started feeling pain in my throat and it felt as if I cannot breathe anymore. It’s been ages I have left it because I got scared. Never took tobacco or anything else. Initially, I didn’t tell this to my own doctor, but then later one day, I told him I used to take naswar. It’s been 27 years now.”*

[...]

*“Umm...I started using it when I got married. My mother- in - law used to take it. I copied her [laughs]...that’s it...this is true... but later I got scared when I used to get suffocated. Then left it completely you know.”*

[...]

*“No, there was nobody else who used naswar in our house. My husband used to smoke though. That’s it. He has left smoking since ages now. Both the brothers have left it. My mother in law still takes naswar you know. She is 100 years old and still takes it. She is addicted to it from childhood. But I left it after 4 years as I told you. Now my children, none of them has any such addictions. They are well educated you know.”*

Rukhsana started consuming naswar after her marriage. Her mother- in- law was a heavy user of naswar since childhood and was using it even at the age of 100 years.

Rukhsana copied her behaviour. A clear link between generations of women can be noted. Use of naswar prompted Rukhsana into thinking about her mother in law and her habits. It seems like she is blaming her mother in law for introducing her to naswar. Later, she stopped using naswar when it gave her allergic reactions and left her breathless. Her husband was a smoker but none of Rukhsana's children had any addictions. Rukhsana who did not receive any education suggested that it was education that played a role in saving her children from any addictions. It is worth noting how Rukhsana calls me a 'Doctor' as she reveals the 'truth' behind her oral cancer to me. It was only later in the interview that Rukhsana seemed to have developed a trust in me to disclose her interpretation of the reason for her oral cancer.

Similarly, Wazira Khatoon started taking naswar as a remedy in order to relieve herself of a toothache. She said:

Wazira:

*"My eldest daughter was 6 months old when my jaw started hurting so I used to place naswar in that area. She is 23 years old, but I left it way earlier. There would be an ulcer near a tooth and as soon as I would place naswar, it will get better so I got that tooth extracted. But only felt good with the naswar inside my mouth otherwise I would feel the pain very often..."*

[...]

*"I used to make a ball of it and put it where the jaw hurt the most. And I would feel so good. I used to sleep well after taking naswar. But little did I know it could be so dangerous..."*

[...]

*"I never knew it could do this to me. Had I known I wouldn't have died everyday like this. My life wouldn't have been so hard like this. I did not know naswar could do it."*

Wazira started taking naswar to heal an ulcer in her mouth. Whenever she would place it on the site of the ulcer, it would relieve her of the pain immediately. It

became habitual and even made her sleep better after taking naswar. Wazira was also not aware of the harmful effects of naswar and it being one of the risk factors for oral cancer. She reiterated that she would have never used naswar despite the soothing effects, had she known that it could be so devastating. It can be noted how Wazira's consumption was very private and how this sits with her 'ignorance' about what it was doing to her. According to Express Tribune 2010, both men and women living in Khyber Pakhtunkhwa, Pakistan use naswar to get 'high'. The people who do not use it habitually are looked down upon and considered 'boors'- meaning a rough person.

Zahida Kalsoom shared a similar experience with naswar being part of the household culture and not regarded as something out of the world:

Zahida:

*"Dear, nothing else but naswar, I used naswar for very long, I was using it since I was a child, in fact everyone in our household used naswar, it was just a norm in those days, they even use cigarette, the area where I live, everyone smokes, the younger generation uses it less, but the women of my age, they all smoke and use naswar still, I used to place naswar in my mouth till I got cancer [chuckles], no I have left it, finally, now I have lost so much, can't eat, can't even talk properly, what is left of me, now I have left naswar."*

For Zahida, using naswar had been the norm since her childhood whereby the whole household was using it. The women in her village also smoked tobacco along with using naswar. She stopped using naswar after being diagnosed with oral cancer and losing her chewing and talking ability. Zahida gives a public account of the consumption of naswar and compares her generation with the younger one. We can see that for her everyone uses naswar but that the younger generation does not use it that often. She told that the use of naswar was a norm in Chakwal, where Zahida lived. Even now, her fellow women regularly smoke and use naswar. We can see from the research that naswar consumption has been related with a 20 times higher risk of developing oral cancer than the non-users (Khan 2016). As per the findings of

a nation wide survey conducted in 2012, it was evaluated that over 7% of Pakistan's total population consumed naswar with the highest usage (15%) in the province of Khyber Pakhtunkhwa. Four systematic reviews from South Asia (Guha et al. 2014, Gupta et al. 2014, Khan et al. 2014 and Sinha et al. 2014) have reported a relatively higher risk of oral cancer in female SLT users than males. It should however be noted that there is an increased risk of selection and recall bias and this may have influenced reported risk estimates.

### **iii. Use of Areca nut**

Areca nut known as 'Sapari' is readily and cheaply available in the Pakistani market. Despite its toxicity, it is aggressively advertised in the print media in Pakistan and available to be consumed by children and adults without any gender differences (Khan et al. 2012). In my sample, for Shamim Akhtar, it was 'Sapari/Saunf' that caused oral cancer. She was a habitual user of Sapari and would take a lot of it worth 50 to 60 rupees (30 to 35 pence) at one time.

Shamim:

*"Actually I used to eat sipari a lot. Earlier I used to eat Saunf/Sapari ...then later it developed into sapari...and would you imagine how much...my bag would be filled up with the sapari...I used to eat sapari worth 50 60 rupees (30 to 35 pence) at a time...and used to take it all day long for at least 6 months...so doctors at the hospital say that it has caused oral cancer...because of these sapari...there was a white layer that first formed. It was a tissue like layer that formed around my tongue...then it worsened..."*

Shamim was taking a huge amount of cheaply available areca nut everyday for six months, which led to the development of a white layer. This was the time when she decided that she should seek help from the doctor. In Pakistan, sapari (areca nut) is habitually used after meals as a 'mouth freshener' like in other South Asian countries. According to a review of human carcinogens, a significant association between areca nut chewing (with or without tobacco) and oral cancer has been

found (Secretan et al. 2009). Regular chewing may also lead to poor oral health and periodontitis leading to increased risk of oral cancer (Chang et al. 2013).

It has been suggested that regular chewing of areca nut may induce inflammation, chronic irritation and damage to epithelial cells (Hernandez et al. 2017). Many potentially malignant disorders such as oral submucous fibrosis, leukoplakia and erythroplakia are linked with areca nut chewing (Mortazavi et al. 2014). In India, five million people were reported to have oral submucous fibrosis (pre malignant condition) due to prolonged usage of Sapari (Joshi et al. 2014). Of central importance to Shamim's story however is her close relationship with the doctors and her ability to understand and accept what they were saying.

#### **iv. Occurrence of boils/ ulcers**

Shafeen Bibi stated that she was not addicted to tobacco, naswar or chillum. Although her mother used naswar, her sister smoked Hookah, and her brother smoked tobacco, she was not involved in any such behaviour. According to Shafeen Bibi, it was some 'mouth problems' and the rapidly occurring boils and ulcers in her mouth that turned into oral cancer:

Shafeen:

*"I used to get boils and ulcers in my mouth. But they got better after taking medicine or using mouthwash. This time I tried everything but no use. This time, you know, the boil started to grow and went up to my palate...That's why...I got a bit late and then my brother died and I spent 15 days there ...so I saw the doctor late, got the tests done which revealed that I have oral cancer..."*

It is evident from the above quote that Shafeen was not aware of the initial lesions in her mouth and therefore used mouthwash or medicine to heal them. When the ulcer/boil did not heal and spread up to her palate, she got alarmed for the first time. Research on oral cancer suggests that the mouth ulcers that have a suspicion of oral cancer may not present as painful (Mouth cancer Foundation 2018). The pain of the initial lesions is controllable and thus does not seem an emergency to the

patient. Shafeen also presented late for diagnosis because her brother died. And as the post funeral proceedings can take up to 40 days in Pakistan depending on the culture and background, Shafeen may have presented late for her diagnosis of oral cancer. This private tribulation resulted in late presentation but demonstrates the importance and priority that kinship ties have over personal health problems.

Similarly, Muzammil Bibi made sense of her reason for developing oral cancer and stated that even though she took care of her oral health, after every two or three years, she would feel a boil/ulcer in her mouth, which would heal on its own. She remembered never worrying about it. But this time, it upset her when the ulcer/boil did not dissolve:

Muzammil:

*“Yes absolutely, I used to brush my teeth daily, but after every 2 to 3 years, I used to get an ulcer which resembled a lump, and it used to go away after brushing, I used to get well, but this time, it did not go away...”*

The presence of pre-cancerous lesions being referred to as ‘boils/ulcers’ and ‘mouth problems’ expose the way cancer appears in its initial stages of oral cancer among the participants leading to delay in diagnosis. Oral cancer is largely preventable (WHO 2018) if detected early. This indicates the importance of public awareness regarding the symptoms of the pre malignant and malignant lesions in the oral cavity. It is argued that a lack of awareness about these symptoms can often lead people to present late in the disease process (Warnakulasuriya et al. 2016). But this also raises the challenge of understanding why this is the case? It may be because the signs and symptoms of oral cancer are often interpreted as insignificant oral conditions, which leads to further delays in diagnosis (Scott et al. 2005). A systematic review to explore an association between patient related delay in presenting to the primary care facility and the stage of cancer at diagnosis, found that the people with oral cancer who delay 1 month in seeking care following the onset of the symptoms are twice as likely to have advanced stage oral cavity cancer (Goy et al. 2009).

#### **v. Past sins**

It was interesting to note how intersubjectivity developed and strengthened over the course of three interviews with Muzammil Bibi. Initially in the interview, she regarded some boils and ulcers as the cause of her oral cancer, but later in my second interview with her, when we had established comparatively better rapport between us, Muzammil declared to me that her past sins might have caused Allah to punish her. She called it a test from Him. She articulated her concern clearly many times and kept chanting 'Taubah' (forgiveness) from Allah during the course of interviews. She said:

Muzammil:

*"I never used to do hookah or paan Challia even, nothing, [coughs] I just keep worrying nothing else, I think a lot, then I recite verses to ask for forgiveness that may Allah forgive my sins, sometimes my heart gets so stressed and disturbed, that Allah...don't know if He will grant me health or not, don't know in what confusions Allah has put me in, I never even did bad to anybody, don't know why then, don't know what Allah has written in my fate, I think a lot about it."*

While she chanted on Taubah, she feared that Allah may never forgive her sins and as a punishment may never grant her health. This is important because this is how she made sense of the reasons for her disease. The influence of religious beliefs and faith will be explored in detail in section 6.3.1.

#### **vi. Bleeding gums**

For Maqsood Akhtar, it was not tobacco or any other substance that caused her oral cancer, but her bleeding gums:

Maqsood:

*"...the doctors ask me about paan and cigarettes, but trust me I have never used any such substance not even sapari that contains betel nut, never, I have no addictions, nor I was ever interested in any such thing. All I can think is that this right side of mine, I had a couple of teeth which were in a worse condition, then I had bleeding gums, got them extracted, doctors said there became an ulcer there, and that ulcer got worse later, although I took all medicines prescribed, it just got worse"*



*day after day, later I could not eat or drink anything, I would feel spices burning all over in my mouth, then I used to feel so much pain in all my jaws and ears and it became unbearable once, I got them checked a lot but no use, was then sent here for further treatment and was diagnosed with cancer. I think the bleeding gums caused it all..."*

And lack of dental care:

*"...I never brushed my teeth (laughs)"*

It is interesting to see how Maqsood negated all the other apparent reasons of oral cancer and made sense of it on her own. She was of the opinion that because of her poor oral hygiene, an ulcer formed in her mouth. The ulcer got worse and developed into cancer. When it started aching out of control, she visited the doctor and was diagnosed with oral cancer. This finding supports the work by Zheng et al. 1990, who found a seven - fold higher risk of developing oral cancer in China among men who did not brush their teeth regularly. There are several studies that exhibit that poor oral hygiene may cause oral cancer but it should be kept in mind that these studies did not address the social determinants of oral cancer. For instance, Guha et al. (2007) described the results of two multicentric case control studies (with thousands of participants) in Latin America and central Europe and reinforced that poor oral hygiene because of infrequent brushing can lead to aggravated periodontitis and tooth loss and then to oral cancer. It is however still not clear if these associations are due to insufficient control of confounding factors such as socioeconomic status, smoking and alcohol consumption. Similarly, two studies in Asia (Sato et al. 2011; Chang et al. 2013) also reported a causal link between poor dental health status and oral cancer. A study in Japan reported a six-fold increase in aero digestive tract including oral cancer in individuals who infrequently brushed their teeth (Sato et al. 2011). Likewise, Chang et al. (2013) demonstrated a strong association between bleeding gums, greater number of missing teeth, less dental visits with development of oral cancer. For these studies, the investigators used many self - reported indicators of poor oral health and not all of them were associated with oral cancer within or across studies.

On being asked, Maqsood Akhtar then clarified and gave a public account of why was she not able to take care of her oral health:

Maqsood:

*“To be honest in those days, we had no awareness that we needed to brush our teeth or take care of the cleanliness of the mouth, we used a ‘manjan’ (Dentifrice) sometimes, that’s it, never used anything else... they never let us use toothpaste as it was regarded as beautifying ourselves before marriage. But now I try to use a brush.”*

Maqsood mentioned that she used ‘manjan’ (dentifrice) to clean her teeth like everyone else. This memory is important because it prompted her to reflect on the other norms in those days - of not using toothpaste as it was regarded as beautification. Maqsood also presents a past and present comparison by telling that now she uses a brush to clean her teeth.

As identified in the literature review, most of the research on oral cancer in dentistry tends to focus on the life style risk factors and victim blaming discourses rather than looking at the ‘causes of the causes’ (Sheiham and Watt 2000). It is noteworthy that the choices made by my participants were largely determined and conditioned by the social environments in which they grew and worked and had little control over. Their interpretation of the reasons for oral cancer also allude towards the conditioning by the dental practitioners that it must be the patients’ fault that they developed oral cancer.

This section provided an interpretation of how the participants made sense of the reasons for their oral cancer. The next section will detail how religious beliefs, alternative medicine and home remedies influenced their perspectives of the treatment of oral cancer and in turn their journey to diagnosis of oral cancer.

### **6.3 Participant’s perspectives of the treatment of their oral cancer**

As the participants made sense of the reasons of their oral cancer, they also recounted their perspectives about the treatment. It was interesting to note that religious beliefs, alternative medicine and home remedies formed a large part of

their narratives about experience with oral cancer. I was aware of the potential sensitivity of the topic therefore did not probe unnecessarily. However, my participants were eager to talk about Allah and religion. It should be noted that participants present both their public and private accounts about the treatment of oral cancer. These narratives emerged as a result of making sense of their disease and how the participants thought they were cured or will get cured. Majority of the participants regarded religion as the main source of healing followed by doctors and alternative medicine.

The connection between psychosocial adjustments and religious beliefs has become very popular in health care research. Spiritual/ religious beliefs have become significant in playing a therapeutic role in the recovery of patients (Puchalski 2001), but also in the case of life limiting diseases such as cancer (Sankhe 2017). It is believed that religious involvement calms patients and supports them in dealing with stress. It can also help them stay hopeful and build their self-confidence and self esteem. A recent poll in America shows that 82% of the Americans believe that prayers can cure illness (Ameling 2000). Similarly, prayer was reported to be very helpful by Harvard Medical School study (McCaffrey et al. 2004). It is also believed that religious people are comparatively healthier and lead healthy lives requiring minimal health services (Hummer et al. 1999).

Social, physical and spiritual factors influence Muslims interpretation of health, which means that engaging with health care and professionals depends on where they perceive disease is coming from (Ashy 1999). For instance, for some Muslims disease comes from Allah and so they abstain from seeking any treatment (DeShaw 2006). All the participants in my study identified themselves as Muslims and believed in Allah as their sole saviour and were hopeful that He would cure their cancer. Belief in Allah is a central part of Islam. Therefore, even common conversations include praising Allah and paying gratitude. The conversations with the participants of this study were no different. Almost all participants mentioned Allah frequently. They would thank Him for His blessings while mentioning something good about their life and seek forgiveness from Him while talking about any adverse or sad

event. What was noteworthy however is the different dimensions of religion that participants tended to follow, including belief in the power of prayers and words of Allah, as well as in spiritual/faith healing in terms of their encounters with oral cancer. While all the participants eventually resorted to medical treatment, most of them visited spiritual healers, local doctors, tested alternative medicine and even tried home remedies before presenting to the dentist for the first time. The following section will describe the participant's perspectives of the treatment of oral cancer and how they made sense of it.

### **6.3.1 Religious beliefs of the participants**

#### **i. Power of prayers/words of Allah**

All the participants in my study believed in the notion that it was Allah who had given her the disease and He will cure it as well. For instance for Wazira, her belief in Allah and her prayers was the key to her successful operation and painless experience afterwards. Her faith also strengthened even more after the operation as she reported:

Wazira:

*"I praised Allah all the time even during the time I was getting operated." Ya Allah Ya Muhammad..." (O Allah, O Muhammad). That's what I used to say all the time. Hoping things to get better in those eleven hours. I have so firm faith in Allah you cannot imagine. He did not make me feel the pain of operation and I woke up next day wondering if I was still going to get operated. But my family told me no it's the day after and the operation has been successful. All praises to Allah only. I never complaint about this disease though thinking it will annoy Allah. He might get angry with me. If He has given me the disease he will cure it too. I had gathered so much patience and strength don't know how."*

It can be noted in the above quote that Wazira is firm in her opinion that because of her chanting " Ya Allah Ya Muhammad..." (O Allah, O Muhammad), she has been successful in getting her oral cancer operated without pain. In the fear of making Allah angry, she chose not to complain about the disease. She reinforced a common

belief among Muslims that Allah befalls a disease on people and only He has the power to cure it. Any word of ungratefulness may earn Allah's anger and in turn disease. For majority of the Muslims, practicing religion properly always leads to good health (Al Gesir 1961). For instance, praying five times a day and supplications is believed to reduce psychological stress, keep a consistent structure in life (Hamdan 2010) and be utilized as primary sources of health (Al Gesir 1961; Padela and Raza 2015). Muslims are of the belief that health is a gift of Allah and therefore any illness comes from Him too (Al-Shahri and Al-Khenaizan 2005). As stated in the Quran:

*"We have sent down in the Quran that which is healing and a mercy to those who believe."*

*(Quran 17:82)*

Quran (the word of Allah) therefore has been used as a treatment to cure diseases (Ashy 1999). Qidwai et al. (2009), in their study, which explored the patients' perception on the healing effects of prayers in Karachi Pakistan, reported that more than 95% of the sample (N = 400) believed that prayers could heal the disease. Also, the majority of the participants of the study addressed Allah and His Prophet (PBUH) or saints in their prayers in order to speed up the process of acceptance of the prayer. Similarly, it was noted that prayers fill an individual with a spiritual energy that can aid in both the psychological and physical healing of the patients (James 1917). This is consistent with the findings of Breslin and Lewis (2008) who suggested that prayers might activate a latent energy, which is valuable for the well being of the believers.

For Muzammil Bibi, words of Allah had utmost importance and had healing powers. Throughout the course of three interviews I conducted with her, she continuously chanted verses of the Holy Quran, praising and seeking forgiveness from Allah. She displayed a firm belief in the healing power of Allah's word:

Muzammil:

*"...Then dear there was somebody when I came to get the injection, there was some lady who told me that you should read Surah Mariam*

*on some water and drink that water for 41 days, dear I did that for 41 days with full concentration, if I was not able to do it, I would ask my son or daughter in law, and then drink it, now somebody else has asked me to read Surah Yaseen on water and drink it, I drink that everyday now, it is the word of Allah, it has power and blessings, may Allah bless me with health, He has got the power to heal, I cant do anything, what can I do as a human being..."*

[...]

*"My mouth doesn't open...it opens just this much [tries to open her mouth]... I get stressed and when I get sad, I do a tasbeeh (reciting on a string of beads) of thanking Allah, that okay Allah I still thank you for keeping me in any state you want me to be, thank God, cant even sleep at night...whole night spent thinking where did I go wrong."*

[...]

*"I used to ask forgiveness from Allah, and thanked Him for blessing me with a great life, now I don't know what did I do that annoyed Allah or He disliked it, Allah please forgive [chants on taubah (asking for forgiveness from Allah) again] day and night I chant on taubah just like this and wish that He forgives me if I have wronged anyone."*

[...]

*"Still now I say ' Allah, I have spent such a good life, my husband beat me, abused me, whatever he did, Allah I forgive him 100 times, you please forgive him too, Allah forgive him and me as well' I still stand up to pray and ask Allah the same thing, I didn't knew I will get this pain, this set back, I did not know..."*

[...]

*"Okay I know Allah will grant me health slowly, no problem, I will take it as a test from him, I will still thank Him."*

Due to her last stage of oral cancer, Muzammil Bibi was unable to open her mouth widely or drink or eat properly but her unwavering belief in Allah remained. She continued to praise Allah and ask for forgiveness. She used to read Surah Mariam and Surah Yaseen and blow it on water to drink in order to heal from oral cancer. Muzammil again describes a common belief among Muslims to read certain surahs

for healing. It is stated in the Quran that the verses of Allah are powerful, healing and can cure a diseased person (Rafique et al. 2017). In Muzammil's account, complete submission towards the will of Allah can be noticed as well. Patients with terminal illnesses like cancer are often encouraged by their family members to become more spiritual and religious and make their relationship with Allah stronger (Gatrad and Sheikh 2002). Although Muzammil Bibi was steadfast in her belief on Allah and His words, she was also of the opinion that she must have done something really wrong in her life that Allah punished her with this disease. During the interviews she was repeatedly trying to make sense as to what wrongdoing she must have committed and if she never complained to Allah about her abusive husband, she expected to be rewarded with health in return.

Muzammil took oral cancer as a test from Allah and chose not to complain. Muslims are reassured many times in the Quran that every suffering they encounter in their worldly lives in fact purifies their soul and has a reward in their afterlife (Qur'an 2:153–157, 39:10; Laird, Amer, Barnett, and Barnes 2007; Sachedina 2012; Pew Research Centre 2013). Such reassurances and ideas make them believe that all the afflictions are tests or trials and a step ahead in the spiritual journey and can purify them from all the sins and yield immense rewards in the hereafter. Rashid et al. (2012) also explored the psychosocial effects of cancer in adult patients in Pakistan and found that majority of their participants (87%) believed that religion (praying and putting trust in Allah) helped them cope and respond positively to the cancer. These findings are also consistent with the other studies conducted on the quality of life of cancer patient which identified religion to be an important coping mechanism whereby regular prayers and recitations from the Holy Quran gave hope to the patients and had a positive effect on the disease outcome (Salsman et al. 2011; Seyedrasooly et al. 2014).

There is an additional concern for the afterlife for the Muslims as well, where they would be thinking about whether or not they had enough good deeds to let them enter paradise or to prevent them from the fire of Hell. The time towards death is

for repentance from hurting any other human being and is an opportunity to seek forgiveness not only from Allah but also the fellow beings (Qur'an 4:18; Smith and Haddad 2002). The afterlife is an important and meaningful time where deeds (both good and bad) are rewarded or punished. Therefore the time towards the end of life is regarded as significant as death represents the point at which the actions in this life are sealed (Qur'an 29:7, 99:7–8; Sheikh 1998; Bloomer and Al-Mutair 2013).

One particular study explored the perceptions of the patients regarding the healing effects of prayers, its method of practice and its role in combination with other treatment modalities (Benson 1996). It was found that 90% of the patients at the Agha Khan hospital in Karachi, Pakistan experienced healing through prayers. Patients were also of the opinion that prayers had the ability to shorten the duration of the disease period. Forty nine percent of participants believed that the length of life could not be prolonged with prayer. However, forty percent firmly believed that prayer could prolong life and 97.5 % of respondents said that prayers should accompany medical treatment in order to fully recover from the disease. Faith in God has been attributed to have a health promoting effect where out of 296 physicians, 99% believed that strong religious focus fosters healing and 75% believed that prayers made by others is beneficial for recovery from diseases (Benson 1996). Similarly, several studies identified by a recent systematic literature review on Islamic traditions and Islamic values (Padela and Zaidi 2018) demonstrate that recitation of Quran and regular supplications had therapeutic effects on the physical as well as psychological well being of the patients (Jan and Smith 1998; Morioka – Douglas, Sacks and Yeo 2004; Carroll et al. 2007). Similarly, a meta - analysis exhibited reasonably strong evidence supporting religious remedies over traditional remedies in a Muslim population (Smith et al. 2007).

## **ii. The role of fatalism**

We can see the traces of fatalism working in the lives of the participants in my sample where they do understand that it was 'Allah's will' they had cancer but also



that it was their free will to access treatment. Shafeen Bibi while making sense of her disease was firm in her belief that the illness and cure both were to come from Allah:

Shafeen:

*“I told you that this is from Allah. He gave me so much courage that I never lost hope. It’s not in human control, these things. I will live whatever life’s been granted to me. This is what I kept on thinking...The one who created me, will also cure me...”*

[...]

*“When I feel scared, I then tell myself that it’s by Gods will, He can do whatever he wants. I am okay with it. Hope he blesses with me some more life.”*

Shafeen Bibi was steadfast in her belief that humans could not control what would happen to them, it was Allah who was in power of it all. It is important to note that while Shafeen believed that her disease was unavoidable, the statement does not apply to everyone who has oral cancer. Muslims facing illness are often encouraged to brace themselves up with ‘tawakkul’ (firm belief in Allah) and have patience that may draw divine attention of healing towards them (Arozullah et al. 2018). Another interesting role played by fatalism can also be seen, where Shafeen is submitting to the decree of Allah in the hope to be granted some more life. Atkin et al. (1998) demonstrated that parents with children with an inherited disease regarded it, as ‘Allah’s will’ with the belief that Allah would grant them the strength to bear it all. Similarly during the interview, Muzammil Bibi declared her acceptance of fate and will of Allah but also feared His anger:

Muzammil:

*“I can’t eat because my mouth is shut, can’t eat anything, I so crave for that... And wonder if Allah has written this in my fate that she wont be able to eat anything now, I stay very stressed because of it, there are other illnesses, at least one is able to feed themselves and the stomach properly, now I cant even do that. This pain that was written in my fate, I do pray in front of Allah that okay, you gave me*

*this sorrow you give happiness too, but now please grant me health, be merciful on me, I pray a lot, but my prayers don't get accepted I think, they don't get accepted, I am in so much pain."*

For Muzammil, it was written in her fate that she wont be able to eat and even after taking so much stress she prayed to Allah. Everyday posed a challenge for Muzammil and it continued to get difficult for her. She talked about her constant supplications, crying out to Allah and asking forgiveness from Him to bless her with health. However, it is essential to note that even after believing in the illness and cure coming from Allah, Muzammil did report to the clinic for treatment.

The recent interest of research in the role of fatalism in health alludes towards the notion that fatalistic mind-sets are related with little intent for behaviour change and may contribute to various negative health outcomes (Powe and Finnie 2003). Disproportionate levels of fatalism exist among minority and deprived populations (Sankar et al. 2004; Lange and Piette 2006). In terms of cancer, people use fatalistic or religious approaches as a coping mechanism (Sharf et al. 2005). Cancer fatalism is regarded as a central barrier to screening for breast cancer in traditional societies (Powe and Finnie 2003). Women with breast cancer had fatalistic beliefs because they did not acknowledge the usefulness of screening tests in reducing their risk of cancer (Straughan and Seow 1998). Similarly, Johnson et al. (1999) demonstrated that South Asian women regarded breast cancer as 'disease of fate' and that they were destined to suffer. Only some of these women believed that through praying and medical treatment, their suffering could be cured. The Muslim Asian women considered breast cancer as 'Gods will' and that the onset and the disease course is in Allahs hands (Rajaram and Rashidi 1999).

Dr Moin Qazi (2016) in his article on the concept of Islamic Fatalism says, "Islam is considered, as a fatalistic religion that teaches that everything is predestined by God and man has no control over the consequences of their actions". He further argues,

however, that the concept of fatalism has not been seen in the totality of Islamic religion. It is a concept used by Muslims to underpin their faith with complete submissiveness, while the same concept may be regarded as 'dependency' and 'hopelessness' in the West. It can be argued however, that if seen in the totality of Islamic religion, the 'fatalistic attitude' can be understood well. Islamic belief of 'Qadar' (divine will) does not deny the free will of human beings. Prof. Shahul Hameed from Quran Online Archive 2018 says that "Allah has given us freedom, not complete freedom, but freedom within the boundaries he has set."

Now this indicates towards a very clear notion of 'Qadar' based on the Ayahs from the Holy Quran itself. On one hand Allah says:

*"And not an atom's weight in the earth or in the sky escapes your Lord, nor what is less than that or greater than that, but it is (written) in a clear Book. "*

(Yunus 10:61)

And;

*"To Him belong the keys of the heavens and the earth. He enlarges the provisions for whomsoever He pleases and straitens it for whomsoever He pleases. Surely He knows all things full well."*

(Ash-Shura 42:12)

And;

*"And say not of anything, "I shall do it tomorrow," unless Allah wills."*  
(Al - Kahf 18:23-24)

These verses speak of Allah's power over His creation as well as of His plan and Will. It should be noted that in Islamic writings, disease is considered to be a test/trial from God but Azaiza and Cohen (2008) argue that it also conveys a message that people should take care of themselves and promote their own wellbeing. It can be argued that one of the most devastating effects of cancer is the loss of control and behavioural research has shown that people who have higher levels of self-efficacy feel and function better and have improved quality of life. Therefore it is important

for the patients to have a say in their treatment and disease management so that they can confidently abide by it.

The other aspect of Qadar can be seen in the following verses from the Quran:

Quran:

*“Whatever misfortune happens to you is because on the things your hands have wrought, and for many (of them) He grants forgiveness. “*

(As-Shura 42:30)

And;

*“If any do deeds of righteousness, be they male or female, and have faith, they will enter Heaven and not the least injustice will be done to them.”*

(An-Nisaa’ 4:124]

And;

*“It is the truth from your Lord; wherefore let him who will, believe, and let him who will, disbelieve.”*

(Al-Kahf 18:29)

It is noteworthy from the above verses from the Holy Quran that the free status as human beings has not been precluded in Islam. It is also clear that whatever misfortune befalls on the human beings is because of their own bad deeds, most of which Allah forgives. The common people who think that Allah is punishing them for their sins sometimes misinterpret these verses.

Fatalistic beliefs may have influenced the health seeking behaviours of women in my sample but it is possible that determinants like lower levels of education and poverty may have played a bigger role in hampering their decision to seek treatment. The women in my sample did seek treatment despite their firm belief in the will of Allah. This finding is in contrast to the findings of a recent study (Islam et al. 2017) conducted on Muslim women in America, which showed that most Muslim women in their study did not get screened for breast cancer because for them cancer was ‘inevitable’ and from Allah and nothing could be possibly done to avoid it.

### **6.3.2 Use of alternative and complimentary medicine for treating oral cancer**

Research on factors influencing the decision making and focusing on Islamic medicine has revealed that patients resort to complementary form of treatment such as Islamic healing because of three main reasons which are: recommendations from family, friends and doctors; belief in Islamic healing; and because of previous discontentment with the conventional treatment. Patients also tend to follow their husbands decision followed by family members especially parents as their blessings are thought to be more fruitful for the treatment (Muhammad et al. 2012).

Likewise religion remains an important dimension towards decision. As written in the Quran:

*“And when I am ill, it is (Allah) who cures me.”*

(As-Shura 26:80)

The belief in power of words of Allah and fatalism has, to an extent played a significant role in influencing the decision for health seeking made by the women in my sample. An interesting thing to note here is that, none of the participants in my sample had ever accessed dental services before the appearance of the ulcer in their mouths through out their lives. Also, they did not access health services or dental clinics until the ulcer in their mouths or ‘pimple’ on their faces became aggravated. They either tried home remedies, or their first consultation was with local dispensaries, or the spiritual healers in their areas, which resulted in significant delays in diagnosis. Tovey et al. (2005) attempted to understand the decision making on complementary and alternative medicine use in people with cancer in Pakistan. They found that due to the high cost of cancer treatment in Pakistan, more than 80% patients require financial support for treatment and because of its unavailability, either the patients receive poor quality care or do not receive treatment at all and eventually die. The less expensive and affordable means of treatment include home remedies, Unani Tibb, Prophetic medicine and/or spiritual healing. The women in my sample tend to use:

### **i. Use of home remedies for the treatment of oral cancer**

According to WHO 1998, self-medication is an important component of self-care which is:

*“The selection and use of medicines (including herbal and traditional remedies) by individuals to treat self-recognized illnesses or symptoms.”*

(WHO 1998)

Likewise, home based treatments also called ‘self care’ is defined by as:

*“The ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider.”*

(WHO 2009)

In my sample, family members suggested Nisbah to avoid certain foods that are “hot” in effect and to apply certain herbal medication on her ulcer:

Nisbah:

*“Whoever at home used to tell me about any herbal medicine or any other medication I applied that and ate that but it was all in vain.”*

[...]

*“Although I went to a very good doctor in the village and he gave a tube to put on the ulcer. I kept using that, And then I used ‘tawway ki kalak’ (the grease on hot plate) as well but no use (coughs). He was very sure that it would heal the ulcer. You know when the water gets discharged form it, it gets better. But it didn’t improve it just progressed...”*

Nisbah also resorted to a ‘doctor’ in her locality who advised her to use grease on hot plate – the ulcer would heal when the pus gets discharged. But to her surprise, neither the herbal medicine nor the home remedy suggested by the ‘doctor’ improved her ulcer in anyway and so she had to come all the way from her village to Foundation hospital to get the treatment. Because of the glad tiding by Allah and His Prophet (PBUH) regarding taking care of the sick, it is norm in a Muslim household to

treat the sick with kindness. Therefore when an individual becomes sick, all the family members get involved to suggest remedies for the betterment of the individual. Health care decisions are often made by the families and may include traditional or natural remedies (Silbermann and Hassan 2011). A study conducted on 18 Malay Muslim cancer patients also suggested that one of the main reasons they sought Islamic medicine in form of herbs was because of recommendations from friends and family (Suhami and Muhammad 2015).

For Ameena, in the initial days of disease when the ulcer first appeared in her mouth, her brother and other friends and family suggested her a number of things for curing the ulcer based on their own understanding and knowledge:

Ameena:

*“...Then some of my colleagues, one of them advised to put on doctrine gel, some said about other tubes which I used, I was also thinking that because I have used so many medications for rheumatoid arthritis, maybe this ulcer is their side effect, so I started using things that had cold effects for instance, my brother advised me to drink sugarcane juice or use carminative mixture that will set my stomach right and this ulcer will go away...”*

It can be noticed that Ameena’s family suggested her several remedies in trying to make sense of the ulcer in her mouth. Some advised her to apply some gel; the others suggested the ulcer might be a side effect of the arthritis medication. Although Ameena was educated, she still seemed to be caught up in the traditional ‘hot’ and ‘cold’ foods. On her family’s advise, she started using things that were cold in effect. For Ameena, the time wasted in these remedies led her to present late for diagnosis. In the field of traditional Chinese medicine, the foods are grouped as cold and hot. This does not refer to the temperature of the food but to the effect the food has on one’s body. According to Nagata et al. (2017), the balance of hot and cold food intake is vital for good health. The cold food includes vegetables, fruit and grains and is suggested to use daily to promote internal balance. While the hot food include nuts while the hot ones include nuts and fish meat which provide greater

energy for activity are higher in calories and are mostly used in winter to keep the body warm.

It is a common belief in Pakistan that eating too much hot or cold food creates an imbalance in the body resulting in a number of ailments. For instance it is believed that those who consume too many hot foods may be consuming too many high calorie food and may feel warm, constipated, and anxious. On the other hand, those who consume cold foods experience depression, weakness and diarrhoea. Patients who attend the physicians also ask doctors for any particular food restrictions during any episode of illness. The dietary advice given by the doctors is often by on their experience and is not based on any scientific evidence (Inam et al. 2003).

Suggestions of remedies by the family members for 'common' ulcers seemed very common for the women in my sample. For example, Wazira's family members advised her to use home remedies to treat her facial palsy:

Wazira:

*"As I mentioned earlier I had that 'laqwa' (facial palsy) and that disoriented my face already and I took so many medicines for it. Can't even begin to tell you. I even ate pigeons. Would you believe that? And that is so warm in effect. That caused me this cancer of mouth. And then I started using things that are cold..."*

Wazira was taking medicines to treat her facial palsy. She even ate pigeon's meat to cure it. According to her, the pigeon's meat is hot in effect, which caused her oral cancer later. She then started taking the 'colder' remedies to cure her oral cancer. In a study conducted in Pakistan, Anwar et al. (2015) describes that their participants used a variety of home remedies, spiritual healing, homeopathic and herbal medications and sometimes allopathic medicines as well to fight common and minor ailments and as a part of self-medication routine. They are also regarded as the first point of contact for relieving minor illnesses. Self-medication is a common practice in Pakistan and considered important because of lack of resources, access to health care and poverty (Van der Geest and Hardon 1990).



## ii. Consulting the piirs (spiritual healers)

Some of the participants in my sample tended to take help from piirs before opting for any medical treatment. For instance, Maqsood was advised by her neighbours to visit a spiritual healer who was famous for healing cancers of all sorts. She reported:

Maqsood:

*“My neighbours in the village, when she saw me with oral cancer, she advised me to get it checked by a piir who will blow some verses on this wound and it will go away, I did go to him thrice, but I never went for my teeth to him, just went to him and he said it will heal in no time. But then even after his blowing, the wound remained, all that improved was the colour of the wound, all the blueness went away, but the pain and discomfort remained. We are also told to go to another Maulvi in our village, I went to him too for some blowing, but it didn't get better, I don't know why, so then I came here to this hospital...”*

Maqsood visited a piir (spiritual healer) to get some verses from the Holy Quran blown and order to get her oral cancer treated but it did not work out as she had expected. Only the colour of the wound changed but it did not heal. She also visited a ‘Maulvi’ (religious leader) in the village, which again did not improve her condition. Later, she decided to visit the hospital instead. These findings are consistent with the findings of a study conducted on a sample of oral cancer patients belonging to low socioeconomic status in Pakistan revealing an unmatched trust of patients on the spiritual healers and doctors in their locality (Zahid et al. 2014). It has however been suggested that doctors in these localities should be trained to identify the initial lesions/pre malignant oral cancer lesions and refer to special care afterwards. In this study it is reported that people from low socioeconomic groups were less educated and as a consequence often did not understand the danger of the presenting complaint. They then tended to accept treatment from whoever claims to have the cure for their disease. Similarly, Nisbah also visited spiritual healers before visiting the hospital. The piir blew the words of Quran in a process called ‘dam’ or ‘duwa’ or ‘as she reported:

Nisbah:

*“I even went to a ‘Piiir’ for the healing, before coming to hospital. There was somebody near my village and he treated me thrice but it was in vain. He was famous for healing cancers but nothing worked doctor, it just spread day by day. Now they ask me to get both the treatments. So lets see what I do. I believe so much in both the doctors and pirs. It will have double effect. So that the disease doesn’t spread.”*

Nisbah consulted the spiritual healer (known for treating cancers) in her village because they were the most accessible from where she lived. Consultations with the piir did not bear any results. Nisbah reported that her family then suggested her to seek a medical treatment side by side –for a double effect. One of the main reasons people living in remote areas in Pakistan consult the spiritual healers in their vicinity is because of their proximity, cheap availability, affordable fee, family pressure and strong opinions of the community they reside in (Shaikh and Hatcher 2005). The providers of such care are thought to be more religious and supreme and are called ‘Piirs’; people tend to believe in them more as compared to doctors (Tovey et al. 2005). Patients visit their shrines for the purpose of healings. Suhami and Muhammad (2015) confirmed that recommendations from the family regarding faith healers was not questioned and acted on immediately. Moreover, the informants of the study declared trust and confidence in Islamic healers for they were considered to be ‘moderators’ between Allah and them. They also believed that because Islamic healers used words from the Quran and supplications of the Holy Prophet (PBUH), they were best for healing. The women also showed reservations regarding the conventional cancer treatment, as it did not prove to be beneficial for them and also gave them side effects. It is interesting to note that Nisbah equally believed in the treatment of both the physicians and the spiritual healers.

Another participant shared the belief in piirs as well. Shehnaz begum also consulted spiritual healers but was disappointed that there wasn’t a positive outcome:

Shehnaz:

*“Yes we did go to a few piirs. I went to them so they would blow some surahs on me. But it didn’t work. We went to so many before coming here to this hospital. Nothing worked.”*

Shehnaz also consulted the ‘piirs’ to get some surahs blown over the face before getting the medical expertise, which further strengthens the notion that the participants of this sample accessed the most acceptable and available options, first.

Similarly, Muzammil Bibi, who was a firm believer of Allah’s words and the Quran also believed that spiritual healers could heal her by blowing verses of the Quran on her face:

Muzammil:

*“Oh dear, they just used to blow a few verses from the holy Quran on my face, it was not a one time thing, did that 5 or 6 times in one go, but in vain, no cure...[breathes heavily and just mumbles some words]...”*

Muzammil however was disappointed, as even after visiting the piir several times, she was not cured.

Annabel Symington (2014) wrote about her experience with one of the famous spiritual healers in Lahore, Pakistan. She described how the piir proclaimed him self as a living saint- someone who is considered an important entity in some branches of Islam. Also, they are considered to be closer to Allah as compared to common human beings and can offer spiritual advice and remedies in times of disease and need. The title of ‘piir’ is passed down from generation to generation and many of them form a part of huge land owning families that control majority of the rural Pakistan. According to Shaikh and Hatcher (2005), alternative therapies such as faith healers are the first choice for problem such as infertility, epilepsy, psychosomatic troubles and depression in Pakistan. Mariam Khan (2014), a blogger at Huff Post reports (2013) that because 50% of the population in Pakistan has never attended schools they cannot think on their own. As a result they will follow what the

comparatively educated and influential people suggest to them.

Most of the spiritual healers in Pakistan, according to Mariam (2013) claim to be a 'one-stop shop' mainly offering all the solutions to all the problems an individual have. Name it, and they will have a solution for it. These 'spiritual healers' charge the people large amounts of money for the treatments and healings and often leave them in debt for years to follow. It is not advised by Islam to charge money for healing the followers and such a practice is deceitful and unethical. This system of faith healers charging huge amounts of money for healing is also considered unethical in African traditional health care system whereby the traditional medicine man/women are not expected to charge people any amount of money or gain profit from curing ill health (Omonzejele 2008). Mariam (2013) also emphasized on the importance of education so that these people do not go astray and spend all their savings on the fake spiritual healers in the name of religion. It should be kept in mind that not all spiritual healers are fraudulent or using this therapy to make money, some spiritual healers are effective and actually aim to ease people's worries. However, the similarities in the conduct make it very difficult to differentiate between them. As one of the piirs told The News that while some are fake:

Faith healer (2009):

*“ There are many who are serving the public through the verses of the Holy Quran.”*

Although Islam does not encourage seeking help other than Allah, the penchant for spiritual healers and black magic is deeply embedded in Pakistani society. From rich landlords to poor people, Pakistanis routinely resort to spiritual healers either to cure diseases from cancer to leprosy and epilepsy, marriage and children problems and even for 'talkative daughter in laws'. In the name of faith healing, it has been reported on many occasions in newspapers and television documentaries, that some of these 'healers' have even tortured, raped and murdered their 'patients'. It is indeed the responsibility of the Islamic scholars to educate common people of the dangers of putting one's trust in the fake faith healers which have no place in Islam.

### iii. Using combined alternative and medical healing

For some of the participants in my study, belief in medical treatment was equally important as the spiritual healing. They believed in the power of 'piirs' (spiritual healers) as well as the treatment provided by the doctors. Some of the participants also mentioned the use of 'amulets' made by the spiritual healers. The piirs make 'amulets' or 'taweez' based on the passage of Quran for the patients to wear at all times in order to speed up their recovery (Tovey et al. 2005).

For instance, Nasreen Akhtar believed the medical treatment and spiritual healing combined proved to be more effective for healing:

Nasreen:

*"Just that, Allah gave me this cancer. It was not in my control. I even went to a piir to get the surahs blown over my face. He did it. He gave me an amulet. I asked the doctors here if they would let me go to any piir. And they said it was my choice. So I did. And see it worked (smiles)."*

[...]

*"Of course yes, it was both. Piir and the doctors here at the hospital. The doctors did the entire cutting and stitching and the peer healed it you see. We ourselves, sitting at home cannot do what the piirs do."*

It can be noted how Nasreen had accepted the disease from Allah and entrusted the piirs to cure her through Quranic verses. Nasreen was also given an amulet by her piir on which some verses of the Quran were blown. Her physicians allowed her to visit any piir if she wants to and she availed the opportunity alongside her treatment from the hospital. Nasreen believed that both doctors and piirs healed her oral cancer. Her physician understood her strong belief system and therefore advised her to use both the methods. There is indeed a dire need to incorporate an individuals belief system in treatment plans to promote healing.

It is interesting to find that a spiritual healer in Malaysia (Merriam and Muhammad 2013) made a similar comment regarding his patients.

Abas:

*“The doctor treats this part, while I treat another part. The doctor basically treats the physical part and I treat for the spiritual part. I say the azan [prayer] seven times and I take a deep breath and the patient can feel a little calm after that.”*

*(p. 3597)*

Merriam and Muhammad (2013) also identified that people go to traditional healers to find cure for their physical ailments. Whether people suspect themselves to have cancer or who have not yet been diagnosed with cancer, all resort to their therapy. Traditional healers use plant roots and spiritual incantations and blow it on the drinking water. One of the village healers used pure natural honey and white pepper and called it a ‘king of medicine’. He had also devised a 10-day treatment for breast cancer but in worst cases he ‘cannot treat’. Another healer told that she uses betel leaf, lime, sugar and gambir to treat cancer if the lump is small. Another healer used to make his medicine using a leaf from the money plant or the root of white hibiscus plant and mix it with wasps nest and shallots which were all mixed together and pasted on the affected area. The healer was firm in his belief that he would just dip the betel nut leaf in honey, recite some (Quranic) verses and transfer the pain. He would say “you don’t stay there, come here...” and point towards the breast and then touch with his finger and the disease would not stay in the person and transfer to his finger. We can find similar practices in Pakistan as well.

Rukhsana begum also believed in the power of Quranic verses that are blown by the Piirs in the form of ‘amulets’ and the treatment done by doctors. She said:

Rukhsana:

*“I think I went to a Piir very early on when I got cancer. That piir was famous for putting a ‘haar’ (garland) in the neck to heal the diseases. So I went there, got that haar and drank the water on which Quranic surahs were blown. Otherwise, I have never done those black magic things nor I believe in them. I just trusted Allah and then doctors. That’s it. I trust these doctors a lot and I know I am getting better.”*

For Rukhsana, the first point of consultation early in the disease process was a piir who would blow verses from the Quran on a garland and put around her neck. She also drank water on which Quranic surahs were blown and was known to provide her health.

Sabra Bibi on the other hand, believed that cancer heals through spiritual prayers only if there is a medical treatment accompanying it. She also agreed to the advise of her local doctor and reported:

Sabra:

*“No I never went to any, people do go to such people. When I went to that doctor I told you about in Gujjar khan, he told me ‘Amma ji, please do not go to any piir or faqeer or any such person, just go and see a specialist.’ So I did the same I did not go. People do go to piirs but then their disease aggravates, it seldom gets healed, it only gets healed if there is treatment with it. There was no cure for cancer earlier you know.”*

Sabra did not visit any piir because she thought that in the absence of any medical treatment, the works of piir are in vain. She consulted a medical specialist instead.

A similar view can be noticed in Wazira Khatoon’s narrative. She also believed in the string of life being in Allah hands only as she said:

Wazira:

*“Yes we got some surahs blown over me by some piirs, they asked us not to get it operated and that they would heal it. But doctors advised us otherwise. I was really confused. But then whatever Allah wishes happens. These piirs are nothing if Allah has destined for something to happen.”*

Wazira did visit a piir in her locality who advised her not to get any medical treatment done. The doctors at the hospital advised her otherwise. A conflict of opinion and apparent confusion in the minds of the patients can be noticed. Wazira was of the opinion that piirs could do nothing if Allah willed otherwise.

The narratives of people belonging to a comparatively higher social class differed in that they did not believe in any piirs or amulets. For instance, Sughran Bibi was the only participant in my sample who completely denied any belief in spiritual healers and said:

Sughran:

*“Oh no...We don't believe in such things. We believe in Allah, everything is from Him. He gives hardships and He is the One to cure (happiness and hardships both are from Him) we don't believe in piirs and we don't go to them for help. This is not the way of our family.”*

[...]

*“No no...We did not opt for any herbal treatments. We have doctors at home. My son is with us 24hours, so if we have any problem, he can solve it. It's not my habit to listen to all different people and do what they advise.”*

Sughran belonged to a well-educated family and therefore did not feel the need to get opinions from anybody else regarding her disease and treatment. We can see how Sughran has completely entrusted in Allah for being the saviour and the one to cure all illnesses. She also spoke of this being a family norm that they never visited or sought help from spiritual healers. Likewise, Sughran showed complete disbelief in homeopathy as most of her children and grandchildren were qualified medical doctors.

In my study, it was also interesting to find that the two working women belonging to a middle class family mentioned being against homeopathic medicines. While describing how other people with cancers resort to alternative medicine for treatment, Ameena said:

Ameena:

*“Then the things I have seen, that some get oral cancer operated and don't get the chemotherapy, some don't get the radiation therapy done, some go to piirs, homeopathic medicine, and they think that*



*now the operation is done, everything is sorted, but they are wrong and then they die...”*

The above quote signifies the advantages of a more affluent socioeconomic background and education that may have empowered Ameena not to opt for homeopathy or spiritual healing.

Similarly, family and even her husband suggested Shamim to choose homeopathy but she did not opt for it:

Shamim:

*“No...I didn't go to any Piir...but yes I was told and suggested by my family to use homeopathic medicine because they said there are certain herbs and medicines that can cure cancer without operation... but I never believed it...I don't trust such things ever. I know only medical interventions can help. They said they will put a medicine that will shrink it...but I didn't trust them... even my husband was very keen to suggest me such medicines...he was very worried about me.”*

Shamim did not go to any piir for healing or used any herbal medicines suggested by her family unlike the others in the sample. She believed that medical treatment could cure her cancer no matter how effective the other treatment modalities seemed.

There are around 45, 000 traditional healers working in Pakistan out of which three quarters are based in rural areas. Therefore, their presence in the rural areas is regarded as the source of health care (Sheikh and Hatcher 2005). It should however be noted that due to the non availability of medical facilities in the villages and towns, patients resort to comparatively less expensive faith healers and other alternative therapies (Khan et al. 2014).

The effectiveness of specific healers or the therapies they offer has not been subjected to any research in Pakistan. Maybe because of the reluctance to question or test anything that has spiritual or religious roots. However, the issue of spiritual healers has been much debated about in blogs and newspaper articles. The findings

of my research are consistent with the previous literature indicating that strong belief in Allah and spiritual/faith healers brings good health. Also, people tend to resort to complimentary and alternative medicine even home remedies, however, I do not make any claim as to which is more beneficial to good health. Pakistan has a long history of traditional medicine but there has been very little research to map its use. Further work is needed to operationalise the construct and to identify the factors related to traditional medicine in disease progression in order to understand the role of spirituality and religion in the lives of people with oral cancer. Also, it is important to understand the way traditional and spiritual healers operate in Pakistan so that they can be employed to work together with the health services in identifying the early stages of oral cancer. It is of crucial importance to tease out ways to facilitate communication between both.

This chapter detailed the perceptions of the participants regarding the reasons and treatment of their oral cancer. This adds to the limited literature available on how strong religious beliefs, alternative and complimentary medicine influenced the patient's oral cancer journey. The oral history accounts of the participants in my sample also represent how they made sense of their disease within their social context. The lived experiences of people with oral cancer in my sample will be detailed in the next chapter to indicate how the participants of my sample used oral history to reconstruct their life stories and how they made sense of their experience with the disease after diagnosis.

## Chapter 7. The Aftermath: women's lived experiences after the diagnosis

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## Chapter 7. The Aftermath: women’s lived experiences after the diagnosis

### Summary of the structure of the chapter

The previous two chapters have discussed in detail the participants, their social background, how they made sense of the reasons of oral cancer and its treatment and how certain religious and cultural practices influence the journey to diagnosis of oral cancer in Pakistan. This chapter will now describe the lived experiences of the women in my sample after their diagnosis.

### 7.1 Introduction

Each woman in my sample, while sharing common experiences related to oral cancer and its treatment had her own story to tell and her own path to walk. As these women began to come to terms with the diagnosis of oral cancer, uncertainty and threat took up a permanent place in their bodies. Regardless of the stage of their oral cancer, each of them remembered the time of diagnosis and the emotional trauma they experienced. The table below illustrates participant’s disease stage at the time of the interviews. It should be kept in mind that these stages might have had a huge impact on what and how they chose to disclose on the day of the interview.

Table 7.1 Disease statuses of the participants at the time of interview

No	Name of participant	Disease status at the time of interview
1	Ameena Mehboob	Was diagnosed one week before the first interview. Was undergoing chemo/radio therapy period at the time of second interview.
2	Razia Begum	Operated a year ago, was on a follow up.
3	Shehnaz Bibi	Was diagnosed two weeks before the interview.
4	Muzammil Bibi	Was in Palliative care at the time of all three interviews.
5	Imtiaz Bibi	Was scheduled for operation in a couple of weeks after the interview.

6	Maqsood Akhtar	Operated a year ago, was on a follow up.
7	Nasreen Akhtar	Operated a few months ago, was on a follow up.
8	Rukhsana Begum	Had undergone her first surgery 3 months before and was on a follow up visit at the time of the interview.
9	Sabra Bibi	Was on a follow up.
10	Shafeen Bibi	Was operated two months before the interview.
11	Shamim Akhtar	Operated a few months ago, was on a follow up.
12	Sughran Bibi	Operated two months before the interview.
13	Wazira Khatoon	Operated a few months ago, was on a follow up.
14	Zahida Kalsoom	Operated two years ago, regularly getting reconstructive surgeries.
15	Nisbah	Operated a few months before the interview. In remission

Further to the previous section on how the women in the sample tried to make sense of their reasons for oral cancer, the main focus of this section will be on the societal attitudes towards oral cancer and women's internalized beliefs that have been derived from society which influence their lived experiences of oral cancer.

The themes that will follow are derived from the narratives of the women in this study. However, it should be borne in mind that they are particular viewpoints and may not necessarily speak for the whole patient population.

## **7.2 Living under the death sentence of oral cancer**

For many women in this study, the pathway was associated with the fear of death. The process of recalling the time of diagnosis prompted many emotional feelings in the participants. As they began to construct their narratives based on the memories, they also started to make sense of the diagnosis and how it made them feel. Regardless of the early diagnosis or the likelihood of long-term control against the

disease, the diagnosis of cancer represented an impulsive and agonizing turning of the body against itself and against all that had been hoped for in the future. Their families thought of cancer synonymous with death and that made the participants more scared. For instance, before Nisbah reported to the hospital, everyone in her house thought she would die very soon. They gathered around her bed as if she was about to die. They clearly misinterpreted her anxiety and suffocation, which in turn heightened her fear even more:

Nisbah:

*“I was in such a mess even before I got admitted to the hospital. I used to feel suffocated and it felt as if my breathing will stop any minute. I used to lie down on charpai (sort of a bed) all day long and my brothers and sisters used to sit around me as if I’m dying any minute because I felt like choking. My father used to cry a lot looking at me and it made me feel worse...(crying)”*

Nisbah articulates a sense of complete hopelessness. There is also an implied dilemma where the first thought that comes to mind when people hear the word ‘cancer’ is death. It seemed as if her family had given up on her. Had they given her a positive feedback, she may not have felt this bad. Nisbah seemed to have internalized their feedback into thinking that she may die soon. Cancer meant death in the society Nisbah was a part of. It does not necessarily mean that she was certain that she would die. It is imperative for the doctors at this stage who are treating cancer patients to consider talking to the patients about their fear of death as they may be dealing with a lot of emotional collateral damage. As described earlier in her description, Nisbah came across as a very strong person initially but she cried many times narrating her story of the cancer diagnosis. To me as a researcher, it was important because I could see the relationship between her and myself building and getting strengthened. She was expressing her deeply embedded emotion in front of me.

Similarly, Ameena faced a similar situation at her home when she first heard of the cancer diagnosis. Although she was educated and belonged to a comparatively

affluent social class, even in her family cancer was thought to be associated with death:

Ameena:

*“Do you know I have not discussed this with my extended family yet because what they will do is come to my house... And then what they talk about is full of negativity and hopelessness, oh she has cancer, she will die soon, I mean I am observing the reactions of my extended family, majority of them...even my own brother and sister are worried that I may die...”*

[...]

*“Then there are illnesses that we think that okay if we will get them treated, they will be cured, but in cancer, it is like, don’t know if I will survive or not...And it is good from one side in that doctors do console...but I have a three month experience that I have spent with my husband in the hospital... There are very low chances...very very rare chance only by luck you survive, maybe it is all getting researched till date, like the way people get scared of snakes the same way people get scared of cancer, this word is horrible, I have seen children suffering from cancer, elderly as well...”*

Ameena articulated her reservation regarding telling her family of her cancer because they talked negatively about cancer being a sign of death. The kind of positive and hopeful person Ameena was, she could not stand the negative reactions of her own siblings towards her as well. Leader et al. (2017) found that the majority of participants in their study did not disclose the diagnosis of cancer to their community because they were unsure about the type of support they will receive if at all. Ameena was also unable to reconcile messages of hope from the doctors about improved survival rates with her experience with her husband’s cancer. The death of her husband made her aware that her own death was possible. She was certain that only if one is lucky they could survive cancer. She regarded cancer as a ‘snake’ implying the terror it instils in people because it slinks along silently, strikes without warning, its bite can be deadly and dying from its venom can be slow and agonizing. Other participants in my study shared this general sense of fear as well.

For instance, when Wazira was first diagnosed with oral cancer, she was taken a back. She recorded a normal response to a cancer diagnosis. Not knowing how to handle it, she was just worried and stressed:

Wazira:

*“At first I did not know what to do, how to handle it, the pimple was so bad and aggressive and seeing that growing big every day I was sure that I wont survive it. I will die for sure. I was so sure. I prayed Allah bless me...”*

Here, it seems as if Wazira had gotten a ‘death sentence’ making her adamant that she would die. She kept praying for her well - being because her cancer had aggravated. She had no clue how to handle her diagnosis. A study conducted in Turkey (Duran 2011) on the health belief model of women’s attitudes towards cervical cancer, it was found that majority of the women were fearful of the outcome of the screening test and were expecting to be ‘devastated’, sad and ‘depressed’.

Despite the advances in cancer treatment and measures in early diagnosis, cancer still inspires fear. The reason might be because cancer has been historically thought of as ‘slow painful death’ (Barker and Jordan 2003). A nearly third to half of the population in USA and UK declare that they fear cancer more than any other disease (Barker and Jordan 2003; Vrinten et al. 2015). The fear of cancer may range from death, disability, treatment or incapacitation.

John Diamond, a renowned British journalist and commentator published a personal account on experiences with oral cancer as a result of years of smoking in 1998 in his book called ‘C: Because Cowards Get Cancer Too’. To the best of my knowledge, this book is the only extensive and detailed account of living with oral cancer published to date and is contemporaneous as it focuses on specific themes rather than the broad sweep of life narrative. John Diamond, writing about his reaction to the diagnosis of oral cancer expresses what any ordinary person facing such disease would do.



John:

*"Tell anyone that you have cancer and what they'll hear is that you are about to die. Why would they not?"*

(Diamond 1998, p. 7)

[...]

*For the one thing that everyone knows about cancer is that it kills. There is no curing the cancer patient: the most that can be hoped for is a temporary remission while the appeal court argues about the precise date of execution."*

(Diamond 1998, p. 37)

John was certain that he would die because this is what everyone thinks when they hear of cancer. The societal attitudes towards cancer are really important because it influences individual's perceptions of the disease as well. He believed that cancer patients never really get cured, they can go in remission but that too is temporary and cancer has the tendency to return. John used a metaphor of 'the appeal court argues about the precise date of execution' for the course of the cancer, which is thought of as potentially fatal. Sontag's (1978) 'Illness as Metaphor' suggests that cancer was not talked about because the very name had an immense power. It could even kill patients who may not have died so quickly otherwise from the malignancy itself. Cancer was treated as an 'evil, invincible predator' because its presence demoralized people. It was also thought that once cancer occurs, it couldn't be reversed or completely diminished from the body. Sontag however, argued against the use of metaphors for illness because she felt metaphors could reinforce negative thinking. For instance, 'fighting with cancer' and 'overcoming cancer' leads us to imply that cancer is a war and if you lost, you did not try hard enough.

In a recent systematic review and meta-analysis, Vrinten et al. (2016) aimed to explore the different kinds of fears cervical and breast cancer instils in people. They found that the patients viewed cancer not just as a disease but also something with a 'malicious character'. The fear associated with death was found in majority of included studies in which the participants regarded cancer as a death sentence.

It can be noted from the quotes from my participants that cancer had certainly taken a position of a disease that has become a sign of repression, pain, and suppressed emotions. Surely it is the society that has informed the perceptions of cancer. The understanding of cancer is indeed influenced by the societal constructions that have become internalised. In my data, while some of the participants openly talked about their fear of death, the rest of them chose not to open up. They talked about the other uncertain consequences of their lives after the cancer diagnosis.

### **7.3 Living with the uncertain consequences of oral cancer diagnosis**

The fear associated with cancer is worrisome and unpleasant and has the potential to affect health-seeking behaviours. For instance, fear of cancer may cause people to abstain from getting screened and in some cases it may even motivate them (Vrinten et al. 2017). In my sample, where the women were so firm in the belief in Allah, they were also scared of cancer and its potential. This was an interesting aspect of their narratives- they spoke of faith and utmost submission but feared cancer.

Shehnaz Bibi, who was recently diagnosed with oral cancer and was waiting for surgery, for her the word cancer, was a fear in itself as she explained:

Shehnaz:

*“I feel very scared. Believe you me, it is very scary. Because, it’s the name. Some people say it gets cured, some say it doesn’t. Cancer is like that... don’t you think? it is scary. It is in the name. I get very scared you know... I am very sad about it actually. It is a big setback in my life. I never heard of it but people say sometimes it gets cured. I don’t want to call it by its name. I will call it a ‘thing’.”*

Shehnaz did not even want to call cancer by its name because it instilled in her a sense of fear. Kawar (2013) also found the same fear in Palestinian and Jordanian American women who were of the opinion that they might get breast cancer just by uttering the word ‘cancer’. Other studies have mentioned thinking and talking about cancer as ‘risky’ (Remennick 2003; Greiner et al. 2005; Cohen 2009). Not talking, thinking or worrying about cancer was considered a protection against cancer

(Vrinten et al. 2017). Shehnaz was not hopeful that she would be able to survive, as she never heard of survival from cancer from the people around her. Fear itself was burdensome for Shehnaz but it affected her behaviours positively and she wanted to get it treated. This is in contrast to the quantitative studies that suggest that such fears often become a barrier in help -seeking (Dubayova et al. 2010) and screening (Hay et al. 2005) in order to avoid getting diagnosed (Balasooriya et al. 2015). John Diamond in his book also shared a similar feeling:

John:

*“Such is the potency of the word ‘cancer’ that it can never be delivered without sorrow- even by a doctor who knows the cure rate of this sort of cancer is up there in the 90 percent area.”*

(Diamond 1998, p. 42)

Diamond describes how the word cancer was always associated with sadness and worry even by the physicians who know that cancer could be cured.

Fear of cancer is also related to the uncertainty it brings with itself. Sabra Bibi was uncertain about her future when she got diagnosed with oral cancer. In her spoken narrative she said:

Sabra:

*“Oh yes, I used to think if it would ever get cured. I thought it was so dangerous, the cancer, and don’t know how the operation will be, some people get those tubes through their throat, that scared me. I have seen other cancer patients, my goodness me, may Allah forgive me, He has been kind to me and I prayed a lot. My sons were so worried. They had lost their father and now mother was suffering like that so it was all in all a miserable experience.”*

Sabra clearly articulated her sense of danger associated with her cancer, the lack of control, fear of medical treatments. Uncertainty invaded her life and demanded a response. It impacted on her worries regarding her treatment but also her family and her children. She relates how her children felt having lost a father and how their suffering and her diagnosis all made for a ‘miserable experience’. Witnessing cancer

consequences in other people, seeing them dying of cancer and its treatment related side effects, also instigate fear through contemplation of ones own destiny in the hands of cancer (Vrinten et al. 2017). Sabra also conveys her experience to divine judgment and her supplication in the face of this. We can notice a similar experience shared by Muzammil Bibi in the previous section, who continuously chanted on 'Astaghfar' (seeking forgiveness from Allah) during the interview.

Talking to the participants with oral cancer alluded that suffering and uncertainty go hand in hand in relation to cancer. As soon as an individual is diagnosed with a suspected cancer, they are inflicted with the uncertainty of whether they have cancer or not, the effectiveness of the treatment modalities, their capacity to achieve their goals and ambitions in life, making it through their mundane routines and last but not the least if they will survive the cancer. Kleem et al. (2000) demonstrated that this uncertainty stays with people from the time of diagnosis till treatment and the final years of life. If cure is possible, the patients become hopeful but if it is not the outcome, patients tend to accept that they are dying and their whole perspective on life starts changing immensely (Little and Sayers 2004). People with colorectal cancers frequently discussed their uncertainty with their doctors in terms of treatment and quality of life (Beaver et al. 2010). They also complained that their physicians did not provide them adequate details to address their concerns, which increased their uncertainty and anxiety.

Ameena recalled that when she was asked for a biopsy, she felt really scared because her knowledge of biopsies led her to believe that it is only done for cancers.

Ameena:

*"The last few duties I did, a few days ago, I cried a lot although I did not know anything... but I was very hopeless and sad. There was this anxiety and confusion and tension that only the ones with cancer are asked for a biopsy otherwise for something small nobody asks you to get a biopsy...that's all that's going on these days..."*

[...]

*"Many thing go in my mind all the time, sometime my morale is very up [chuckles a little] that okay when I get the operation done, I will be*

*fine it is not that big of an issue and sometimes I think that no, when cancer strikes, it does not leave you. I don't know really..."*

Talking about the uncertain consequences of oral cancer diagnosis, Ameena described her feelings of anxiety, fear and confusion as to what the future held for her. She experienced ups and downs of faith whereby she would feel hopeful at one time and extremely hopeless at other times. Ameena was uncertain if cancer would completely finish from her body.

Similarly, for Rukhsana Begum, as she remembered, the diagnosis of oral cancer was really stressful and full of uncertainty:

Rukhsana:

*"When I used to get stressed, I would always think about what would happen next? Will I get better or die just like that? So my eldest daughter and then this younger daughter as well as my son who came in with me today, they all stayed with me throughout. I was in pain, but they were dying every moment with me. "*

Rukhsana was uncertain about her life and if she would ever get better from oral cancer. She worried about her children a lot and conveyed that even they were 'dying' with her. Recent research suggests that the feeling of uncertainty is related to the engagement of the patients with the illness process (Carduff et al. 2018). The participants of my study were not engaged fully in their disease process. They were scared and did not want more information regarding their cancer. This also implies that they were not partner in their care and the structure of the medical care certainly is a reflection of Pakistani society. This is a big contrast to the UK where the human dimension of care is central in health care (Bramley and Matiti 2014). Cancer diagnosis scared them so much that they did not want to know more about it or its effects. This partial engagement certainly added to their uncertainty. To what extent the women in my sample expected compassion and empathy from their physicians is unknown. They however talked about doctors as their saviours and had no complain about them.

Sughran Bibi who was in remission just worried and hoped not to depend on anyone in the face of her illness. She feared that cancer may return but also hoped for it otherwise:

Sughran:

*“No no... I did not think about what’s coming. Even if I thought about it for a minute, I would just ask for forgiveness from Allah. I just prayed to Allah not to make me dependent on anyone, to make me better. This is all I worry about, to be dependent on someone esp. when I have this joint pains and I can't walk easily ...my children and grandchildren when see me struggling to get up, they would run to give me a hand, get my walking stick. Alhamdulillah. I just pray that I don't have to face any more illness after what I have been through. Everyone in my family has prayed a lot for me and that's how Allah helped me to get better.”*

For Sughran, it was her firm faith in Allah that did not make her uncertain about her future after diagnosis of oral cancer. Sughran only sought forgiveness from Allah to prevent her from old age dependency on the family. She was grateful and had the support of her family member unlike some other participants in the study who faced stigmatisation and seclusion. As Sughran began to talk about her family, the pride in her eyes was evident. She was actually very lucky and grateful to Allah for having a supportive family amidst of all the worries cancer brought. It could be that because Sughran belonged to a comparatively better social class and her children were educated and living good lives, she was not focussed on remembering the negative parts of her cancer story. Rather she was being hopeful and positive unlike some of the others in my sample.

Similarly, Shafeen Bibi spent a fairly peaceful time between her diagnosis and surgery. She did not feel any uncertainty regarding what would happen. Nothing in life had changed for her as she proudly told:

Shafeen:

*“I was fine to start with. Nothing changed. I didn't give it a second thought. I thought to myself that this hardship is from Allah swt so I'll*

*have to bear it. I thought there is not point thing about it... even when they took me for operation, I went happily. After the operation when they took me to the other hospital. I was ...I would say they did a very good job with the operation. There is no need to say otherwise. It went fine, I had no problem."*

The role of faith and fatalism can be seen here as well. Shafeen considered oral cancer, as a hardship from Allah so there was no way she could escape it or shun it. The other reasons why Shafeen did not feel scared or uncertain about the outcome of her diagnosis could be attributed to her socioeconomic status and immense family support just like Sughran Bibi.

The diagnosis of oral cancer did not upset Shamim in any way. She recalled having no uncertainty regarding her disease. According to her she was so stressed in her life anyway so even getting oral cancer was not traumatic for her as she stated:

Shamim:

*"No...I was never scared...it was painful initially I had severe pain when I would eat anything... Then after operation when I regained consciousness I ate my favourite dessert (rice pudding) (laughs)...and slowly I began to eat small portions...the wound got better later with time. I didn't even get any radiations..."*

[...]

*"...When I heard about cancer... I didn't think of anything bad...I know that life and death is in Allah's hands...when you are going to die there is nothing that can stop it...so I thought if I am destined to die with this cancer then be it...and then what have I gained by living this life? So it is okay to die too...(smirks) nothing will happen if I die...what has life given me? Just sadness and despair? No happiness ever. So it will be okay if I die. I am not scared of dying at all...and there is nothing to left in life anyway..."*

[...]

*(Smiles and tears in her eyes) "I say it because life has not given me anything except sadness... and trials...there has been no happiness since childhood then when I was young and now when I am getting old...there is nothing...to be happy about..."*

[...]

*“It would just be a miracle nothing else...if something happens that makes me happy (smiles) I think I need peace...when one doesn't get it then only human beings get frustrated and sad. I think it is all a matter of fate...no amount of money can find you peace...look I am earning very well. I have got all the money I need...(silences down)...still I got the disease...I have got everything I need thank God, I am even very grateful to Allah for all this...”*

It was interesting to note how Shamim made sense of her disease experience. How the uncertainties of her life in general did not make her upset about oral cancer at all. Shamim further described that fate and destiny played a part in ones life and that death was inevitable. She had accepted her fate and chose not to worry or get stressed. It can be noted that the reason Shamim did not express any uncertainty may be due to her fatalistic views about the happenings in her life. She was not scared to die as for her there was no good left in life anyway. She clearly articulated how unhappy her life was so it did not matter if there was any adversity inflicted upon her. Shamim has also pointed towards the irony of the situation whereby she has money, she eats and lives well, has got a well payed job, and still gets cancer implying that everything is in Allahs hands and no riches could save you if you are destined for something. I remember how sad Shamim was while she narrated this part of her life. She had completely lost hope in any good thing in life. She broke down many times during the interview and there were long pauses and silences in between but she still wanted to share her story with me. It could be that she was trying to understand and make sense of her stories and memories in those silences.

Living with cancer and its uncertain consequences was indeed not an easy road to take for the participants in this study. This may have occurred due to several reasons. First, at the time of diagnosis, the doctors did not inform the patients fully. Second, they were kept in the shadow as to what would happen to them both physically and mentally; participants found themselves in complete ambiguity. Finally, they were not informed about the treatments and their side effects unless they were educated enough to ask questions. The only hope for many women with



oral cancer in my sample to curb their anxiety and the feeling of uncertainty was their faith in Allah. They looked up to Him and sought His mercy and were also proud of themselves because of the prospect of potential reward in the afterlife for bearing so much misery in this life.

#### **7.4 Patient's worry for the family**

The women in my sample were in a way a typical representation of women in a common Pakistani household whereby they take a step back in almost every sphere of life and focus all their attention to their families. Even when they are seriously ill, they worry for their family more than about themselves. Many women in my study disregarded their initial symptoms of oral cancer, because they did not want loved ones and family members to get worried. They continued performing their roles in the household until the severity of the symptoms increased. They were also reluctant to share their painful experience with family members. For instance, Wazira shared her experience of being silent about her 'misery'.

Wazira

*"I don't share this with anybody...if I talk to my children they get worried a lot easier. And I can't stand that. So I keep it to myself and tolerate it...Children don't know in what misery their mother is. Whom else should I tell? Can't they see it with their eyes (voice trembling) I cant tell anyone my hearts tale? I can't even eat anything anymore. This adds to my misery even more..."*

Here we find that Wazira kept her silence not wanting to worry her children and not wanting to share her 'misery' but she also beseeches them to see her suffering. Wazira wants to voice her story and let the others know how painful the experience of oral cancer is for her but she chose to stay silent instead.

This bearing the pain in silence was a common theme in the accounts of women in this study. Zahida Kalsoom who used to live with her nephew and his wife was cautious in telling her family about the pain she was in.

Zahida:

*“It still did not heal, then it formed a hole, even then I did not understand what it could be, I could not sleep at night, whenever I used to close my eyes, It would ache so much that I would sit all night long but I did not tell to my nephew thinking he has so much work to do all day, why stress him more?”*

[...]

*“My bones ache so much, so whenever I feel pain dear, I cry myself to sleep, got no mother or sister who would be with me, so what do I do? Nobody else other than your blood relation would ever be able to feel the pain you are in... See dear, I can see some tears in your eyes, not everyone feels your pain...”*

Zahida chose not to tell about her pain to her nephew because she did not want to burden him. She did not tell how painful the nights are for her to anybody. Instead she resorts to crying. It can be noticed how Zahida notices the tear forming in my eyes during the interview. As mentioned earlier in her description, the interview with Zahida has been a really heart breaking experience for me. To be honest, I actually felt her pain and the way she was narrating her story upset me a lot. Instead of saying anything, I opted to hold her hands a few times during the interview to make her feel comfortable, heard and understood.

Shamim was also managing herself and her disease all - alone without telling any of her experiences to her immediate family and friends as she reported:

Shamim:

*“Yes, I have got a few friends but I don’t share anything with them...I just keep everything in my heart...and never ever tell anything to anybody...sometimes if the things go out of hand and I cant help it keeping to myself then I share it with my madam in the office. That’s it...she takes care of me a lot. Keeps asking about me so I share stuff with her some times...not all the time though. I am living an unhappy life you see...And then my sisters. With them too...they take care of me only some times I share. Rest I keep things to myself only...But today, I have shared and am sharing so much with you...I have no fear of sharing you see... “*

Shamim only shared when she reached her threshold level. Bottling up feelings and stresses inside had made her life really unhappy. She only shared sometimes with her supervisor at the hospital or her sisters. Shamim shared a lot of her personal life

and feelings with me, maybe because she did not feel threatened sharing her feelings with me. It may also be because she was scared of sharing with her immediate family because of their role in life.

Early on the disease process, Ameena recalled that she started to worry about her children and how will they be after she had died. She started telling me what share of the property she would give her daughters and what would be for her son. This was important because she was sharing a very crucial and sensitive part of her life with me. She was telling me one of the most important decisions of her and her children's lives. I was honoured that she shared it with me. To preserve the confidentiality, that part of the interview has been removed from the excerpt for this thesis.

Ameena also believed that although there might not be any financial issues for her children, she still worried about them having no one to look up to:

Ameena:

*"Sometimes, I feel like completing all my chores, go to the bank and tell them that fix all these things on the name of my son. The land and house I have, I want to keep it for my daughters so they have something too, but I cant tell them this. They are still young, cant even tell them that... cant even hand it over to somebody else, there is not a single person to whom I can say that after me take care of my son for at least 4 years... it is not about money, it is about getting that care that one receives from parents, so I can hand it over to such a person and tell them that when my son grows up give all this to him, cant directly give it to my son... everything is going on...have not been to bank yet...nor visited any of the lands, so sometimes I think that the shop and house I can transfer it on my sons name, so he can at least spend an easy life it should not strike him in life..."*

[...]

*"Just want that my son should not feel that his parents are not alive..."*

Ameena consistently worried about her youngest son and his well being after her. She was making arrangements and unconsciously preparing herself and her children for any adversity. Ameena was going through a roller coaster of emotions while she

said she could not trust anyone in the family to look after her children. She was trying to make sense of little things during the interview. I am glad that even when she could not share her hearts desire with anyone else in the family, she shared it with me. I remember how grateful Ameena was to be given an opportunity to talk about how she was feeling. She was also happy that her interview was getting audio recorded so later she could save it for her family.

As noticed with the others in the sample, Imtiaz Bibi's narration of her experience with oral cancer was not very descriptive of her and just focused on how her cancer will affect her children and their well - being. She was uncertain about the outcome of her oral cancer diagnosis and its impact on her children:

Imtiaz:

*"Of course I get scared. About what will happen. If I will survive or not. What will happen to my children? What will they do after me? Who will take care of them?"*

While on being asked how cancer affected *her instead*, she quickly said:

*"No it (oral cancer) has not affected me in any way. I am living a very fine life. Allah has given this to me. I wont complain. That's it."*

It can be noted that Imtiaz was worried about her children more than her own disease and how it was affecting her own health. She worried if she would survive or not but more about the well being of her children. As Judith Wuest (1997) argues that the consequences of the role of women as care provider for the children and the family may include fatigue, reduced sleep, less leisure time and more risk of poverty for full time carers, which results in negative affects on both physical and mental health. The demands for caring are ever changing and competing as they care for themselves and the others in the family. The key thing about this is that it has a dramatic effect on how women seek help for their illnesses. For instance, Maqsood Akhtar talked about her daily busy routine and how it intersected with her health:

Maqsood:

*“The doctor insisted on getting this ulcer treated and especially get the tests done first. Then we as a family got busy in other things and chores and I was looking after my children’s needs day to day, even my husband got very busy in his land lord affairs and I totally didn’t pay any attention to it.”*

For Maqsood, as she recalled, her visits to the hospital were dependent on more ‘important’ things like looking after the family. It also reflects how she had to depend on her husband to take her to a doctor or hospital. She too presented late for diagnosis of her oral cancer. This finding is similar to the work of Qureshi et al. (2008) in their study on health seeking behaviours among tuberculosis patients in Pakistan. They found that women tend to delay seeking help longer than men. The reason cited was that women in Pakistan delay seeking help, as they are not given authoritative positions in the family and are dependent on their husbands both socially and economically. Qureshi et al. (2008) also suggested that women were also often not educated enough to voice their concerns. This is another reflection of their weak position in Pakistani society. As a consequence they tend to seek treatment when the symptoms had worsened. This however contrasts with the work of Balasubramanian et al. (2004) who found that men in India tended to delay their diagnosis of tuberculosis longer than women. So whilst there might be gender related differences in help seeking behaviours, these are by no means universally held by women.

The findings from my oral history accounts are also consistent with the findings of feminists and historians who have long established that women downplay their own activities and struggle to put themselves at the centre of attention while exalting the position of rest of the family (Isabel Bertaux- Wiame 1982). It is understood that the women are the main care providers for the children and the rest of the family; however, it may have dire consequences in the form of negative affects on both physical and mental health of the women, which they tend to ignore. It can be argued however that although the women in my sample were worrying more about

their families than themselves, they were not 'reluctant' to talk about themselves. Their narrations of their lives speak volumes about their individual identities.

Similarly, for Nisbah, her life revolved around her father. She recalled that she often prayed to Allah for his father's good health and long life.

Nisbah:

*"Now when I see my father, I pray for my own long life so that I can take care of my father on my own, I don't want him to depend on anyone else doctor, just me. I can take care of him. When I was ill, I used to look at my father and cry because nobody respected or took care of him (starts crying)..."*

[...]

*"I wish I live longer for my father so he does not have to go through this hatred and disrespect. It is of no use. I just think to myself I don't know when will be this over. It makes me think that only daughters take care of their parents in old age, nobody else bothers to, but I am okay today but still doctor it makes me sad. "*

Nisbah broke down while narrating how miserable she felt about her helplessness regarding her condition. She was in distress about leaving her father in the hands of her brothers and sisters-in-law because according to her only daughters were able to take care of their parents. This is another reflection of Pakistani society where a daughter in law is considered an outsider and is often perceived negatively by the in laws. There could also be power dynamics existing between Nisbah and her sisters in law that remain untouched and I did not find it appropriate to probe into this aspect of her life which she was clearly unhappy about.

The worry for family was also demonstrated in terms of financial burden by some of the participants in my sample. For instance, Wazira regarded the whole disease and treatment process as stressful and it made her cry even during the interview several times. It could be that the day she arrived for the interview was not a good day for her. She was not only worried for her children but also frustrated for the amount of money that was spent on her treatment:

Wazira:

*“I am stressed because of my children. Almost two to three lakhs have been already spent on this. It isn’t free is it? Then travelling costs. It is stressful isn’t it? But what can I do? Have to survive this life... (Pause) but (mumbles something that is inaudible)...but what to do now... I don’t know what is this...”*

[...]

*“And I don’t want to spend money on my treatment anymore...this is because it’s of no use. Its time for my children to be happy in their lives rather than worrying about me all the time. It’s not my time to get treatments. I want to spend money on getting two children married rather than spending it on my treatment. It’s of no use. Isn’t this good? To see my children settling down? Wouldn’t that make me the happiest woman on earth? Money that I have already spent on my treatment is gone. Now lets see what else has Allah got in store for me. Till now I am fine. I hope everything stays fine in the mouth. They would just give me medicine for 6 days right...nobody gives it for the whole month so I don’t have to spend on traveling. I am sick of it. We have been travelling since yesterday morning and reached here today.”*

Wazira perceived herself as a burden for her family financially as well as emotionally. She even told me that she would not get the treatment done, as it was her children’s time to live a happy life, which they could not do if the money was going to be spent on her treatments. Wazira thought that getting her children married would make her the happiest woman on earth. The hospital was quiet far from where she lived and there was no specialized care unit in her vicinity. Financial problems and social complexities added to her already difficult life. She was clearly frustrated from the whole process and seemed fed up of all the travel expenses and time restraints. There is little data to address the financial issues that cancer patient face in Pakistan. Also, it is imperative for the Government to support medical care so that people belonging to low socioeconomic status groups can report to clinics and hospitals without having to worry about the travel costs at least.

It can be noted from the narrations of the women in my sample that the women reconstructed the past focusing on their families more than themselves. Although

they took pride in telling me about their triumphs and sharing their experiences, they perceived their illness to be a burden on their family. This is also because in Pakistan majority of the population relies on an income of a single family member. Women are totally dependent on their husbands, brothers or fathers for treatment and have a little money of their own. Furthermore, bulk of the patient population pays out of pocket for the treatment in Pakistan with limited state support (Zaidi et al. 2012). Many people do not opt for any treatment because of the cost and those who do, sell their property, house, car, gold and other jewellery to bear the expenses (Rashid et al. 2012). The financial disability would then lead to depression in most of the cases. Therefore cancer becomes an emotional, physical and financial burden on these families. The patient's self-perceived burden has also been the focus of some qualitative research conducted around people with life threatening illnesses such as cancer. Wilson et al. (2005), in their study on 69 patients with advanced stage cancer reported that 77% of their sample represented themselves as a burden on their family and caregivers. Although the research identifies no correlation between self-perceived burden and physical symptoms, they did find a strong association with the patient's psychological symptoms. They argue that this is an under researched cognitive area amongst terminally ill patients. Similarly Usher et al. (2008) found that patients' perception of being a burden on the family is an important factor for their psychological wellbeing. A Kenyan study identified financial burden to be the main worry of the patients with terminal illness (Grant et al. 2003). This was mainly due to the cost of treatments being borne by the patients and their families. On the other hand, a study conducted in Canada on self-perceived burden did not identify financial burden to be frequently mentioned by the patients (Mc Pherson et al. 2007). This may be because in Canada, medical care is subsidized. Likewise, cultural norms dominated other concerns for patients with terminal illness in China (Bowman and Singer 2001). Therefore, there can be financial, psychological and cultural reasons why patients tend to think of themselves as a burden on their families.



## 7.5 Inability to eat

Imtiaz Bibi felt bad for not being able to chew food because of oral cancer:

Imtiaz:

*“Many problems dear. Because of this cancer I cannot eat properly anymore. Earlier I used to eat properly and enjoy my food. But now the cancer has started getting bigger and I cant chew the food. Rest I am okay with what is happening.”*

Imtiaz was really distressed when she was narrating her experience of not being able to eat. She wanted to enjoy her food like before or at least eat her food easily.

Because her oral cancer was progressing, it was hindering her chewing and swallowing abilities.

For Nasreen Akhtar, her life had diminished alongside her ability to eat properly:

Nasreen:

*“Life is almost gone you see. No teeth. Can’t eat properly. Can’t speak properly. What else can I say?”*

It can be clearly seen how eating food and being able to enjoy food was an integral part of Nasreen’s life. The inability to eat had greatly affected her quality of life. After all eating is one of the most important dimensions of human experience. This prominence is heightened when the patients have neither the desire nor the capacity to eat. The inability to eat reduced their quality of life remarkably (Plotnikoff 2014). Among the many consequences of being a cancer patient, inability to eat comes with its own emotional value, which regularly prompts ailing health and loss of weight, which thus makes it troublesome for the patients to adapt to the effects of disease and its treatment (Gellrich et al. 2015). Fatigue, anxiety, emotional disturbances and depression, which are often the result of treatment itself, are also the major causes of inability to eat (Capra et al. 2001). It has been advised that all cancer patients should be regularly screened for risk of malnutrition and a stepwise nutritional intervention should be given to them (Arends et al. 2017). For instance, Malnutrition and weight loss affects the patients negatively making them have a gloomy and hopeless view of their life and future. Some patients avoid meeting with

friends and family and restrict their daily activities because they feel weak (Ravasco et al. 2007). Difficulty in swallowing and eating is a common consequence of oral cancer but advice can be sought regarding the food menu that is gentle on the mouth and throat providing sufficient calories, vitamins and minerals to heal it (Healthline 2018). However it was noted that in my sample, none of the participants stated that they were referred to a nutritionist for support or guided explicitly about what sort of food was best for them. This may have further heightened their worry. Similarly, Zahida also voiced her inability to eat the fruits she loved but because of poverty and her loss of teeth and a part of her jaw, she could not eat:

Zahida:

*“Allah did not give me any children, my nephew was saying to me yesterday that ‘auntie, you look very weak’, now you tell me, just a bit of roti (bread) I eat and that too not on time, and sometimes with lentil soup, or anything, never eaten any sorts of fruits since ages, I cant afford any to be honest, but still Thanks to Allah, I cant eat apple, but I would love to eat a banana dear, I cant afford it, can have juice as well, but who will get it for me? And where will I get it? [Chuckles]”*

[...]

*“Now, I feel so hungry at times you know, but I cannot eat much, it has been ages since I last tasted meat, I am still hungry you know, rather I am hungry all the time because I eat very less, and maybe because I have less blood in me, I don’t feel like eating in the morning, but at this time, I cannot tolerate the hunger, so back in village, I don’t have money to afford meat, I don’t think I remember eating it since a decade now, can you believe it? I miss eating it, Although I can eat it [laughs] but I cannot afford it, cannot eat rice that much, but I would love to eat spicy rice [laughs loud], I love spicy stuff, I cant eat much sweet things, but give me spicy food and I will devour it like anything, But still thanks to Allah, I am just counting my days and spending them , God bless my nephew and his wife back home who take care of me and give me some food everyday, I have one room, have got one small cooler, one bowl for water, then a few utensils for my own use dear.”*

Zahida had undergone several surgeries and due to the contraction of the scar tissue over the passage of time, she felt pain while eating. She could not eat anything solid.

It has been observed that people with oral cancer develop contractions of muscles of mastication along with the contraction and fibrosis of scar, which leads to the inability to open the mouth wide (Kolokythas 2010). There is more to Zahida's quote above than just her inability to eat. We can notice how she was trying to curb her desires in the face of poverty. She loved eating meat but could not afford it. She wanted to eat fruits but she did not have enough money to buy them. I remember Zahida's face when she talked about food. I did not know since how long she had not eaten fruits, food or her favourite spicy rice, but at the end of the interview I offered Zahida to have lunch with me in the hospital café. She felt embarrassed but on insisting agreed to honour me with her presence. She ate her favourite meal quickly. It was great to see her laugh and enjoy the food. Every now and then she thanked Allah and me and showered me with lots of prayers. I cannot forget this incident because it touched me a great deal. I also reflected that it was interesting how the inability to eat because of oral cancer makes you think about little things that you may otherwise take for granted.

Many aspects of life appear to deteriorate as time progresses for patients with oral cancer and have been evaluated through quality of life (QOL) scales (Agarwal et al. 2014). From Agarwal and colleagues study, QOL aspects included speech, appearance, taste, and saliva production, swallowing, chewing, speech and shoulder pain. They found that one of the most important domains; chewing ability, deteriorated with the passage of time whereby the patients were not able to chew and swallow the food they used to eat pre-operatively. As a consequence, they were only able to take liquids and semi-solid food. Furthermore, swallowing, taste perception and saliva production reduced as a result of radiotherapy. Zahida was maybe experiencing the same situation. After her several rounds of radio and chemotherapy, she was unable to chew on hard food and would prefer fruits and lentil soups to counter her limited chewing ability.

Ameena was very fond of eating before she was diagnosed with oral cancer. She used to enjoy eating out with her children and family. But after diagnosis she was

unable to eat the simplest of foods. In her narration of life, she described her inability to eat and enjoy the food on several occasions.

Ameena:

*“Last night I had a bowl of salad in front of me, it had radish and cucumber, I was so tempted to eat them and I wondered if I will be ever able to eat them again...I wanted to chew the biggest wish in life at the moment is to chew the radish...people have so many big wishes, I have just this small one.”*

[...]

*“I could not tolerate not eating those radish... a few days ago, on 24th in the market I saw some stall with radish and a lot of spice on it, I was again so tempted to go and grab them and eat them... but I could not...but my will power is so strong that I would do anything to get better and eat it again...it is my desire to go back home, cut it and eat it...this is my desire... [Laughs] “*

[...]

*“For people it might be an ordinary thing but for me it is a lot... it is easily available for everybody else and I cannot eat it...I am missing so many things...eating...cant even eat rice because any could go and hit my ulcer and it would start hurting again...although doctors have not forbidden me to eat anything, its only that I am being careful, I feel pain and cant even swallow properly, they are just giving me mashed food...I mean now I cant say lets go to that restaurant and eat that dish, I have always like ‘chicken tikka’, but there is no question that I eat it... cant even take things cooked in black pepper...cereals...they are so liquid...I cant even swallow it... it stings my throat...these days I am not chewing just swallowing...even the sweet juice stings me... when I drink water, it feels as if somebody has poured salt on my hurting throat... cant even tolerate water... I returned from market one day, I wanted to drink a lot of water and I asked my daughter to give me two glasses of water, I had completely forgotten that I had this issue...when she came to me with water, I couldn’t drink it... I cant even drink water...I m yearning to drink water...”*

I noticed during my conversation with Ameena, how little things started to matter her after diagnosis. Like many other aspects, she was eloquent about her inability to eat. She missed having food with her family. It has been observed that both the

patient and family may undergo intense emotional and social changes when illness is accompanied by neither the capacity nor the desire to eat (Plotnikoff 2014). Also these patients limit their social interactions (Gamba et al. 1992) and depression is commonly observed (Telfer and Shepherd 1993). Ameena described in detail how miserable she felt when she couldn't swallow or felt pain even with drinking water. It was becoming hard for her to resist her temptations from eating her favourite foods now that she could not eat. The pain in her voice was palpable when she mentioned she was yearning to drink water. Her biggest wish in life was to chew food, but she could not. Ameena's portrayals were heart breaking.

## 7.6 Seclusion

Stigma usually refers to a visible or non-visible attribute that makes an individual a part of an undesirable social category (Jones et al. 1984). The stigmatised individual then becomes 'devalued, segregated and discredited' (Goffman 1963). Out of all the participants in my sample, only Nisbah faced seclusion in her own house. The other participants did not mention anything about being treated differently or being secluded at home or at work. Nisbah was secluded in her own house because her family stigmatized cancer and thought that it may spread to the other members of the family.

Nisbah recalled being treated as somebody infectious and not allowed in the kitchen or to do household chores because of the risk of catching the infection. All she could do was rest and watch television:

Nisbah:

*"Now ever since I got this disease, my sister-in-law doesn't let me work. They don't let me go in kitchen or wash clothes. They fight and argue with me. But I tell them I need to keep working to be healthy and me to stay fit. So sometimes I pick up the broomstick and start cleaning the house myself. They make a big deal out of this too. Otherwise all I do is lie down in bed and watch TV. They don't let me work anymore because of my disease."*

[...]

*“When the rest of the village got to know about my disease, they used to talk about it. But then later my own family decided that they would seclude me. They separated my clothes, my bed, my utensils; they even didn’t allow their children to come near me.”*

[...]

*“Doctor, I myself became very cautious, I kept away from them. I was telling you about my little nephew I was so attached to, he never used to eat without me, he could not live without me, he never loved his own parents as he loved me but when I got cancer, I myself kept away from him. Because I thought he is just a child and children catch germs very quickly. I did not want him to suffer. I told Faisal, my brother even to be careful and not let the children come near me. This niece who came with me today she has a little son as well I don’t even let him come near me. When I used to eat earlier, before feeding food to myself, I used to feed these children, I used to love them so much, but now I keep away from them and have separated my glass, mug and plate away from them. I think they will get cancer too.”*

[...]

*“Doctor of course I get deeply saddened when they do this with me, I am a human being too, why treat me any differently. Sometimes my father tells me to let this go if they don’t let me work I shouldn’t stress much, but it keeps bothering me... my sister-in-law doesn’t even let me do any other work. This is what pinches me the most. They don’t let me touch anything. But when my father and I are alone at home, I cook meal and roti for him with my own hands. I love to do this for him but they let me. They all hate me for this. Only my sisters and father don’t.”*

[...]

*“My hands work fine doctor, and only tongue has this disease right? But they don’t let me work. They hate me and I fight with them for this. I cry even sometimes. They don’t even let me pour water in the glass. This is not fair is it?”*

[...]

*“They hate me even when I’m okay now. My sister asks me not to cry but I can’t help it. This was not in my hands doctor. It was god sent...”*

Nisbah’s family members secluded her in the house and would not let her do the dishes or wash clothes in the fear of catching an infection from her. She broke down

many times during the interview telling me about her misery at home. Her sisters-in-law treated her with disregard. Distant relatives in the village started talking about her disease and even her own family members started treating her differently. Nisbah told me that she herself became cautious and started believing that her cancer is contagious which may infect her nephew and nieces who were very dear to her. Nisbah explained with a heavy heart how she was fighting with everyone to treat her equitably. Sontag 1978 noted that illnesses become stigmatizing because they are associated with certain negative myths and beliefs that take up symbolic meanings and also allude towards physical limitations. Likewise, people with oral cancer are often stigmatized leading to social, physical and mental indisposition (Peter - Golden 1982). A similar belief exists about breast cancer patients in Pakistan whereby it is widely believed that women with breast cancer may spread the cancerous cells to their unborn child (Banning 2009). Botero - Jaramillo et al. (2017) has demonstrated similar oral history accounts of patients with Hansen disease in Colombia. They have also exhibited how the people with Hansen disease perceived as being secluded in three 'Leper colonies' around the country. It was impossible to escape isolation, as it was the country's law to seclude patients. They had to say goodbye to their possessions and family members and the 'world of healthy'. For patients, travel to these colonies meant torture. They also had to suffer a ban on marriage between the 'diseased' and the 'normal'. Overall the oral histories represented how the patients place themselves in the disease process and how it slowly permeates their entire existence.

According to Fife and Wright (2000), stigmatisation also leads to reduced self-esteem, which in turn causes strained social relationships. On being asked if this differential treatment made her sad or angry, Nisbah responded that she 'hated' being treated differently and prevented from doing the household chores. She was upset that because of her disease she was considered different and segregated from the rest of the family members. They were not supporting her in coping with the disease and its treatment. The need for support is an important aspect of coping mechanism in illness trajectory (Perreault and Bourbonnais 2005). Lack of support

from her immediate family members made Nisbah feel uncomfortable and sad. This finding is contrary to the findings of Banning et al. (2009) whereby majority of the breast cancer patients in Pakistan received immense support from their family including their husbands which impacted positively on their coping mechanisms. Nisbah was getting anxious while stating her experiences. Her thoughts give an indication that she may be suffering from depression as well. In Pakistan, where there are limited mental health services with the cancer units, it becomes imperative for the physicians to be aware of the mental health issues that their patients may be going through.

A study conducted in Karachi, Pakistan suggests that cancer was considered to be an infectious disease and the patients faced a social stigma because of which they isolated themselves from their relatives and friends, which lead to depression in majority of the participants (Ali and Baig 2006). One particular study conducted to explore the perceptions of stigma in people with lung cancer in the United Kingdom, identified that some of the family members of the patients severed any ties with the patients as soon as they heard of their cancer (Chapple et al. 2004). This was mainly because they regarded cancer as 'dirty'. A woman in Chapple and colleagues' sample argued that people with lung cancer are thought to be dirty and blameworthy because they smoke. The study also inferred that such stigmatization might deter the patient from seeking any treatment. Stigma is regarded as one of the main barriers to accessing cancer treatment in South Africa; leading to late diagnosis, delayed treatment and consultations with the traditional healers (Oystacher et al. 2018).

It may be that the other participants faced stigmatisation at work or in their homes but shoes not to declare it to me because of the acceptance in the Pakistani society to be scared of cancer and to treat the cancer patients differently. This is not only a worrying situation but sad at the same time as well.



## 7.7 Identity and oral cancer

The notion of self-image is very important in human life. People want to be remembered by their strengths and all the good aspects of their being. Disease, on the other hand, has some other plans. Disease distorts the self-image. It brings out the ugly and negative parts, which nobody wants to highlight or let people know.

In my study, Razia begum was in no different position. Because of the nature of the 'pimple' that had formed on her face and the facial disfigurement after surgery, she did not want to look in the mirror anymore:

Razia:

*"Would you believe I don't look in the mirrors? I have never seen myself in mirrors since I don't know when...it was just so irritating and embarrassing to see myself like that you know."*

Razia was not happy with how her face looked after the oral cancer diagnosis and its treatment so she preferred not to look at herself. Concerns of embarrassment along with behavioural and emotional difficulties were reported by 75% of the sample of patients (N = 280) with oral and pharyngeal cancer (Fingeret et al. 2011). Facial disfigurement concerns are common in people with oral cancer leading to anxiety and extreme distress (Balfe et al. 2016). The facial surgeries associated with cancer have been regarded as a 'destruction of self' (Turpin et al. 2009), and people with facial disfigurement are subjected to negative responses, stigma and are devalued by society (Bonanno and Esmaeli 2012).

Along with seclusion, the stigmatization Nisbah had to face from the relatives and her own siblings (as explained previously) not only made her feel dreadful but also made her 'hate' her face and disease:

Nisbah:

*"Trust me it was very small at the beginning and then it got worse and got bigger and it did just leave a little part of my tongue otherwise it was spread all over my tongue. I hated to look at them; I hated what was forming on my tongue. I never even looked at my face in the*

*mirror. When I used to tell about it to others, they would stand away from me even my own brother and sisters...and used to ask me what will happen to you and your tongue this looks so gross."*

Nisbah felt distressed looking at her face. She chose not to see her self in the mirror for the fact that she could see a 'gross looking' ulcer on her tongue. Maqsood Akhtar for whom the cancer not only affected her physical self but also her confidence shared a similar notion of a self-image:

Maqsood:

*"This disease of mine cancer, this has nearly destroyed me and my confidence in everything."*

Every cancer diagnosis brings unique challenges to physical as well as emotional functioning. People with oral cancer may be vulnerable and at an increased risk of getting depression. This may be because the surgical interventions for people with oral cancer often leave them with visually challenging facial alterations. In turn these visual changes may have a huge impact on their daily functioning for example eating, drinking, swallowing and speaking. The cancer becomes more obvious as the disease progresses and the side effects of the treatment become more evident. Patients often complain of a reduced quality of life particularly referring to their appearance (Rosman 2004). It may affect their sense of being (Knapp et al. 2014) or their ability to relate to their 'new' face. Visual disfigurement is reported to trigger high levels of stress (Rumsey et al. 2004). The stress may be attributed to the attached importance of the facial region a person has with their self-image, identity, their communication and formation of social relationships (List et al. 1999; Lockhart 2000). In a study on the patient's perspectives of facial appearance after operation of oral cancer, it was found that 41% of the patients were really anxious and worried about their facial appearance (Millsopp et al. 2006). However, it has been argued that patients sense of self and personal motivation can play a major role in the recovery process (Taneja 2013).

John Diamond (1998) voiced very similar thoughts in his journals on oral cancer. He identified that he was no longer the person he was before the disease, or who the friend and family knew. He displayed a very negative idea of the disease. Oral cancer for him had the potential to destroy everything in its pathway, be it self-esteem, talents or voice:

*"...But meanwhile this is what disease does to us. It wrecks our faces and our voices and any talents that we may have lying around, and then it makes us separately depressed so that we are unable to deal with the wreckage..."*

(Diamond 1998, p. 170)

After diagnosis and treatment, he was not able to communicate through his voice, which for him was his 'sole quality', and the above quote reflects the wreckage that oral cancer had wreaked on him.

The participants in my study did not only experience physical impairment but also psychological debilitation. They were very conscious of not talking to me without covering their faces. For instance, Wazira covered her face even during the interview and was very conscious about showing her face. She was sad about her facial appearance and the way that one side of her face had drooped down because of facial palsy initially and then because of oral cancer surgery; reporting she never looked in the mirror now because she felt ugly:

Wazira:

*"When I had this facial disorientation, people used to make fun of my face...some asked me not to look at the mirror, some used to pity on me. You can see this right eye, it is curved downwards, I don't look at myself in the mirror anymore. I feel ugly. I have everything otherwise, great children, food to eat, shelter but my heart, it has this sadness inside of it...this is the greatest sadness of my life to be like this. My face turned disfigured from the right side first then the left...but I don't want to get anything treated now. I don't care."*

[...]

*"I don't like my face. It is disfigured and I wonder what will people think when they see me. It is disfigured. When I eat or drink it feels*

*weird and awkward. Even if my family doesn't say anything, people from outside wont stop you know."*

Wazira also mentioned people making fun of her appearance and so she put a veil on her face in order to save herself from the tormenting comments by the people around. She felt uncomfortable eating and drinking in the presence of people. The distress that Wazira had to face made sense because it has been found that people with visible facial disfigurements tend to have higher levels of stress and anxiety attributed mainly to the importance of facial region. This finding is consistent with the findings of Rumsey et al. (2004), Lockhart (2000) and Rhoten et al. (2013). Also, many people who have oral cancer tend to isolate themselves from their friends and family because of their appearance (De Boer et al. 1999). Wazira's concern also makes sense as many women feel that their body reflects their selfhood and is a measure of their worth, losing a part if it affects them emotionally and physically. Losing a breast, leg or parts of mouth is a visible change. It can be argued that a leg or breast deformities can be covered up but it is far more difficult to cover face unless you are completely veiled. Likewise, surgeries on the uterus or any other internal organ may leave a scar that is visible on the skin. But the meaning of loss of that organ is not always apparent to the others but the one who is involved. The impact of facial difference is huge as it effects the everyday interactions.

The findings from my study support a previous study conducted to explore the cancer related traumatic distress and stigma in the participants with a head and neck cancer (Threader 2016). Deep sense of trauma and loss of identity was expressed by participants in the study. The loss or change of facial features made them more vulnerable to stress and stigmatization from the society. These participants later changed their traumatic feelings and stigma into a positive growth with the help of social support and family. They started seeing themselves beyond the boundaries defined by physical realms. Their acceptance of themselves greatly impacted on their self - esteem and psychological growth. Unfortunately, for the participants in my study, no such support was available at the time of interviews.

Furthermore, the journey of oral cancer for participants in my study was daunting and lonely because of diminished self worth. It not only changed their perceptions of how they looked, but also altered their thinking process completely. They started identifying their worth based on their ability to be of any 'use' to the surroundings. It seemed that they saw themselves through the eyes of the society and people around them. For instance, Ameena, despite being educated and from a comparatively well off family, felt lonely and 'useless':

Ameena:

*"Even my children, my youngest daughter, she understands me but I still cant share it with her. What is going on inside me, I cant share it with them, I can see everyone's reactions and observe them closely, and I feel I have become useless now, just important for a few people now, sibilings and kids, that's it, but for the rest, I don't matter, everyone else is waiting for my death..."*

[...]

*"Although I bear this pain as well, it is just that my family members get worried because I don't sit and talk with them anymore, I don't watch TV, I don't play with my grandchildren, because I think that my heart is so stressed because of chemotherapy, I just don't feel like doing anything, I prefer to stay in bed all day, sometimes my body gets so warm sometimes so cold, I get so sweaty sometimes so I literally throw the quilt away in anger, cant tolerate socks, I get irritated by everything even the clothes, I will take these sweaters off as soon as I reach home today, cant tolerate them anymore, that's it... I just feel useless..."*

Ameena had started remembering and comparing her present self with how 'useful' she used to be earlier for everyone before oral cancer inflicted her. She was also of the opinion that due to her cancer, everyone in her family was waiting for her death. The most stress Ameena felt in all her disease journey was when she was going through the rounds of chemotherapy. She had secluded herself in a room and stopped talking or watching television with her family. She did not even enjoy

spending time with her grandchildren anymore. She felt nauseated and did not feel like eating anything. Her tolerance level had undoubtedly declined during chemotherapy and she was going through intense mood swings, irritability and lack of pleasure in any activities she was enjoying earlier. It seemed as if her confidence and positive self had hit the floor. She was clearly suffering and her health was deteriorating with every round of chemotherapy. These findings are consistent with many studies done on the impact of chemotherapy on the cancer patients whereby it is found that adverse effects like nausea, inability to taste and eat, fatigue affects their functional and working capacities in a great deal (Dodd et al. 2001; Karthikeyan et al. 2012; Younus et al. 2012; Farrell et al. 2013). Patient's emotional and psychological health declines as well. Patient frequently reported of isolation and thought of themselves as a burden on the families (Banning 2010) and had altered sense of self – image. Findings of these studies are consistent with the findings of Chagani et al. (2016) exploring the effects of chemotherapy on the adult patients in Pakistan.

For some of the participants in my study, oral cancer possibly had all the potential to destroy their sense of who they were as a person. For many of them, the diagnosis and its consequences made them regret their life at present. Zahida shared a similar notion of being useless as she compared her present self with how she used to be when she was young and disease free:

Zahida:

*“I remember, our houses were not made of stone but only of mud, I used to do so much hard work, used to pick up bricks, cut and sow in the fields, used to get water from far off places in the village, now look at me, I cant even make something for myself to eat even, I have nobody now to help me, nobody calls me even, maybe because I am useless now, I am of no use to anybody, not even myself dear, this illness was so big...”*

Zahida made an interesting contrast between the past and present - how energetic and full of life she was when young and after the diagnosis of oral cancer she is not

even able to make food for herself. She called herself useless because of the deleterious effects of oral cancer and was feeling distressed and anxious.

In the context of the rapidly changing public understanding of the cause of their illness, the vast array of treatment options available, the relationship between a patient and their health care providers and the inclusion of different groups, especially women, is important in research and health care planning. As women remain the main consumers of health care around the world, it is therefore logical to provide them with necessary health care information and support in coping with diseases. The voices of women who journey along the pathway of oral cancer are difficult to bear amidst the cacophony of science. Beyond science, undergoing the diagnostic tests, living each day through the treatments and living with oral cancer. We have seen from the findings that women' voices speak of a different reality, in a different language - full of silence and fear. For the women in this study, cancer is about suffering, pain, and isolation. It is about divine judgment, supplication and loss. These voices scream of the reasons why the women turn up late for diagnosis. They are rarely seen in the literature on oral cancer. It is almost as though the views of women from Pakistan have had no place in the history of the disease, until now.

## Chapter 8. Discussion and Conclusions

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## Chapter 8. Discussion and Conclusions

### Summary of the structure of the chapter

This chapter will detail the summary of findings from this study and its contributions to literature and research. Further reflexive insights will also be provided. The possible limitations, recommendations and areas for further research will also be detailed. The final part of this chapter includes an epilogue.

### 8.1 Aim of the study and findings

The aim of this study was to explore how people make sense of their experience with oral cancer from within the social context of Pakistan. The main objective of this study was to give voice to people with oral cancer in Pakistan and to understand their pathways to diagnosis. A summary of the key findings of my study is as follows:

- Socioeconomic status (education, income and social class) plays an important role and is one of the main determinants of oral cancer in Pakistan.
- Social inequalities are entangled. The lack of economic resources and education led many of the women in my study to present late in the disease process, use home remedies and engage in extensive consultations in the initial stages of oral cancer with spiritual healers.
- Religion and faith are important determinants of health seeking behaviours in Pakistan. It can influence people both in health promotion as well as be used as a tool to abstain/resist from receiving any treatment for oral cancer. When diagnosis happens, women regarded the disease as God's will and accepted their fate. For some it came as a death sentence or punishment for their past sins. Findings also indicate that belief in Allah and the power of prayers cures oral cancer and brings good health.
- Alternative and complimentary medicine is one of the major influences on the pathways to diagnosis with oral cancer in Pakistan due to cheap availability, closeness to the residential areas, use of Quranic verses, belief in spiritual healing and lack of trust in conventional medicine.

- Gender plays a subtle direct and a strong indirect role in the pathways to diagnosis of oral cancer. Gender resulted in women's isolation from health, education and wider social participation. As a result they tend to delay seeking health care and present late in the disease progression because of their lack of authority within households. Some participants reported having to go through their husbands and complex networks of friends and neighbours in order to secure their diagnosis.
- The voices of women with oral cancer in Pakistan reveal how women can have a lonely and complicated oral cancer experience in Pakistan. Verbatim accounts from women in my study express their experience of oral cancer and suggested opportunities for support. Each of the interviews may be a tiny window into individual experiences but they represent how women explain their feelings and the view of illness in context of what is important to them. It also provides data on how women interact with the health care system. Although this research has yet to tap all the diverse groups of Pakistani women or to study their illness experiences, these tiny windows have opened more potential avenues for counselling and therapy than the predictors or facts and figures on the prevalence and incidence of oral cancer could have.

## **8.2 Contributions to research and literature**

This study on women in Pakistan has unveiled many powerful and novel narratives that have the potential to contribute towards the existing literature.

My study adds to the literature on the experience of oral cancer by focussing on Pakistan, which is one of the South Asian countries where the incidence of oral cancer is the highest. It highlights the role of smokeless tobacco products such as naswar and betel quid (with or without tobacco) as the most important risk factor for oral cancer (Khan et al. 2014), demonstrating how the consumption of this is linked to the interaction between gender and social status. My study findings

compliment the works of Warnakulasuriya (2009) on the global epidemiology of oral cancer by identifying the major causes of oral cancer in Pakistan based on participant's interpretation.

This thesis develops and applies the literature on 'lay epidemiology' - a term used to describe "the processes through which health risks are understood and interpreted by laypeople" (Allmark and Todd 2006) on oral cancer. For instance, in chapter 6, 'past sins' has been identified as the cause of oral cancer making a novel contribution to the aetiology of oral cancer as interpreted by people with the disease. Furthermore, this thesis also reveals the value of lay perspectives for the development of a sensitive health care system in Pakistan that acknowledges the needs and views of the people with the disease. As a result, patient – physician communication and patients satisfaction can be improved. These narratives equipped the women in my sample with courage, raised self-esteem and self-confidence, but also directed attention towards the health care system in Pakistan which prevents the participation of patients in choices and decisions about their health.

My research challenges the notion that "lifestyle risk factors" and "behavioural changes" are the key areas that need to be addressed to reduce the incidence of oral cancer. Rather, the findings put emphasis on understanding the social determinants and 'causes of the causes' as suggested by Marmot (2005). This includes considering socio economic status (education, occupation, income and area of residence), gender, religious beliefs and a focus on the health care system and its policies when endeavouring to reduce oral health inequalities.

Previous literature tends to focus on socioeconomic status (including education, income and social class only) as the key social determinants (Conway 2008; Warnakulasuriya 2009; Johnson 2012). My study contributes to this existing body of research on oral cancer in Pakistan by highlighting that religious beliefs are entangled with social status so that people from low socioeconomic groups with low income and less/no education, strong religious influences and beliefs in alternative

medicine experience delays in diagnosis. The findings also compliment the observations made by Johnson et al. (2012) whereby high socioeconomic groups are more aware of oral cancer and access health services more rapidly.

The findings from my study in terms of the health related beliefs and employing alternative medicine provide data of direct relevance to health policy makers in Pakistan. It alludes towards incorporating patient's religious beliefs and health related perspectives while making treatment plans.

My research findings also identify that gender has never been considered a major determinant of oral health and inequalities separately. It highlights how gender in particular could be a major determinant of women's oral health in relation to oral cancer. In Pakistan, gender discrimination is a major contributor towards health inequalities. It was interesting, however, to find that none of the participants in my study explicitly declared or recognised gender as a determinant of their disease. This was because of their internalized acceptance of how their culture and society worked. For these women, gender worked as a determinant throughout their lives in terms of access to basic necessities, education, health care, as well as wider social participation and in their pathway to the diagnosis of oral cancer. It was often hidden from view.

The emerging themes from the thesis identify the probable reasons why women with oral cancer in Pakistan present late for the diagnosis of oral cancer. Education, social class, income, religious beliefs and alternative medicine practices are the major factors that influence pathways to diagnosis of oral cancer in Pakistan as emphasised by my research study. Faith is an integral part of the lives of people, particularly women in Pakistan and there is limited evidence on the role of religion and power of prayers in Pakistan due to its sensitive nature. The women in the sample displayed fatalism, a reliance on religion and the power of prayer as a way of coping and dealing with the uncertain consequences of oral cancer. These findings compliment the works of Thune - Boyle et al. (2006) in identifying religious coping as having both cognitive and behavioural components. The women also portrayed their

beliefs in the power of recitations from the Holy Quran, which compliments the findings of Banning et al. (2009) on women with breast cancer in Pakistan. These findings are important in exploring the influence of these factors in health seeking behaviours as well as in planning an oral cancer treatment in Pakistan.

Similarly, my study also contributes on the limited existing body of research on the use of alternative medicine in Pakistan. There is also a lack of data on the use of these therapies for oral cancer. The effectiveness of home remedies, spiritual healers and combined use of spiritual and medical treatment for the treatment of oral cancer in my study is a substantial contribution to the works of Malik and Qureshi (1997) and Tovey et al. (2005) in teasing out the patterns health seeking behaviours and reporting the effectiveness of alternative medicine on oral cancer patients. Contrary to the works of Butler et al. (1998) and Rikard – Bell et al. (2003), health professionals are not the only important source of information to deliver advice to the patients. This research shows that we should perhaps be using spiritual/traditional healers and working with them rather than against them to improve early diagnosis of oral cancer. In most cases, these healers are the first point of contact with the health care system; consequently they should be integrated in the health system. This means that collaborating with traditional healers could reduce the divide between traditional and modern medicine. Worldwide, many integrative programs have emphasised on training traditional healers to deliver medical services. For instance, Poudyal et al. (2003) appraised the effectiveness of a biomedical training model for traditional healers in Nepal. They found that a year after training, the trained healers were significantly better in understanding and application of allopathic medicine, had better knowledge of the symptoms and prevention of diarrhoea, malnutrition, HIV/AIDS and acute respiratory infection. The traditional healers also referred the patients to government hospitals. Similarly, Colvin et al. (2003) found that by involving traditional healers in an already working tuberculosis treatment program in a rural district in South Africa, helped in improving the management of infectious diseases. Other integrative health delivery programs such as Zimbabwe's Traditional Healers Association (ZINATHA) and

Uganda's Traditional Healers and Modern Practitioners Together Against Aids (THETA) have used traditional hears to promote prevention of HIV/AIDS and assist patients (Kayombo et al. 2007). Similar models can be used for the prevention of oral cancer and health promotion in Pakistan.

The limited use of qualitative approaches in oral cancer research in Pakistan means that this study using oral history interviewing provides a niche for the establishment of an oral history archive in the field of Medicine and Dentistry in Pakistan with a particular focus on oral cancer.

The oral histories of the experiences of women with oral cancer in Pakistan contribute towards the literature on the lived experiences after an oral cancer diagnosis and its importance in terms of understanding the psychological states of the patients. The experiences are both unique and consistent in comparison to other research data on cancer collected in Pakistan and South Asia. These first - hand accounts comprise of powerful yet heart-breaking stories of how these women encountered both physical and psychological deterioration with time. Some faced stigmatisation, seclusion within their own home, while the others faced long bouts of depression, stress, identity crisis and appeared to be constantly fighting to make sense of what was happening to them. These findings are in line with the previous comparative research on women with breast cancer in Pakistan whereby they were considered infectious and faced similar seclusion, identity crisis, anxiety, and depression (Banning et al. 2009).

### **8.3 Reflexivity**

This research process has involved an attempt to be reflexive and in chapter three; for instance, I indicated how my experiences at the dental school in Pakistan and dental public health research experience in the UK guided my PhD study. In chapter four, I have detailed how I managed the ethical concerns associated with this research study. In this section, however I want to address my own development during the research process.

During the literature search, I was disappointed when I did not find any study from the perspectives of the patients with oral cancer in Pakistan. However I felt excited that my study would be the first of its kind. Little did I know at that time that it was not just about uncovering facts about people's lives but the meaning they associated with those experiences. In the first interview, it was difficult for me to decipher the social determinants acting in the lives of my participant. The determinants were each entangled and difficult to separate. The stories were rich and I wanted obvious themes to emerge following interviews. I was also worried that because I had never used the oral history approach and I felt I had limited interview skills; this would make the interviews difficult. Reflecting back on the research process, it is evident that my anxieties could be attributed to my initial inexperience. I noticed I was much more relaxed and confident in the later interviews as I began to connect with my participants and started relating the findings and emerging themes with literature on the social determinants of health and inequalities. I was beginning to unveil the 'causes of the causes'. The potential for this research to be the first study to consider the importance of giving voice to women in healthcare in Pakistan felt really exciting to me. The interest of the women to take part in the study, share their stories with their real names and allowing them to be used for the research purposes says a lot about their potential but subtle changed status in the society. The more my participants opened up to me, the more sense of mutual satisfaction prevailed. My work speaks out for the inclusion of women in further research studies.

A further reflexive concern involved having a female only sample. Only women agreed and were willing to take part in my study when I was seeking both men and women. It worried me initially because although a woman from Pakistan, I have to say that I am not a feminist at heart. This meant that confronting feminist debates and ideas was difficult for me because being a Pakistani woman; I was conditioned into thinking that women have no voice and that it was perfectly normal to stay silent about the experiences that affect us. I was also wary that an all women sample might not generate detailed data because of a pre - conceived idea that women might not be able to talk at length about themselves and their experiences.

However, I realised early on in the interviewing process that the fact that women in my sample did not see themselves, as being discriminated on the basis of gender is important. Despite this, they were willing to narrate their stories. The depth and richness of their narrations was incredible. It seemed as if they were waiting for an opportunity to talk and express themselves. In almost all of the narratives women kept themselves at the centre of the story, and majority of them were able to adopt the 'performative mode' with no reluctance or difficulty in turning themselves into narrative subjects without being given any chance of public speaking before. These observations contradict the notions presented by Dana Jack (1991), Anderson and Jack (1991), Minister (1991) and Summerfield (1998) who argue that women often have difficulty in adopting a performative role and making themselves the centre of their narrative. Based on Julia Swindell's (1989) analysis that 'rather than liberating women we should take the responsibility of analysing the conditions of their lives', the interpretation and analysis of the stories of women in my sample have largely focused on the social background and the conditions in which they resided. Being aware of my position in the research process and following Nancy Siefer (1976)'s suggestion, I tried my best not to impose my own voice on my participants, after all I am from a relatively well off background. Instead I sought to interpret their text from different perspectives.

The analysis and interpretation of the findings from my study however contradict the approach of Elizabeth Hampsten (1982) who encourages the use of authority as interviewers to comment, examine the form and content of the stories and question if the stories reveal women's own experiences or someone else's. For me, it was important to focus on what meaning my participants attached to their experience with oral cancer and in the way they choose to narrate it. It was not about me in this research process but about them. It was nonetheless encouraging to see the women in my sample telling their stories and sharing their experiences. I have to say that my research challenged my own pre-conceived ideas about Pakistani women. I also think that I found my own voice by giving voice to the participants in my research.



This research process has given me more confidence in expressing my feelings and ideas and instilled in me a sense of gratitude for life.

By considering the reflexive concerns identified above and throughout this thesis, I hope I have provided transparency to the research process as far as possible. In the next section I will be detailing the limitations of this study.

#### **8.4 Limitations**

The methodological considerations have been dealt with throughout the previous sections but there are a number of limitations associated with undertaking this research project. First, the initial goal of the study was to interview both men and women for their experiences of oral cancer. No male patients showed any interest in this project. However, for the future, it is advised to include both men and women for a broad view on social determinants of oral cancer in Pakistan. Nevertheless, the women who participated have given a major insight into the gendered nature of being an oral cancer patient.

A second challenge is that for the translation and transcription aspect of the study, no professional help was sought. This was due to financial constraints in the self-funded PhD project. Not using professional translation and transcription services may have slowed the research process but nonetheless strengthened my grasp on the data more thoroughly and enabled me to begin analysis of the data at an early stage.

Third, participants would have been more comfortable narrating their experiences if they were in a setting they were accustomed to such as their homes. However, it was not possible for me to go to their homes because they belonged to far off areas. Also, recognising their social status and living conditions, it would have been difficult to locate a room in their house with complete silence. The ease with which the participants shared their experiences with me would have been limited in the boundary of their own house. The data that has been gathered considering the settings is commendable.

Fourth, since oral history interviews are unique to each person, their generalizability can be questioned. Hobsbawn (1997) suggests, “One person cannot be representative beyond anyone else other than himself or herself.” It can be argued that oral history aided in knowing the experiences of people with oral cancer in Pakistan but the enabling of ‘the telling’ of those experiences in their own words strengthens the reliability of this research.

Lastly, most of the participants just gave me one interview because of their own time and financial constraints considering they were travelling from different areas. Two or three interviews over the course of several days would have given them a chance to remember a lot more and with ease.

### **8.5 Recommendations**

Instead of revamping the whole health care system, it is imperative to re – orient the existing health/ oral health care system in Pakistan, which will help in achieving preventive and oral health promotive control on diseases like oral cancer. As identified in the literature review, existing approaches to tackle oral health inequalities have focused on a combination of behaviour and clinical preventive measures. However, the effectiveness of such a downstream approach remains limited. Watt (2007) argues for the adoption of a more upstream approach to tackle the underlying determinants of oral diseases.

On the basis of the challenges identified in the literature review and the potential contribution of this study, the following are the recommendations of this study:

- It is essential to strengthen the research culture and initiate international collaborations for quality health care research with a special focus on oral cancer. Welcoming research teams and including them in working on diseases of public health importance like oral cancer will yield great results. This is important because it may also attract more research funding to Pakistan.
- In the long run, there is potential for building a Pakistan health system that focuses on preventive oral health care and that caters the needs of the

population by including their voices. It will also help in exploring how patients are interacting with the health care system and providers.

- The formation of a national cancer registry for effective reporting and registering of cancer cases annually in order to develop health strategies. Strengthening the national, provincial and district levels 'integrated disease surveillance and response system' with a focus on 'early warning system' could help in early diagnosis and prevention of oral cancer.
- Launch of 'health promotion committees' in the villages and rural areas for oral health promotion are also suggested. These committees could include health workers, health and education professionals, local doctors in the village, school teachers, social workers, local councillors especially women in order to support and transform health related behaviours of the population living in the rural areas of Pakistan. They will be responsible for creating the environments that support health. Lady health workers and midwives can be trained to promote oral health and detect early signs of oral cancer and provide referral to specialized care. They can also be prepared/coached to gather epidemiological data.
- There is potential for developing a system to involve piirs (spiritual healers), and Islamic healers in the health care preventive strategy; train the workforce to identify the early signs of oral cancer, allot them the regions that will come under their consultancy, involve them in oral cancer screening and equip them to refer cases to specialized care. There is also a need to incorporate and take into account the religious beliefs of patients for the effective delivery of care.

### **8.6 Future work**

Insights gained from this study contributed to a wider and deeper understanding of oral cancer from the perspectives of women in Pakistan. Implications from this study are relevant for an oral health policy development in Pakistan as well as toward incorporating social determinants of oral health and inequalities in understanding of

oral cancer. Therefore future research should entail a number of potential research projects that can lead on from the current study. Future work:

- Needs to consider a feminist perspective for conducting research with women in Pakistan.
- Could also look to include the perspectives of both men and women in order to understand their experiences of oral cancer via the gender lens.
- Could tease out the influence of religion on the health seeking behaviours of people with oral cancer in Pakistan as well.
- Could explore how alternative medicine delays the diagnosis of oral cancer in Pakistan.
- There is also a potential for more oral history interviews to be conducted with people in palliative care (with a diagnosis of oral cancer) in Pakistan.

### **8.7 Dissemination of findings**

I have presented the findings of my study in a thesis form but my intention is also to convey them to the relevant audiences. Several aspects of this study have already been presented at peer-reviewed conferences. There are three publications in preparation based on the findings of this study as well (See Appendix 7).

### **8.8 Epilogue**

Based on the literature review and findings of this study, as a co-investigator, I have received funding from the Global Challenges Research Fund (GCRF) of £7000 to help establish a cross-country collaboration between the UK and Pakistan to develop a network and priority setting for future work. The project is titled 'Pakistan Oral Cancer Collaborative- overcoming challenges and barriers to diagnosis and treatment'. The project will involve people with oral cancer in Pakistan that have been previously hidden from the history of the disease and will help in building an inclusive oral health care system in Pakistan. The collaborators from Pakistan visited The University of Sheffield in early April 2019 to initiate discussions and identify priority areas for oral cancer research in Pakistan. A systematic review to collate literature on late presentation of people with oral cancer in Pakistan, community

involvement – undergraduate dental students accompanying Lady Health Workers to help identify initial lesions in rural communities as a part of high risk opportunistic screening, involvement of stakeholders at community and national levels for policy development have been proposed. These priority areas have the potential to influence policy change regarding oral health and also towards development of diagnostic and referral pathways. Further PhD projects and fellowships to develop this work have also been proposed and will form part of the next GCRF funding.

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# APPENDIX ONE

## Ethical approval from The University of Sheffield



Downloaded: 16/02/2019  
Approved: 13/02/2017

Mariam Khokhar  
Registration number: 150254157  
School of Clinical Dentistry  
Programme: Dentistry (Science) (PhD/ Dentistry (Science) FT)

Dear Mariam

**PROJECT TITLE:** Oral histories and Dentistry  
**APPLICATION:** Reference Number 011821

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 13/02/2017 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 011821 (dated 02/02/2017).
- Participant information sheet 1025816 version 1 (10/12/2016).
- Participant consent form 1025817 version 1 (10/12/2016).
- Participant consent form 1025821 version 1 (10/12/2016).

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

## APPENDIX TWO

### Ethical approval from The Foundation University College of Dentistry

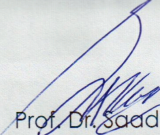
**FOUNDATION UNIVERSITY MEDICAL COLLEGE**  
**RAWALPINDI**  
Ethical Review Committee

To:

**Mariam Ahmad Khokhar,**  
PhD Student  
School of Clinical Dentistry,  
The University of Sheffield, UK

Subject: **Decision for Ethical Approval of Your Study Project**

The research project application titled "**Oral Histories and Dentistry**" re-submitted to Foundation University Ethical Review Committee on December 5, 2016 has been reviewed by the members of the committee. After amendments it has been found that this study project does not raise any ethical issues.

  
Prof. Dr. Saadat Ali Khan  
President Ethical Review Board  
Foundation University Islamabad Campus

No. 217/FF/FUMC/ERC  
Date: December 06, 2016

## APPENDIX THREE

### Participation information sheet



### Oral histories and dentistry

#### Participant information sheet

We would like to invite you to take part in a study at the University of Sheffield. Before you decide to take part you need to understand why we are asking you to help and what it would involve for you. Please take 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.

#### What is the purpose of the work?

My name is Mariam A. Khokhar. I am conducting a PhD study from the University of Sheffield looking at what impact oral cancer has on people's lives. The purpose of this work is to gain an understanding about how a range of people lives their lives and their experiences of oral cancer. I am genuinely interested in knowing people's experiences of oral cancer in Pakistan and give them a voice in the process.

#### What are you asking from me?

I will be asking a range of people to talk to me about their lives in general. You can tell me anything you feel is important, so for example it could be about your schooling and education, it could be about the area where you live or lived previously, it could be about things you feel have affected your life that you had no

control over, it could be about your work, or it could be about people who you feel may influence your life. The story you tell is up to you; everybody has a story to tell.

### **What will happen?**

If you decide that you wish to take part please read this information sheet, and fill in the attached form with your details so that you may be contacted. I will then contact you and arrange to meet you once before the actual interview in order to know you better and introduce myself to you. Soon after, I will arrange to record your story in confidence at the Fauji Foundation Hospital with a small recording machine. This should take approximately 1 - 2 hours depending on what you feel you need to tell me and how you feel on the day. It could be that you have a lot to tell in which case this can be done over more than one sitting. This is up to you. After the recording has taken place it will be uploaded onto a password protected computer that has been bought for this purpose. No names will be attached and all identifiable details removed. You can choose a false name for yourself so your name will not be attached to the recording. If you agree, your identity will be made known; otherwise your privacy will be maintained in all published and written data resulting from the study. No other data will be loaded in the computer apart from different people's stories.

### **What effect will this have on me?**

There will be no effect on you because you are choosing what you want to tell. If there is anything you do not wish to discuss then you can always choose not to tell me your story. There will be no effect on your treatment. There will be no benefit to you, apart from being able to tell your story to an unbiased listener. Your story can help generations of people and researchers to understand how different people's lives can be effected by oral cancer and their experiences of the disease.

### **Do I have to take part?**

We feel that you can make a valuable contribution to help understand how oral cancer affects different people's lives. But you do not have to take part. If you decide take part you will be asked to sign a form about your story to agree to have it



recorded. If there are any conditions you wish to be attached to your story please either write them on the form at the end, or ask me to write them for you. If you decide to withdraw you do not have to give a reason, just let me know.

### **What will happen to my story?**

If you allow, your story will be used for teaching purposes. Generations of students will be able to read about how different people with oral cancer live and experience life in Pakistan. It will be archived at the University of Sheffield and then people from Pakistan doing historical research can get access to it. In the future, it could form a part of an academic paper; it could be used to as part of historical research in the area, or it could be partly used at a teaching conference to illustrate the power of story telling. It will not be used at scientific meetings. It really depends on what story is told as to how it may be used. Oral history interviews are confidential until you give signed consent to be on the public record. Oral history interviews are intended for public access. Of course, it is your right to withdraw at any point.

### **Who is funding the work?**

The University of Sheffield is supporting the students by buying the laptop and recording machines. The staff members have given their own time to train the students in ways of taking people's stories, and will be available to discuss the stories with students to help them develop understanding. The students do not have to take part; they are doing this in their own time. I am funding my PhD study by myself.

### **Has this been ethically approved?**

Yes, the University of Sheffield Research Ethics committee has given ethical approval for the work and the Fauji Foundation Research Ethics Committee has reviewed the planned work.

### **Who will be informed about details of my story?**

You will choose what you want to tell the researcher. After your story has been collected it will be saved onto a computer. We must however caution you that any disclosure regarding the intent to harm or compromise the safety of another

individual or criminal activity will need to be reported. You will have the right to terminate the interview at any point without giving a reason.

**I want further information who can I contact?**

There are 4 members of staff involved: they are all willing to discuss further should you so wish. Their details follow next.

Name and details	Name and details
<p>Dr Michelle Winslow</p> <p>Research Fellow / Macmillan Oral History Lead</p> <p>School of Nursing and Midwifery</p> <p>Barber House</p> <p>University of Sheffield</p> <p>387 Glossop Road</p> <p>Sheffield, UK.</p> <p>S10 2HQ</p> <p>Tel: +44 (0)114 222 2077 / 226 6892</p> <p>Email: <a href="mailto:m.winslow@sheffield.ac.uk">m.winslow@sheffield.ac.uk</a></p>	<p>Dr Janine Owens</p> <p>Lecturer in disability and health,</p> <p>Academic Unit of Dental Public Health</p> <p>School of Clinical Dentistry</p> <p>University of Sheffield</p> <p>19 Claremont Crescent</p> <p>Sheffield, UK.</p> <p>S10 2TA</p> <p>Telephone: <u>+44 (0)114 271 7891</u></p> <p>Email: <a href="mailto:jan.owens@sheffield.ac.uk">jan.owens@sheffield.ac.uk</a></p>
<p>Dr Barry Gibson</p> <p>Reader in Medical Sociology,</p> <p>Head of Academic Unit of Dental Public Health</p> <p>School of Clinical Dentistry</p>	<p>Mariam A. Khokhar</p> <p>PhD Student</p> <p>The School of Clinical Dentistry</p> <p>The University of Sheffield</p> <p>19 Claremont Crescent</p> <p>Sheffield, UK.</p>

University of Sheffield 19 Claremont Crescent Sheffield, UK.  S10 2TA Telephone: +44 (0) 114 271 7889 Email: <a href="mailto:b.j.gibson@sheffield.ac.uk">b.j.gibson@sheffield.ac.uk</a>	S10 2TA  Tel Pak: Tel UK: +44 (0) 114 271 7923 Email: <a href="mailto:makhokhar1@sheffield.ac.uk">makhokhar1@sheffield.ac.uk</a>
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If you think you can help please fill in your details below and you will be contacted to arrange a time for you to give your history.

I would like to take part in the study.

Name:.....

Contact details:.....

Email address:.....

## APPENDIX FOUR

### Participant's consent form



## Participant Consent Form

Title of Research Project: **Oral histories and dentistry.**

**Participant Identification Number for this project:  
Please initial box**

1. I confirm that I have read or I have had it read to me and understood the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.
  
2. I understand that my participation is voluntary and that I am free to leave the project without giving any reason and I can withdraw my information.
  
3. I understand that my story will be kept anonymous until I sign the release form. I give permission for members of the research team to have access to my story.
  
4. I agree for my story to be used in future research.

5. I understand that any disclosure regarding the intent to harm or compromise the safety of another individual or criminal activity will need to be reported.

6. I agree to take part in the above research project.

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\_\_\_\_\_  
\_\_\_\_\_

Name of Participant  
impression

\_\_\_\_\_

Date

Signature/ Thumb

\_\_\_\_\_  
\_\_\_\_\_

Name of person taking consent

Date

Signature

*To be signed and dated in presence of the participant*

## APPENDIX FIVE

### Clearance form

University of Sheffield



## Oral History Interview

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### CLEARANCE NOTE AND DEPOSIT INSTRUCTIONS

The purpose of this deposit agreement is to ensure that your contribution can be added to an archive repository in strict accordance with your wishes. All material will be preserved securely. Please state below if you do *not* wish your contribution to be available for access as a permanent reference resource for use in research, publication, education, lectures and the Internet.

I give permission for my recordings to be kept securely as a resource for future research.

Yes / No

I hereby assign the copyright in my contribution to the University of Sheffield.

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Signed ..... Date .....

Address .....

.....

Email .....

Signed (by interviewer) ..... Date .....

People in charge of the work:

Name and details	Name and details
<p>Dr Michelle Winslow</p> <p>Research Fellow / Macmillan Oral History Lead</p> <p>School of Nursing and Midwifery</p> <p>Barber House</p> <p>University of Sheffield</p> <p>387 Glossop Road</p> <p>Sheffield, UK.</p> <p>S10 2HQ</p> <p>Tel: +44 (0)114 222 2077 / 226 6892</p> <p>Email: <a href="mailto:m.winslow@sheffield.ac.uk">m.winslow@sheffield.ac.uk</a></p>	<p>Dr Janine Owens</p> <p>Lecturer in disability and health,</p> <p>Academic Unit of Dental Public Health</p> <p>School of Clinical Dentistry</p> <p>University of Sheffield</p> <p>19 Claremont Crescent</p> <p>Sheffield, UK.</p> <p>S10 2TA</p> <p>Telephone: <a href="tel:+44(0)1142717891">+44 (0)114 271 7891</a></p> <p>Email: <a href="mailto:jan.owens@sheffield.ac.uk">jan.owens@sheffield.ac.uk</a></p>
<p>Dr Barry Gibson</p> <p>Reader in Medical Sociology,</p> <p>Head of Academic Unit of Dental Public Health</p> <p>School of Clinical Dentistry</p> <p>University of Sheffield</p> <p>19 Claremont Crescent</p> <p>Sheffield, UK.</p> <p>S10 2TA</p>	<p>Mariam A. Khokhar</p> <p>PhD Student</p> <p>The School of Clinical Dentistry</p> <p>The University of Sheffield</p> <p>19 Claremont Crescent</p> <p>Sheffield, UK.</p> <p>S10 2TA</p> <p>Tel Pak:</p> <p>Tel UK: <a href="tel:+44(0)1142717923">+44 (0) 114 271 7923</a></p> <p>Email: <a href="mailto:makhokhar1@sheffield.ac.uk">makhokhar1@sheffield.ac.uk</a></p>

Telephone: +44 (0) 114 271 7889	
Email: <a href="mailto:b.j.gibson@sheffield.ac.uk">b.j.gibson@sheffield.ac.uk</a>	

**If there are any conditions you wish to place on access to your story, please state them here. Otherwise leave this space blank.**

## **APPENDIX SIX**

### **Geographical locations of the participants**

#### **Chakwal**

Three participants (Maqsood Akhtar, Zahida Kalsoom and Nisbah) were born in and were living in Chakwal at the time of the interview. Chakwal is the capital and main city of Chakwal district, Punjab Pakistan (Wikipedia 2018). It is located 270 kilometres from the provincial capital, Lahore and 90 Kilometres from the federal capital, Islamabad. It has a population of 104, 365 people, which is much smaller than 1.9 million population of Islamabad (Chakwal 2015). It consists of 5 tehsils<sup>6</sup> (headquarters). Geographically, farmland and villages surround most of the area around Chakwal. Where farming is not the primary occupation, men in Chakwal tend to work within the town as labourers, or work within restaurants and boutiques. It is also common for the men to work abroad as labourers or in the army. For the women, like other parts of the country, under the influence of social – cultural patriarchy, it is uncommon to work outside of the home (Mumtaz et al. 2013; Qadir et al. 2011). Most of Chakwal district comprises of a rural population. In 1998 consensus, Chakwal was considered to be the most rural district of Pakistan. It is however now relatively well - developed (Mumtaz et al. 2013). There is a strong

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<sup>6</sup> Tehsil (district)- an administrative division that is hierarchically above a local city, town or village but subordinate to a larger state or province.



upper and lower class system, whereby women from low social class tend to work (as maids, dishwashers or cleaners) in the houses of upper class families mostly known as 'Chaudhris'. Women's mobility within the town and beyond is limited which is a key hurdle in accessing health services (Durrant and Sathar 2000). Many of the well-known Sufis of Islam like 'Bari Imam' and 'Sufi Muhammad Abdullah Khan' were born in Chakwal and people attend their anniversary celebrations in huge groups from all over Pakistan. People still believe in their miracles and visit their shrines to pay their respects.

### **Rawalpindi**

Interviews were conducted in Rawalpindi, Pakistan. Two participants (Ameena Mehboob and Shamim Akhtar) were living in Rawalpindi at the time of the interviews. It is located adjacent to the capital of Pakistan, Islamabad, jointly known as the 'twin cities' because of strong social, political and economic links. Rawalpindi is an important commercial, administrative and industrial centre (Britannica 2011). The population of Rawalpindi is around 1,743,101 (World Population Review 2018). According to the 1998 census of Pakistan, Rawalpindi was regarded as the second most urbanized district in Punjab. Rawalpindi has a range of recreational opportunities such as 3D cinemas, parks, and golf courses.

Rawalpindi has several medical and dental colleges and the army headquarters are also based in Rawalpindi. According to 2015 data, Rawalpindi was ranked as the number one district in terms of education and school infrastructure facilities. Women from the urban parts of Rawalpindi enjoy the same education opportunities as men. However, in rural areas, women's education rates are significantly lower. The industries of gas, cotton, brewery, and textiles are located in Pindi. It is also the starting point of route to Kashmir and connects through the grand trunk road with the cities of Peshawar and Lahore. It is also connected to other major cities in Pakistan through the Motorway road network. It also has one of the largest airports in Pakistan. Rawalpindi has a well-developed road network within the city making it easier for people to travel to different parts of the city and surrounding areas. The

medical colleges and health centres are also accessible for the population residing in the villages and tehsils surrounding the city.

### **Gujjar Khan**

Razia Begum and Sabra Bibi were born and were living in Gujjar Khan at the time of the interviews. Gujjar Khan is one of the main cities of the Rawalpindi District. It is 55 Km from Islamabad and 220 Km from Lahore (Wikipedia 2018). According to the population census 2017, Gujjar Khan has a population of 678,503. There are small educational establishments and the quality of the educational services and infrastructure is not known. There is a main district hospital providing medical facilities to the population along with other small private and public medical care services. Gujjar Khan is home to many Hindu temples and Sikhs Gurdwaras that have been maintained by the residents of the area. Rail, minor road and bus services link Gujjar Khan to few major cities of Pakistan like Lahore, Jhelum and Rawalpindi.

### **Gujrat**

Shehnaz Bibi belonged to Gujrat, which is an ancient city of Pakistan, located between two famous rivers, Jhelum River and Chenab River and in the northeast of the Punjab province (Wikipedia 2018). It has a population of about 2,756,110. Gujrat has a total of 1,475 schools at primary and secondary level, out of which, 60 percent are for girls. It has two main hospitals that are providing primary health care facilities. In terms of education, there is no accurate data on the number of schools present in Gujrat, but there are several colleges that are affiliated with the University of Punjab. Recently, the University of Gujrat has opened which caters most of the women population in the city. The majority of the country's furniture, pottery, electric fans, cotton goods, and foot wear; brassware and carpets are manufactured in Gujrat (Britannica 2006). Gujrat is connected with other cities of Pakistan largely through rail and bus services. There is a small airport situated in Gujrat city as well.

## **Faisalabad**

Muzammil Bibi was born and living in Faisalabad at the time of the interview.

Faisalabad is the third most populous city in Pakistan after Karachi and Lahore and the second largest city in the eastern province of the Punjab (Wikipedia 2018). It has grown to become a cosmopolitan metropolis. Faisalabad is a major industrial and distribution centre in Pakistan because of its central location in the region and connecting roads, rail and air transportation. It is also known as the “Manchester of Pakistan”. The main hallmarks of Faisalabad are agriculture and industry. Faisalabad is the main producer of superphosphates, cotton and silk textiles, dyes, industrial chemicals, hosiery, pulp, paper, printing and clarified butter. It is also home to major agricultural universities and educational schools. The healthcare system in Faisalabad is comparatively well developed. It has a number of government run hospitals including the Allied hospital and Faisalabad Institute of Cardiology. There are several private hospitals and clinics as well providing reasonable medical facilities to the citizens.

Faisalabad is well connected to other parts of the country through road, rail and air networks. A number of arts councils are situated in Faisalabad and literary festivals are conducted throughout the year. Public libraries and museums are openly accessible to the public. Cinemas, parks and open spaces are also well maintained in Faisalabad (Wikipedia 2018).

## **Sohawa**

Shafeen Bibi belonged to Sohawa, a town in the city of Jhelum. Due to major developments in transport, education and health, Sohawa has grown from a small village to a town. It comprises of different tribes of people. The majority of the citizens are either in the armed forces or settled in foreign countries. The main source of livelihood is agriculture (Wikipedia 2018).

The health care in Sohawa is poorly developed compared to other towns and cities. The main hospital in Sohawa and its surrounding rural areas consists of very basic facilities and is a 40- bed Tehsil Headquarters Hospital. For serious health problems,

people have to travel to major cities such as Gujar Khan, Jhelum and Rawalpindi/ Islamabad. There is one main rural health centre and a number of Government run rural dispensaries present in Sohawa.

### **Mansehra**

Shamim Akhtar was born in Mansehra, which is a district in the Khyber Pakhtunkhwa province of Pakistan. It is an important tourist location because of the Kaghan Valley and the Karakoram Highway passing through the district. It has a population of 1,556, 460 (Wikipedia 2018). Mansehra is connected to Azad Jammu Kashmir and Khyber Pakhtunkhwa by a road network. No airport is available. The health services started deteriorating when a major earthquake destroyed the area and thousands of lives were lost alongside many hospitals and rural health centres. The health services still lack efficient doctors with many posts for specialists lying vacant.

### **Sadiqabad**

Ameena Mehboob was born in Sadiqabad, Rahim Yar Khan, Pakistan, which is situated at the border of Sindh and Punjab. It has an urban population of 263, 176 and rural population of 1,002,576 people (Wikipedia 2018). No other accurate information is available for this city online.

### **Jhang**

Sughran Bibi was born and based in Jhang. It is one of the districts of Punjab with a population of 2,743,416 people (Wikipedia 2018). Sultan Bahoo, a famous Sufi saint was born in Jhang. People from the all over Pakistan visit his shrine in Jhang to gain spiritual healings and blessings. According to an Internet source:

*“His grave is not a mausoleum, but a furnace from where one’s soul is purified.”*

(<https://www.sultanbahoo.net/life/mausoleum/>)

### **Kallar Syedan**

Nasreen Akhtar was born and lived in Kallar Syedan located in the Rawalpindi district of the Punjab, Pakistan, 51 kilometres south east of Islamabad. It has a population of about 217,273 people (Wikipedia 2018).

### **Mithial**

Imtiaz Bibi was born and belonged to Mithial, located in the Attock region of the Punjab province, 77 kilometres west of Islamabad, Pakistan and the nearest to Foundation Hospital. Geographically, the area is mainly dissected plain (Wikipedia 2018). The Indus River flows on the northwest side of Mithial. Because of its location, it is regarded as a central hub of all the economic activities in the area (The Mithial blog 2009). All the main facilities like roads, electricity, water and telephone are provided in Mithial except Gas. The education system in Mithial is developing as well and comprises of both government and private schools.

Mithial is nearest to Fauji Foundation Hospital and is therefore the first point of contact for the local population.

### **Azad Kashmir**

Rukhsana Begum was born in Arang Kel, Azad Kashmir (AJK), which is part of the greater Kashmir region. It borders Pakistan's Punjab province to the south and to the east, Azad Kashmir is separated from the Indian-administered state of Jammu and Kashmir by the 'Line Of Control', which is the *de facto* border between India and Pakistan (Wikipedia 2018). Azad Kashmir is approximately 105 kilometres south east of Islamabad. It has a population of 4.45 million. The main source of livelihood is agriculture. Most of the population migrated to UK after the completion of Mangla Dam in Pakistan. Today, remittances from British Mirpuri community make a critical role in AJK's economy.

In 2004, the literacy rate of Azad Kashmir was 62%, which was higher than any other region in Pakistan. However, only 2.2% graduated (2.9% average for whole Pakistan).

There are many colleges and universities, which have been recognised by Higher Education Commission (HEC) Pakistan.

### **Mianwali**

Wazira Khatoon was born and belonged to Mianwali, which is a district in the northwest of Punjab Province of Pakistan. Mianwali has a total population of 1,546,094 people (Wikipedia 2018). In the education score index of Pakistan District Education Rankings in 2017, Mianwali was ranked on the 50<sup>th</sup> position. It is below average as compared to many other districts of the province. Residents of Mianwali complain of below average syllabus, out-dated textbooks and lack of basic facilities in the schools. Majority of the population is rural.

## **APPENDIX SEVEN**

### **Papers in preparation**

- Khokhar, M. A., Gibson, B. J., Owens, J., Winslow, M., (2019). Oral histories of people with oral cancer in Pakistan. The University of Sheffield, United Kingdom. Unpublished.
- Khokhar, M. A., Gibson, B. J., Owens, J., Winslow, M., (2019). “The poor have no memories”- experiences of oral cancer in Pakistan. The University of Sheffield, United Kingdom. Unpublished.
- Khokhar, M. A., Gibson, B. J., Owens, J., Winslow, M., (2019). Religious influences in pathways to diagnosis of oral cancer in Pakistan. The University of Sheffield, United Kingdom. Unpublished.