

**A LONGITUDINAL QUALITATIVE STUDY ON
LIVED EXPERIENCE OF ORAL CANCER
PATIENTS DURING COVID-19 PANDEMIC IN
KHYBER PAKHTUNKHWA PAKISTAN**

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UNIVERSITI SAINS MALAYSIA

2023

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PATIENTS DURING COVID-19 PANDEMIC IN
KHYBER PAKHTUNKHWA PAKISTAN**

By

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**Thesis submitted in fulfillment of the requirements
for the degree of
Doctor of Philosophy**

February 2023

ACKNOWLEDGEMENT

I would like to begin by thanking Allah, the Almighty for allowing me to complete this work, and for all of His innumerable blessings upon me. I express my heartfelt gratitude and appreciation to my main supervisor, Associate Professor Dr. Norkhafizah Saddki, for her encouragement, advice, support, expertise, and knowledge, all of which contributed to my Ph.D. journey being a memorable one. I will cherish my time with you for the rest of my life. Throughout the project, I worked closely with my co-supervisors, Dr. Zohaib Khan, Prof. Zia ul Haq, and Prof. Muslim Khan. I owe them a huge debt of gratitude for all of their assistance. Dr. Zohaib Khan was the first person to work on my ideas; without his direction, I would not have been able to give my work meaning. I want to express my gratitude to Prof. Dr. Muslim Khan, who, despite his busy schedule, gave me a lot of support while I worked on the data collection during the peak of the COVID-19 infection period. I want to express my gratitude to Prof. Dr. Zia ul Haq for helping me stay motivated during this journey. "A good Ph.D. is a finished Ph.D" he once said, stuck in my head. With tears in my eyes and my head bowed, I take this opportunity to thank my mother Jameela Jan Khattak, my brother Dr. Saad Ishaq Khattak, my sister Nargas Khan, and my sister in law Dr Hafiza Sumayya Shaukat for their unending encouragement, prayers, and support throughout my life. Last but not least, this humble work is a tribute to my late father Muhammad Ishaq Khattak (may Allah have mercy on him), whom I lost due to COVID-19 just a few months ago. Dad, my last words to you were "you have been an exemplary father," and no matter what your lonely daughter writes to acknowledge your love, care, and support throughout my life it would not do justice to your deeds.

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LIST OF ABBREVIATIONS

AJCC	The American Joint Committee on Cancer
HPV	Human Papillomavirus
OR	Odds Ratio
OSCC	Oral Squamous Cell Carcinoma
QOL	Quality Of Life
SARS-COV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SLT	Smokeless Tobacco
WHO	The World Health Organisation

LIST OF PUBLICATIONS

1. Khattak, M.I. et al., 2022. Experiences of Newly Diagnosed Oral Cancer Patients during the First Wave of the COVID-19 Pandemic: A Qualitative Study from Pakistan. *International Journal of Environmental Research and Public Health*, 19(14), p.8508.
2. Khattak, M.I. et al., 2021. The Experiences Of Oral Cancer Patients: A Narrative Review. *Malaysian Journal of Public Health Medicine*, 21(2), pp.168–177.

**KAJIAN KUALITATIF LONGITUDINAL MENGENAI PENGALAMAN
KEHIDUPAN PESAKIT KANSER MULUT SEMASA PANDEMIK COVID-19 DI
KHYBER PAKHTUNKHWA PAKISTAN**

ABSTRAK

Pengalaman kesihatan kanser mulut adalah mendalam dan kompleks untuk pesakit walaupun pada masa terbaik. Walau bagaimanapun, terdapat sedikit pengetahuan tentang bagaimana pengalaman kesihatan pesakit kanser mulut boleh berubah dan berkembang sebagai tindak balas kepada perubahan persekitaran pandemik COVID-19. Kajian ini meneroka pengalaman fizikal, sosial dan psikologi pesakit kanser mulut semasa diagnosis, enam bulan selepas diagnosis, dan satu tahun selepas diagnosis, dengan tumpuan khusus kepada bagaimana pengalaman mereka berubah semasa melalui tempoh masa yang berbeza sewaktu pandemik COVID-19. Kajian ini melibatkan pesakit yang didiagnosis dengan kanser mulut di Kolej Pergigian Khyber, Peshawar, Pakistan. Para peserta dipilih menggunakan kaedah persampelan bertujuan variasi maksimum untuk mengambil bahagian dalam kajian ini. Reka bentuk kualitatif longitudinal telah digunakan menggunakan prinsip inkuiri fenomenologi. Tiga temu bual separa berstruktur telah dijalankan seperti berikut: pada diagnosis (T1), enam bulan selepas diagnosis (T2), dan dua belas bulan selepas diagnosis (T3). Sampel semasa T1 dan T2 terdiri daripada 17 peserta. Sampel semasa T3 terdiri daripada 12 orang peserta. Temu bual dijalankan dalam bahasa Pashto, iaitu bahasa tempatan Khyber Pakhtunkhwa. Temu bual yang dirakam audio telah ditranskripsikan secara ad verbatim dalam bahasa Inggeris dan dianalisis secara tematik. Data disusun menggunakan perisian ATLAS.ti versi 8. Lapan tema

peringkat luas utama diperolehi semasa T1: (1) kesakitan dan kelemahan fizikal umum, (2) kejutan semasa diagnosis, (3) tekanan psikologi akibat pandemik COVID-19, (4) kepercayaan dan agama, (5) kehilangan pekerjaan berganda, (6) pengasingan sosial, (7) sokongan sosial daripada penjaga, dan (8) kekurangan sokongan daripada profesional penjagaan kesihatan. Semasa T2, lima tema peringkat luas utama diperolehi: (1) kemerosotan dan batasan fizikal, (2) kelemahan psikologi, (3) kebergantungan kepada Tuhan untuk perlindungan, (4) ketersediaan sistem sokongan sosial, dan (5) kemerosotan kewangan. Akhirnya, empat tema peringkat luas utama telah diperolehi semasa T3: (1) normal baharu, (2) ketakutan keseluruhan, (3) kepercayaan terhadap amalan penyembuhan tradisional, dan (4) berusaha ke arah normal dalam kehidupan sosial. Kesimpulannya, kajian kualitatif longitudinal ini memberikan gambaran tentang kerumitan hidup dengan kanser mulut semasa wabak tersebut. Naratif dalam kajian menyerlahkan pengalaman fizikal konvensional sambil meningkatkan kebimbangan psiko-sosial semasa diagnosis. Sokongan sosial pesakit bertambah baik sedikit enam bulan selepas diagnosis, tetapi peningkatan beban kewangan, tekanan psikologi dan gejala fizikal berterusan. Akhirnya, selepas dua belas bulan, pesakit cuba untuk pulih secara fizikal dan mencapai kenormalan sosial, tetapi kebimbangan psikologi tentang berulangnya kanser mulut dan pandemik COVID-19 masih berlarutan. Dualiti pengalaman kanser mulut biasa dan pengalaman tambahan akibat pandemik terbukti dalam ketiga-tiga fasa yang menjejaskan kesejahteraan fizikal, psikologi dan sosial pesakit kanser mulut di Pakistan.

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ABSTRACT

Oral cancer health experiences are profound and complex for patients even at the best of times. There is, however, little knowledge of how oral cancer patient's health experiences may alter and develop in response to the COVID-19 pandemic's changing environment. This study explored the physical, social and psychological experiences of oral cancer patients at diagnosis, six months after diagnosis, and one year after diagnosis, with a particular focus on how experiences change through the different periods of time during the COVID-19 pandemic. Patients diagnosed with oral cancer at Khyber College of Dentistry, Peshawar, Pakistan were included in the study. The participants were selected using a maximum variation purposive sampling method to participate in this study. A longitudinal qualitative design was employed using the principles of phenomenological inquiry. Three semi-structured interviews were conducted as follows: at diagnosis (T1), six months after diagnosis (T2), and twelve months after diagnosis (T3). The sample at T1 and T2 comprised 17 participants. The sample at T3 comprised of a total 12 participants. The interviews were conducted in Pashto, the local language of Khyber Pakhtunkhwa. The audio-recorded interviews were transcribed *ad verbatim* in English and thematically analyzed. Data was organized using ATLAS.ti software version 8.

Eight major broad-level themes were derived at T1: (1) pain and generalized physical weakness, (2) shock at diagnosis, (3) psychological distress of the COVID-19

pandemic, (4) faith and religion, (5) double hit loss of employment, (6) social isolation, (7) social support from caregivers, and (8) lack of support from health care professionals. At T2, five major broad-level themes were derived: (1) physical impairment and limitations, (2) psychological vulnerability, (3) reliance on God for protection, (4) availability of social support systems, and (5) financial decline. Finally, four major broad-level themes were derived at T3: (1) the new normal, (2) the sum of fears, (3) belief in traditional healing practices, and (4) striving towards normalcy in social life. In conclusion, this longitudinal qualitative study provides insight into the complexities of living with oral cancer during the pandemic. The narratives in the study highlight conventional physical experiences while heightened psycho-social concerns at diagnosis. Patients social support slightly improved six months after diagnosis, but increased financial burdens, psychological distress, and physical symptoms continued. Finally, after twelve months, patients attempted to recover physically and gain social normalcy, but unwavering psychological concerns about the recurrence of oral cancer and the COVID-19 pandemic lingered. The duality of the common oral cancer experiences and additional pandemic-inflicted experiences were evident in all three phases which affected the physical, psychological, and social well-being of oral cancer patients in Pakistan

CHAPTER 1

INTRODUCTION

This chapter aims to provide the rationale, the context, and the importance of this thesis. It provides an overview of the definition, diagnosis, staging, and epidemiology including trends, etiology, risk factors, treatment, impact, and survival of oral cancer. In addition, it provides an overview of the severe acute respiratory syndrome coronavirus 2 (SARS-COV-2), or the COVID-19 pandemic, and its impact on oral cancer. This chapter also identifies the issues and knowledge gaps in these areas. Finally, this chapter describes the problem statement, justification, and research objectives of this study.

1.1 Background

The definition of oral cancer varies in the literature even though the oral cavity boundaries are clearly well-demarcated (Tapia and Goldberg, 2011). The lack of consensus on the oral cancer definition is well documented in research studies, and the root cause of the problem is related to the terminology dilemma (Moore *et al.*, 2000; Tapia and Goldberg, 2011). Most studies define oral cancer as malignant neoplasms of the oral cavity which include lips, tongue, sinus regions, major salivary glands, hard and soft palate region, and the pharynx (Warnakulasuriya, 2009; De Camargo Cancela *et al.*, 2010; Zini *et al.*, 2009). Other literature defines oral cancer as cancers occurring in the mouth and tongue, also termed as oral cavity cancer, while cancers occurring in the oropharynx are termed oropharyngeal cancer – the terms oral cancer, oral cavity cancer, mouth cancer, and oropharyngeal cancer, however, are used interchangeably (Kato *et al.*, 2020). The

World Health Organisation (WHO) International Statistical Classification of Diseases and Related Health Problems, 10th revision, coded oral cancer as malignant neoplasms of lip, oral cavity and pharynx including the inner lip (C00.3-C00.9), other and unspecified parts of the tongue (C02), gum (C03), floor of the mouth (C04), palate (C05), and other and unspecified parts of the mouth (C06); oropharyngeal cancers comprising of the base of the tongue (C01), lingual tonsil (C2.4), tonsil (C09), oropharynx (C10), and the pharynx (C14) (World Health Organization, 2011).

In 2012, 14.1 million new cancer cases were recorded worldwide, out of which 300,400 were oral cancer cases , adding a burden of more than 2% of new cancer cases, and caused 145,400 or 1.7% cases of deaths (Ferlay *et al.*, 2015; Ali *et al.*, 2016). The most common and prevalent type of oral cancer is oral squamous cell carcinoma (OSCC), which begins within the squamous cells of the surface lining tissue. More than 90% of oral cancers histologically originate in the squamous cells (Lingen *et al.*, 2008; Rivera, 2015).

The incidence, prevalence, and mortality rates of oral cancer exhibit variability according to geographical locations in which it is diagnosed (Warnakulasuriya, 2009; Gupta *et al.*, 2017). While the prevalence and mortality rates of oral cancer have been steadily declining in most developed countries such as in the Europe, developing countries of the South-Central Asia such as Pakistan continues to have one of the highest prevalence in the world (De Camargo Cancela *et al.*, 2012). It was reported that Pakistan has an age-standardized incidence rate for oral cancer of 9.8/100,000 (Ferlay *et al.*, 2012; Z. Khan *et al.*, 2017). According to Globocan 2018, oral cancer is the most common type of cancer amongst males in Pakistan with its prevalence being the highest in the world, and the

second most common among both sexes (Qureshi *et al.*, 2021; GLOBOCAN, 2020). A recent study suggested that the cancer of the lips and oral cavity has emerged as the second-highest cancer with an incidence of 8.6% among males and females in Pakistan (Sarwar and Saqib, 2017). Oral cancer was also the second-highest reason of death, contributing to 7.2% of all cancer related mortality in the country (Sarwar and Saqib, 2017). The burden of oral cancer in Pakistan was expected to be on the rise, with hospital-based data trends reporting a high oral cancer rate of 9.9%, which is considerably higher than other member states of the WHO Eastern Mediterranean Region (Bile *et al.*, 2010).

Oral cancer cases are mostly linked to genetic, lifestyle, and environmental risk factors which includes tobacco, alcohol, variable chewing habits, infections by the human papillomavirus (HPV) and family history (Gupta and Gupta, 2015; Warnakulasuriya and Greenspan, 2020). Exposure to these risk factors of oral cancer may vary according to the geographical locations. While smoking, alcohol and HPV are the main risk factors in Americas and European countries (Tenore *et al.*, 2020; Ferreira Antunes *et al.*, 2013; Zhang *et al.*, 2015), the use of areca nut, chewing tobacco and other types of smokeless tobacco (SLT) are the main risk factors in the South Central Asian countries (Tenore *et al.*, 2020; Ferreira Antunes *et al.*, 2013; Khan *et al.*, 2014). The trends of oral cancer incidence also revealed an association with the changes in exposure to risk factors (Montero *et al.*, 2012). For example, a downward trend in oral cancer cases in the United States was noted, and the decline was linked to the country steady reduction in alcohol and tobacco consumption (Sankaranarayanan *et al.*, 2015). On the other hand, South Central Asian countries like Pakistan continue to exhibit a rise in the number of oral cancer

cases due to an increase in consumption of areca nut and SLT products (Sankaranarayanan *et al.*, 2015; Khan *et al.*, 2019; Z. Khan *et al.*, 2017; Siddiqi *et al.*, 2015).

The use of SLT is a common practice in the South East Asian countries like Pakistan, India and Bangladesh (Khan *et al.*, 2014; Siddiqi *et al.*, 2015). The SLT users have been reported to have twenty fold higher risk of developing oral cancer compared to the non-users with an odds ratio (OR) of 21.2 (95% CI=5.4-153.9) (Z. Khan *et al.*, 2017). The SLT is commonly consumed in Pakistan and is easily available in public marketplaces (Ibrahim *et al.*, 2017; Bile *et al.*, 2010; Khan *et al.*, 2019). Use of SLT related products are socially accepted and it is reported to be consumed by 54% men and 20% women in the country (Zakiullah *et al.*, 2012).

The common methods to diagnose oral cancer are by physical examination to look for abnormalities, and if a suspicious area is found, a biopsy will be done for histopathological examination (Borse *et al.*, 2020). Once oral cancer is diagnosed, the extent (stage) of cancer is determined using radiological imaging techniques (Ulaganathan *et al.*, 2017; Greene and Sobin, 2008). The most common and widely accepted method of cancer staging is the TNM staging system, where 'T' indicates tumor size and extent of spread of the primary tumor, 'N' indicates the extent of spread to regional lymph nodes, and 'M' indicates spread to distant organs (Hartl *et al.*, 2022). The TNM staging system is grouped from stage 0 to IV, which corresponds to the increase in severity of disease, decrease in the survival rate and quality of life (QOL) of patients (Sankaranarayanan *et al.*, 2015; Mahalingam *et al.*, 2022; Edge and Compton, 2010). A summary of staging developed by The American Joint Committee on Cancer 7th Edition (AJCC) (2010) for oral cancer is illustrated in Table.1.1

Table 1.1 AJCC staging for oral cancer

Stage	Tumor	Nodes	Metastasis
Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T3	N0	M0
	T1 - 3	N1	M0
Stage IVA	T4a	N0 - 1	M0
	T1 - 4a	N2	M0
Stage IVB:	Any T	N3	M0
	T4b	Any N	M0
Stage IVC:	Any T	Any N	M1

At Stage 0, the cancer is within the epithelium of oral cavity (Tis) and none of the cancer cells are existing in the lymph node (N0), other structures nearby or at far away sites (M0) (Jamal and Anjum, 2022). At stage I, the oral cancer is a primary tumor which is less than 2cm or equal to 2cm (T1), none of the cancer cells are existing in the lymph node (N0), other structures nearby or at far away sites (M0) (Jamal and Anjum, 2022). At

stage II the oral cancer is a tumor which is across 2 to 4 cm (T2), none of the cancer cells exist in the lymph node (N0), other structures nearby or at far away sites (M0) (Jamal and Anjum, 2022). At stage III, oral cancer presents two scenarios: first situation the tumor is less than 4 cm across (T3) and none of the cancer cells are existing in the lymph nodes (N0), other structures nearby or at far away sites (M0); the other situation is where the tumor is of any size (T1,T2,T3) and is not existing in structures nearby or at far away sites (M0) but the cancer cells have affected one lymph node located on the same side of the tumor and is less than 3 cm (N1) (Jamal and Anjum, 2022). At Stage IV oral cancer has reached the most advance stage and can mean different things depending on Stage IVa, IVb, IVc, but generally at this stage the tumor may be of any size (T1-T4b/Any T), it may or may not spread to any structure nearby or far away (M0-M1) and may or may not affect any lymph node (N0-N3/Any N) (Jamal and Anjum, 2022).

The current mainstay treatment for oral cancer is surgery, followed by radiotherapy and chemotherapy, or combined treatment modalities that are recommended in a locally advanced stage disease (Mehta and Kuriakose, 2021; Huang and O’Sullivan, 2013). The side effects of surgery for oral cancer include facial alteration and defects in oral functions (Goswami and Gupta, 2019) including eating, chewing, swallowing and speaking, as well as taste dysfunction (Turner et al., 2013; Mehta and Kuriakose, 2021). The radiation therapy itself is painless, but the side effects are inevitable (Röing *et al.*, 2007; Dilalla *et al.*, 2020), including mucositis, dryness of mouth, limited jaw movement due to osteoradionecrosis and extensive fibrosis (Turner *et al.*, 2013; Kanchan *et al.*, 2019). The side effects of chemotherapy in oral cancer patients largely vary depending on the type, length and dose of drugs (Turner *et al.*, 2013). The most common side effects of

chemotherapy reported by oral cancer patients are mouth blisters, weight loss, nausea, nail changes, skin changes, and hair loss (Mason *et al.*, 2016; Turner *et al.*, 2013).

The primary goal of oral cancer treatment is to improve survival. However, oral cancer treatment can also have a negative impact on patients' QOL (Abbas *et al.*, 2019; Chen *et al.*, 2018; Gellrich *et al.*, 2015; Graboyes *et al.*, 2019). The survival and QOL of oral cancer patients are multifaceted and may be influenced by the availability of a multidisciplinary team management which comprises of maxillofacial surgeon for primary surgery, oncologist for radiation therapy and chemotherapy, plastic surgeon for reconstructive surgery, and various therapists for rehabilitation of functions (Shang *et al.*, 2021; Nguyen *et al.*, 2008). Reports suggest that the survival rates of oral cancer patients in the low and middle-income countries are lower compared to the developed countries, reflecting disparities not only in the accessibility and affordability of the diagnostic and treatment facilities, but also the health related experiences and QOL (Sankaranarayanan *et al.*, 2015; Sankaranarayanan *et al.*, 2010; Lambert *et al.*, 2011), which may be achieved through rehabilitation and reconstruction treatments (Meier *et al.*, 2019; Clarke *et al.*, 2016).

The survival rate of oral cancer patients can be increased by early diagnosis and improvement of their QOL through understanding their experiences (McConnell *et al.*, 2017; Le Campion *et al.*, 2017; Sankaranarayanan *et al.*, 2013), particularly with issues related to physical, psychological, and social functioning (Hatano *et al.*, 2013; Losi *et al.*, 2019; Goswami *et al.*, 2019). Following diagnosis, oral cancer patients experience a range of difficulties including problems during eating, talking, hearing, and seeing (Hatano *et al.*, 2013; Badr *et al.*, 2017). Oral cancer patients may also express emotional and

psychologically traumatic experiences, primarily because the oral region is a prominent part of the body (Zabora *et al.*, 2001). Additionally, studies have also suggested that oral cancer patients develop multifaceted social challenges which disturb their daily lifestyle causing deviations in interpersonal communication, social activities, and work related activities (García-Peris *et al.*, 2007; Semple *et al.*, 2008). Assessment of QOL outcomes measured in physical, psychological, and social domains have become essential part for improving oral cancer treatment and survival rates (Chandu *et al.*, 2006; Oskam *et al.*, 2010). These QOL measures have gained the interest of the cancer research community since they provide evidence that is crucial to both assessing patients' living conditions and developing clinical procedures for better clinical outcomes (Bachmann *et al.*, 2018; Oskam *et al.*, 2010; Montazeri, 2009).

The WHO announced a global pandemic of the COVID-19 on March 11, 2020 (Cucinotta and Vanelli, 2020). The global COVID-19 emergency drove the health care systems around the world to prioritize the prevention and management of COVID-19 which led to changes in management of patients with other medical conditions (Solis *et al.*, 2021). The global burden of COVID-19 pandemic was noted to have serious implications for cancer care (Richards *et al.*, 2020). Firstly, patients with cancer seemed to be more susceptible towards worse outcomes from the COVID-19 infection, as well as greater demand for ventilator support, and increased mortality rates (Liang *et al.*, 2020; Onder *et al.*, 2020; Richards *et al.*, 2020). Secondly, there was a delay in diagnosis and treatment for cancer patients because many countries suspended routine health care services, and cancer patients were reluctant to access health care services due to the fear of COVID-19 exposure (Iacobucci, 2020; Richards *et al.*, 2020). Thirdly, to minimize

exposure of cancer patients to COVID-19 infections, many countries throughout the world changed their regular treatment pathways of cancer care (Brugel *et al.*, 2021; Richards *et al.*, 2020). Fourthly, routine health care delivery was minimized to allow the health care systems to respond to the COVID-19 pandemic, resulted in compromised care for cancer patients did not receive optimal care, unlike the pre-pandemic time (Richards *et al.*, 2020). While health care organisations throughout the world were busy dealing with the COVID-19, the incidence of cancer and other diseases did not halt. The pandemic has worsened the health and emotional conditions of those patients who were already in a precarious state such as cancer patients (De Berardinis *et al.*, 2021). The pandemic was observed to have stronger negative impact on the health care systems particularly in the low and middle income countries (Wible, 2022; Bong *et al.*, 2020; Teoh *et al.*, 2022). Some of the countries have failed to provide and deliver optimal level of patient care due to scarce resources, outdated infrastructure, lack of health care staff, limited medical supplies, and meagre access to technology (Wible, 2022; Bong *et al.*, 2020).

In Pakistan, the first COVID-19 case was detected on the 26th February, 2020, and in early March 2020 the country was challenged with low-level community spread (Bhutta *et al.*, 2020). The government, with the aim to avoid the spread of COVID-19 through hospital admissions, imposed a nationwide lockdown, subsequently closing down out-patient departments and cancelling all elective procedures including surgeries (Raza *et al.*, 2020). This action triggered a restraint on the standard clinical activity in the hospitals, and the health care system did not have optimal capacity to accommodate routine care for the cancer patients across the country (Yusuf, 2020). Although limited services for cancer patients continued, there were severe disruptions in the routine cancer care in Pakistan

during the first wave of the pandemic (Yusuf, 2020). Prior to the pandemic, there were already substantial disparities been reported in cancer care amongst the patients from urban and rural settings of the country (Bashir, 2015). To make matters worse, the travel restrictions imposed by the COVID-19 pandemic in Pakistan have negatively impacted access to care further, particularly for patients who were reliant on urban cancer care hospitals (Ahmed *et al.*, 2021).

Oral cancer, like other cancers, was also significantly affected by the COVID-19 pandemic (Solis *et al.*, 2021; Juneja *et al.*, 2021). Evidence suggests that patients did not receive treatment during the initial months of the lockdown, and one of the reasons was that major surgical procedures were considered to be a source of high aerosol generation, thus, becoming a threat for increased risk of COVID-19 infection (Siddiqui *et al.*, 2021; Venkatasai *et al.*, 2022). Similarly, a survey of 346 cancer centers from 54 nations across the globe, reported that nearly 88% of centers faced issues whilst delivering care, suggesting an extensive global loss on cancer care during the pandemic (Jazieh *et al.*, 2020). A thought provoking analytical modeling study suggested that the impact of delayed access to care on survival rates during the pandemic varies significantly across all cancer types, but disproportionately affects patients with oral cavity cancers with a significant reduction in survival among those with stage I, II, and III (HR, 1.061-1.161 per month of delay based on stage of disease) (Hartman *et al.*, 2020).

1.2 Problem statement

A systematic review has drawn attention to some limitations in the knowledge about the QOL outcomes and support needs of oral cancer patients (Moore *et al.*, 2014a). These

limitations were found to be in both theoretical and methodological nature including the lack of attention to the impact on individual experiences of oral cancer patients (Moore *et al.*, 2014a). The QOL and support needs of oral cancer patients are largely derived from QOL questionnaires which are not entirely conclusive, and unable to highlight the complex subjective nature of the condition (Moore *et al.*, 2014a; So *et al.*, 2012). It is inevitable that QOL measures will be unable to answer questions about an individual's interpretation of oral cancer symptoms, which may have a negative impact on subsequent help-seeking behaviour or information about experiences with health care providers, all of those which can be answered in a subjective context (Baumann *et al.*, 2018; Hoesseini *et al.*, 2020; Basharat *et al.*, 2019).

Many research studies have focused on the association of the effects of oral cancer on the physical, psychological, and social functioning of oral cancer patients (Koizumi *et al.*, 2013; Abbas *et al.*, 2019). It has been noted that oral cancer treatment can have distressing multifaceted effects on the patients' ability to communicate, appear in public, oral functionality, self-image, and interpersonal relationships (Hatano *et al.*, 2013; Ellis *et al.*, 2019; Kanchan *et al.*, 2019). The experiences of oral cancer patients are devastating, the extent may be understood by the fact that oral cancer patients are reported to be twice more at risk to suicide attempt in comparison to other types of cancers (Rathod *et al.*, 2015; Osazuwa-Peters *et al.*, 2018). However, oral cancer research has traditionally been focusing on the measures and predictors of disease survival based on quantified scores, when there is an urgent need to explore these issues through a broad sociological lens to gain insight into individual lives (Pateman *et al.*, 2015).

Quantitative investigations of the QOL domains of oral cancer patients could only provide a limited perspective on the individual experiences of oral cancer patients throughout the cancer trajectory. Some researchers have turned their attention to exploring individual experiences through cross-sectional qualitative methods (Macedo and Anjos, 2019; Goswami and Gupta, 2019; Chen, 2012). The challenge with one-time cross-sectional qualitative exploration is that information gained about a specific phenomenon largely depends on only that specific time, place and phase the individual is going through (Hermanowicz, 2013; Neale *et al.*, 2012). It is known that experiences for individuals may vary at different points in time because of the nature of their condition, and the varying problems faced by the phenomena (Fadyl *et al.*, 2017; Garner *et al.*, 2017). Therefore, there is a possibility that the subjective exploration of oral cancer experiences as a one-off data set may not be able to illuminate the entire diagnosis, illness and recovery trajectory of patients, to inform future health care priorities.

During the initial phase of the COVID-19 pandemic, the majority of the oral cancer patients worldwide faced challenges such as accessing health care services, social restrictions, travel restrictions, fear of hospital exposure, and the psychological stress of missed or delayed follow-up visits (De Berardinis *et al.*, 2021; Solis *et al.*, 2021; Mahl *et al.*, 2020; Venkatasai *et al.*, 2022; Gallo *et al.*, 2021). While there have been many reports concerning management of cancer patients during the COVID-19 pandemic, little is known about the experiences of cancer patients during the COVID-19 pandemic, and none were specific on the experiences of oral cancer patients (Ciężyńska *et al.*, 2020; Wang *et al.*, 2020a). In particular, none of the studies have longitudinally explored the experiences of oral cancer patients right from the time of diagnosis across the oral cancer continuum

during the COVID-19 pandemic. Therefore, the current research is focused on addressing this information gap; to explore oral cancer patients' physical, psychological, and social experiences, and understand their subsequent journey after being diagnosed over a period of 1 year during the COVID-19 pandemic.

1.3 Justification of the study

Oncology care is complex and most difficult for patients in developing countries even in the best of times. The emphasis on improved treatment and better outcomes for cancer patients has led researchers to focus on patient experiences and making sense of individual life experiences becoming priorities (Di Maio and Perrone, 2003; Tsianakas *et al.*, 2012). It is believed that the key to improving the survival rate and QOL of cancer patients is to understand their experiences; health care professionals should focus on appropriate personalized and tailored care (McConnell *et al.*, 2017).

In Pakistan, cancer patients are usually treated in public tertiary care hospitals which are capable of providing all forms of treatments such as surgery, radiotherapy, and chemotherapy whenever deemed appropriate (Saeed *et al.*, 2019). One of the woefully lacking key areas across Pakistan is that there are only twenty-one dedicated hospitals for cancer diagnosis and treatment, and a mere 125 registered oncologists to cater to the needs of such a large population of approximately 220 million people (Noronha *et al.*, 2012; Yusuf, 2013). Moreover, there are other issues related provision of health care services such as lack of internal referral system at the public tertiary care hospitals, unavailability of appropriate palliative services, absence of exchange of information between psychiatrists and family practitioners, and non-existent community mental health services

(Gadit, 2006). The severe shortages in availability of mental health services in Pakistan were due to two main reasons. First, there was only a few state-run psychiatric hospitals, and second, there was insufficient number of registered mental-health professionals with only 250-300 psychiatrists, 480 psychologists, and 600 mental health care workers catering to the needs of the population of the country (Ahmad, 2007; Muhammad Gadit, 2007; Javed *et al.*, 2020). Pakistan is an example of a developing country that has great cancer morbidity in combination with restricted health resources (Noronha *et al.*, 2012). With the aforementioned hostile starting point for cancer patients within Pakistan, achievement of favorable QOL outcomes for cancer patients within the country seems to be very difficult to accomplish.

In Pakistan, the COVID-19 pandemic has stressed the already burdened health care system since the beginning of the pandemic in March 2020, and the oncology hospitals faced various challenges while managing patients undergoing cancer care (Yusuf, 2020; Bhutta *et al.*, 2020). Cancer patients have been identified as being vulnerable to the COVID-19 due to their current pathology, and complex treatment requirements (Asghar *et al.*, 2021). As a consequence, the government of Pakistan recommended that the management of such patients be modified including deferring elective surgeries, reducing hospital visits and stays, and initiating symptom management treatment when possible (Bhutta *et al.*, 2020; Yusuf, 2020). This environment led to the curtailment of normal clinical activity, shortages of health care staff, financial uncertainties, restrictions on travel, and nominal health resources to be spent on cancer screening and detection (Ahmed *et al.*, 2021).

The oral cancer research globally and in Pakistan has predominantly focused on quantitative studies, mostly determining the underlying risk factors, genes associations, disease and treatment trajectories (Bile *et al.*, 2010; Z. Khan *et al.*, 2017; Merchant *et al.*, 2000). However, quantitative studies have an inherent limitation of being unable to provide an understanding of life with oral cancer, the individual experiences of oral cancer patients, and how these experiences change over time through the pandemic. Unlike quantitative studies, lived experiences derived from qualitative methods can elicit a comprehensive understanding of the meanings people attach to various elements of their care such as the experience of having the disease, hospital stay, and surroundings (Goodrich and Cornwell, 2008; Saunders *et al.*, 2021; Knaul *et al.*, 2020). The knowledge gained from qualitative studies on oral cancer experiences in Pakistan and globally remains very limited. There is a dearth of qualitative literature examining oral cancer population in Pakistan. It has proved not possible to find longitudinal qualitative literature to provide an understanding of how the COVID-19 pandemic affected oral cancer patient experiences in Pakistan or in other lower and middle-income countries. Previous studies have failed to provide an interpretation of exploring the journey and experiences of patients after being diagnosed and receiving treatment for oral cancer during the COVID-19 pandemic.

The current context of the COVID-19 pandemic has affected the physical, social, and psychological domain of life of oral cancer patients. Therefore, it is imperative to carry out qualitative work in Pakistan for this particular patient group, in order to gain insight about their experiences during diagnosis, six months after diagnosis and twelve months after diagnosis during the COVID-19 pandemic. Given the complex and multifaceted

constraints due to the COVID-19 pandemic during the first wave, it is important to learn about oral cancer patients experiences throughout the journey of being diagnosed up to an year. In order, to understand how the experiences of oral cancer patients change in the following COVID-19 pandemic waves, as well as to develop alternative coping ways acceptable to patients and to provide patient-centered care in one of the resource-limited countries. Therefore, there is a need to understand how patients understand and experience oral cancer at diagnosis, six months after diagnosis, and one year after diagnosis, during the COVID-19 pandemic in Pakistan.

1.4 Research objectives

General:

1. To explore the physical, social and psychological experiences of oral cancer patients at diagnosis, six months after diagnosis, and one year after diagnosis, with a particular focus on how experiences change through the different periods of time during the COVID-19 pandemic.

Specific:

1. To explore the physical, psychological and social experiences of patients diagnosed with oral cancer during the COVID-19 pandemic.
2. To explore the physical, psychological and social experiences of oral cancer patients six months after diagnosis with particular focus on how the scenario of experiences change during the COVID-19 pandemic.

3. To explore the physical, psychological and social experiences of oral cancer patients one year after diagnosis with a particular focus on how the scenario of experiences change during the COVID-19 pandemic.

CHAPTER 2

LITERATURE REVIEW

This chapter reviews the literature that is pertinent to the thesis. Firstly, this chapter explores thoroughly the current state of knowledge regarding the physical, psychological, and social experiences of patients with oral cancer. Secondly, this chapter provides a wider context about the factors influencing the experiences of oral cancer patients. Thirdly, this chapter elaborates on the impact of the COVID-19 pandemic on the survival and experiences of cancer patients, with a particular focus on the potential effect of the COVID-19 pandemic on oral cancer patients. Finally, this chapter provides an overview of the qualitative research approaches and methods described in the literature to explore subjective information.

2.1 Experiences of oral cancer patients

Cancer research globally has indicated the need for probing explicit explanations from cancer patients about their illness and its consequences, rather than simply focusing on causes and treatments for cancer, with oral cancer being no exception (Corner *et al.*, 2007; Coronado *et al.*, 2017). The cancer research emphasis on improved treatment outcomes has led to patient experiences becoming a top priority for improving cancer patients' survival rate and QOL (Williams *et al.*, 2020). Recently, the National Cancer Survivorship Initiative launched in the United Kingdom, recommends that health care professionals need to provide personalized care pathways to people with all cancers (Alfano *et al.*, 2019).

In such a scenario, it is essential for health care professionals to understand the impact of cancer on patient's lives by exploring experiences such as psychological consequences (for example impact of cancer on patients and psychological attitude towards recovery), social consequences (for example impact on daily life and employment), and physical functioning (impact of cancer on mobility), to create satisfactory health care pathways (Goswami et al., 2019; Cherif et al., 2020; Viney et al., 2022). The broad consequences of cancer diagnosis and treatment are known to break patients in all three important domains of life, not only affecting them physically but also psychologically, and socially (Naughton and Weaver, 2014; Coronado et al., 2017). Therefore, it is recommended for practitioners to regularly assess patient needs typically in the following three domains: physical, psychological and social, to cater a personalized care plan (Alfano et al., 2019; Alessy et al., 2022; Coronado et al., 2017).

2.1.1. The physical experiences of oral cancer patients

It is a well-known fact that physical symptom burdens have a substantial influence on the life of cancer patients (Jehn *et al.*, 2019). Numerous studies reported physical limitations for oral cancer patients beginning as symptoms at the time of diagnosis, and becoming greater physical difficulties as the disease progresses (Inchingolo *et al.*, 2020; de Melo *et al.*, 2019; Zohoori *et al.*, 2012). However, the description of physical experiences faced by oral cancer patients are thought-provoking difficulties including pain, dryness of mouth, sticky saliva, alteration of facial structures, and problems with eating and speaking (Goswami and Gupta, 2019; Röing *et al.*, 2009). Physical symptom burdens varies in correspondence to the stage of cancer and type of treatment, and careful

attention is needed since these burdens may lead to significant disability and worsened quality of life as the disease progresses (Ou *et al.*, 2022; Hanna *et al.*, 2015).

Pain is the most common complaint and frequently reported by oral cancer patients (Viet and Schmidt, 2012). It is a well-known fact that oral cancer patients experience orofacial pain which is one of the initial symptom that may lead to dental visit and subsequent diagnosis (Lam and Schmidt, 2011). While primary surgery can almost completely relieve the discomfort and pain due to oral cancer, patients may also require radiation therapy (Kolokythas *et al.*, 2007). The oral cancer patients receiving radiation therapy reported pain during therapy which typically peaks at the two-week mark, and continues through the three-month mark (Epstein *et al.*, 2009). Over 50% of oral cancer patients experienced ongoing pain, and about 80% of patients reported both ongoing pain and periodic pain episodes (Epstein and Miaskowski, 2019).

Pain can be triggered by functional movements such as speaking or eating, and sometimes as a neuropathic pain prompted by chemotherapy and radiotherapy (Datta and Pai, 2006). Patients may also experience pain after receiving treatment as a side effect of the treatment or certain anti-cancer drugs that have been used (Kanchan *et al.*, 2019). The changing characteristics of oral cancer pain makes it difficult to manage. To some extent, near-total pain relief can be provided to patients that have undergone complete surgical resection (Kolokythas *et al.*, 2007). However, in most cases complete excision of the area is not possible due to the anatomical positioning of the cancer or patients are weak to undergo surgery (Viet and Schmidt, 2012; Amarasinghe *et al.*, 2019). The severity of pain for patients without complete surgical resection increases as the disease progresses, leading to oro-facial restrictions (Ye *et al.*, 2011).

The intensity of pain frequently shows improvement after post-operative stage for a period of one year, however, the likelihood of pain improvement in patients with advanced stages of oral cancer may be feeble (Schliephake and Jamil, 2002). Interestingly, sometimes patients may under-report their physical sufferings because of the fear of being weakened further by the disease, or fear of dependence on opiates (Moore *et al.*, 2004). In other scenarios, patients may tend to increase the usage of opiates, and the medication usually causes vomiting, nausea, and respiratory depression which leads to further reduction in QOL of oral cancer patients (Viet and Schmidt, 2012; Ko *et al.*, 2020). The extent of this physical symptom burden of pain can be explained by the virtue of its ability to impair patients ability to speak, masticate, drink, and prohibiting them from carrying out inter-personal relationships (Viet and Schmidt, 2012). The consequences of pain are severe enough for patients to lose interest in their normal social activities (Scott *et al.*, 2006; Chen, 2012). The combination of inability to speak and masticate properly can cause prolonged disruption to patients' QOL; oral cancer survivors reported fear about sounding unusual in front of other people for three months to twelve years post-diagnosis (Philiponis and Kagan, 2015; Rigoni *et al.*, 2016).

Functional impairment of the oral cavity and issues such as dry mouth, taste disturbances, poor dentition, inability to open the mouth are also well known aftermaths of receiving treatment for oral cancer (Crowder *et al.*, 2018). Patients may experience dry mouth at early stage, describing it as an unusual and unpleasant sensation in the mouth, as if something is stuck (Larsson *et al.*, 2007). There may also be some eating difficulties related to dry mouth such as greater sensitivity to spicy food, texture, and temperature (McLaughlin and Mahon, 2014). Subsequently, patients may have great difficulty in

swallowing after treatment and describe their experience as ‘pure hell’ (Patterson *et al.*, 2015). These issues make it significantly difficult for patients to chew or swallow (Cousins *et al.*, 2013). The simple joys of life such as eating food becomes difficult due to pain. Patients experiencing swallowing difficulties may need tube feeding for sustenance of their dietary status and require months of swallowing therapy (Sinha *et al.*, 2019). These problems aggravate malnutrition, causing loss of weight and fatigue, compromising the QOL further (Borges *et al.*, 2010). Upon completion of the treatment, patients will experience a decrease in the severity of the symptoms, but some declare swallowing is highly unpredictable while others still have similar suffering to the past (Patterson *et al.*, 2015).

Many patients experienced incapability to be free from symptoms which raise concerns about the difficulties becoming permanent (Molassiotis and Rogers, 2012; Ottosson *et al.*, 2013). These multifaceted physical experiences lead patients to have a gloomy view of their future and may reduce their chances of survival (van Wayenburg *et al.*, 2010). Acceptance of the physical limitations through the oral cancer trajectory is multifaceted, and the coping strategies varies among patients (Platteaux *et al.*, 2010). It is believed that some patients feel denial and shame because of their physical limitations leading to avoidance of social gatherings, while others develop new stronger relationships (Griffiths *et al.*, 2008). Similarly, some patients recover or adjust to the alterations in their life and identity, while others have low spirits about their future (Lang *et al.*, 2013).

Facial alterations is another most commonly reported concern related to physical experiences of oral cancer patients (Costa *et al.*, 2014; Fingeret *et al.*, 2013; Foxwell and Scott, 2010; Röing *et al.*, 2009). Facial alterations are not only a consequence of surgical

treatment but sometimes the cancer itself (Costa *et al.*, 2014; Thompson *et al.*, 2020a). The extent of facial alteration is dependent on the site of the tumor, disease progression, and type of treatment received (Garden *et al.*, 2004; Thompson *et al.*, 2020a). Despite advancement in treatments, facial alteration is the price paid for receiving treatment for oral cancer (Costa *et al.*, 2014; Threader and McCormack, 2016). After receiving surgery, patients report varying facial alteration experiences that may prompt the need for wide-ranging functional and aesthetic rehabilitation (Fingeret *et al.*, 2013). At the pre-operative period, 77% patients were found reporting concerns about their facial appearance, scars after surgery, loss of dentition, or loss of hair due to radiotherapy (Fingeret *et al.*, 2010). Immediately as the post-operative period begins, patients have reported being strongly affected by their facial alterations which frequently led them to social isolation (Chen, 2012). This concern may become a continuous pattern for the years to follow (O'Brien *et al.*, 2012; Yang *et al.*, 2010; Röing *et al.*, 2009).

Furthermore, facial alterations may also become a basis for inability to eat or swallow, which may lead to patients experiencing malnourishment before initiation of adjuvant treatment such as radiotherapy and/or chemotherapy (Harriët Jager-Wittenaar *et al.*, 2011; Langius *et al.*, 2010; Elting *et al.*, 2007; Chasen and Bhargava, 2009). As the treatment progresses, facial alterations become more obvious in patients, and evidence suggests that in such cases a prominent increase in malnourishment ranging from 44% to 88% can be found (Unsal *et al.*, 2006; Chasen and Bhargava, 2009; Elting *et al.*, 2007; Ehrsson *et al.*, 2015; Harriët Jager-Wittenaar *et al.*, 2011). It has been recognized that malnourishment in such patients is associated with weakened physical functioning, lowered immune system, radiotherapy induced toxicities, weakened chemotherapy response, impaired

QOL, and increased risk of mortality (Harriät Jager-Wittenaar *et al.*, 2011; Meyer *et al.*, 2012; Crowder *et al.*, 2018; Haughey and Sinha, 2012). Moreover, permanent facial alterations due to treatment can cause lifelong physical experiences by damaging the ability to chew, swallow, speak, and sometimes alter the ability to see, smell and hear (Hu *et al.*, 2009). However, in some oral cancer patients, personalized intraoral prosthetic appliance made by the maxillofacial prosthodontist team, and the rehabilitation aid provided by a speech therapist may be able to bring improvement in swallowing and speech to some extent (Depprich *et al.*, 2011; Haug, 2007).

Although research has revealed that facial alterations are inevitable part of oral cancer treatment, its impact is known to be beyond physical limitations, with statements pronounced by oral cancer patients such as “feeling lessened” (Foxwell and Scott, 2010; Wang *et al.*, 2018; Flexen *et al.*, 2012). Oral cancer patients have reported not only encountering functional disability due to facial alteration, but also face psychological distress and social stigmatisation as part of their oral cancer treatment journey (Threader and McCormack, 2016; Bonanno and Esmaeli, 2012). Evidence suggests that the extent of facial alteration is negatively associated with patients’ psychological and social well-being, thus impacting their QOL (Clarke *et al.*, 2014; Rana *et al.*, 2014; Thompson *et al.*, 2020a).

2.1.2 The psychological experiences of oral cancer

Individuals who are diagnosed with oral cancer frequently report death to the forefront. Psychological distress in oral cancer patients is a reason why patients start questioning themselves about their existence. A considerable number of research on