Oral and Oropharyngeal Cancers Surveillance and Control in Alberta: A Conceptual Framework

by

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Abstract

Background: Oral cancer is a deadly public health issue worldwide with steady survival rate (50%-60%) for decades. Alberta is positioned as the 4th province for oral cancer incidence and related death prevalence in Canada. While the importance of early detection of oral cancer is well-documented, Alberta lacks a solid oral cancer screening and prevention strategy, and little is known about the province's oral cavity cancer (OCC) and oropharyngeal cancer (OPC) status.

Objectives: The overall goal of this PhD research was to generate a comprehensive knowledge of oral and oropharyngeal cancer in Alberta and develop a conceptual framework that may contribute to improving health of Albertans.

Methods: A convergent mixed-method design was used wherein findings from quantitative and qualitative data analyses were merged. In ***phase 1***, I conducted a scoping review to gather the existing information about OCC and OPC in Alberta including prevalence, demographics, mortality, morbidity, initiatives, allocated funding, and health system functioning. ***Phase 2*** was a population level cross-sectional study, done for the first time in Alberta, to collect oral health profile data and associated risk factors for OCC and OPC from one of the most vulnerable demographic populations in Edmonton. In ***phase 3,*** I used a qualitative design to explore barriers to early detection of OCC and OPC in Alberta at the clinician-patient-system level using initial medical consultation notes of oral cancer patients.

Results: In ***phase 1***, Alberta Cancer Registry data (2005-2017) showed that most of the OCC and OPC lesions were diagnosed at an advanced clinical stage (i.e. III and IV), with a high percentage of them being in stage IV (OCC= 45.2%, OPC= 82.4%). Survival levels were lowest

in rural and First Nations areas. Further, 35% of HPV-associated cancers were linked to oropharyngeal cancers, which were more prevalent in men and younger age groups(Statistics, 2016). No routine public oral cancer screening program currently exists in Alberta. General practitioners/dentists refer patients to specialists, often with long waiting times. In ***phase 2***, a total of 322 participants with a mean (SD) age of 49.3 (13.5) years completed the study. Among them, 71.1% were male, 48.1% were aboriginal, and 88.2% were single. The prevalence of oral cancerous lesions was 2.4%, which was higher than the recorded oral cancerous lesion prevalence in Canada (0.014%-1.42: 10,000) and Alberta (0.011%- 1.13:10,000). The clinical examinations indicated that 55 of the participants (17.1%) presented with potentially malignant oral lesions (PMOL), 176 (54.7%) of participants had oral lesion/inflammatory changes of oral mucosa, and 61.5% had high level of Decayed, Missing, Filled Teeth (DMFT) scores. Risk of cancerous/PMOL was 1.68 times higher in participants living in shelters vs. those living alone. Oral lesion/inflammatory changes of the oral mucosa showed a significant association with cancerous/PMOL ($p<0.001$) compared to those who did not have cancerous/PMOL. In ***phase 3***, five main categories were identified from qualitative analysis of 34 initial medical consultation notes of oral cancer patients: patient appraisal interval, help-seeking interval, formal diagnosis interval, pre-treatment interval, and contributing factors. In addition to biological factors, health-related behaviours, sociodemographic and tumor characteristics, and other risk factors that negatively contributed to early detection of oral and oropharyngeal cancers included factors related to patients, providers, and healthcare system.

Conclusions: The project successfully gathered the information from numerous resources to provide a comprehensive overview of what we already knew and shed light on dark and previously unseen corners of our provincial OCC and OPC challenges. This study revealed that

OCC and OPC patients in Alberta continue to be diagnosed in stage IV, with high mortality rates. The prevalence of oral cancerous/PMOL in the Boyle McCauley Street area, an underserved community in Edmonton, was higher than that of the general population. Our study supports the need for developing opportunistic oral cancer screening and oral health promotion strategies in deprived communities. The main contributors to total patient delay identified in this research were patients' general lack of awareness about early symptoms of oral cancer and high-risk anatomic areas, inaccurate clinical judgement of attending physicians and dentists, and lengthy access to care. A sustainable plan is needed for enhancing public awareness and implementation of a solid curriculum for the training of medical and dental students. Additionally, a mandatory integration of opportunistic screening of oral lesions as part of routine medical and dental health care with a special focus on at-risk patients is strongly recommended.

Preface

This thesis is an original work by Parvaneh Badri. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board for the Project Name: “A Comprehensive Oral Health Needs Assessment Among Underprivileged Communities in Edmonton”, No. Pro00060953, February 8, 2016 (Appendix I). Research ethics approval was also received from the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) for two Project Names: “Oral Cancer Surveillance and Control in Alberta: A Conceptual Framework”, and “Factors Associated with Late Detection of Oral Cancer in Alberta: A Retrospective Qualitative Study”, HREBA.CC-17-0370, September 8, 2017 (Appendix II).

A version of Chapter 2 of this thesis has been published as Badri P, Ganatra S, Baracos V, Lai H, Amin M: Oral Cancer Surveillance and Control in Alberta: A Scoping Review. J Can Dent Assoc 2021;87: l4. I was responsible for the study design, data extraction and analysis as well as the manuscript composition. Ganatra S assisted with data extraction and charting and contributed to manuscript edits. Baracos V and Lai H contributed to data acquisition, interpretation, and manuscript review and edits. Amin M, as the senior author, was involved with concept formation, design, and manuscript composition.

Chapter 3 of this thesis will be submitted the Canadian Medical Association Journal (CMAJ) as Badri P, Lai H, Ganatra S, Baracos V, Amin M: Factors associated with oral cancerous and potentially malignant oral lesions in a high-risk underserved community in Edmonton, Canada: A population-based study. I was responsible for the study design, project

execution, data collection, analysis, interpretation of results, and manuscript composition. Lai H, as second author, was the key expert in research methods and statistical analysis. Ganatra S assisted as a senior clinical examiner in the detection of cancerous and potentially malignant oral lesions in the research field as well as in the interpretation of results and manuscript edits. Baracos V assisted in the interpretation of the results and manuscript composition. Amin M, as the primary supervisor, was closely involved in developing the study design, data collection, data analysis, and manuscript composition.

A version of Chapter 4 of this thesis will be submitted to (TBD) as Badri P, Baracos V, Lai H, Ganatra S, Samim F, Amin M: Factors Associated with Late Detection of Oral Cancer in Alberta: A Retrospective Qualitative Study. I was responsible for study design, development of open-ended questions, project execution, data collection and analysis, interpretation of results, and manuscript composition. Baracos V, who has been a database expert on consecutively diagnosed head and neck cancer patients in northern Alberta since 2004, supported data acquisition concerning the diagnosis of cancers of oral and oropharyngeal cancer and contributed to manuscript review and edits. Lai H contributed to research methods and manuscript composition. Ganatra S assisted as team expert for the oral and oropharyngeal cancer domains. She was involved in interpretation of results, and manuscript review and edits. Samim F contributed to the generation of the qualitative open coding process of analysis units and intercoder agreements. Amin M, as senior author, was closely involved in developing the study design, data collection, data analysis, and manuscript composition and edits.

Dedication

Every challenging work requires self-effort as well as the support and guidance of those closest to your heart. My humble effort is dedicated to my sweet and loving:

Husband, Fariborz,

for your touching love, friendship, patience, and care in my everyday journey.

Parents,

whose affection, love and prayers day and night helped me achieve such honour.

Brothers,

who are so much a reason for who I am today. Thank you for your great support and continuous care.

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I was also blessed during this project to have the exceptional group support from some wonderful individuals for the Boyle McCauley Street study. I would like to express my special thanks to **Dr. Firoozeh Samim**, **Dr. Rafael Figueiredo, Dr. Sharon Compton**, **Dr. John Valentine**, **Nadia Kobagi**, **Rana Dahlan**, **Medha Singh, Silvia Ortiz, Barbara Gitzel**, **Elnaz Yazdanbakhsh**, **Ivana Prada**, **Sanaz Bohlouli**, **Salima Asifali, Maham Masoud, Mahnoor Shahab**, **Karin Frederiksen**, **John Manolakos**, **Lana-Rae Lavergne** whose unconditional support helped to accomplish the Boyle McCauley Street study project.

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Table of Contents

List of Tables

List of Figures

In writing the present thesis, I used the first person “WE” instead of “I”, which is expected in reports of qualitative studies to expresses my deepest respect to all whose collective efforts supported my work. These efforts were garnered through reviews, general input, and valuable experience and expertise kindly provided by my supervisor Dr. Maryam Amin, and supervisory committee members Dr. Seema Ganatra, Dr. Vickie Baracos, Dr. Hollis Lai in the process of doing my PhD project.

1 Chapter One: Introduction

In this chapter, I first briefly describe oral cavity and oropharyngeal cancer including the respective definitions, clinical representations, and treatments. I then discuss the epidemiological characteristics of oral and oropharyngeal cancer from global, Canadian, and Albertan perspectives. Next, I present the problem statement, followed by my research questions and objectives. Finally, I outline the study's methodology.

1.1 Background

1.1.1 Oral Cancer

The literature currently lacks consensus on the definition of oral cancer. Multiple terms are used interchangeably, such as oral cavity cancer (OCC), oral cancer (OC), and oral squamous cell carcinoma (OSCC). Furthermore, the reported malignancies of oral cavity and oropharyngeal anatomical subsites of Head and Neck cancer are often grouped together. This can cause confusion, given the etiological role of human papillomavirus (HPV) infection in oropharyngeal cancer and its different responses to treatment and survival outcomes. In this study, oral cancer is defined according to the International Classification of Disease for Oncology, Third Edition, Topographical Codes- C00-C14: malignant neoplasm of lip, oral cavity and pharynx, in adherence to the 10th version (ICD-10) WHO Version for 2016.

Oral cancer as a subsite comprises nearly 30% of the malignancies of head and neck (Alberta Health Services, 2014, February). These types of cancers, which arise from squamous

epithelial cells lining the mucosal surfaces of the oral cavity, pharynx (nasopharynx, oropharynx, hypopharynx), larynx, paranasal sinuses and nasal cavity, and salivary glands, are referred to as squamous cell carcinoma (SCC) (National Cancer Institute, 2017, March 29). SCC accounts for more than 90% of oral cavity cancer cases (Alberta Health Services, 2014, February). The incidence and mortality rates of oral cavity are not well-documented, as they are often reported in aggregation with oropharyngeal cancers (Alberta Health Services, 2014, February). Anatomic sites of oral cavity cancers comprise the buccal mucosa, floor of the mouth, anterior tongue, alveolar ridge, retromolar trigone, and the hard palate (Alberta Health Services, 2014, February). A multifactorial causation is considered for oral cavity cancer and squamous cell carcinoma.

1.1.1.1 Oral Cancer Etiology

The etiological factors of oral squamous cell carcinoma are divided in extrinsic factors (e.g., tobacco smoke, alcohol, lifestyle, habits and demographics) and intrinsic factors, which include systemic or generalized states such as malnutrition or iron-deficiency anemia, periodontal disease, radiation, and immune deficiency (Alberta Health Services, 2014, February; Neville, Damm, Allen, & Chi, 2015). Genetic factors could also influence geographic variations in the incidence of disease (Alberta Health Services, 2014, February). There is a well-documented association between oral cavity SCC and precancerous lesions (Neville et al., 2015; Yanik et al., 2015; Yardimci, Kutlubay, Engin, & Tuzun, 2014). The development of oral cancer is classified by the World Health Organization (WHO) as a two-step process. Oral cancer first appears as a pre-cancerous lesion with altered tissue structure and subsequently develops into a malignant stage, which is more likely to occur in persons with precancerous lesions than its apparently normal counterpart (Steele & Meyers, 2011).

By definition, precancerous lesions are a group of clinical white or red ulcerations, or a combination of these conditions. This stage is usually asymptomatic and has a risk for malignant transformation at different ratios (Kerr AR., 2010). The terms 'precancerous', 'premalignant' or 'potentially malignant oral lesions' (PMOL) are often used interchangeably in the literature (Kerr AR., 2010).

The most common PMOL is *oral leukoplakia*, which represents 85% of such lesions (Neville et al., 2015). This form of PMOL is defined by the WHO as a white patch or plaque of oral mucosa that cannot be rubbed off and cannot be categorized clinically as any other disease. According to the literature, the prevalence of leukoplakia is 1.1% to 11.7%, with a 1% to 9% risk for transformation to an invasive condition for homogenous-type changes and a more than 70% risk for non-homogenous lesions such as *proliferative verrucous leukoplakia* (PVL) (Yardimci et al., 2014) . The next most common PMOLs are *Erythroplakia* (red patch or plaque) and *Erythroleukoplakia* (red/white changes +/- ulceration), with a prevalence of 0.02%-0.83% and a high risk of malignant transformation of 14% to 50%, respectively, followed by *oral lichen planus*, with a prevalence of 0.5%-3% and a 0% to 10% risk of malignancy, and *oral submucous fibrosis*, with a 7%-30% transformation risk for malignancy (Yardimci et al., 2014).

1.1.1.2 Oral Cancer Screening

Screening is an important concept used in medical practice and public health. It is characterized by the application of one or more tests or examinations to people who presumptively are healthy and disease-free in order to detect those who may have disease (Speight et al., 2017). In the oral cancer context, however, screening is defined as identifying changes through the application of a visual oral examination or test, which might predict or precede the likelihood of oral cancer

development in individuals, who would then be referred to specialists for a definitive diagnosis (Speight et al., 2017). There is no national oral cancer screening to date, despite many researchers' attempts to evaluate screening mythologies, including a 15-year follow-up in a cluster-randomized controlled trial in Kerala, India (Sankaranarayanan et al., 2013).

The implementation of a screening test in a defined population on a regular basis for a particular disease requires evaluating the screening program and meeting a number of criteria, including maximum public health benefit and cost effectiveness. There are 19 criteria required by the United Kingdom's National Screening Committee, the United States' National Cancer Institute, and the U.S. Preventive Services Task Force for implementing a screening program (Speight et al., 2017). By 2016, oral cancer screening had met only nine.

Sensitivity and specificity are measures used to examine the validity of a particular test. A higher rate of false positives is expected for the most sensitive screening test, which disqualifies it for a population-based screening (Miles, Cockburn, Smith, & Wardle, 2004). In contrast, higher test specificity at the population level minimizes false-positive results, thus reducing physical and psychological harms (Miles et al., 2004). Although a conventional visual oral examination showed a fluctuating degree of sensitivity of 0.50-0.99 and a consistently high scale of specificity of >0.80, more RCTs are warranted to support a population-wide oral cancer screening program at the highest level of evidence for practice (Speight et al., 2017).

Advocated alternatives to routine population-wide oral cancer screening are opportunistic screening and targeted screening. Opportunistic screening may lead to early detection of a particular disease in individuals who have presented to health care providers for other purposes (Lim, Moles, Downer, & Speight, 2003). Targeted cancer screening, on the other hand, refers to

screening a specific group of a population considered at higher risk of developing disease and therefore more likely to benefit from screening (Marcus, Freedman, & Khoury, 2015).

Early detection of potentially malignant oral lesions is recognized by oral health clinicians through visual oral examinations with validated sensitivity and specificity (Philip et al., 2018). In addition, the Kerala study showed that the oral cancer mortality rate can be significantly reduced in high-risk populations by visual oral screening (Sankaranarayanan et al., 2005). Where population-based screening has not yet met the required criteria to be implemented, opportunistic oral cancer screening of all patients in a primary care environment (including general dental practices) and screening targeting high risk groups for signs of potentially malignant oral lesions are advocated in the literature (Nagao & Warnakulasuriya, 2020; Philip et al., 2018; Speight et al., 2017).

1.1.1.3 Clinical and Radiographic Features

Oral squamous cell carcinoma is often diagnosed in older men who have history of asymptomatic alteration of oral mucosa for about four to eight months prior to pursuing medical attention. The lack of notable pain in the early stages of epithelial dysplasia causes delays in seeking professional health care, with longer delays of 8 to 24 months among lower socioeconomic and underserved populations (Neville et al., 2015). The clinical features of oral squamous cell carcinoma include an *exophytic lesion*, which is characterized as irregular, fungating, papillary or verruciform, and an *endophytic lesion*, which is often centrally depressed, irregular, and with a rolled border (Neville et al., 2015). The lesion displays various colours from pink to white to red, or a combination of these colours according to the amount of vascularity and keratin (Neville et al., 2015). The typical radiographic feature for oral cavity cancer

represents “moth-eaten” radiolucency with ill-defined or ragged margins that show destruction of the underlying bone (Neville et al., 2015). The tissue biopsy and histopathological examination is recognized as the gold standard diagnosis for oral squamous carcinoma (Neville et al., 2015).

1.1.1.4 Treatment and Prognosis

For decades, the survival rate for oral cancer has remained steady (50-60%), despite advances in cancer management (C. W. LeHew, J. B. Epstein, L. M. Kaste, & Y. K. Choi, 2010; Lingen, Kalmar, Karrison, & Speight, 2008). Oral cavity cancer treatment consists mainly of surgical excision, radiotherapy, and chemotherapy or a combination of these approaches according to the clinical staging of the case and the accessibility of the tumor (Alberta Health Services, 2014, February). The complexity of subsite tumors and their anatomical locations demands a multidisciplinary team of health professionals. Treatment of early oral cancer stage T1/T2 can often be managed by surgery or/and radiotherapy, with five-year survival rates based on the patient’s history and the dimension, penetration depth, and location of the tumor (A. Ross Kerr, 2010). Lateroventral tongue, floor of mouth, soft palate, tonsil, base tongue, and oropharynx are considered high-risk sites for invasive malignancy (A. Ross Kerr, 2010). Additionally, there is a growing debate around practicing neck dissection at early stages, given the 30% chance of lymph nodes metastasis and 10-40% of occult (or subclinical) involvement, which demand more randomized controlled trial evidence (Wang et al., 2019). Neck dissection improves survival rates, but has a dramatically negative impact on quality of life caused by “shoulder syndrome” post-surgery (Wang et al., 2019), among other significant issues. Selective neck dissection

techniques with removal of only selected cervical lymph node groups was also associated with decreased morbidity (Neville et al., 2015).

Cases involving advanced stage III and IV require complex management with a poor prognosis. A combination of surgery, radiation therapy, and chemotherapy with/out surgery is employed in these cases.

1.1.2 Oropharyngeal Cancer

Oropharyngeal carcinoma (OPC) is an additional subsite entity of head and neck cancers and anatomic sites of involvement include soft palate, base of tongue, tonsillar region (i.e., tonsil, tonsillar fossa, and pillars), and the posterior pharyngeal wall. In the past two decades, OPC has shown a rapid increase in incidence rate globally (Castellsagué et al., 2016; S. Habbous et al., 2013). The incidence of oropharyngeal cancer often has been reported in association with oral cavity cancer, further complicating its public health impact (de Camargo Cancela, de Souza, & Curado, 2012). The current worldwide increase in reported OPC cases has caused substantial interest in researchers to investigate the risk factors implicated in the new OPC trend.

1.1.2.1 Oropharyngeal Cancer Etiology and Risk Factors

The etiology of OPC is multifactorial; however, tobacco and alcohol consumption have been established as primary risk factors for OPC (Sturgis & Cinciripini, 2007; Sturgis, Wei, & Spitz, 2004). There is a 10- to 25-fold lifetime risk of developing OPC for moderate to heavy smokers (American Head and Neck Society, 2016). While chronic light to heavy alcohol usage is known to be associated with OPC, a combination of tobacco and alcohol usage has been shown to reinforce the risk of developing malignancy (Mashberg, Boffetta, Winkelman, & Garfinkel,

1993). In addition to cervical cancer, the attribution of the human papilloma virus (HPV) in developing OPC is scientifically recognized (Neville et al., 2015). There is a distinct difference between the risk profile of individuals diagnosed with HPV-associated OPC compared with its non-associated HPV counterpart. In contrast with non-associated HPV cancer patients, there is growing evidence indicating strong associations between HPV-positive cancers and being a young white individual in a high socioeconomic class with no history of tobacco and alcohol use but a history of sexual activities with multiple partners (Gillison et al., 2008; Heck et al., 2010). Approximately 70% to 80% of OPCs occur in the tonsillar region, which also is the preferred location for HPV-associated oropharyngeal infection (Neville et al., 2015).

1.1.2.2 Clinical Features

The clinical presentation of oropharyngeal carcinoma is basically similar to oral cavity squamous cell carcinoma. The posterior location of oropharyngeal carcinoma often causes longer diagnostic delays than oral cavity carcinoma with larger tumors and a higher proportion of distant metastases(Neville et al., 2015). The common presentation of oropharyngeal carcinoma, as indicated by patients, is persistent sore throat, difficulty in swallowing (dysphagia), and painful swallowing (odynophagia). The pain has dull/sharp characteristics and is often referred to the ears (Neville et al., 2015).

1.1.2.3 Treatment and Prognosis

The currently accepted standard is for a multidisciplinary team of health professionals to evaluate a patient upon confirmation of a cancer diagnosis. The patient then undergoes imaging investigations for a thorough evaluation of the tumor, such as a computed tomography (CT

scan), magnetic resonance imaging (MRI) of the neck to evaluate the pharynx and lymph nodes in the neck, a CT scan of the chest to evaluate the presence of metastatic cancer in the lungs or lymph nodes of the chest, and in advanced stage cases, positron emission tomography (PET scan) for pre-treatment evaluation (American Head and Neck Society, 2016). In comparison with non-HPV oropharyngeal cancer patients, HPV-associated oropharyngeal patients have shown much better response to treatment and higher survival rates due to the radiosensitivity of these tumors (Steven Habbous, Chu, Lau, Schorr, Belayneh, Ha, Murray, O'Sullivan, et al., 2017; Petrelli, Sarti, & Barni, 2014). Detection of the high-risk HPV E6 and E7 oncogene expression analysis by quantitative reverse transcriptase polymerase chain reaction (qRT-PCR) is the gold standard for diagnosis of HPV-associated carcinoma using fresh-frozen tissue and demanding a sophisticated technique. In comparison, immunohistochemistry performed on formalin-fixed paraffin-embedded tissue is widely available for detection of p16 with a high sensitivity surrogate for transcriptionally active high-risk HPV infection in oropharyngeal cancer (Neville et al., 2015).

1.1.3 Epidemiology of Oral and Oropharyngeal Cancers

The epidemiological approach assists in describing the burden and nature of oral cavity and oropharyngeal cancers in a population, which is the mainstay of disease surveillance (D. I. Conway, M. Purkayastha, & I. G. Chestnutt, 2018). Such insights are necessary for the identification of cancer distribution, patterns, and risk factor determinants. The epidemiology of oral cavity and oropharyngeal cancers show various incidences according to geographic location and population demographics, socioeconomic, and associated risk factors covered through geographic locations and descriptive patterns (Gupta et al., 2016).

1.1.4 Regional Variations and Descriptive Patterns

The WHO has reported variations in oral cancer distribution across the five continents (Cancer, 2012). A study among countries with available reliable administrative oral cancer data identified India with the highest and Belarus with the lowest incidence rates (Sankaranarayanan, Ramadas, Amarasinghe, Subramanian, & Johnson, 2015).

1.1.4.1 Europe

A total number of 73,860 new oral cancer cases and 25,770 new oropharyngeal cancers were reported in Europe in 2012 (Gupta et al., 2016). The Russian Federation and Germany showed a high incidence of oral and pharyngeal cancer, while Iceland and Cyprus identified a lower incidence (Gupta et al., 2016). Although central and eastern European countries were reported to have a relatively low incidence rate in contrast to western European countries, their mortality rates associated with OCC and OPC were higher (Warnakulasuriya, 2009). France and Hungary showed the highest estimated age-standardised incidence among males and Denmark and Hungary among females (J. Ferlay et al., 2013).

The most common reported anatomical site for oral cancer within the European population is the tongue (Gupta et al., 2016). Europe has a similar five-year survival rate to 50% of cases worldwide, mostly due to late-stage diagnosis, despite the visual accessibility for clinical examination and potential for early diagnosis (C. W. LeHew et al., 2010; Lingen et al., 2008). The age-standardised incidence for the United Kingdom in 2012 was reported as 4.6 per 100,000, with a mortality rate of 1.0 (Cancer, 2012). Central and western Europe showed the highest mortality rates. Similarly, new studies support the changing trend in favour of oral and

oropharyngeal cancers incidence and mortality among those younger than 40 years, both in Europe and globally, which has been attributed to lifestyle and sexual behaviour changes (Gupta et al., 2016).

1.1.4.2 Asia

Oral cancer continues to be a deadly public health challenge in India, Pakistan, Taiwan and China, where chewing betel quid with or without tobacco or areca nut is a common habit (Sankaranarayanan et al., 2015). In 2012, an estimated 168,850 new cases of lip and oral cavity cancer were diagnosed in Asia. It was the 12th most common cancer in the region, which ranked 8th for all cancers in South-Central Asia among men with an age-standard incidence rate (ASIR) of 9.9 (Cancer, 2012). In addition, a 3.8 standard incidence rate and a 2.2 age-standardised mortality rate (ASMR) were reported for Asia in 2012. However, a lower standard incidence rate of 2.1 was reported for oral cavity cancer in the eastern and western parts of Asia (Cancer, 2012). In South Asian countries, including Bangladesh, India, Pakistan and Sri Lanka, oral cancer was found to constitute one-third of all reported cancers. Sri Lanka showed the highest age-standard rate of 10.3 (N. W. Johnson & Amarasinghe, 2016), while China showed a 3.79 crude incidence rate for oral cancer, accounting for 1.3% of all cancers (S.-K. Zhang et al., 2015). The most common anatomic sites of oral cancers in South and Southeast Asia are buccal mucosa, followed by tongue (World Health Organization: International Agency for Research on Cancer, 2020b). Consumption of various forms of tobacco in this part of the world is attributed to 90% of the oral cancer cases (N. W. Johnson & Amarasinghe, 2016). The five-year survival rate for India is less than 35%, which far less than the 50%-60% rate worldwide. The five-year survival rate for

China, the Republic of Korea, Pakistan, Singapore, and Thailand is between 32% and 54% (Sankaranarayanan et al., 2010).

1.1.4.3 Africa

Data have been collected from a few available hospital-based cancers in Africa (Sankaranarayanan et al., 2015). An estimated 17,276 new cases of oral cavity and lip cancers were detected in 2012, positioning these cancers as the 15th most common in Africa overall and the 7th most common in middle Africa (Cancer, 2012). The standard incidence rate for the African continent in 2012 was 2.6 per 100,000, 1.5 per 100,000 in western Africa, and 4.0 per 100,000 in southern Africa. The age standardised mortality rate for Africa in general was 1.6, while the rate in eastern and middle Africa was 2.2% and 2.3%, respectively, as reported in 2012 (Cancer, 2012).

1.1.4.4 Oceania

In 2012, a total of 3,631 new cases of oral cancer were diagnosed in the Oceania region, with an age-standardised incidence rate of 7.4 and an age-standardised mortality rate of 1.9 (Cancer, 2012). Oral cancer was the 9th most common cancer in Oceania, with an 8.8 standard incidence rate. Oral cancer in New Zealand, on the other hand, was the 14th most common cancer, with an age-standard incidence rate of 5.5 (Cancer, 2012). The reported high prevalence of oral cancer in Papa New Guinea and the Solomon region was attributed to smoking tobacco and chewing betel quid. Vanuatu was reported to have the lowest incidence rate of new oral cancer cases (Lumukana & King, 2003).

1.1.4.5 South America

Across all geographic region in South America, the age-standardized incidence rate was found to be 3.8 per 100,000 and the age-standardized mortality rate was 1.4 (Cancer, 2012). Oral cancer was the 7th most common cancer in Brazil in 2012, with 6,930 new cases and 3,020 death in that year (Cancer, 2012). The age-standardized incidence rate for Brazil was 7.2 per 100,000 people (Cancer, 2012).

1.1.4.6 North America

1.1.4.6.1 United States

Oral cavity and oropharyngeal cancers make up 3% of all malignancies of men and 2% of females in the United States (Siegel, Miller, & Jemal, 2019). The reported estimate of new oral and oropharyngeal cancers in 2019 for the United States was 53,000, comprising 38,140 males and 14,860 females. The total 2019 estimated death number was reported as 10,860, comprising 7,970 males and 2,970 females (Siegel et al., 2019). Black patients have a lower survival rate and later stage diagnosis for oral cavity and oropharyngeal in the United States (Siegel et al., 2019). Across all geographic locations in the Unites States, the age-adjusted incidence rate for OCC and OPC was estimated as 11.4 per 100,000 for both sexes, while the age-adjusted mortality rate for both sexes was reported as 2.5 (National Cancer Institute: Surveillance, 2020).

In the U.S., oral cancer is the 11th most common cancer among men(National Cancer Institute: Surveillance, 2020), whereas in Mexico, it is the 13th most common (Cancer, 2012). In contrast to the slight decrease in oral cancer incidence in men explained by controlling the tobacco epidemic, the incidence and mortality rates of oropharyngeal (mostly tonsils and base of

tongue) increased rapidly from 2012 to 2016. This increase may be explained by the increase in papillomavirus infection due to changes in sexual behaviour in younger people with regard to oral sex practices (Hashibe & Sturgis, 2013; Siegel et al., 2019).

Furthermore, a study on ethnic groups in the U.S. found an increasing rate of tongue cancer among young white women and higher rates among Black, Hispanic and Asian female immigrants (Brown, Check, & Devesa, 2012). There was a more than five-fold regional variation within the United States for mortality rates, state by state (N. W. Johnson & Amarasinghe, 2016). This was explained by a combination of regional variations of mixed ethnicity, socioeconomic differences, prevalence differences, and severity of risk factors such as high smokeless tobacco usage in the southern states (N. W. Johnson & Amarasinghe, 2016).

1.1.4.6.2 Overview of Canadian Oral Cancer Status

Oral and oropharyngeal cancer is a public health burden in North America, with 53,000 diagnosed new cases and 9,750 deaths in 2019 (The Oral Cancer Foundation). According to 2020 Canadian Cancer statistics (CCS), 5,400 Canadians were anticipated with oral cancer (3,700 males and 1,650 females), of which 1,500 died (1,050 males and 440 females) (Canadian Cancer Society, 2020). Oral cancer is three times more common than cervical cancer and almost twice as common as liver cancer, based on a 2009 Government of Canada report (Government of Canada, 2019, November).

In the past, squamous cell carcinoma of the oral cavity and pharynx was known as a disease of the elderly with a long history of tobacco and alcohol consumption (Nichols et al., 2013). However, in Canada, there is indirect evidence in population-based studies showing

changes in trends of oral and oropharyngeal cancers regarding sociodemographic, etiology, and survival. The success of public health initiatives since the 1960s led to substantially decreased smoking rates and in parallel, to a decline in the rate of oral squamous cell carcinoma (Nichols et al., 2013; Reid, Hammond, Burkhalter, & Ahmed, 2013). In contrast, oropharyngeal carcinoma associated with human papillomavirus increased dramatically among young people and non-smokers, with advanced nodal disease compared to HPV-negative cases. Similar to the U.S., this trend has been attributed to changes in sexual practices regarding oral sex and sexually transmitted infection of HPV (D'Souza et al., 2007). Similarly, the most commonly diagnosed anatomic subsites with oropharyngeal carcinoma were tonsils, followed by the base of the tongue, with improvement in the 5-year survival rate, particularly for tonsillar carcinoma (A. Auluck et al., 2010; Nichols et al., 2013).

According to 2018 Canadian Cancer Statistics (CCS), 53% of all oral carcinomas were diagnosed at stage IV. This report confirmed 100% availability of oral and oropharyngeal cancer staging data for all Canadian provinces, except Newfoundland and Labrador (80.5%), and Northwest Territories (36.6%). In addition, 2018 CCS reported an estimated total of 4,700 new cases of oral cancer (3,200 males and 1,450 females). The position rank for the incidence rate of new cases for both sexes was 13 (9 for males and 14 for females). The position rank for the mortality rate for both sexes was 16 (13 for males and 17 for females). The ASIR for both sexes was 11.9 (17.1 for males and 7.1 for females) and the ASMR for both sexes was 3.1 (4.6. for males and 1.8 for females). The total number of deaths was 1,250 (850 males and 400 females). The five-year survival percentages for both sexes were 63% (60% for males and 68% for females). In their summary of key cancer control and outcome characteristics across Canada, 2019 CCS estimated that at least 50% of cancers are preventable and screening programs can

detect treatable precancerous lesions. This report also indicates that opportunistic early detection is available and that survival rates are 50%-79%. The 2019 estimated total number of new cases (5300) and mortality (1450) shows an increase trend compared to the just released 2020 estimated value of 5,400 new cases of diagnosed oral cancer and 1,500 deaths. The available Canadian population-based studies across the country are supportive of OCC and OPC disparities, with higher incidence rates among the most socioeconomic deprived population (Ajit Auluck et al., 2014).

1.1.4.6.2.1 Alberta and Oral Cancer Status

In Alberta, oral cancer is positioned as the 13th most common cancer (Alberta Health Services: Healthier Together, 2018b). According to 2019 Canadian Cancer Statistics, 490 individuals (350 males and 140 females) were diagnosed with oral cancer in Alberta (ComPARe: Canadian Cancer Society, 2019). Evidence supports a trend change of older age to youngers for developing oral and oropharyngeal cancers, with a beginning age of 45 keeping higher prevalent for males (Alberta Health Services: Healthier Together, 2018b). Further, the literature shows that in Alberta, 41% of new cases of oral cancer were linked to tobacco smoking, 17% were associated with alcohol consumption, and 8% were linked to human papillomavirus infection (Grevers et al., 2019; Poirier et al., 2019; Volesky et al., 2019).

The treatment for oral cancer is highly complex because of the variety of tumour subsites and the anatomical constraints of the head and neck. A recent study showed a significant population of oral cancer survivors in Alberta who were younger, male, and diagnosed with oropharyngeal cancers, which corresponds with new trends and pattern changes of oral cancer globally and in Alberta (Song, Vallance, Biron, & Jeffery, 2020). Even though the survival rates

have improved, patients often face serious quality of life issues related to changes in appearance and function, particularly with regard to talking, chewing and swallowing (Alberta Health Services, 2014, February).

1.2 Problem Statement

While the importance of early detection of oral cancer is well-documented, CCS 2018 reported 14.6% of stage I as early diagnosis for oral cancer in Alberta compared to highest range of 33.6 % stage I proportion for Manitoba. Alberta lacks a solid oral cancer screening and prevention strategy. In fact, little is known about the province's oral cancer status among the general population and its underserved subgroups. Therefore, the goal of my PhD research is to address this knowledge gap by first examining the available data on oral cancer in Alberta and then by working with one of the most vulnerable communities in Edmonton to determine their oral health profile and to find barriers to early detection of oral cancer at the clinician-patient level using initial medical consultation notes. Our strategic analysis will create a platform for oral cancer stakeholders to inform policy in Alberta by better understanding the shortcoming and challenges in the provincial health system that cause delays in oral cancer detection (Güneri & Epstein, 2014).

1.2.1 Objectives

The overall goal of this research proposal is to generate comprehensive knowledge of oral cancer in Alberta and develop a conceptual framework that may contribute to improving the health of Albertans. The following three objectives were addressed through three phases that linked up at the end of the study.

1.2.1.1 Specific Objectives

1. To comprehensively summarize oral and oropharyngeal cancer information in Alberta, including prevalence, demographics, initial diagnosis, prevention, management, and research funding allocated for early oral cancer detection.
2. To determine the demographic and oral/general health profile, and the prevalence of adult oral cancer and precancerous lesions of a high-risk population and associated risk factors for oral cancer.
3. To better understand the barriers experienced by clinicians and patients for attaining an earlier-stage diagnosis of oral and oropharyngeal cancers.

1.2.1.2 Research Questions

Phase 1:

- What is the prevalence, demographics, initial diagnosis, prevention, management, and research funding allocated for early stage of oral cavity and oropharyngeal cancer detection in Alberta?

Phase 2:

- What is the prevalence of adult oral cancer and precancerous lesions in the Boyle McCauley Street community, a high-risk community in the city of Edmonton?
- What is the sociodemographic profile of adults living in the Boyle McCauley Street community and what are their risk factor(s) for oral cancer and precancerous lesions?

- What are the prevalence of oral lesion/inflammatory changes of the oral mucosal of adults living in the Boyle McCauley and is it a risk factor for oral cancer and potentially malignant oral lesions?

Phase 3:

- What are the challenges experienced by clinicians and patients regarding early detection of oral cancer in Alberta?

1.3 Methodology

1.3.1 Mixed Method Design

For investigating complex processes and systems in health and healthcare, mixed method research offers powerful tools through conceptualization of the study and integration (Michael D Fetters, Leslie A Curry, & John W Creswell, 2013). This can be accomplished by three basic designs (exploratory sequential, exploratory sequential, and convergent) or four advanced mixed method frameworks in tandem with incorporating one of the basic designs.

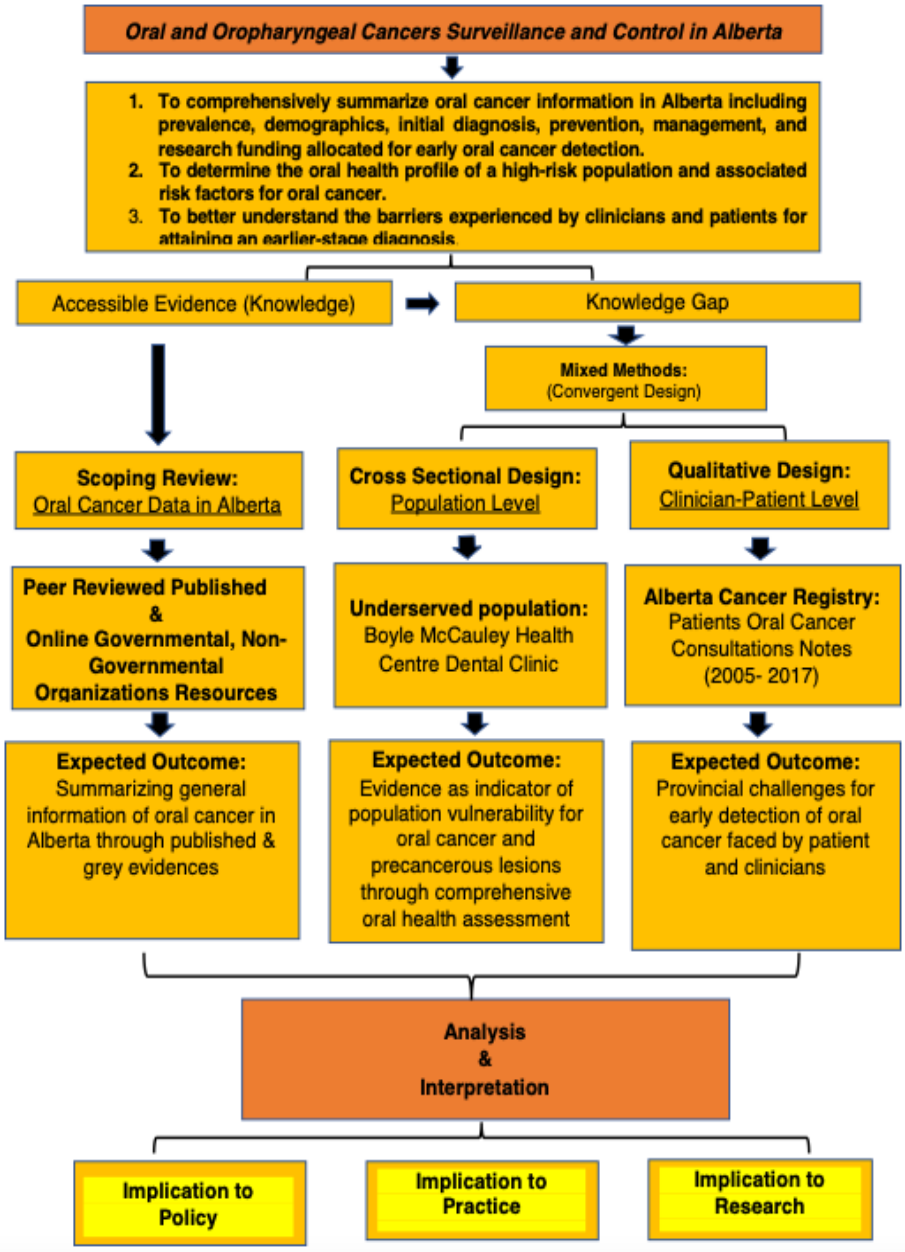
Table 1.1 Levels of Integration in Mixed Methods Research (Fetters et al., 2013)

Integration Level	Approaches
Design	3 Basic designs Exploratory sequential Explanatory sequential Convergent 4 Advanced frameworks Multistage Intervention Case study Participatory—Community-based participatory research, and transformative
Methods	Connecting Building Merging Embedding
Interpretation and Reporting	Narrative—Weaving, contiguous and staged Data transformation Joint display

Table 1.2 Integration through Methods (Fetters et al., 2013)

Approach	Description
Connecting	One database links to the other through sampling
Building	One database informs the data collection approach of the other
Merging	The two databases are brought together for analysis
Embedding	Data collection and analysis link at multiple points

Figure 1.1 Flowchart of the Study Design



For the present study, a convergent mixed method design was adopted (please refer to **Table 1.1** and **Figure 1.1**), where results from a scoping review, quantitative, and qualitative data analyses are *merged* (Creswell, 2014; Michael D Fetters et al., 2013). The *jointly displayed* **(Table 1.2)** interpretation and reporting bring together, organize and conceptualize the qualitative and

quantitative analytical results through visual means, such as figures, graphs and flowcharts to provides new insights that may extend beyond the results gained from each study's findings. In other words, the combined results enable us to see the issue from multiple perspectives (Creswell, 2014; Michael D Fetters et al., 2013). Ethics approval has been obtained for phases 1, 2 and 3 (**Appendices 1. 2**). The three phases of the study are outlined below.

In ***Phase 1***, I conducted a scoping review to gather the existing information about oral cancer in Alberta, including its prevalence, demographics, mortality, morbidity, initiatives, allocated funding, and health system functioning. ***Phase 2*** was a cross-sectional study, where for the first time in Alberta at the population level, oral health profile data and associated risk factors for oral cancer were collected from one of the most vulnerable demographic populations in Edmonton. ***Phase 3*** used a qualitative design to explore barriers to the early detection of oral cancer in Alberta at the clinician-patient level using initial medical consultation notes from oral cancer patients.

1.3.1.1 Scoping Review

In Phase 1, a *scoping review* was conducted in order to collect and summarize general information on the prevalence of oral cancer in Alberta, where and by whom patients with oral cancer are diagnosed for the first time, the allocation of funding for oral cancer early detection research, and the ongoing program for oral cancer prevention in Alberta. A scoping review is a type of review that uses a particular technique to "*map"* relevant literatures and evidence in the field of interest in order to identify the gap of knowledge in the focused phenomenon (Creswell, 2014). In our study, the knowledge gap being filled is oral cancer in Alberta. In contrast to a systematic review, which focuses on a well-defined question with a particular study design, a

scoping review is apt to address broader topics, such as different types of study designs (Arksey & O'Malley, 2005). In addition, unlike a systematic review, where a narrow range of answers is provided to the posed questions and the quality of the included studies is evaluated, scoping review are less likely to answer specific research questions or to apprise the quality of the included studies (Arksey & O'Malley, 2005).

1.3.1.2 Cross Sectional Study

In Phase 2, a cross-sectional study was conducted at the population level to collect oral health profile data and associated risk factors for oral cancer from one of the most vulnerable demographic populations in Edmonton. A cross-sectional study is a popular type of research approach in the health sciences that is used to examine health-related states in a defined population at a single point in time (Public Health Action Support Team (PHAST), 2020). Cross-sectional design is also used to detect trends in disease among specific populations in the oral health epidemiological science (Organization, 2013).

1.3.1.3 Retrospective Qualitative Design

In Phase 3, a *retrospective qualitative content analysis* design was used by implementing the seven steps suggested for conducting narrative clinical document analysis(Sarkar & Seshadri, 2014) .A retrospective medical record study could include pre-recorded, patient-centered data in the form of electronic databases, diagnostic test results, and notes from health service providers to answer one or more research questions (Vassar & Holzmann, 2013; Worster & Haines, 2004). The methodology is popular and commonly employed in epidemiology, quality assessment, professional education/residency training, inpatient care, and clinical research

healthcare-based disciplines (Gearing, Mian, Barber, & Ickowicz, 2006). Attesting to the popularity of the retrospective medical record review technique, about one-quarter of all the research published in three emergency medicine journals adopts this methodology (E. H. Gilbert, Lowenstein, Koziol-McLain, Barta, & Steiner, 1996).

Theory-driven deductive content analysis was used in the present study. Content analysis is employed by researchers to communicate a meaningful description of human perspective and experiences (Kyngäs, Mikkonen, & Kääriäinen, 2019). The methods and resources for inductive and deductive content analysis data collection are similar, e.g., interview observations, meeting documents, and *patient records*. Moreover, in medical science, patient records can be included as input for content analysis (Kyngäs et al., 2019).

Depending on the study aim, deductive content analysis might apply either a structured or an unstructured matrix of analysis (Kyngäs et al., 2019). The aim in this study is to better understand the barriers experienced by clinicians and patients in attaining an earlier-stage diagnosis in Alberta.

Table 1.3 Data analysis in thematic analysis and qualitative content analysis process (Mojtaba Vaismoradi, Turunen, & Bondas, 2013)

Analysis phases and their descriptions	
Thematic analysis (Braun & Clarke, 2006: 87	Content analysis (Elo & Kyngas, 2008: 110; Polit & Beck, 2012; Schreier, 2012)
Familiarising with data by reading and rereading the data	
Generating initial codes Coding interesting features of the data systematically across the entire data set, collating data relevant to each code. ***Searching for themes*** Collating codes into potential themes, gathering all data relevant to each potential theme. ***Reviewing themes*** Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map. ***Defining and naming themes*** Ongoing analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme. ***Producing the report*** The final opportunity for analysis. Selection of vivid, compelling exact examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis.	***Preparation*** Being immersed in the data and obtaining the sense of whole, selecting the unit of analysis, deciding on the analysis of manifest content or latent content. (Either inductive or deductive) ***Organising*** Inductive approach: Open coding and creating categories, grouping codes under higher order headings, formulating a general description of the research topic through generating categories and subcategories as abstracting. Deductive approach: Categorization matrix development, whereby all data are reviewed for content and coded for correspondence to or exemplification of the identified categories. The categorization matrix can be regarded as valid if the categories adequately represent the concepts, and from the viewpoint of validity, the categorization matrix accurately captures what was intended ***Reporting*** Reporting the analysing process and the results through models, conceptual systems, conceptual map or categories, and a story line. (Either inductive or deductive)

Accordingly, for the present research, building an analysis matrix was a requirement in the data collection phase. Data collection was guided by interview questions and a modified Andersen theoretical model and then structured. The data were evaluated by two researchers to ensure they were related to the research questions. The sentences related to the research questions were fully

recorded in the analysis matrix. For deductive content analysis, accurate sample size is based on data saturation, but we continued our analysis inductively for possible new data.

Health researchers often use qualitative content and thematic analysis as two descriptive approaches in qualitative studies (Mojtaba Vaismoradi, Turunen, & Bondas, 2013). While the purpose of content analysis is to describe the *characteristics* of the content document of interest (Bloor & Wood, 2006), thematic analysis is "a method for identifying, analyzing and reporting the *patterns* within data" (Braun & Clarke, 2006). (**Table 1.3**)

Content analysis is an approach well-suited to exploratory studies where not much is known. In this case, the focus is the straightforward reporting of common issues within the data and developing a model to describe the phenomena in a conceptual form (Elo & Kyngäs, 2008; Green & Thorogood, 2005). This is a suitable strategy for extracting the desired qualitative information from a larger body of archived records, such as Initial Consultation Notes, when analyzing multi-dimensional and sensitive phenomena in the health science and nursing fields (Motjaba Vaismoradi, Salsali, & Marck, 2011).

1.4 Summary

The literature reviewed in this chapter has shown that oral and oropharyngeal cancer is a public health challenge not only globally, but also in Canada and specifically in Alberta. Oral cancer epidemiological patterns, risk factors, survival rates in various geographic regions, and similarities and differences in trends were discussed. Despite advances in cancer management, the survival rate for oral cancer has remained steady (50-60%) for decades. Late diagnosis of oral cancer leads to a lower chance of survival, identified as a key burden worldwide. Alberta is

positioned 4th in Canada in new case incidences of oral cancer. Accordingly, the demand for generating comprehensive knowledge about oral cancer in Alberta and developing a conceptual framework that may contribute to improving health of Albertans was suggested.

In this dissertation, Chapter 2 presents a scoping review that collected and summarized general information on the prevalence of oral cancer in Alberta, as well as details on where and by whom patients with oral cancer are diagnosed for the first time, the allocation of funding for oral cancer early detection research, and the ongoing program for oral cancer prevention in the province. Chapter 3 presents a cross-sectional study that investigated the oral health profile of adults living in the Boyle Street McCauley community (a high-risk population in Edmonton) and associated risk factors for oral cancer. Chapter 4 presents the findings of a retrospective clinical chart review qualitative study that identified some challenges experienced by clinicians and patients regarding early detection of oral cancer in Alberta. Chapter 5 presents a comprehensive discussion of the findings, the developed conceptual framework, and conclusions.

2 Chapter Two: Oral Cavity and Oropharyngeal Cancer Surveillance and Control in Alberta: A Scoping Review

Published Article:

Badri, P, Ganatra, S, Baracos, V, Lai, H, Amin, M. Oral Cavity and Oropharyngeal Cancer Surveillance and Control in Alberta: A Scoping Review. J Can Dent Assoc 2021;87:l4.

2.1 Abstract

Objectives: This scoping review provides a comprehensive overview of oral cavity cancer (OCC) and oropharyngeal cancer (OPC) in Alberta.

Methods: A database search was conducted up to 2018 using Web of Science, Scopus, Medline, PubMed, and Embase, along with a hand-search of gray literature. Data from the Alberta Cancer Foundation's dedicated fund for research, Cancer Surveillance and Reporting and Alberta Cancer Registry were also collected.

Results: Our review included 8 published papers and 14 other sources, including data on 3448 OCC and OPC patients from Surveillance and Reporting and Alberta Cancer Registry. Cancer registry data (2005–2017) showed that most OCC and OPC lesions were diagnosed at an advanced clinical stage, with a significantly large number of advanced OPC lesions in stage IV

(OCC 45.2%, OPC 82.4%); 47.9% of these patients died. Survival rates were lowest in rural and First Nations areas. In Alberta, 35% of HPV-associated cancers were linked to OPCs, which were more prevalent in men and younger age groups. No routine public oral cancer screening program currently exists in Alberta. General practitioners and dentists refer patients to specialists, often with long waiting times.

Conclusion: OCC and OPC patients in Alberta continue to be diagnosed in stage IV and experience high mortality rates.

2.2 Introduction

Oral and pharyngeal cancer remains a significant global public health issue, with about 657.000 new cases reported each year, and more than 330,000 deaths (Rosin et al., 2008). In 2019, 53,000 North Americans were diagnosed with oral and oropharyngeal cancer (OPC), resulting in over 9,750 deaths (B). The 2019 Canadian Cancer Statistics report estimated that 5,300 Canadians will be diagnosed with oral cancer (3,700 men and 1,600 women), of which 1,480 died (1,050 men and 430 women)(Committee, 2019). Oral cancer is three times more common than cervical cancer and almost twice as common as liver cancer (Canada, 2018). Despite existing evidence indicates that early detection of precancerous and early-stage lesions can significantly improve the survival rate and quality of life of oral cancer patients (Kujan et al., 2005).

Alberta is 4th, after Ontario, Quebec and British Columbia, in term of oral cancer incidence and related death prevalence among Canada's ten provinces and territories (Committee, 2019). This ranking is expected to rise, given the fast growth of the South Asian community in Alberta as the province's second largest immigrant group. The literature has shown a high prevalence of oral cancer in this population, mostly attributed to their lifestyle practices such as excessive use of bidis (handmade low quality tobacco cigarettes), chewing tobacco, and betel nut products (Kujan et al., 2005; Warnakulasuriya, 2009).

Oral cancer represents almost 30% of malignancies of the head and neck (H&N). The development of cancer in the oral mucosa is classified by the World Health Organization as a two-step process. Oral cancer is thought to arise in premalignant lesions that undergo malignant transformation. Precancerous lesions of the mouth include leukoplakia (white patch) and erythroplakia (red patch), which are considered clinical terms. Oral cancer is more likely to occur

in people with precancerous lesions than their apparently normal counterparts (Séamus S. Napier & Paul M. Speight, 2008). Unfortunately, oral cancer continues to be diagnosed mainly in advanced stages, giving patients less chance of survival (Joel B & Michaell A, 2015). For decades, the survival rate for oral cancer has remained steady at 50-60%, despite several advances in cancer management (C. W. LeHew, J. B. Epstein, L. M. Kaste, & Y.-K. Choi, 2010). In India, which is well-known for its high rate of oral cancer, a study showed that prevention and early detection through visual screening of precancerous lesions dramatically decreased oral cancer mortality rates and improved quality of life in high risk populations (Kujan et al., 2005).

Late detection of oral cancer can result in poor quality of life, profound psychosocial consequences, and complications in the H&N area after conventional treatments such as radical surgery, radiation therapy, and chemotherapy (Charles W. LeHew et al., 2010). The poor prognosis is because many vital functions, including speaking, smelling, swallowing, hearing and mastication, can be seriously affected (Charles W. LeHew et al., 2010). Evidence has shown a strong correlation between the late detection of oral cancer and poor quality of life compared to patients diagnosed in early stages(Charles W. LeHew et al., 2010). Moreover, early detection of oral cancer leads to treatments for that is less costly for families and the health care system compared with cases diagnosed in advanced stages (Laronde DM, 2008 Apr). One study conducted in Greece compared oral cancer treatment that was provided early versus treatment given at advanced stages. The study showed a statistically significant increase in oral cancer treatment cost per person for stage III (US$ 10,316) and stage IV (US$ 11,467) compared to stage I (US$ 3,662) and for stage II (US$ 5,867) (Zavras et al., 2002). To date, there is a lack of treatment cost data specifically for oral cancer in Canada and Alberta. The researchers in our oral cancer research program are conducting a new study to measure a comprehensive set of

healthcare costs associated with the management of oral cancer in Alberta and cross-examine it with patients' income and treatment outcomes.

Recent evidence has shown significant shifts in the etiological factors and age groups at risk for oral cancer (Isayeva, Li, Maswahu, & Brandwein-Gensler, 2012). Oral cancers have been primarily associated with tobacco and alcohol use and have been more prevalent in older age groups (Denson, Janitz, Brame, & Campbell, 2016). However, increasing numbers of cases associated with Human Papilloma Virus (HPV) occur in younger individuals (Joel B & Michaell A, 2015). Analysis of social, clinical and demographic characteristics and p16 protein status of patients diagnosed with OPC at 5 Canadian cancer centers, including 2 in Alberta showed a steady increase in HPV-associated OPCs, rising from 47.3% in 2000 to 73.7% in 2012 (Steven Habbous, Chu, Lau, Schorr, Belayneh, Ha, Murray, O'Sullivan, et al., 2017). Polymerase Chain Reaction (PCR), reverse transcription PCR (RT-PCR), and p16 immunopositivity are common HPV detection methods. Where human papillomavirus (HPV) DNA PCR methods could overestimate the role of HPV by over-detection of viral infection from adjacent or distant contamination, *E6* and *E7* region *E6*I* mRNA detection by RT-PCR is considered the gold standard for establishing HPV involvement (Leemans, Snijders, & Brakenhoff, 2018). In Alberta between 1975 and 2009, the age-standardized incidence of OPCs increased for each 5-year period by3.4% annually among men ($p < 0.001$) and 1.5% among women ($p = 0.009$) (L. Shack, H. Y. Lau, L. Huang, C. Doll, & D. Hao, 2014).

A meta- analysis of 17 studies (Hobbs et al., 2006) showed the strongest association between HPV and tonsillar cancer, an intermediate association with OPC and the weakest link

with oral cancer. Oropharyngeal cancer as an additional entity, can be screened by dentists/dental hygienists where possible, through a careful examination of the soft palate, tonsils, and neck.

Oral Cavity Cancer (OCC) and OPC are deadly diseases, particularly in stages III and IV. However, the survival rate is more than 80 percent for patients diagnosed in stages I and II (Ribeiro, Barroso, Marques, Melo, & Carreira, 2016). Both diseases continue to be diagnosed at advanced stages even though, in most cases, they of OCC could easily be detected visually by health professionals, especially dentists and family physicians. In the literature describes 2 distinct categories of delays, "patient delay" or time from the patient's awareness of changes to her/his presentation to the health professionals and "professional delay" or time from patient's presentation to the heath care provider to definitive diagnosis and treatment **(Figure 2.1)** (P. Stefanuto, J. C. Doucet, & C. Robertson, 2014). If left untreated, 5% of leukoplakia and 50% of erythroplakia can develop into oral cancer (Queiroz, Medeiros, Silva, & Silveira, 2014). Early clinical detection of oral lesions and confirmation of premalignant status (thus facilitating timely treatment) could prevent the development of aggressive malignancies. A comprehensive investigation is required to unfold how and where suspicious lesions are ignored. The sooner a patient with oral cancer is identified, diagnosed, and given the initial treatment, the better their chance of survival.

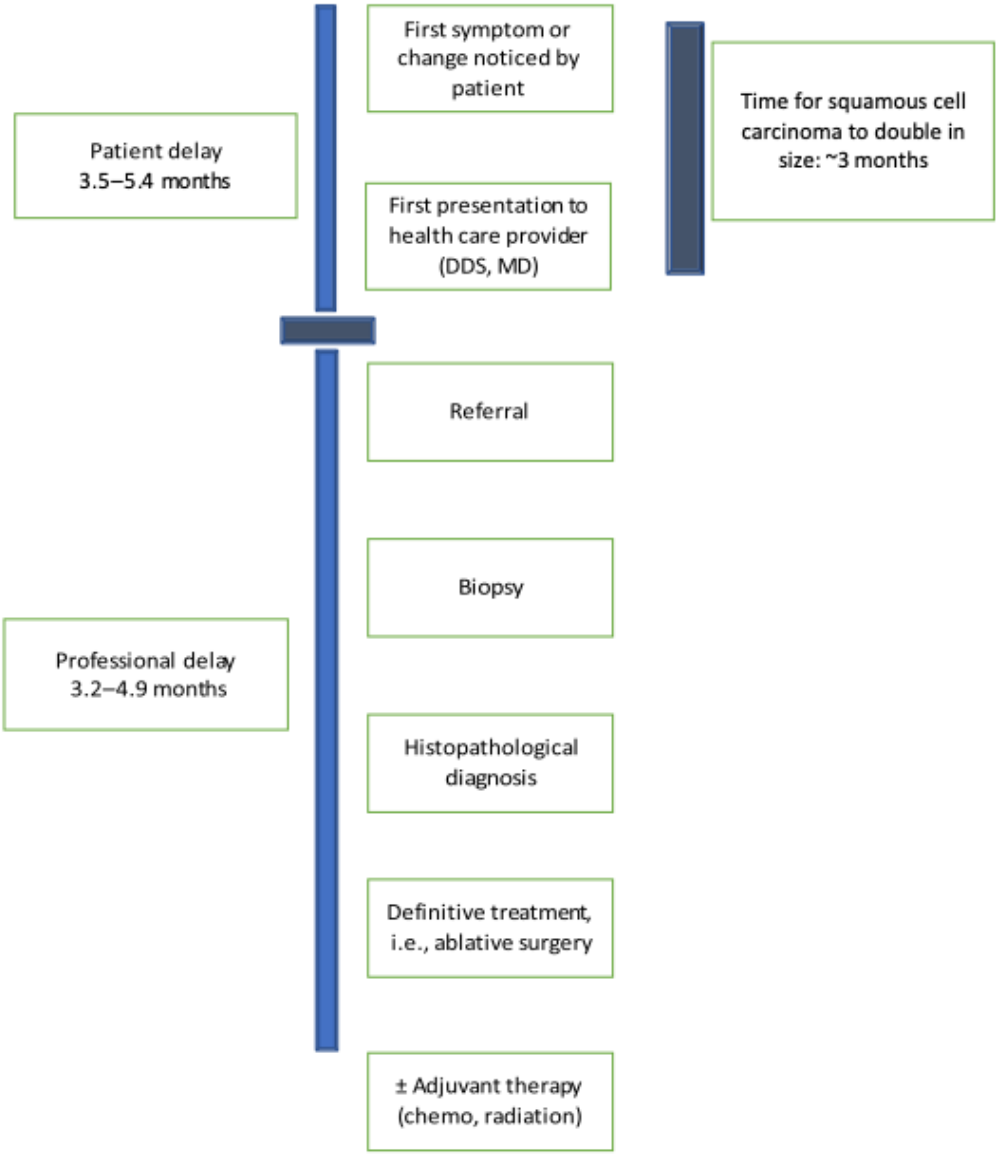
The statistical evidence regarding OCC and OPC incidence and related projected death rates in Alberta is alarming: an increase of 76.1% in new cases of OCC and OPC is expected between 2003-07 to 2028-32 (C. C. Statistics, 2015). Few valuable peer-reviewed studies show the status of OCC and OPC in the province, and the most important related data are scattered

across a number of governmental and nongovernmental institutions and organizations. Therefore, the objectives of this scoping review were to investigate:

- The prevalence of OCC and OPC in Alberta according to patients' demographics and tumor characteristics.
- The usual route from detection of OCC and OPC to treatment.
- Existing OCC and OPC prevention initiatives.
- Funding of OCC and OPC prevention.
- Where and by whom patients with OCC and OPC are initially diagnosed.

A preliminary search for scoping reviews of this topic was conducted at Web of Science, Scopus, Medline, PubMed, Embase, the Joanna Briggs Institute Database of Systematic and Implementation Reports and the Cochrane Database of Systematic Reviews, but no related review was found.

Figure 2.1 Two categories of delay in diagnosis of oral cancers: patient and professional (P. Stefanuto et al., 2014)



2.3 Materials and Methods

Our protocol was developed based on the methodological framework for scoping review studies proposed by Arksey and O'Malley (Arksey & O'Malley, 2005). It consists of 5 stages: identifying research questions and objectives; identifying relevant studies based on inclusion criteria; selecting studies; charting the data; and collating, summarizing, and reporting the results. Ethics approval for data extraction from the Alberta Cancer Registry was obtained from the Health Research Ethics Board of Alberta's - Cancer Committee.

Research question: What is the prevalence, demographics, initial diagnosis, prevention, management, and research funding allocated for early detection of OCC and OPC in Alberta?

2.3.1 Inclusion Criteria:

This scoping review included adults aged 18 years and older living in Alberta.

Provincial OCC and OPC data are reported in a diverse media, and our search strategy aimed to gather data from as many resources as possible. These included peer-reviewed, published, unpublished, and hand-searched gray literature (e.g., primary research studies, systematic reviews, letters, guidelines, Google and Google Scholar). In addition, the search included governmental and non-governmental institutions and organizations.

A 3-step search strategy (Peters et al., 2015) was performed for the timeframe of 1990-2018. We used all the key terms to cross-search all databases, including Web of Science, Scopus, Medline, PubMed, and Embase. We also conducted a search of the Joanna Briggs Institute

Database of Systematic Reviews and Implementation Reports and the Cochrane Database of Systematic Reviews to retrieve potential similar published reviews. Keywords were ((mouth or oral or gingiv* or lip or lips or palat* or tonsil or parotid or sublingual or lingual or tongue or cheek*) and (cancer or neoplasm* or tumor* or tumour* or malignan* or carcinoma*)) *AND* TOPIC: (alberta or calgary or edmonton).

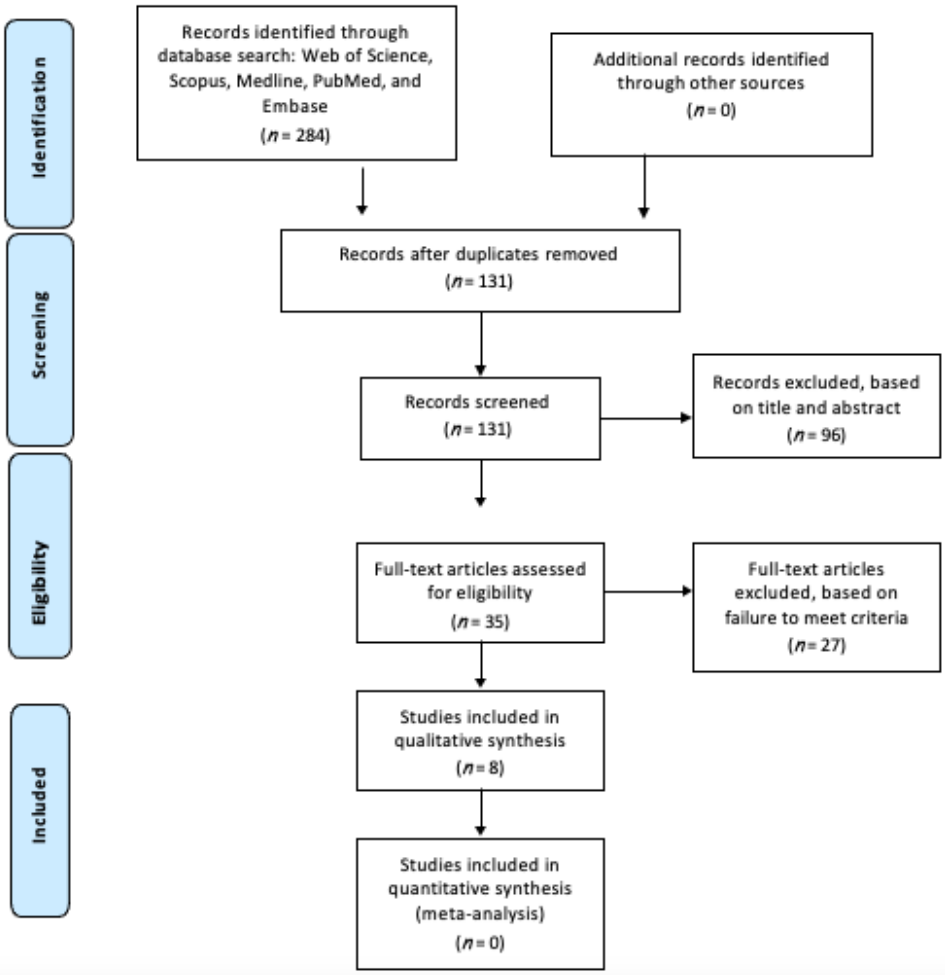
We also conducted a hand-search of gray literature and used the Google and Google Scholar search engines to find relevant articles. Finally, we emailed and telephoned Alberta Cancer Foundation, Surveillance and Reporting, Alberta Prevents Cancer, Alberta Health Services and Alberta Cancer Registry to gather relevant information uncovered by the search engines.

2.4 Results

2.4.1 Study Selection

***Published literature*:** The search strategy resulted in the identification of studies from Medline (n=48), Embase (n=74), Pubmed (n=33), Scopus (n=74) and Web of Science (n=55) for a total of 284. Of these, 153 were eliminated because of duplication. Two reviewers excluded 96 irrelevant studies based on title and abstract. After reviewing the full text, 27 more studies were screened and excluded as they did not meet the inclusion criteria of the study. A final set of 8 studies (Barber et al., 2015; Biron, O'Connell, & Seikaly, 2013; Collie et al., 2014; Erickson, Biron, Zhang, Seikaly, & Côté, 2015; Marzouki, Biron, Harris, O'Connell, & Seikaly, 2016; L. Shack et al., 2014; Thompson, Southern, McKinnon, Dort, & Ghali, 2004; H. Zhang et al., 2015) were included in this review **(Figure 2.2**).

Figure 2.2 PRISMA Process for selection of records for review (Moher, Liberati, Tetzlaff, & Altman, 2009)



***Gray literature*:** Relevant thesis monographs (N=2) (Friesen R., 2018; Grattan KS., 2013), and clinical guidelines for H&N cancer delivery and management in Alberta (N=2) (Alberta Health Services, 2014, February; Services, 2019, February) were identified and included in the study. Other sources were Canadian Cancer Statistics for 2015-2017(C. C. Statistics, 2015; Statistics, 2016, 2017) , the Alberta Cancer Foundation (Alberta Cancer Foundation, 2018), data on 3,448 patients retrieved from the Surveillance and Reporting-Alberta Cancer Registry, Alberta Health Services (Alberta Health Services, 2018; C. C. A. Alberta Health Services, 2016; Alberta Health Services: Immunization, 2018), Alberta Innovates (Alberta Innovates, 2018), Canadian Cancer Society and Alberta Cancer Prevention Legacy Fund (ACPLF) (Alberta Health Services: Healthier Together, 2018a), and Canadian Institutes of Health Research (Government of Canada: Canadian Institutes of Health Research, 2018).

2.4.2 Charting the Data

The information that was relevant to our study objectives, including descriptive and numeric data, reports and chart information on patients, was extracted and charted according to Joanna Briggs Institute guidelines (Peters et al., 2015). For the recorded published studies, extracted data included: author(s)/year/country of origin; aims; population/characteristics/size; study design; concepts relevant to our study objectives; context relevant to our study objectives; and outcome relevant to our study objectives.

Of the 8 published studies 7 were quantitative (Barber et al., 2015; Biron et al., 2013; Erickson et al., 2015; Marzouki et al., 2016; L. Shack et al., 2014; Thompson et al., 2004; H. Zhang et al., 2015), and 1 was qualitative (Collie et al., 2014). All were conducted in Alberta and published between 2004 and 2016. They focused on care plans and quality management of OCC

and OPC (Collie et al., 2014), factors influencing survival (Biron et al., 2013; Erickson et al., 2015; H. Zhang et al., 2015), comorbidity and risk management (Barber et al., 2015; Thompson et al., 2004), and epidemiological evolution of HPV associated with OCC and OPC (Marzouki et al., 2016; L. Shack et al., 2014). Detailed characteristics of these studies are presented in **Table 2.1**.

Table 2.1 Summary of data extraction from 8 published papers

Author(s), Year of publication	Aim(s) of study	Study population/ characteristics/ total number	Study design	Concepts relevant to our study objectives	Contexts relevant to our study objectives	Duration of study	Outcomes relevant to our scoping review questions
1- Biron et al. 2013	To evaluate disparities in clinical vs pathological TNM staging in oral cavity squamous cell carcinoma (OCSCC)* patients and any impact of this on survival	All patients undergoing surgical treatment for OCSCC in Alberta	Quantitative	Staging diagnosis management	Survival pathway	1998-2006	Some disparity exists in clinical vs pathological staging in OCSCC; however, this does not have any significant impact on disease-specific survival.
2- Zang et al. 2015	To investigate the association between survival and geographic location	554 charts of patients diagnosed with OCSCC in Alberta	Quantitative	Geographic demographic	Survival pathway	1998-2010	Patients from urban locations had improved overall, disease-specific, and disease-free survival compared to rural locations.
3-Erickson et al. 2015	To assess First Nations survival trends	583 patients' records from Cancer Registry in the province of Alberta	Quantitative	Ethnicity demographic	Survival pathway	1998-2009	Survival and disease-specific survival are significantly lower in FN patients compared to non-FN patients with OCSCC.
4- Thompson et al. 2004	To determine the incidence of perioperative stroke in patients undergoing neck dissection	499 records of discharge data for all neck dissections performed in a geographically defined health region in Alberta	Quantitative	Treatment risk assessment	Oral cancer quality management	1994-2002	The incidence of perioperative stroke in this study is significantly lower than that previously stated in the literature. This suggests that preoperative screening and/or intervention for carotid artery disease may not be necessary in this patient population.

Table 2.1 CONT: Summary of data extraction from 8 published papers

Author(s), Year of publication	Aim(s) of study	Study population/ characteristics/ total number	Study design	Concepts relevant to our study objectives	Contexts relevant to our study objectives	Duration of study	Outcomes relevant to our scoping review questions
5- Barber et al. 2015	To assess depression as a predictor of Postoperative Functional Performance Status (PFPS) and treatment adherence in H&N cancer patients	All new adult H&N cancer (HNC) patients undergoing surgery as primary therapy for HNC	Quantitative	Post-treatment risk assessment	Oral cancer quality management	May 2013 to January 2014	The incidence and severity of PDS in HNC patients treated with surgery is high (53.5 %).
6- Shack et al. 2014	To assess temporal, age-specific and sex-specific changes in the incidence of noncervical and cervical cancers associated with HPV in a population-based study.	Identified 8120 HPV associated cancer records from Alberta Cancer Registry records out of all cancers diagnosed in the province of Alberta, Canada, targeting patients with cancers of the oropharynx, cervix, vulva, vagina, anus and penis	Annual percentage change using join point regression.	New HPV-associated oropharyngeal cancer trend	Oral cancer based on age and sex in younger cohort	between Jan. 1, 1975, and Dec. 31, 2009	Increased incidence of HPV-associated cancers of the oropharynx and anus among men and women and increase in cervical cancer among younger women.
7- Marzuki et al. 2016	To investigate the possible epidemiological association between oropharyngeal carcinomas and anogenital tumors	2015 male patients diagnosed with oropharyngeal squamous cell carcinoma (OPSCC)* and anogenital cancer in the province of Alberta	Quantitative	HPV Epidemiologic pathway	Lifestyle diversity	1980-2011	No significant risk factors for anogenital cancer associated with OPSCCs.
8- Collie et al. 2014	To evaluate care plans for H&N cancer survival	21 H&N cancer survivors in Alberta	Qualitative	Quality of care and treatment	Survival and quality management	NA	Survivorship care plans could help to improve the transition to cancer survivorship.

The 2 master's thesis reported on quality of life, especially for young patients diagnosed with OCC and OPC in Alberta (Grattan KS., 2013), and referral patterns of patients to the University of Alberta oral medicine clinic, a specialty clinic where dentists refer patients with suspicious oral lesions to be evaluated by certified specialists in oral medicine and pathology in Edmonton(Friesen R., 2018). Detailed data from gray resources are presented in **Table 2.2-Table 2.6 and Figure 2.3.**

Table 2.2 Summary of data extraction from 8 published papers

First Monograph (Master Thesis) (Grattan KS., 2013)	
Author(s), Year	Grattan, 2013
Aim(s) of study	Evaluation of physical, psychosocial, and sexual quality of life for young H&N patients
Study population/ characteristics/No	Ten H&N patients, aged 18-65 years
Study design	Mixed methods
Relevant concepts to our study objectives	HPV as new recognized risk factor associated with oral cavity and oropharyngeal cancer in younger age
Relevant context to our study objectives	Diverse aspects of quality of life, mostly for young H&N cancer patients infected with HPV
Duration of study	N/A
Outcome relevant to our scoping review questions	Recent trend of Human Papilloma Virus (HPV) associated oropharyngeal cancer in younger individuals and the special burden of quality-of-life vs that of older patients
Second Monograph (Master Thesis) (Friesen R., 2018)	
Author(s), Year	Friesen, 2018
Aim(s) of study	Assessment of referral patterns to an Oral Medicine Clinic at the University of Alberta
Study population/ characteristics/No	Review of 924 patients' charts
Study design	Quantitative
Relevant concepts to our study objectives	Pathway referrals and efficacy of management services
Relevant context to our study objectives	Demographic, distance travel to the center, waiting time from referral to first appointment for suspicious oral lesions
Duration of study	One Year (2015)
Outcome relevant to our scoping review Questions	- Of 924 patients with suspicious oral lesions, 361 (39%) were male and 563 (61%) were female. - Average Distance: 55.44 km; Median distance: 16.60 km; Max. distance: 2028.00 km; Min. Distance: 1.40 km. - Patient waiting time: 100 patients = 0-30 days. 340 patients = 31-90 days; 484 patients > 90 days.
Study research question: What is the referral pattern to an Oral Medicine Clinic at the University of Alberta?	General Dentist: 688 referrals (74.5%) + Total dental specialists: 64 referrals (6.8%) = 752 referrals (81.4%). Family physician (GP): 146 referrals (15.8%) + Dermatologist (16), ENT (8), Rheumatologist (2) = 172 referrals (18.6%). Cumulative percent: 81.4 +18.6 = 100

Table 2.3 Characteristics of patients diagnosed with oral cavity cancer (OCC) and oropharyngeal cancer (OPC), based on data from the Alberta Cancer Registry, 2005-2017

Variable	Category	NO-OCC	NO-OPC
Sex	Male	1,026(58.20%)	1377 (81.72%)
	Female	737 (41.80%)	308 (18.28%)
	Total	1,763 (100%)	1,685 (100%)
Age Group	< =45	166 (9.4%)	98 (5.8%)
	46-65	799 (45.3%)	1139 (67.6%)
	> 65	799 (45.3%)	448 (26.6%)
	Total	1,764 (100%)	1,685 (100%)
Average Income*	< 45,000	447 (25.4%)	411 (24.39%)
	45,000 - 75,000	779 (44.2%)	664 (39.41%)
	> 75,000	537 (30.46%)	610 (36.2%)
	Total	1,763 (100%)	1,685 (100%)
Region	Rural	677	17.5
	Urban	3,188	82.5
	Total	3,865	100.0
Diagnosis Location	Z1 (South Alberta)	132 (7.49%)	127 (7.54%)
	Z2 (Calgary)	663 (37.61%)	628 (37.27%)
	Z3 (Central Alberta)	236 (13.39%)	206 (12.2%)
	Z4 (Edmonton)	572 (32.44%)	536 (31.81%)
	Z5 (North Alberta)	160 (9.08%)	188 (11.16%)
	Total	1,763 (100%)	1,685(100%)
Survival status	Alive	818 (46.40%)	977 (58.30%)
	Dead	945 (53.60%)	707 (41.70%)
	Total	1763 (100%)	1672(100%)
Age at Death	< =45	25 (2.65%)	9 (1.27%)
	46-65	278 (29.42%)	319 (45.12%)
	> 65	642 (67.94%)	379 (53.62%)
	Total	945 (100%)	707 (100%)

Table 2.4 Sites of oral cavity cancer and oropharyngeal cancer, based on data from the Alberta

Cancer Sites	Male (%)	Female (%)	Total	%
Base of Tongue	546 (32.40)	96 (5.70)	642	38.10
Floor of mouth	184 (10.44)	94 (5.33)	278	15.77
Gum	102 (5.79)	86 (4.88)	188	10.66
Lip	52 (2.95)	18 (1.02)	70	3.97
Lip, Oral Cavity & Pharynx, other & unspecified	11 (0.65)	2 (0.12)	13	0.77
Oropharynx	154 (9.14)	50 (2.97)	204	12.11
Mouth, other & unspecified	172 (9.76)	126 (7.15)	298	16.90
Palate	79 (4.48)	81 (4.59)	160	9.08
Tongue, other & unspecified	447 (57.30)	333 (42.70)	780	78.91
Tonsil	656 (38.93)	159 (9.44)	1685	48.37

Cancer Registry, 2005-2017

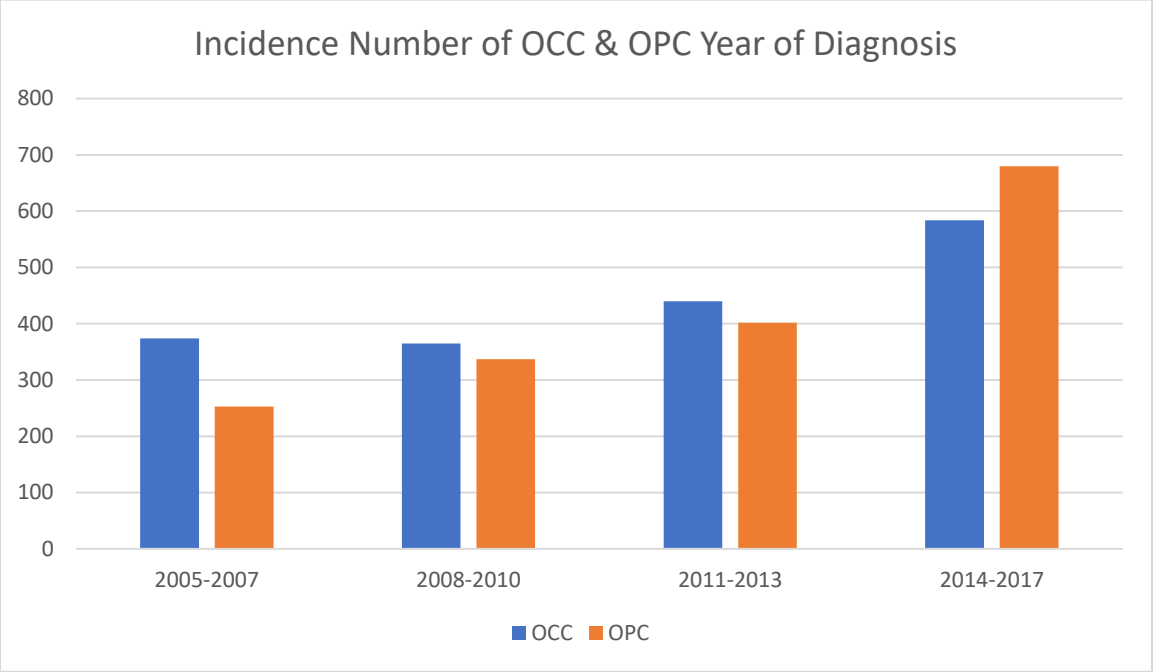
Table 2.5 Stages of oral cavity cancer and oropharyngeal cancer, based on data from the Alberta Cancer Registry

Tumor stages (Total N=3448)	OCC (N%)	OPC (N%)	Total OCC/OPC
I	446 (29.1)	41 (2.60)	487
II	221(14.45)	78 (4.95)	299
III	151(9.87)	158 (10.04)	309
IV	691 (45.19)	1296 (82.39)	1,987
Unknown (UNK)	234	112	346

Table 2.6 Summary of data extracted from gray literature

	Research Questions	Gray Literature Data
1	What is the prevalence of Oral Cavity Cancer (OCC) and Oropharyngeal Cancer (OPC) in Alberta?	- OCC and OPC increased in prevalence between 2005 and 2017. - During a 12-Year period (2005-2017 of 3448 total cases, 1763 (51%) were diagnosed as OCC and 1685 (48.8 %) represented OPC. - OCC and OPC was more prevalent in men and occurred at a younger age, with significantly higher risk for oropharyngeal cancers. - The percentage of patients diagnosed with OCC and OPC was higher in urban (82.5%) versus rural (17.5%) areas. Survival was found to be lowest in rural and First Nations. - Deceased (2005-2017): OCC=945 (27.4%); OPC=707 (20.5%) Total number:1,652 (47.9%) - Stage IV (2005-2017): OCC=691(45.19%); OPC=1296 (82.39%) Total number: 1,987
2	What is the ongoing OCC and OPC prevention strategy in Alberta?	Other than HPV vaccinations young men and women since 2008 (HPV-9 vaccine is up to 99% effective in preventing human papillomavirus related disease from the 9 HPV strains including 25% of H&N cancers), currently, there are no preventive or routine oral/head and neck cancer screenings in place in Alberta.
3	What funds are allocated for OCC and OPC in Alberta?	The funds are mainly allocated for treatment and therapy targeting improving quality of life rather than prevention of disease.
4	What are the pathways for OCC and OPC in Alberta?	"Treatment Algorithms" presented by Alberta Health Services (AHS): - CLINICAL PRACTICE GUIDELINE HN–002 version 1 – ORAL CAVITY CANCER (2014-pp 13-16) [33] - CLINICAL PRACTICE GUIDELINE HN-004 Version 1 OROPHARYNGEAL CANCER TREATMENT (2019-pp 9-11) [34] * No timeline for these Treatment Algorithms guidelines was identified.

Figure 2.3 Trend in the incidence of oral cavity cancer (OCC) and oropharyngeal cancer (OPC), based on data from the Alberta Cancer Registry: 2005-2017



2.4.3 Collating, Summarizing and Reporting the Results

In **Tables 2.1-2.6,** information is classified according to the objectives of the study and it provides an overview of factors associated with OCC and OPC in Alberta.

Tumor location/site was categorized according to the topographical codes in the International Classification of Diseases for Oncology, third edition, ICD-O 3. OCC sites included lip (C00.3-C00.9), oral tongue (C2.0-C2.3, C2.8 and C2.9), gum (C3.0-C3.0), floor of mouth (C4.0-C4.9), palate (C5.0-C5.9), and other and unspecified parts of the mouth (C6.0-C6.9). OPC sites included base of tongue (C01), lingual tonsil (C2.4), tonsil (C9.0-C9.9), oropharynx (C10.0-C10.9), pharynx not otherwise specified (C14.0) and Waldeyer ring (C14.2).

External upper and lower lip (C00.0-C00.1), parotid gland (C07.9), and other and unspecified major salivary gland tumors (C08.0-C08.9) were excluded.

According to the 2005-2017 Alberta Cancer Registry data, 45.2% of OCC patients and 82.04% of OPC patients were diagnosed at stage IV, of which, 47.9% died (OCC: 27.41%, OPC: 20.05%). The tonsils, tongue, and base of tongue were the main locations affected by these cancers. The increased incidence of HPV-associated OPC is most striking in males < 45 years of age (CCS, 2016). Although most mouth and throat cancers were primarily associated with tobacco and alcohol use, about 25-35% of OCC and OPC were attributed to high-risk HPV types (CCS, 2017).

Referrals and access to clinical specialists for patients with suspicious oral lesions were evaluated and reported (Friesen R., 2018).The waiting time between receiving a referral and seeing a specialist was 105.5 days on average, with a maximum of 905 days. The reported travel distance was 55.4 km on average, with a maximum of 2,028 km. In this study, general dentists (74.5%) were found to be the main source of referrals to oral pathologists, oral surgeons and otolaryngologists, followed by family physicians (15.8%). Of all referrals 38% were diagnosed with malignant and premalignant lesions, which represents the highest percentage among all conditions requiring the care of a specialist (Friesen R., 2018). However, according to the Cancer Registry data, otolaryngologists were the most common clinicians referring OCC and OPC patients to oncologists (cancer care) followed by surgeons (general, oral, and thoracic) and general practitioners with dentists being in 8th place.

In general, management was guided by 2 sources(Alberta Health Services, 2014, February; Services, 2019, February). The recommended guidelines for H&N cancer in Alberta

were adapted by the executive of the Alberta Provincial Head and Neck Tumour Team using "The Management of Head and Neck Cancer in Ontario: Section 1, Organizational and Clinical Practice Guideline Recommendations"(R. Gilbert, Devries-Aboud, Winquist, Head, & Group, 2013). The guideline considers H&N cancer a complex chronic disease that should be managed by a qualified team with particular recommendations for: health care team components; minimum cancer center and team member volumes; infrastructure; and waiting time. The practice guideline will be updated at least annually with any new evidence or contextual information. The latest guidelines for OCC 2014 and OPC 2019 are presented in **Table 2.6**.

Oral cancer survival was explored in recent studies (Erickson et al., 2015; H. Zhang et al., 2015). They found that geographical location (H. Zhang et al., 2015), ethnicity (Erickson et al., 2015), quality of management (Collie et al., 2014), and disparities in clinical versus pathological staging diagnosis (Biron et al., 2013) could affect survival outcomes.

Pre-/post-operative risk assessments and quality of life were investigated in 3 studies (Barber et al., 2015; L. Shack et al., 2014; Thompson et al., 2004). Although the findings of 1 study (Thompson et al., 2004) indicated that the risk of stroke in patients undergoing neck dissection surgery is low and there is no need for pre-operative screening, another study (L. Shack et al., 2014) showed that there was a higher risk for hypothyroidism after radiation therapy in OCC and OPC patients. Thus, patient screening was recommended to achieve a higher quality of care. In addition, severity of depression was identified as a predictor of post-operative functional performance, quality of life, and adherence to treatment (L. Shack et al., 2014).

We did not identify any H&N cancer screening programs in Alberta. However, preventive HPV vaccination was approved for females aged 9-26 in 2006 and males aged 9-26 in

2012 to prevent 95% of cervical cancers and 25% of OPC (Statistics, 2016). Furthermore, multiple websites offer intraoral cancer information and risk factors for developing oral cancer, and preventive recommendations for the public(Alberta Cancer Foundation, 2018; Alberta Health Services, 2018; C. C. A. Alberta Health Services, 2016; Alberta Health Services: Immunization, 2018; "Cancer Patient Education, Symptom Management, Mouth and Dental Care," 2016). The resources of multiple health funding agencies(Alberta Health Services: Healthier Together, 2018a; Alberta Innovates, 2018; Government of Canada: Canadian Institutes of Health Research, 2018) are dedicated mostly to OCC and OPC treatment studies and research investigations that target better post-treatment quality of life for OCC and OPC cancer patients rather than studies aimed at identifying effective preventive strategies for those cancers in Alberta.

2.5 Discussion

According to the Alberta Cancer Registry data from 2005 to 2017, although the incidence of OCC increased somewhat, the number of OPC cases increased significantly. In our study, the numbers of OCC and OPC cases included were almost equal (51% and 49% respectively). Although male predominance was found in both OCC and OPC, the gender difference was larger for OPC (82.7% males among OPC *vs* 58.2% for OCC).

This scoping review provides an overview of OCC and OPC in Alberta based on various data sources distributed across multiple bodies. Our finding is in agreement with the recent literature that HPV-associated OPCs Occur in younger people compared to those diagnosed with oral cancers associated with smoking and alcohol consumption.

Although we found no published studies on strategies for preventing OCC, we did note that the upward trend in HPV-associated OPC has received significant attention. Canadian Cancer Statistics 2016, which was dedicated to HPV-associated cancers, stated that the annual number of OPC cases (for both sexes combined) is already rivaling cervical cancer in Canada (Statistics, 2016). The report predicted that the age-standardized incidence of OPC in males may surpass that of cervical cancer in females in the near future, which is alarming. A study conducted by Shack and colleagues (L. Shack et al., 2014) confirmed this trend in Alberta.

Following the lead of Prince Edward Island, Alberta has introduced a public health policy to vaccinate young people of both sexes, 9- 26 years old, to prevent HPV-associated cervical cancer. However, effective preventive strategies for non-HPV-associated OCC and OPC-e.g., regular oral/H&N cancer screenings- are still lacking in Alberta, even for populations with higher vulnerability, such as those who are socioeconomically disadvantaged and/or exposed to tobacco, alcohol and recreational drugs.

The findings of this study indicate that, as in to Ontario (2003-2013)(Cancer Care Ontario, 2019, January), men in Alberta are at higher risk for OCC and OPC. However, a retrospective study conducted in British Columbia analyzing OCC and OPC in 1981-2020 shows that incidence is for OCC decreasing in men and increasing in women, while rates for OPC are increasing in both men and women(Ajit Auluck et al., 2010).

In contrast, new evidence points to an increasing incidence of OCC among Caucasian women in the United States in (1973 – 2012), rising to the same level as men(Tota et al., 2017). This might be explained by recent changes in lifestyle. The trend also accords with the findings of a study that investigated recent OCC and OPC data globally (Sankaranarayanan et al., 2015).

Our study shows that, as of 2017, Alberta is 4th in term of new cases of OCC and OPC (430) behind Ontario (1,950), Québec (1,070), and British Columbia (600)(Statistics, 2017). Compared with earlier data, these numbers are rising, except for a slight decrease in British Columbia(Ajit Auluck et al., 2010). The large number of Southeast Asians and Chinese ethnic minorities, known scientifically for their high incidence rates of OCC (South Asians) and OPC (Chinese) could explain the high rates and increases in the disease in Ontario, British Columbia, and Alberta (Ajit Auluck et al., 2010; Warnakulasuriya, 2009). This shows that ethnic-associated practices, such as particular smoking habits are associated risk factors for OCC and OPC, despite current geographic location(Ajit Auluck et al., 2010; Gupta et al., 2016). Further investigation is needed to identify potential risk factors in Québec.

Our finding for Alberta are in accord with worldwide reports and confirm the lack of improvement in term of delays in diagnosis and survival of OCC and OPC patients, as found in the literature. This continues to be a tremendous concern for health providers and health authorities. From 2005 to 2017, more than half the accumulated cases of OCC and OPC were diagnosed in stage IV, and 47.9% of all patients died. This finding is striking and deserves attention. There is a lack of data on prevalence of stage IV OCC and OPC in general population in Canada. Analysis of various datasets suggests that the Assessment section of Alberta's guidelines need further investigation of the gaps identified in this scoping review regarding late access to initial clinical assessment(Friesen R., 2018) and late diagnosis of OCC and OPC.

This study found that the treatment and management of OCC (2014) and OPC (2019) in Alberta is guided by the Alberta Health Services H&N Cancer guidelines(Alberta Health Services, 2014, February; Services, 2019, February). However, there is a lack of emphasis on the efficacy of the practice algorithm for patients, including the required waiting time for each step.

Suspected premalignant white and red oral lesions are the most common reasons for referral of patient to specialists, and our findings highlighted a long waiting time for these patients (Friesen R., 2018). This deserves further attention as these lesions have a high potential of becoming considered cancerous in an interval of 1-30 year time period (Leukoplakia: 0.1%–36% and erythroplakia: 14%–50% malignant transformation) (Queiroz et al., 2014; Vieira, Minicucci, Marques, & Marques, 2012). Reducing waiting times and facilitating access for patients in remote areas to competent oral health care professionals, including oral medicine specialists, oral pathologists, oral surgeons and otolaryngologists/ear, nose, throat specialists could improve the detection of these lesions at an earlier stage. Earlier access to care can have a tremendous impact on care and regular follow-ups, which, in turn, would lead to a much better treatment outcome. Friesen's study also indicates the need to enhance dentists' and physicians' skills in the initial assessment of oral precancerous lesions (Friesen R., 2018). This finding was confirmed by other studies worldwide(Abdullah Jaber, 2011; Psoter et al., 2015).

Multiple governmental and nongovernmental organizations and websites that provide information to raise awareness about OCC and OPC and preventive instructions. Although this information could contribute to better public knowledge, no studies have evaluated the effectiveness in preventing OCC and OPC in Alberta.

2.5.1 Strengths and limitations

This study included every category of data source to answer the comprehensive objectives under review. However, in a scoping review, no quality assessment is provided, mostly because of the diversity of sources(Peters et al., 2015).

2.6 Conclusions

In Alberta, the high prevalence of stage IV OCC and OPC and the associated mortality rate indicate an urgent need to investigate strategies that may improve the detection, diagnosis and management of these diseases across the province. Some suggestions include public awareness about signs and symptoms of OCC and OPC and when to approach a physician or dentist. Barriers, such as long waiting lists for first visits and long travel distances to specialized health care centres, should also be addressed. Also, implementing routine oral/H&N cancer screening in public settings, especially in at-risk communities, may lead to early detection and, consequently, better outcomes in the management of OCC and OPC in Alberta

2.7 Implication for Research

This study shows significant evidence of late diagnosis of OCC(45.2% of patients diagnosed at stage IV) and OPC (82.4%) in Alberta between 2005 and 2017. In-depth qualitative analysis of initial consultation letters of oral cancer patients and interviewing health care providers and patients may help us understand the knowledge gap causing continued late detection. In addition, exploration of the following identified knowledge gaps could generate a better picture of the shortcomings of oral cancer diagnoses in Alberta.

- Is poor coordination between dentists and physicians to blame for the high number of stage IV OCC in Alberta?
- Are dentists sufficiently trained to detect and diagnose premalignant and malignant oral lesions and refer patients with these conditions to the appropriate specialists?

- What is the reason for the lack of dedicated research funding for oral cancer prevention or early-stage detection?
- How is Alberta doing relative to other jurisdictions in Canada and globally? Are there other areas in Canada or in the rest of the world with lower prevalence of stage IV OCC and OPC cases? If so, how was this accomplished?

Addressing the latter research questions requires conducting a national/international multi-institutional collaborative studies to generate data and identify the prevalence of oral cancer stages for each jurisdiction and location.

2.8 Implications for Practice

Our findings identified some structural barriers to care for patients with premalignant and malignant oral lesions, including long wait times and transportation issues. Ultimately, addressing barriers and facilitating access to care for potential OCC and OPC patients could result in earlier cancer detection and thus have a crucial impact on turning a dismal outcome associated with stage IV cancer into much-improved survival resulting in better quality of life.

3 Chapter Three: Factors associated with oral cancerous and potentially malignant oral lesions in a high-risk underserved community in Edmonton, Canada: A population-based study

3.1 Abstract

Introduction: Lower socioeconomic groups are at higher risk of developing oral cancer with a lower survival rate. The objective of this study was to determine the oral health profile of a high-risk population and the associated risk factors for oral cancer.

Methods: In this cross-sectional study, English-speaking adults aged 18 years and older living in a high-risk underserved district in Edmonton were recruited from four not-for-profit centres in the Boyle McCauley Street community. Data were collected through conventional oral examinations (COE) and a questionnaire recording information on demographics, socioeconomics, living conditions, oral mucosal lesion/ inflammation, and sexual behaviors. Descriptive statistics, chi-squared tests, and logistic regressions were applied.

Results: This study confirmed our hypothesis that the prevalence of oral cancerous lesions (2.4%) in the Boyle McCauley Street community was higher than the national oral cancerous lesion prevalence in Canada (0.014%-1.42:10,000) and Alberta (0.011%-1.13:10,000). In total, 322 participants with a mean (SD) age of 49.3 (13.5) years completed the study. Of these, 71.1%

were male, 48.1% were aboriginal, and 88.2% were single. The clinical examinations, which were conducted by two registered oral health practitioners, indicated that 55 of the participants (17.1%) presented with potentially malignant oral lesions (PMOL), 176 (54.7%) had red, lichenoid, yellow, and pink changes of oral mucosa of various sizes, and 61.5% had a high level of decayed/missing/filled teeth (DMFT) index ranging from 0 to 28 for dental caries, with a mean of 13.4 and a standard deviation of 7.20. The risk of cancerous/PMOL was 1.68 times higher in participants living in shelters vs those living alone, after accounting for multiple predictors. Oral lesion/inflammatory changes in oral mucosa showed a significant association with cancerous/PMOL ($p<0.001$). Participants aged 45-65 years, and/or with education $<10^{th}$ grade, smoking and >20 years of tobacco exposure, recreational drugs usage, alcohol usage, fair to poor oral health perception, and lacking information about oral cancer showed a higher point estimate among the cancerous/PMOL group compared to their counterpart cohort.

Conclusions: The prevalence of oral cancerous/PMOL in the Boyle McCauley Street community was higher than that of the general population. Our study supports the need for developing opportunistic oral cancer screening and oral health promotion strategies in deprived communities.

3.2 Introduction

Oral health is a general reflection of overall health. Oral cancer and potentially malignant oral lesions (PMOL) are oral health conditions that could tremendously affect a patient's overall health and quality of life, if not detected and treated. Over 90% of oral cancers are diagnosed as oral squamous cell carcinoma (OSCC), which has a high mortality rate and comprises 30% of all head and neck malignancies (Alberta Health Services, 2014, February; Omura, 2014; John D Webster, Martin Batstone, & Camile S Farah, 2019). Head and neck cancers comprise 4% of cancer incidences in the United States and Canada (Stephanie Johnson, McDonald, Corsten, & Rourke, 2010). Most PMOL and early cancerous lesions are symptomless, resulting in the pursuit of medical attention at advanced stages and leading to a poor prognosis and low survival rate (John D Webster et al., 2019). This is an unfortunate outcome, considering the feasibility of visual oral examinations for identifying suspected high-risk premalignant lesions of the mouth. The most common PMOL are leukoplakia (white changes), erythroplakia (red changes), and a combination of white and red changes (erythroleukoplakia), defined as clinical terms for white/red patches that cannot be rubbed off and clinically cannot be characterized as any other disease (A. Ross Kerr, 2010).

Cancer risk and interventions are not one-size-fits-all across different populations (Fogleman, Mueller, & Jenkins, 2015). According to the World Health Organization, oral cancer varies in distribution from region to region. Two-thirds of the global incidence of oral cancer occurs in low- and middle-income countries such as South Asia, with India accounting for one-fifth of the world's cases (Omura, 2014). Furthermore, the etiology of oral cancer is multifactorial and includes socioeconomic status (SES), education, health literacy, general

health, access to care, nutrition quality, oral hygiene, and exposure to known risk factors such as tobacco and alcohol (McDonald, Johnson-Obaseki, Hwang, Connell, & Corsten, 2014). These factors could be considered as social determinants of health.

Recent evidence indicates that health inequality in Canada persists (although is narrowing) and that unequal distribution of wealth along with social determinants of health resources lead to inequity in health outcomes in lower socioeconomic classes (Mackenzie, Skivington, & Fergie, 2020; Ravaghi, Farmer, & Quiñonez, 2020). It is these classes who experience the most multidimensional deprivation and are known to be at higher risk for developing chronic diseases such as oral malignancies with worse survival rates and significantly reduced quality of life (Booth, Li, Zhang-Salomons, & Mackillop, 2010; E. Hwang, Johnson-Obaseki, McDonald, Connell, & Corsten, 2013). There is substantial evidence indicating that underserved groups residing in deprived socioeconomic neighbourhoods are at higher risk for adopting unhealthy behaviours and being exposed to synergic consumption of tobacco, recreational drugs and alcohol, resulting in poor nutrition and oral hygiene (A. Auluck et al., 2010). All of these factors are known to be risk indicators for oral cancer and oral premalignant lesions. By "underserved" in this study, we refer to populations who are disadvantaged in their abilities to pay for or access care and health care, and/or are experiencing race, language, gender, or social status disparities.

In various places around the world, including in Alberta, there has been increasing incidence recently of oropharyngeal cancer associated with Human Papillomavirus (HPV). This emerging trend is recognized as being attributable to changes in sexual behaviours (oral sex

practice) among the younger generation (L. Shack et al., 2014). Hence, HPV infection should be counted as a risk factor for OPC in underserved neighbourhoods.

A number of studies investigated the correlation of deprived socioeconomic status (SES) and oral cancer incidence (A. Auluck et al., 2010; Hung et al., 2020; E. Hwang et al., 2013; Stephanie Johnson et al., 2010; McDonald et al., 2014). Hwang and colleagues assessed the risk of oral cancer incidence in a high-risk population with smoking habits and introduced a predictive model for oral cancer in Taiwan (Hung et al., 2020). Accordingly, an oral cancer screening policy for high-risk groups that may benefit from early detection was recommended. A study conducted in Germany examined the impact of lack of awareness and low-income status among underserved groups on late oral cancer diagnoses (Baumann et al., 2016). A research team in Ottawa, Canada, comprehensively investigated the impact of multiple SES variables on the incidence of head and neck cancers and survival in both Canada and the United States and reported their results in multiple consecutive articles (E. Hwang et al., 2013; Stephanie Johnson et al., 2010; S. Johnson, McDonald, & Corsten, 2008; McDonald et al., 2014) . In their studies, the association of SES variables, demographic characteristics, marital status, family income, level of education, immigration status, average household income, smoking behaviour, and dental visits were assessed with the incidence of head and neck cancers (E. Hwang et al., 2013; Stephanie Johnson et al., 2010; S. Johnson et al., 2008; McDonald et al., 2014). The findings confirmed a significant impact of socioeconomic deprivation on head and neck cancer incidence and survival.

Researchers in British Columbia, Canada, investigated how oral cavity and oropharyngeal cancer incidence varied according to a neighbourhood's SES, including

magnitude of inequalities such as average income of neighbourhood, housing tenure, educational attainment, family structure, employment, and ethnic variations (A. Auluck et al., 2010; A. Auluck et al., 2014). The findings support community-based interventions to address access to care and distribution of educational health promotion among the most SES-deprived communities in BC (A. Auluck et al., 2014). Ethnic minorities were also found to be at a higher risk for oral cancer compared to the general population (A. Auluck et al., 2010).

Similar to SES deprivation that could be associated with chronic diseases and cancers, chronic inflammation, such as inflammatory changes of oral mucosa at high-risk sites (e.g., lateral border of tongue, floor of mouth, oropharynx and periodontal diseases), do contribute significantly to the process of developing oral cancer (Shamami, Shamami, & Amini, 2011). Inflammation is a biological response of body tissues to trauma and harmful stimuli, pathogens, damaged cells or trauma(Ferrero-Miliani, Nielsen, Andersen, & Girardin, 2007) while oral inflammation is any inflammatory process affecting mucous membrane of the mouth and lips with/out ulceration(Stewart, 2011). Inflammatory cells are essential constituents of the microenvironment of cancers and can promote cancer cell proliferation and survival, as well as the ability of these cells to invade and metastasize (Goertzen et al., 2018). The inflammatory mediators, which include nuclear factor kappa B, vascular endothelial growth factor, inflammatory cytokines, prostaglandin pathways, TP53 tumor protein gene, reactive oxygen and nitrogen species, and microRNAs, are the major inflammatory mediator key players in the pathogenesis of oral cancer (J. B. Patel, Shah, Joshi, & Patel, 2016).

While relatively few Canadian provinces have examined how the incidence of oral malignancy may be impacted by SES deprivation, Alberta has received considerably less

population-based research attention. Therefore, the objective of the present study is to determine, for the first time, the oral health profile of a high-risk population in the province of Alberta and investigate the association, if any, between oral cancer and PMOL incidence and sociodemographic characteristics, unhealthy behaviours, and oral mucosal lesion/ inflammation.

3.3 Methods

A *cross-sectional study* was conducted from January 2017 to February 2020 in a marginalized and high-risk community in Edmonton, Canada. In our research, we defined a high-risk and underserved population as poor, frail, disabled, economically disadvantaged, homeless, a racial and/or ethnic minority, persons with low literacy, victims of abuse or persecution, and persons with social risk factors such as isolation and limited access to care (Institute of Medicine Committee on Health, 2004). This study targeted the Boyle McCauley community population as an indicator of vulnerability for oral lesions in general and cancerous/PMOL in particular.

Ethics approval was obtained by the Research Ethics Board at the University of Alberta (Pro00060953_REN4).

3.3.1 Setting and Sampling:

The Boyle McCauley Street area is one of the most high-risk and underserved communities in Edmonton. It is located in central Edmonton, just east of the city's downtown core (Goverment of Alberta, 2019, December). According to the 2014 census, 6,240 adults older than 18 years reside in the community. We collected data from four major not-for-profit charitable centres that provide relevant and accessible primary health care and wellbeing support to some of the most

vulnerable members of this community, including those experiencing poverty, homelessness, mental health issues, addictions, and social isolation.

English-speaking adults living in the Boyle McCauley Street community were recruited from the Boyle McCauley Health Centre Dental Clinic, the first community-based health centre in Alberta, which was incorporated in 1979 and designed to respond to the often overlooked and unique health care needs of the residents of Edmonton's inner city (Boyle McCauley Health Centre, 2018). Participants were also recruited from the George Spady Society Shelter-Detox-Supervised Consumption Centre, an organization recognized as a leader in the development and delivery of effective services for the care, treatment, and support of individuals with substance-related disorders and dual diagnoses (George Spady Centre Society, 2020). As well, participants were sourced from Operation Friendship Seniors Society, an organization designated by Canada Revenue Agency (CRA) as a registered charity serving Edmonton's inner city seniors since 1969 (Canada Helps, 2020), and from Bissell Centre West, an organization designated by CRA as a registered charity working toward the elimination of poverty in the community (B. C. Canada Helps, 2020).

The executive directors of the organizations facilitated the recruitments through their centres and connections with the community. In addition to the center's regular clients, other eligible individuals were invited by the above centres via telephone calls, posters and community gatherings to participate in the study. An honorarium was provided to participants at the completion of the study. A sample size of 360 was estimated based on the population of the community, with a 95% confidence interval and a 5% error margin.

3.3.2 Data Collection

Data were collected through a voluntary completion of a questionnaire and clinical examinations. Once informed consent was obtained, participants were asked to complete a questionnaire consisting of four sections: demographics, risk factors, oral health perceptions and behaviours, and medical history and health care utilization/access. The questionnaire was adopted from the American Academy of Oral Medicine Clinician's Guideline (A. Ross Kerr, 2010). The clinical examinations were performed by two calibrated licensed oral health care practitioners using a mobile dental chair at the assigned setting locations.

3.3.3 Measures

Sociodemographic measures included sex (male vs female), age (<=44, 45-65, >65), ethnicity (Aboriginal, White, others), educational level (<10, 10-12, >12), family annual income (<$6,000 $6,000-$12,000, >$12,000), employment status (working, not working), marital status (married/common law, divorced-separated, never-married), living status (alone, with family, with others), and housing type (house, apartment, single room occupancy, shelter or street).

The participants' tobacco smoking history included tobacco users (Yes, No), years of exposure (< 20, ≥20), starting age (<15, 15-18, >18), and quantity per day (<20, ≥20); recreational drug use included recreational drug users (Yes, No), starting age (<20, ≥20), usage frequency (Occasional, Often, Everyday), type of recreational drug (Marijuana, Crack/Cocaine, Crystal Meth, Methadone, Mixed); alcohol consumption included alcohol users (Yes, No), starting age (<15,15-20, >20), usage frequency (Occasional, Often, Everyday), type of alcohol

(Beer, Wine, Liquor/Shots, Mixed), years of alcohol consumption (<20, ≥20); and oral sex practices without protection (Yes, No).

Oral health perceptions and behaviours were measured by fourteen items across five domains, including oral health self-perception (Excellent, Very good, Good, Fair, Poor), access to dental care (Yes, No), main complaint (Pain, Eating, Others), oral hygiene (Brushing Frequency, Dental Floss Frequency), and oral cancer knowledge (Yes, No). Medical history and health care utilization and access comprised eleven items across the five domains of general health self-perception (Excellent, Very good, Good, Fair, Poor), history of systemic/chronic diseases (Yes, No), cancer screening history (Yes, No), cancer knowledge (Yes, No), and access to care (Yes, No).

Clinical measures included 1) oral mucosa assessment for detection of red and white cancerous and potentially cancerous lesions (Yes, No), and 2) dental examination for measuring the DMFT Index (Low: 0-4, Medium: 5-9, High: 9+) and continuous scores (0-28). The dental examination also included a periodontal and oral hygiene examination, measuring the plaque index (Excellent: 0.00, Good: 0.1-0.9, Fair: 1.0-1.9, Poor: 2.0-3.0, Edentulous), periodontal pocket depth (Healthy: 0-3 mm; Unhealthy: 4+ mm, Edentulous), and tooth mobility (Class 1: [<1 mm] Horizontal; Class 2: [>1 mm] Horizontal; and Class 3: [>1 mm] Horizontal-Vertical Edentulous).

3.3.4 Statistical Analysis

We used descriptive statistics for analysis. Our outcome variable was oral cancerous/PMOL dichotomously categorized as ‘1’ for presence of a lesion and ‘0’ for absence of a lesion. The

Student's t-test was used to examine differences in continuous variables in patients with and without lesions. To determine whether proportion between outcome variables and all categorical variables exists, we conducted chi-squared tests with phi and Cramer's V option. Univariate analysis determined that the association of sociodemographic characteristics included age, educational level, and living conditions with the presence of a lesion. Adjusted logistic regression was conducted to examine the risk of oral cancerous/PMOL considering the participants' demographic characteristics. An alpha level of 0.05 was used to determine statistical significance. All analyses were conducted using Statistical Package for Social Sciences (SPSS for Windows, version 24.0; SPSS Inc., Chicago, Ill., USA).

3.4 Results

A total of 322 participants completed the study, with no missing data in the final dataset. The participants were aged 18-97 years, with a mean (SD) age of 49.3 (13.5). Of the participants, 71.1% were male, 48.1% were aboriginal, and 88.2% were never married, divorced, or separated. The participants' sociodemographic characteristics and additional risk factors compared with participants diagnosed with cancerous and PMOL are presented in **Table 3.1**.

Compared to their counterpart cohort, the cancerous/precancerous group was identified in the descriptive analysis as having a higher point estimate for the age category 45 to 65 years (56.7% vs. 52.3%), education level lower than grade ten (46.7% vs 36.6%), smoking usage (70% vs 68.3%) and tobacco exposure higher than 20 years (61.7% vs 54.2%), recreational drug usage (56.7% vs 55.7%), alcohol usage (53.3% vs 52%), fair to poor oral health perceptions (66.7% vs 63.7), and lack of information about oral cancer (51.7% vs 45.8%) **(Table 3.5)**.

Table 3.1 Participants Demographic Characteristics vs Oral Mucosa Cancerous/Potentially Malignant Oral Lesion

Boyle Street Data	**Total Number of Participants:**			**322**	
	Oral Cancerous/ Potentially Malignant Oral Mucosa (PMOL):			**55/5**	
	Participants Demographic Characteristics N=322			**Diagnosed with Oral Cancerous/PMOL N=60**	
Factors	**Category**	**N**	**(%)**	**N**	**(%)**
Sex	Female	93	28.9	21	35.0
	Male	229	71.1	39	65.0
	Total	322	100.0	60	100
Age	< =44	114	35.4	20	33.3
	45-65	171	53.1	34	56.7
	> 65	37	11.5	6	10.0
	Total	322	100	60	100
Age		Mean (49.3) SD (13.5) Range (79)			Mean (50.43) SD (12.0) Range (49)
Ethnicity	White/Caucasian	115	35.7	20	33.3
	Other ethnic background	155	13.7	10	16.7
	Aboriginal	44	48.1	28	46.7
	Declined to answer	8	2.5	2	3.3
	Total	322	100	60	100
Education in years	>12	84	26.1	16	26.7
	10-12	114	35.4	16	26.7
	<10	124	38.5	28	46.7
	Total	322	100	60	100
Marital Status	Married / Common Law	8	11.2	8	13.3
	Divorced-separated	20	31.1	20	33.3
	Never married	32	57.1	32	53.3
	Declined to answer	0	0.6	0	0.0
	Total	322	100	60	100
Living Status	With family	51	15.8	7	11.7
	Alone	147	46.7	21	35.0
	Shelter/street	121	37.6	31	51.7
	Declined to answer	3	0.9	1	1.7
	Total	322	100	60	100
Employment Status	Working	35	10.9	7	11.7
	Not working	287	89.1	53	88.3
	Total	322	100	60	100
Annual Income	> $12,000	77	23.9	15	25.0
	< $6,000-12000	180	55.9	31	51.6
	Declined to answer	65	20.2	14	23.3
	Total	322	100	60	100
Financial Aid	Yes	255	69.9	41	68.3
	No	81	25.2	15	25.0
	Declined to answer	16	5.0	4	6.7
	Total	322	100	60	100
Living at Boyle Street	<=3 Months	62	19.3	13	21.7
	3-6 Months	40	12.4	7	11.7
	6-12 Months	27	8.4	10	10.0
	>12 Months	193	59.9	30	56.6
	Total	322	100	60	100

Table 3.1 CON'T: Additional Factors

Boyle Street Data	Total Number of Participants: 322 Potentially Malignant Oral Mucosa (PMOL)/ Oral cancer: 55/5				
		Additional Risk factors N=322		Diagnosed with Oral Cancerous/PMOL N=60	
Variable	**Category**	**N**	**(%)**	**N**	**(%)**
Smoking Tobacco	No	101	31.4	18	30.7
	Yes	221	68.6	42	70.0
	Total	322	100	60	100
Tobacco Exposure in Years	< 20	42	13.0	5	8.3
	>= 20	179	55.6	37	61.7
	Non-Users	101	31.3	18	30.0
	Total	322	100	60	100
Recreational Drug Use	No	142	44.1	26	43.3
	Yes	180	55.9	34	56.7
	Total	60	100	60	100
Alcohol Consumption	No	152	47.2	28	46.7
	Yes	170	52.8	32	53.3
	Total	322	100	60	100
Oral Health Perception	Excellent	5	1.6	2	3.3
	Very good	22	6.8	4	6.7
	Good	64	19.9	8	13.3
	Poor to fair	207	64.2	40	66.7
	Declined to answer	24	7.5	6	10.0
	Total	322	100	60	100
Heard about Oral Cancer	Yes	171	53.1	29	48.3
	No	151	46.9	31	51.7
	Total	322	100	60	100
Oral Cancer Screening	Yes	33	10.2	8	13.3
	No	285	88.5	51	85.0
	Declined to answer	4	1.2	1	0.6
	Total	322	100	60	100
Oral Mucosal Lesion/ Inflammation	No	176	54.7	3	5.0
	Yes	146	45.3	57	95.0
	Total	322	100	60	100
Oral Sex Without Barrier	No	155	48.1	28	46.7
	Yes	143	44.4	28	46.7
	Declined to answer	24	7.5	4	6.7
	Total	322	100	60	100

For substance use, 68.6% of the participants used tobacco, 55.9% used recreational drugs, and 53.1% used alcohol (**Table 3.2)**. Appendix 6, Module II, presents a list of the included tobacco, recreational drugs, and alcoholic drinks.

Table 3.2 Risk Factors (Tobacco-Recreational Drug Use)

Variable	Category	N	(%)
Smoking Tobacco	Yes	221	68.6
	No	101	31.4
	Total	322	100.0
Tobacco Exposure in Years	< 20	42	13.0
	>=20	179	55.6
	Non-Users	101	31.3
	Total	322	100.0
Starting Age Tobacco Use	<15	119	36.9
	15-18	71	22.0
	>18	31	9.6
	Non-Users	101	31.3
	Total	322	100.0
Quantity Smoked Per Day	<20	146	45.3
	>=20	75	23.2
	Non-Users	101	31.3
	Total	322	100.0
Recreational Drug Use	Yes	180	55.9
	No	142	44.1
	Total	322	100.0
Starting Age of Recreational Drug Use	<20	120	37.3
	>=20	60	18.6
	Non-Users	142	44.1
	Total	322	100.0
Frequency of Recreational Drug Use	Occasional (Available)	8	2.5
	Often	93	28.9
	Everyday	79	24.5
	Non-Users	142	44.1
	Total	322	100.0
Type of Recreational Drug	Marijuana	54	16.8
	Crack/Cocaine	14	4.3
	Crystal Meth	24	7.5
	Methadone	3	0.9
	Mixed	85	26.4
	Non-Users	142	44.1
	Total	322	100.0

Table 3.2 CON'T: Risk Factors (Alcohol Use)			
Variable	**Category**	**N**	**(%)**
Alcohol Consumption	Yes	170	52.8
	No	152	47.2
	Total	322	100.0
Starting Age of Alcohol Consumption	<15	76	23.6
	15-20	77	23.9
	>20	17	5.2
	Non-Users	152	47.2
	Total	322	100.0
Type of Alcohol	Beer	53	16.4
	Wine	7	2.1
	Liquor/Shots	30	9.3
	Mixed	81	25.1
	Non-Users	152	47.2
	Total	322	100.0
Frequency of Alcohol Use	Occasional (Available)	24	7.4
	Often	90	27.9
	Everyday	56	17.3
	Non-Users	152	47.2
	Total	322	100.0
Years of Alcohol Consumption	< 20	37	11.4
	>=20	133	41.3
	Non-Users	152	47.2
	Total	322	100.0

Table 3.2 CONT: Known Risk Factors

	N	Minimum	Maximum	Mean	Std. Deviation
Tobacco exposure Years	223	3	77	31.77	12.710
Starting Age of Tobacco Use	223	4	50	15.46	6.738
Quantity Smoked per Day	222	0	50	13.39	8.346
Starting Age of Recreational Drug Use	180	3	61	20.57	11.556
Starting Age of Alcohol Consumption	169	3	57	16.36	7.826
Years of Alcohol Consumption	169	2	81	31.20	14.126

Participants had a better perception about their general health than their oral health. While about 63% perceived their oral health status as fair to poor (**Table 3.3**), 38.8% identified their general health as fair to poor. Furthermore, 62.4% of the participants had no history of cancer screening and 33.2% claimed they had no access to care when needed (**Table 3.4)**.

The clinical assessments indicated that 60 (18.6%) of the participants presented with oral cancerous/PMOL. Of these, five cases were diagnosed with squamous cell carcinoma, which represents 1.5 % and 17.1 % PMOL, respectively. The cancerous proportion is expected to increase by an additional 2.7 %, considering the assumption of a 5% chance of malignancy transformation for the identified 55 cases of PMOL in this study (Seamus S Napier & Paul M Speight, 2008; Speight et al., 2017). Oral mucosal lesion /inflammatory changes, which were comprised of red, white, pink, and traumatic conditions in various dimensions and locations, were detected in 176 (54.7%) of cases. The changes were located at the ventral, dorsal, and borders of the tongue, buccal mucosa, floor of the mouth, retromolar pads, tonsils, and oral gingiva. Nearly 62% of participants had a high decayed/missing/filled teeth (DMFT) categorical score (9≤) with a mean (SD) of 13.39 (7.20) for dental caries, while 52.2% had a fair to poor Plaque Index **(Table 3.6 - Table 3.7)**.

Table 3.3 Oral Health Perceptions and Behaviours

Variable	Category	N	(%)
Oral Health Perception	Excellent	5	1.6
	Very good	22	6.8
	Good	64	19.9
	Fair	108	33.5
	Poor	99	30.7
	Declined to answer	24	7.5
	Total	322	100.0
Recent Dental Visit	Never	9	2.8
	Within the past year	116	36.0
	Within 1-5 years	123	38.2
	> 5 years	74	23.0
	Total	322	100.0
Uncomfortable to eat or drink in the past month	Never	140	43.5
	Once a week	44	13.7
	More than once	132	41.0
	Declined to answer	6	1.8
	Total	322	100.0
Oral pain in the past month	Never	160	49.7
	Once a week	64	19.9
	More than once	87	27.0
	Declined to answer	11	3.4
	Total	322	100.0
How often brush your teeth/dentures	More than once a day	113	35.1
	Once a day	107	33.2
	Once a week	24	7.5
	Do not brush	54	16.8
	Do not have teeth/dentures	14	4.3
	Declined to answer	10	3.1
	Total	322	100.0
How often floss your teeth/dentures	More than once a day	105	32.6
	Once a week	27	8.4
	Do not floss	161	50.0
	Do not have teeth/dentures	18	5.6
	Declined to answer	11	3.4
	Total	322	100.0
What bothers you most about your mouth/teeth	Nothing	71	22.0
	Eating	145	45.0
	Others (Talking/Appearance)	106	32.9
	Total	322	100.0
Main oral problem	Pain	134	41.7
	Others (sharp and missing teeth, bad breath, ill-fitting dentures)	114	35.4
	Declined to answer	74	23.0
	Total	322	100.0
Heard about oral cancer	Yes	171	53.1
	No	151	46.9
	Total	322	100.0

Table 3.3 CONT: Oral Health Perceptions and Behaviours			
Variable	**Category**	**N**	**(%)**
History of Head and Neck Cancer in family	Yes	30	9.3
	No	292	90.7
	Total	322	100.0
Oral cancer screening in the past	Yes	33	10.2
	No	285	88.5
	Declined to answer	4	1.2
	Total	322	100.0
How often oral problem in the past 3 months	Never	130	40.4
	Rarely	68	21.1
	Some of the time	51	15.8
	Most of the time	24	7.5
	All the time	46	14.3
	Declined to answer	3	0.9
	Total	322	100.0
How often social activities affected by oral health issues	Never	164	50.9
	Rarely	59	18.3
	Some of the time	49	15.3
	Most of the time	18	5.6
	All the time	29	9.0
	Declined to answer	3	0.9
	Total	322	100.0
Frequency of avoidance of conversation	Never	167	51.8
	Rarely	47	14.6
	Some of the time	53	16.5
	Most of the time	27	8.4
	All the time	25	7.8
	Declined to answer	3	0.9
	Total	322	100.0

Univariate analyses: The chi-squared test of socioeconomic and biological factors with oral cancerous/PMOL prevalence revealed an association of oral mucosal lesions/inflammation and cancerous/PMOL in participants. [K^2, (DF), (P-value), (Phi) = 48.24, (1), (0.001), (0.38)].

Simple logistic regression: To analyze the association between cancerous/PMOL and living condition, simple logistic regression was conducted. The results indicated that the risk of cancerous/PMOL was two times higher in participants living in shelters than those living alone (OR=2.06; 95% CI: 1.15 - 3.82).

Table 3.4 Medical History & Health Care Utilization and Access			
Variable	**Category**	**N**	**(%)**
General Health Perception	Excellent	19	5.9
	Very good	47	14.6
	Good	122	37.9
	Fair	86	26.7
	Poor	38	11.8
	Declined to answer	10	3.1
	Total	322	100.0
History of any cancer	Yes	33	10.2
	No	286	
	Declined to answer	3	
	Total	322	100.0
Medication use	Yes	148	46.0
	No	172	53.4
	Declined to answer	2	0.6
	Total	322	100.0
Viral infection	No	263	81.7
	Hepatitis B	2	0.6
	Hepatitis C	35	10.9
	HPV	2	0.6
	HIV	2	0.6
	Multiple virus infection	16	5.0
	Declined to answer	2	0.6
	Total	322	100.0
Bacterial infection	No	303	94.1
	TB	11	3.4
	STD	6	1.9
	Declined to answer	2	0.6
	Total	322	100.0
Systemic/chronic diseases	No	171	53.1
	Immune system	1	0.3
	Cardiovascular	31	9.7
	Diabetes	20	6.2
	Multiple systemic diseases	97	30.1
	Declined to answer	2	0.6
	Total	322	100.0

Table 3.4 CONT: Medical History & Health Care Utilization and Access			
Variable	**Category**	**N**	**(%)**
Drug Allergy	Yes	45	14.0
	No	266	82.6
	Declined to answer	11	3.4
	Total	322	100.0
Health professional visit in the past year	Yes	215	66.8
	No	101	31.4
	Declined to answer	6	1.9
	Total	322	100.0
History of any cancer screening	Yes	118	36.6
	No	201	62.4
	Declined to answer	3	0.9
	Total	322	100.0
History of overnight stay at hospital	Yes	176	54.7
	No	139	43.2
	Declined to answer	7	2.2
	Total	322	100.0
Healthcare need and not received it	Yes	107	33.2
	No	199	61.8
	Declined to answer	16	5.0
	Total	322	100.0

Multiple logistic regressions: A multiple logistic regression analysis was conducted to examine the risk of the presence of oral cancerous/PMOL with living status and oral mucosal lesion/ inflammation. In the multiple logistic regression analysis, the risk of cancerous/PMOL was 1.68 times higher in participants living in shelters vs those living alone, after accounting for multiple predictors (OR=1.67; 95% CI: 1.19 – 2.37). The Nagelkerke R square was 0.310.

Table 3.5 Demographic Characteristics Oral Cancerous/Potentially malignant Oral Lesions (PMOL) vs Without

Boyle Street Data	**With Oral Cancerous/PMOL:**	**60**			
	Without Oral Cancer/PMOL:	**262**			
	Total:	**322**			
	With Oral Cancerous/PMOL N=60			**Without Oral Cancerous/PMOL N=262**	
Factors	**Category**	**N**	**(%)**	**N**	**(%)**
Sex	Female	21	35.0	72	27.5
	Male	39	65.0	190	72.5
	Total	60	100.0	262	100
Age	< =44	20	33.3	94	35.9
	45-65	34	56.7	137	52.3
	> 65	6	10	31	11.8
	Total	60	100	262	100
Age		Mean (50.43) SD (11.989) Range (49)			Mean (49.05) SD (13.822) Range (79)
Ethnicity	White/Caucasian	20	33.3	95	36.2
	Other ethnic background	10	16.7	34	13.0
	Aboriginal	28	46.7	127	48.5
	Declined to answer	2	3.3	6	3.0
	Total	60	100	262	100
Education Level	>12	16	26.7	68	26.0
	10-12	16	26.7	98	37.4
	<10	28	46.7	96	36.6
	Total	60	100	262	100
Marital Status	Married / Common Law	8	13.3	28	10.7
	Divorced-separated	20	33.3	80	30.5
	Never married	32	53.3	152	58.0
	Declined to answer	0	0	2	0.7
	Total	60	100	262	100
People Living With	With family	7	11.7	44	17.0
	Alone	21	35.0	126	48.0
	Shelter/street	31	51.7	90	34.3
	Declined to answer	1	1.7	2	0.7
	Total	60	100	262	100
Employment Status	Working	7	11.7	28	10.7
	Not working	53	88.3	234	89.3
	Total	60	100	262	100
Annual Income	> $12,000	15	25.0	62	23.7
	< $6,000-12000	31	51.6	149	56.8
	Declined to answer	14	23.3	51	19.5
	Total	60	100	262	100
Financial Aid	Yes	41	68.3	184	70.2
	No	15	25.0	66	25.2
	Declined to answer	4	6.7	12	4.6
	Total	60	100	262	100
Living at Boyle Street	<=3 Months	13	21.7	49	18.7
	3-6 Months	7	11.7	33	12.6
	6-12 Months	10	10	17	8.0
	> 12 Months	30	56.6	163	60.7
	Total	60	100	262	100

Table 3.5 CON'T: Additional Factors					
Boyle Street Data	**With Oral Cancer:**	**60**			
	Without Oral Cancer:	**262**			
	Total:	**322**			
		With Oral Cancer N=60		**Without Oral Cancer N=262**	
Variable	**Category**	**N**	**(%)**	**N**	**(%)**
Smoke Tobacco	No	18	30.0	83	31.7
	Yes	42	70.0	179	68.3
	Total	60	100	262	100
Tobacco Exposure Years	< 20	5	8.3	37	14.1
	>= 20	37	61.7	142	54.2
	Non-Users	18	30.0	83	31.7
	Total	60	100	262	100
Recreational Drug Use	No	26	43.3	116	44.3
	Yes	34	56.7	146	55.7
	Total	60	100	262	100
Alcohol Usage	No	28	46.7	124	47.3
	Yes	32	53.3	138	52.7
	Total	60	100	262	100
Oral Health Perception	Excellent	2	3.3	3	1.1
	Very good	4	6.7	18	6.9
	Good	8	13.3	56	21.4
	Poor to fair	40	66.7	167	63.7
	Declined to answer	6	10.0	18	6.9
	Total	60	100	262	100
Heard about Oral Cancer	Yes	29	48.3	142	54.2
	No	31	51.7	120	45.8
	Total	60	100	262	100
Oral Cancer Screening	Yes	8	13.3	25	9.6
	No	51	85.0	234	89.3
	Declined to answer	1	0.6	3	1.1
	Total	60	100	262	100
Oral Mucosal Lesion/Inflammation	No	3	5.0	143	54.6
	Yes	57	95.0	119	45.4
	Total	60	100	262	100
Oral Sex Without Barrier	No	28	46.7	115	43.9
	Yes	28	46.7	127	48.5
	Declined to answer	4	6.7	20	7.6
	Total	60	100	262	100
Oral Sex Without Barrier-How many Partners?	1-5	20	33.3	76	29.0
	6-15	2	3.3	27	10.3
	> 15	6	10.0	23	8.8
	Declined to answer	32	53.3	136	51.9
	Total	60	100	262	100
Oral Sex Without Barrier- Partner Gender?	Male	12	20.0	33	12.6
	Female	16	26.7	90	34.4
	Declined	32	53.3	139	53.0
	Total	60	100	262	100

Table 3.6 Oral health screening (Participants: N=322)			
Variable	**N**	**N=322 (%)**	
Oral mucosal lesion/ inflammation	176	54.7	
Potentially malignant oral lesion	55	17.1	
Confirmed squamous Cell Carcinoma	5	1.5	
Oral cancerous and Potentially malignant oral lesions			
Categories	**Number of cases**	**Total N=322 (%)**	**Total N=60 (%)**
Leukoplakia	40	12.4	66.6
Erythroplakia	1	0.3	1.7
Erythroleukoplakia	3	1.0	5.0
Lichen planus	1	0.3	1.7
Submucous fibrosis	1	0.3	1.7
Highly suspicious nonhealing ulcers	14	4.3	23.3
Total: Cancerous/PMOL	60	18.6%	100.0

3.5 Discussion

This study confirmed our hypothesis that the prevalence of oral cancerous lesions (2.4%) in the Boyle McCauley Street community was higher than the calculated national oral cancerous lesion prevalence in Canada (0.014%-1.42: 10,000) and Alberta (0.011%-1.13:10,000).

The point prevalence per 10,000 people was calculated for Canada and Alberta based on the total count of new cases of oral cancer for 2020 (C. C. S. Goverment of Alberta, 2020, February 28; C. C. S. B. D. Goverment of Alberta, Weir HK, Demers AA, Ellison LF, Louzado C, Shaw A, Turner D, Woods RR, Smith LM., , 2020), divided by the reported quarterly population count for Canada (Statistics Canada, 2020) and Alberta (Goverment of Alberta, 2020),

using the latest Statistics Canada and Government of Alberta data, respectively, for the year 2020, multiplied by 10,000. Of the 322 participants in this study, we identified 55 (17.1%) cases of PMOL and 5 cases of biopsied confirmed cancer. (Note that the COVID-19 outbreak interfered with histopathological biopsy for most PMOL cases that this study identified). This finding shows a 1.6% PMOL and 0.7% cancerous lesion increased rate compared to the findings of 15.5% PMOL and 1.7% confirmed cancer in a similar study conducted in Vancouver, BC (Poh et al., 2007). Whereas, Lim et al., in their study conducted in general dental practices in England among 2,265 patients, detected a prevalence of 4.2% PMOL (Lim et al., 2003).

Almost half of the participants in the Boyle McCauley community identified as Aboriginal. Much scientific evidence already attests to health disparities among indigenous people in Alberta and the rest of Canada (Kolahdooz, Nader, Yi, & Sharma, 2015; Macaulay, 2009). We also found a relatively low SES, such as lower level of education, higher rate of unemployment, lower annual income, high number of individuals living in shelters, and limited access to care. In addition, their high exposure to tobacco and alcohol starting at a younger age and a number of systemic diseases and poorer oral hygiene (all known as risk factors for developing cancer) increases their vulnerability to oral cancer (Booth et al., 2010).

We found a positive correlation of the "living in shelter" variable with oral cancerous and PMOL. This result is consistent with research findings that indicate environmental quality and where an individual lives play an important role in cancer incidence (Fogleman et al., 2015; Jagai et al., 2017). A number of physical, infectious, and mental health issues are known to be associated with homelessness and living in shelters (C. J. Frankish, Hwang, & Quantz, 2005; C James Frankish, Hwang, & Quantz, 2009; S. W. Hwang, 2001). Additionally, even while living

with others, individuals living in shelters experience a significant psychological loneliness caused by lack of desired support from family, parents, siblings, or friends. This demands special attention, as the evidence indicates that the experience of loneliness of homeless individuals is significantly different compared to the general population and is strongly associated with an increased risk of cancer incidence and mortality (Algren et al., 2020; Holt-Lunstad & Smith, 2016; Kawachi & Subramanian, 2018; Reynolds & Kaplan, 1990; Rokach, 2005). Feeling lonely and isolated is also associated with health risk behaviour such as low intake of fruit or vegetables, daily smoking, high-risk alcohol intake, and physical inactivity and their co-occurrence (Algren et al., 2020; Holt-Lunstad & Smith, 2016; Kawachi & Subramanian, 2018; Reynolds & Kaplan, 1990).

The present study also noted that important factors such as age between 45 and 65 years, education level lower than grade ten, smoking and tobacco exposure for longer than 20 years, recreational drug use, alcohol use, fair to poor oral health perceptions and not having heard about oral cancer had a higher point estimate among a cancerous/PMOL group, but was not statistically significant. The reason might be that our sample size was calculated to provide the optimum statistical power in a cross-sectional study. Most of the previous reports on the impact of SES on the incidence of oral cancer in underserved populations were designed retrospectively, using a large number of national and international administrative data across a consecutive number of years with stronger statistical power (Al-Dakkak, 2010; A. Auluck et al., 2010; A. Auluck et al., 2014; Baumann et al., 2016; Hung et al., 2020; E. Hwang et al., 2013; Stephanie Johnson et al., 2010; S. Johnson et al., 2008; McDonald et al., 2014).

We identified a strong association between oral mucosal lesion/ inflammation and oral cancer /potentially malignant lesions. The role of chronic inflammation (i.e., a pathological response of the body to nocuous stimuli) in carcinogenesis has been proven since 1963 by many studies (Tampa et al., 2018). In addition, there is consensus in the literature that tobacco and alcohol users with a poor diet and living in vulnerable and underserved communities similar to Boyle McCauley Street are prone to a higher risk of developing oral inflammatory diseases and PMOL, with a higher risk of progressing to a malignant state. Nonetheless, there is an early and cost-effective opportunity to detect cancerous/PMOL of the oral cavity visually. The high observation rate of oral cancer/PMOL and its significant association with oral mucosal lesion/ inflammation in this study urge the implementation of an effective preventive health strategy such as the visual clinical screening of adults living in the Boyle McCauley community. This will improve the detection and follow-up of cases with potential for malignancy as well as the diagnosis of malignancies at earlier stages.

While to the best of our knowledge there is no international, national or provincial program for oral cancer screening, our accumulated evidence does support periodic, cost-effective, opportunistic/target oral cancer screening for high-risk populations in the Boyle McCauley community in Edmonton as a pilot project. This could be feasible and implemented through a collaboration between the School of Dentistry Oral Medicine clinic (conducted by senior residents), the Shine Clinic (run by DDS and DH students), and the four not-for-profit charitable centre collaborators in our study. The Boyle McCauley Health Centre Dental Clinic could be used for the screening. The clinic has collaborated and continues to collaborate with the School of Dentistry and has a good reputation among those most in need in the neighborhood for its friendly and trustworthy environment.

It is worth noting that we experienced significant challenges during the collection of data. First, our target population was hard to reach, and identifying and organizing connections with the administrative representatives for each centre and scheduling data collection events was time-consuming. It also took time to build trust among all parties, including the research team, the centres' administrations, and eligible participants whose unpleasant past histories made them wary of strangers. In addition, the longer than expected renovations of the Boyle McCauley Dental Clinic caused a delay in the data collection process. Furthermore, the research team faced difficulties in acquiring answers to some of the more sensitive questions, such as ethnic background, annual family income, and sexual behaviours. Another issue was that many of the participants, particularly those diagnosed with premalignant lesions, lacked contact information for potential follow-up and further investigation.

Another barrier in our study involved the mechanics of our research efforts. Despite the accessibility of the recently renovated Boyle McCauley Dental Clinic, the lack of a solid health promotion strategy within the community between the not-for-profit charitable centres and the School of Dentistry resulted in our limited use of available dental clinic infrastructure. Instead, we had to approach eligible participants one by one in four different centres using portable dental chairs and instruments. Most of the limitations in our study were also experienced by a similar oral cancer screening study in a high-risk population in Vancouver, Canada (Poh et al., 2007).

3.6 Conclusions

This is the first cross-sectional study to provide comprehensive clinical evidence of the oral health status of one of the most underserved communities in Edmonton, with a focus on oral cancer screening and associated risk factors. This study confirmed that underserved

socioeconomic communities are at a higher risk of being victimized by inequality in health outcomes. Exposure to tobacco, alcohol, and recreational drugs could have a substantial impact on developing premalignant lesions. These facts urge the development of an opportunistic oral cancer screening health promotion strategy using the available infrastructure and potential in the Boyle McCauley Street district and similar communities.

4 Chapter Four: Factors Associated with Late Detection of Oral Cancer in Alberta: A Retrospective Qualitative Study

4.1 Abstract

Background: Oral cancer continues to be diagnosed in advanced stages, giving patients lower chances of survival. The objective of this study was to explore reasons for delayed diagnosis of oral cancer in Alberta.

Methods: A retrospective qualitative design was implemented through seven steps suggested for conducting a narrative clinical document. Data was retrieved from the Alberta Cancer Registry database between 2005 and 2017. A sample of initial consultation notes (ICN) of oral and oropharyngeal cancer patients were identified through a purposeful sampling method and added to the study until saturation was achieved. A deductive analysis approach inspired by the modified Andersen theoretical model was employed.

Results: From 34 ICN included in our deductive analysis, five main categories were identified: "Patient appraisal interval, Help-seeking interval, formal diagnosis interval, pre-treatment interval, and contributing factors." In addition to biological factors, health-related behaviours, sociodemographic and tumor characteristics, other risk factors that negatively contributed to

early detection of oral and oropharyngeal cancers included factors related to patients, providers, and the healthcare system.

Conclusions: Patient's lack of awareness, provider's lack of competence, and prolonged access to care were the main reasons of delay in cancer diagnosis and management in our study. A sustainable plan for public awareness interventions and implementation of a solid curriculum for medical and dental students is needed to enhance their related knowledge, competence in clinical judgement, and treatment managements.

4.2 Background

Being the 11th most common cancer worldwide, oral cancer is a major public health concern (Bray, Ren, Masuyer, & Ferlay, 2013; Jacques Ferlay et al., 2013). The issue of delayed detection of oral cancer is gaining increased attention by clinicians who believe that detecting oral cancer at an early stage is the most effective means of reducing rates of the disease morbidity (Baykul et al., 2010). For decades, the late detection trend for oral cancer has remained a challenge for health professionals and authorities, as it is associated with a relatively poor prognosis (a five-year survival rate of 50%-60%) and lower quality of life (C. W. LeHew et al., 2010). Late detection of oral cancer also leads to higher therapy costs for survivors (Hammerlid et al., 2001).

To date, multiple factors have been investigated in the literature as independent prognostic markers for oral cancer such as age, co-morbidity, immunological or nutritional status, size/location of the tumour, nodal status, oncogene expression, proliferation markers, and tumor DNA content (Llewellyn, Johnson, & Warnakulasuriya, 2004; Seoane-Romero et al., 2012). In addition, numerous modalities have been used to detect precancerous lesions. These include periodic conventional oral cavity examination for symptomatic and/or non-symptomatic non-healing oral mucosa lesions, oral cytology, optical technologies, fluorescence imaging and more (Ford & Farah, 2013). Other factors extracted from patients' histories and activities, include smoking, recreational drug use and alcohol consumption, as well as genetic predisposition and past/present oral HPV infection, immunodeficiency, and poor oral hygiene (Steele & Meyers, 2011; Yardimci et al., 2014).

Selective opportunistic screening has been introduced in some studies as a more realistic and effective solution versus routine screening, particularly in the detection of oral squamous cell carcinomas in a non-symptom-driven examination (Lim et al., 2003; J. D. Webster, M. Batstone, & C. S. Farah, 2019). This approach has led to diagnosis at an earlier stage , similar to the significant early detection of oral cancer in patients who attend regular dental visits (Holmes, Dierks, Homer, & Potter, 2003; Watson, Logan, Tomar, & Sandow, 2009). In their study, Seoane-Romero and colleagues illustrated that delay in diagnosis is not necessarily associated with advanced stage at diagnosis, nor is obtaining a fast diagnosis a guarantee of an early-stage tumour (Seoane-Romero et al., 2012). Nonetheless, any delay in cancer diagnosis is not generally desirable (Seoane-Romero et al., 2012). According to the study, poor tumor differentiation (e.g., deeming the tumor to be biologically more aggressive) is an independent risk factor for diagnosis at advanced stages (Seoane-Romero et al., 2012).

Recently oral cavity and oropharyngeal cancers grouped as the general term oral cancer (OC) has shown an epidemiological changing trend toward oropharyngeal cancer (OPC) (Gupta et al., 2016). Older men of low socioeconomic status used to be the main victims of the disease; however, in the past decade, many young people including women, and higher socioeconomic classes are being diagnosed with OPC (Gupta et al., 2016). This shift has added to the complexity of challenges that patients and healthcare systems have faced for decades because of OC and OPC aetiologies, clinical presentations, management, and survival rate differences.

Among Canada's ten provinces, Alberta is positioned fourth after Ontario, Quebec and British Columbia for oral cancer incidence and related death prevalence (C. Statistics, 2015). Our previous studies have shown that 45.2% of OC and 82.4% of OPC cases in Alberta are diagnosed

in stage IV, with a 47.9% mortality rate. Therefore, in this retrospective study, the objective was to better understand the reasons for delayed diagnosis of oral cancer in Alberta as well as the difficulties experienced by patients and healthcare professionals dealing with oral cancer, using recorded medical Initial Consultation Notes (ICN).

4.3 Methods

A retrospective qualitative design was implemented using seven steps suggested for conducting a narrative clinical document analysis (Mayan, 2016; Salkind, 2010; Sarkar & Seshadri, 2014) : **1.** Identifying the research question; **2.** identifying the appropriate data source; **3.** devising a data extraction plan; **4.** extracting the data; **5.** checking for errors; **6.** analyzing the data; and **7.** archiving and disseminating the findings. Ethics approval was obtained from the Health Research Ethics Board of the Alberta Cancer Committee (Ethics ID# HREBA.CC-17-0370).

A purposeful sample of medical charts constituting the very first Initial Consultation Notes from the multiple consultation list of each case of OCC and OPC patients listed in the Alberta Cancer Registry (ACR) between 2005 and 2017 was included in this study. In contrast to probability sampling in a quantitative study, qualitative inquiry depends on purposefully selected samples that can be applied to not only participants for interviews but also for documents such as medical charts to be included in the analysis (Mayan, 2016; Patton, 1990; Smith, 2000). For our sampling, the charts were selected based on the maximum variation of nonprobability sampling strategy (Smith, 2000). This strategy assists in identifying essential features and variable aspects of the study phenomena among varied contexts (Benoot, Hannes, & Bilsen, 2016). For the purpose of the present investigation, a range of Initial Consultation Notes of oral cancer patients was selected according to age, sex, pathological oral site, geographic zone, annual income,

clinical stage, and vital status (Baumann et al., 2016). There is a growing consensus in the literature for defining stages I and II as early stage and stages III and IV as late stage of oral squamous cell carcinoma with poorer prognosis and survival rates (Baumann et al., 2016; Seoane-Romero et al., 2012). In this study, we only included stage IV patients since there were higher numbers of cases diagnosed at stage IV (OC: 42.2%; OPC: 82.4%) compared to those recorded at stage III (OC: 9.9%; OPC: 10.0%).

Assessment of the data source in terms of accuracy and completion was implemented. The Initial Consultation Notes (ICN) retrieved from the medical charts of patients were reviewed and crosschecked independently by two reviewers (PB and FS) and subsequently verified by a third reviewer using predefined criteria to determine whether they were accurate and/or complete (Hong, Kaur, Farrokhyar, & Thoma, 2015). Data collection was considered complete at data saturation when no new data emerged to answer the study's research questions (Mayan, 2016). Descriptive analyses were performed to assess the inaccuracies and incompleteness of each chart information field using a comparison method of data (Hong et al., 2015).

Table 4.1 Data Extraction Guide

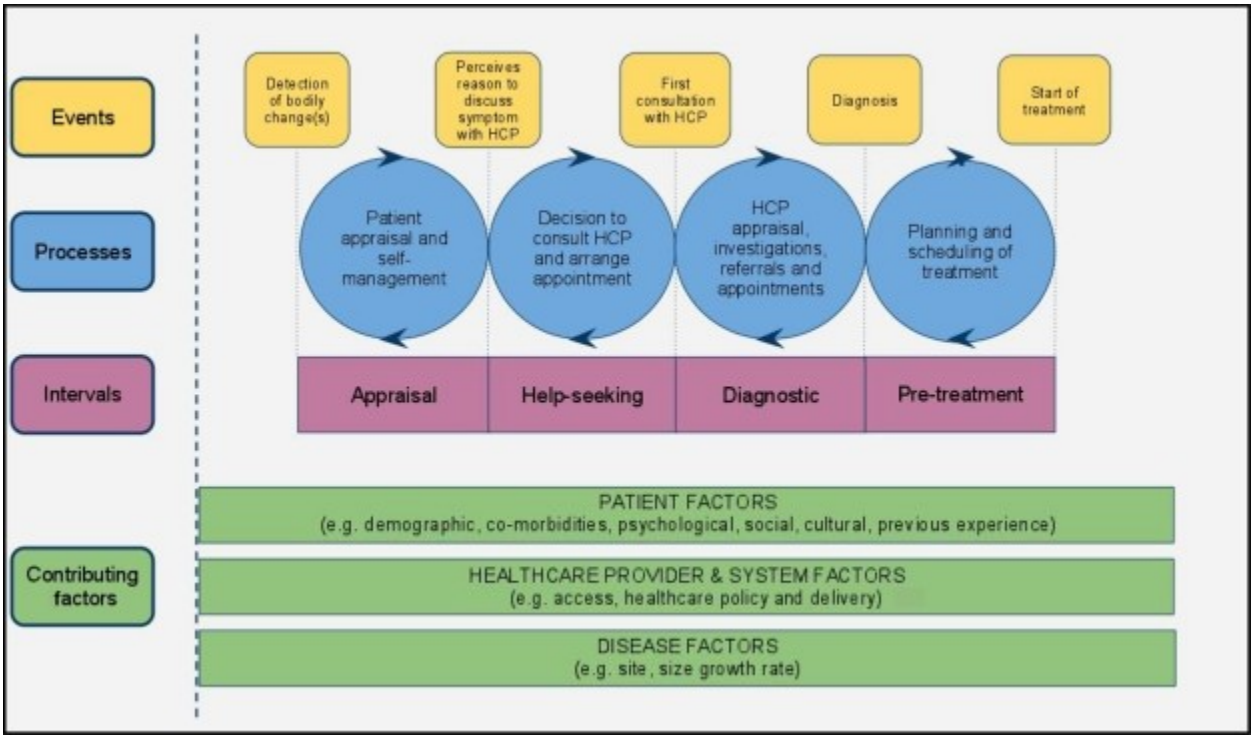
	Open-Ended Questions
1	What brought the patient for the first assessment (first symptoms, if any) and when?
2	What particular underlying risk factors were detected?
3	Did the clinician identify the symptom as potentially malignant or pre-malignant?
4	What tests were ordered?
5	What was the clinician's first attempted intervention?
6	What was/were the outcomes of the attempted intervention(s)?
7	What was the time from onset of the first symptom to contacting a health care professional of any kind?
8	What was the time from first contact with a health care professional to the date of definitive diagnosis?
9	What were the barriers/challenges causing delay in diagnosing the cancerous lesion? • Experienced by whom? Associated factors at any level?

A series of open-ended questions were employed (**Table 4.1)** to assist in extracting data and coding the collected information based on the objectives. These questions clearly indicated that the data elements needed to be extracted from the ICN of the patients. Extraction of data was conducted in accordance with the instrument devised and the element definitions agreed upon by the research team. Two raters coded the data and evaluation of inter-rater reliability was performed. The various terminologies used were defined for clarification. A small sub-sample (approximately 10% of the total) was reassessed to check agreement with the previously coded data and to detect any inaccuracies. The data were analyzed qualitatively using deductive manifest content analysis (Mayan, 2016), which was accompanied by a descriptive statistical analysis of demographic characteristics of patients whose charts were included in the study. Deductive content analysis is an analytical method that aims to investigate a new context using existing categories, theories, models, and concepts (Kyngäs et al., 2019). In contrast to latent content analysis, which refers to the interpretation or underlying meaning of content or interview, manifest content refers to evidence directly seen, such as words in a document requiring the least amount of interpretation (Kyngäs et al., 2019).

A modified version of the Andersen model of Total Patient Delay for cancer was used to analyze and communicate the unknown context experienced by oral cancer patients generated from the ICN documents (Walter, Webster, Scott, & Emery, 2012). This model is one of the most cited theoretical models for cancer diagnosis modified from the original 3-stage Safer et al model (1979), which comprised ‘appraisal delay’, ‘illness delay’, ‘utilization delay’ (Walter et al., 2012). In the original Andersen model, the ‘utilization delay’ was expanded to ‘behavioural

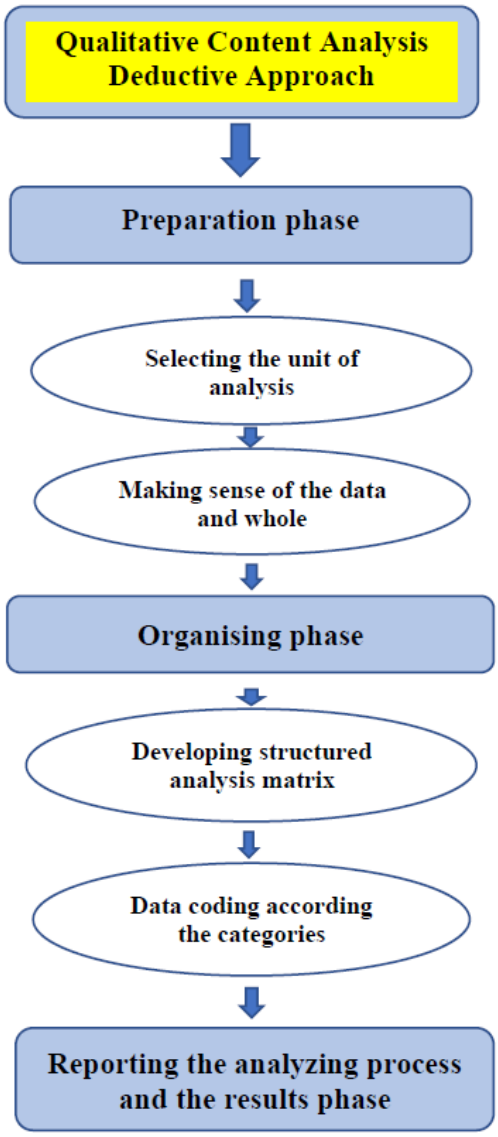
delay', 'scheduling delays, and 'treatment delay'(Walter et al., 2012). The model has been applied in different cancer studies, including oral cancer (X. D. Brouha, Tromp, Hordijk, Winnubst, & de Leeuw, 2005; Diz et al., 2005). However, the use of the term "delay" was found to be inappropriate because the role of factors associated to the lesion (i.e., the site and aggressiveness of the tumors) or healthcare system might be ignored (Diz et al., 2005). Therefore, a new modified model was proposed that included four intervals: *Patient appraisal* (the period when a patient first recognizes his/her symptoms and perceives that a health care professional [HCP] should be consulted); *help-seeking* (the period when the patient first deems it necessary to seek help and makes the first consultation appointment with an HCP); *diagnostic* (the period from the first HCP consultation to diagnosis); and *pre-treatment* (the period from confirmation of diagnosis to initiation of treatment). **(Figure 4.1)**

Figure 4.1 Refinement of Andersen model of total patient delay for cancer(Walter et al., 2012)



The deductive manifest content analysis was performed in three phases: preparation, organizing, and reporting (Elo & Kyngäs, 2008; Kyngäs, 2020). In the preparation phase, the ICN identified as the unit of analysis were analyzed line by line, excluding the detailed description of the treatment, which was outside of the scope of this study. Two authors (PB and FS) read the ICN several times in order to become familiar with the provided information, make sense of the data, and learn "what is going on" (Morse & Field, 1995). The repeated review of the content also helped the two coders to highlight the key meaningful units based on our research questions.

Figure 4.2 Phases of preparation, organizing, and reporting in the deductive content analysis process(Elo & Kyngäs, 2008)



In the organizing phase, a structured categorization matrix was built to reflect the research questions through the modified Anderson theoretical model. The two coders then reached an intercoder agreement for generating the data coding; the agreement involved organizing the coding under the defined categories in order to describe multiple angles of phenomena that are of interest to this study (Hsieh & Shannon, 2005; Smith, 2000). In the reporting phase, the five identified categories enhanced knowledge in order to better understand the challenges experienced by clinicians and patients regarding early detection of oral cancer in Alberta (Cavanagh, 1997). **(Figure 4.2)**

4.4 Results

Of the total 1,987 oral cancer patients registered at stage IV at the Alberta Cancer Registry between 2005 and 2017, 34 Initial Consultation Notes were retrieved and included in our analysis. We met data saturation at the 30th Initial Consultation Note, but the data collection continued for four more documents to ensure there were no additional new data relevant to the study phenomena. The patients' mean (SD) age was 56.3 (14.31) and ranged from 32-90 years; 70.5% were male and 85.2% were living in rural areas. The range of household income was between 27,336 and 138,161 CAD. At the time of data collection, 26 of the 34 included patients (76.4%) were deceased. **(Table 4.2)**

Using the modified Anderson theoretical model, the retrieved information was grouped into five categories: 'patient appraisal interval', 'help-seeking interval', 'formal diagnostic interval', 'pre-treatment interval', and 'contributing factors'. **(Figure 4.3)**

Table 4.2 Descriptive analysis

Case No/Pt. ID	Age	Sex	Anatomical cancer sites	Geographic Zone	Rural/Urban	Median household income $ CAD	Cancer Stage AJCC6/7	Living status	Date: Assumed first symptom (s)	Number of visited clinicians prior to oncologist	First Health Care Provider	Date: First clinician visit
Case 1	53	F	Floor of mouth	Z4-Edmonton	Urban	55468	IVA	D	2006-02-01	3	Dentist	2006-03-01
Case 2	49	M	Floor of mouth	Z5-North	Urban	38876	IVA	A	2007-06-01	3	Physician	2007-06-15
Case 3	55	M	Floor of mouth	Z5-North	Rural	47257	IVC	D	2014-10-01	2	Dentist	2014-10-15
Case 4	58	M	Floor of mouth	Z4-Edmonton	Urban	27336	IVA	D	2008-07-01	2	Unknown	2008-07-15
Case 5	41	F	Floor of mouth	Z5-North	Urban	60127	IVA	A	2004-03-01	Unknown	Unknown	2008-01-15
Case 6	47	M	Base of tongue	Z4-Edmonton	Urban	55403	IVC	A	2014-12-01	Unknown	Most likely Physician	2014-12-15
Case 7	80	M	Base of tongue	Z4-Edmonton	Urban	103738	IVC	D	2008-06-01	2	Physician	2008-07-07
Case 8	55	F	Base of tongue	Z2-Calgary	Urban	97429	IVB	D	2010-06-01	3	Dentist	2010-08-04
Case 9	55	M	Gum (Gingiva)	Z3-Central	Urban	36491	IVNOS	D	2012-11-01	2	Physician	2012-11-15
Case 10	90	F	Gum (Gingiva)	Z4-Edmonton	Urban	114658	IVC	D	2009-09-01	2	Physician	2009-10-01
Case 11	73	M	Palate	Z4-Edmonton	Urban	29283	IVC	D	2005-12-01	1	Physician In-patient	2005-12-01
Case12	75	F	Palate	Z5-North	Rural	49588	IVB	D	1993-04-01	Unknown	Unknown	2013-01-01
Case 13	82	M	Palate	Z5-North	Rural	47024	IVA	D	2005-04-01	Multiple, at least 3	Physician	2008-03-01
Case 14	48	M	Palate	Z1-South	Urban	68382	IVA	D	2003-01-01	Multiple from 2003 to 2010	Periodontist	2003-01-01
Case 15	33	M	Palate	Z5-North	Urban	137218	IVA	A	2007-11-01	Unknown-At least 2	Unknown	2007-11-15

CONT **Case No/Pt. ID**	**Age**	**Sex**	**Anatomical cancer sites**	**Geographic Zone**	**Rural/Urban**	**Median household income $ CAD**	**Cancer Stage AJCC6/7**	**Living status**	**Date: Assumed first symptom (s)**	**Number of visited clinicians prior to oncologist**	**First Health Care Provider**	**Date: First clinician visit**
Case 16	52	M	Palate	Z3-Central	Urban	27450	IVB	D	2006-04-01	Unknown	Most likely Physician	2006-07-01
Case17	62	F	Gum (Gingiva)	Z4-Edmonton	Urban	54666	IVNOS	D	2013-03-01	2	Most likely Physician	2013-03-15
Case18	57	F	Gum (Gingiva)	Z4-Edmonton	Urban	74563	IVA	A	2010-11-01	3	Dentist	2010-11-15
Case 19	61	F	Tongue, other & unspecified	Z4-Edmonton	Urban	36403	IVC	D	2013-05-01	2	Dentist	2013-06-01
Case 20	38	M	Tongue, other & unspecified	Z3-Central	Urban	48051	IVNOS	D	2012-04-01	2	Physician	2013-01-01
Case 21	48	F	Tongue, other & unspecified	Z4-Edmonton	Urban	31002	IVB	D	2012-08-01	2 or more	Physician	2012-08-15
Case 22	68	M	Mouth, others & unspecified	Z4-Edmonton	Urban	49161	IVNOS	A	2014-01-01	4	Physician	2014-01-15
Case 23	52	M	Mouth, others & unspecified	Z5-North	Rural	47351	IVC	D	2006-01-01	Unknown (2?)	Unknown	2006-04-01
Case 24	62	M	Mouth, others & unspecified	Z5-North	Rural	29870	IVB	D	2007-02-01	Unknown	General Surgeon	2007-02-15
Case 25	71	M	Mouth, others & unspecified	Z4-Edmonton	Urban	138161	IVB	D	2014-02-01	Unknown	Most likely Physician	2014-05-01
Case 26	43	M	Mouth, others & unspecified	Z2-Calgary	Urban	149323	IVA	D	2013-10-01	2	Unknown	2014-01-15
Case 27	32	M	Mouth, others & unspecified	Z4-Edmonton	Urban	41366	IVA	A	2012-11-01	2?	Dentist	2012-11-01
Case 28	43	M	Mouth, others & unspecified	Z5-North	Urban	117595	IVA	A	2012-02-01	Unknown	Unknown	2012-07-01
Case 29	53	M	mouth, others & unspecified	Z3-Central	Urban	40844	IVA	D	2011-11-01	2	Physician	2012-02-01
Case 30	49	M	Base of tongue	Z5-North	Urban	75959	IVNOS	D	2014-10-01	3?	Unknown	2015-04-01
Case 31	80	M	Base of tongue	Z4-Edmonton	Urban	103738	IVC	D	2008-06-01	2	Physician	2008-09-01
Case 32	49	M	base of tongue	Z4-Edmonton	Urban	29449	IVC	D	2015-12-01	2? (Inpatient)	Physician	2016-06-01
Case 33	62	M	Base of tongue	Z4-Edmonton	Urban	110266	IVB	D	2006-01-01	3	Physician	2006-02-01
Case 34	41	F	Base of tongue	Z2-Calgary	Urban	47342	IVA	D	2008-11-01	3	Physician	2010-03-01

4.4.1 Patient appraisal interval

Patient appraisal interval: In this interval, diagnosed patients noticed the various types of asymptomatic and symptomatic changes for the first time in their head and neck area. Some of the asymptomatic presentations included abnormal growths in different anatomic areas such as floor of the mouth, gingiva, submandibular, cheek (buccal mucosa), and/or white changes of the mouth, while symptomatic presentations included toothaches, sore throat, ill-fitting dentures, canker sores, burning sensation, and difficulty swallowing. For instance, a 49-year-old male patient noticed a painless lesion on his floor of the mouth for a year without seeking medical attention. Similarly, a 47-year-old male patient, while aware of an enlarging neck mass for a period of time, did not perceive the need to consult a healthcare provider immediately. Patient's lack of awareness repeatedly caused delays in care-seeking until the lesion became symptomatic:

"…. she started to notice weakness in her tongue and difficulty swelling as well as voice changes…" [Initial Consultation Notes, Case 8]

" Mr. … noticed a burning sensation on his tongue, he thought this might have been due to his inhalers for COPD….." [Initial Consultation Notes, Case 20]

"He… first noticed a canker on the left buccal mucosa,,….., he initially attributed this canker to[his] gutka or bitel nut) [used for long time]…" [Initial Consultation Notes, Case 26]

For most cases, there was a gap period from the time the patient noticed the changes to the time they recognized the change as a health issue requiring a medical consultation **(Table 4.3).**

4.4.2 Help-seeking interval

The patients included in this study came from various sociodemographic backgrounds and demonstrated a broad range of health behaviours and concerns. As a result, they responded differently when they noticed unusual asymptomatic or symptomatic changes in their head and neck area. While some patients sought help immediately, for others, it took them from 14 to 1,000 days to seek help. For some patients, it even took much longer (7,215 days) to *perceive* a reason to *schedule an appointment* and discuss changes with an HCP or to seek *alternative help*, such as a holistic approach. For instance, a lady working evenings at a large store noticed a painless growth on her floor of the mouth. She waited for about four years (1415 days) until she decided to see an HCP. In addition, we found that family physicians were the first HCP seen in almost 50% of patients compared to 20% who saw a dentist **(Table 4.2)**.

"Mr. .... began having a toothache about two months ago [Oct. ...]. He was seen by a dentist [Oct. ...] and at that time an intraoral lesion was seen…(14 days)" [Initial Consultation Notes, Case 3].

"Her history dates back to June when she started to notice weakness in her tongue and difficulty swallowing as well as voice changes. She originally saw a dentist in August … (64 days)" …" [Initial Consultation Notes, Case 8].

"Ms. ….who noticed some discomfort and fullness in the left submental area about November …. This progressed to some earache on the left side and some sensation of fullness in the left ear. She subsequently had medical consultation in March …. (485 days)" [Initial Consultation Notes, Case 34].

"…, who is a pleasant 57-year-old lady who has had a left mandibular gingival mass for over 2 years …originally biopsied as verrucous carcinoma. At that time, she was offered a surgical intervention, but based on her personal beliefs and based on the recommendation from her holistic sources, she opted holistic approach to this mass for which she thought was an infection. Over the past 2 years the mass has slowly grown and has grown more progressively and worse over the past 2 months… cause her significant trismus …and ulceration of the skin …overlying her left mandible. This causing her to get significantly worse and had her start doubting her holistic approach to her mass…..")" [Initial Consultation Notes, Case 18].

In our study, the average length from the time a patient noticed the first symptom(s) to the first scheduled appointment was 350 days. However, the actual *help-seeking interval* was

from the time the patient perceived the need for care to the first consultation. Therefore, it was the perceived need that led to the patient's first medical visit with an HCP. **(Table 4.3).**

Table 4.3 Main categories information

Cases: 34	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
Days: Accumulated Patient appraisal and help-seeking Average: 350 Median: 31	**28**	**14**	**14**	**14**	**1415**	**14**	**36**	**64**	**14**	**30**	**0**	**7215**	**1065**
Days Formal diagnostic Interval Average: 184 Median: 38	**210**	**348**	**30**	**13**	**17**	**247**	**87**	**168**	**18**	**78**	**77**	**99**	**1083**
Risk factors	**N**	Mother died of stomach carcinoma. -Smoker for 35-37 years - Drank alcohol every day for past 35 years.	Homeless -Previous orthopedic procedures. - Hypertension. -Anemia -Smoker one to a quarter pack daily -History of alcohol abuse	Father diagnosed with bone cancer -50-pack-year history of smoking -Social alcohol consumption -Marijuana user.	Smoker for the past 26 years -Social alcohol consumption	Smoker 30 -pack-year -Marijuana user occasionally. - Drank alcohol infrequently	History of prostate cancer treated with hormone therapy. -Smoker 50-pack-year history -Five drinks per week.	Significant depression. -Social alcohol consumption.	Smoker 40-pack-year -History of alcohol abuse -History of radiation to left side of head. -History of smoking crack and marijuana.	**N**	Divorced since 1972 and lived alone -Asbestos exposure in the 1960s -Diagnosed with rheumatoid arthritis -Mother died of lung cancer	Significant history of smoking, quit for the past 6 years	Lives alone -Chewing tobacco -Occasional cigarette use -Quit ten years ago
Specialist Access **A=56%** **B=44.1%** **C=20.5%** **O=23.5%**	**A**	**A**	**O**	**A & C**	**A & B**	**A & B**	**B**	**O**	**A & B**	**A C**	**C**	**O**	**A**

	14	15	16	17	18	19	20	21	22
Days: Accumulated patient appraisal and help-seeking Average: 350 Median: 31	**0**	**14**	**91**	**14**	**14**	**31**	**275**	**14**	**14**
Day: Formal diagnostic Interval Average:184 Median: 38	**2722**	**213**	**19**	**21**	**15**	**26**	**93**	**128**	**96**
Risk factors	Father died of prostate cancer -Mother died with breast cancer	**N**	Smoked 15-20 cigarettes per day 40 - pack –year history - 5-6 alcohol per day	Single and lived alone, no children. -Significant smoking history of 6-10 cigarettes per day since age 15. -Excessive alcohol intake history, being an alcoholic from age 15 to 30s, no alcohol for 25 years. She had no family physician	**N**	40-pack-year history of smoking. -She formerly consumed alcohol to excess.	Smoker 30-pack-year history -He also consumed 4 to 5 hard liquor about twice a week	Mother and sister were both diagnosed with breast cancer - Significant smoking history -7 drinks of alcohol per week. -Smoked marijuana	Strong family history of malignancies -Sister had a malignancy involving the Bartholin glands -Father was diagnosed with colorectal cancer -Mother died of some unknown neck tumor -Smoker of half of a pack a day for 20 years - Quit 30 years ago. -3-4 drinks per day for the last 30 years.
Specialist Access **A=56%** **B=44.1%** **C=20.5%** **O=23.5%**	**A & B**	**AB**	**A & C**	**A & C**	**B**	**A**	**O**	**A & C**	**B**

Table 4.3 CONT: Main categories information

	23	24	25	26	27	28	29	30	31	32	33	34
Days, accumulated Patient appraisal and help-seeking Interval Average: 350 Median: 31	**90**	**14**	**89**	**106**	**0**	**151**	**92**	**182**	**92**	**183**	**31**	**485**
Formal diagnostic Interval Average: 184 Median: 38	**6**	**8**	**139**	**20**	**35**	**19**	**8**	**91**	**31**	**29**	**40**	**29**
Risk factors	Smoker 35-pack - year -Drinking alcohol beverages.	History of smoking -Mother had throat cancer -Father had testicular cancer	Smoker for at least 25 years, 25 cigarettes per day -He was a social drinker.	Chewing gutka (betel nut) for over 20 years which he typically holds in his left cheek.	**N**	10-year smoking history, 4 to 8 cigarettes per day, quit in 1993 -He started chewing tobacco in 1993.	Father had colon cancer. - Smoking history of 20-pack-years -A drink a day	History of psoriasis -Smoker 25 pack-year -Alcohol in the past.	Celiac disease -prostate cancer treated with hormone therapy. -Smoker 50-pack- year -Five drinks per week	Hep C. - Smoker 60 pack--year	Heavy smoker and drinker	Celiac and Barrett's diseases
Specialist Access **A=56%** **B=44.1%** **C=20.5%** **O=23.5%**	**A & B**	**A & B**	**O**	**O**	**A B**	**A**	**B & C**	**A & B**	**B**	**B**	**O**	**O**

A: Specialist A; B: Specialist B; C: Specialist C; O: Others

4.4.3 Formal diagnostic interval

The competence of the first HCP (dentists, family physicians) who performed the initial screening and detected the potentially malignant lesions in the oral cavity as well as timely referrals were essential contributing factors to definitive diagnosis and treatment outcomes.

*"Mrs. ...had some dental difficulties for the past one year (about January). A far as she was aware, this was due to some abnormalities within the gum, which been attributed to previous **antibiotic therapy** and extraction of her teeth on the lower right side in March or April ..., and since that time she had been experiencing ongoing pain, and not healing. In September, she was referred to an oral surgeon because she had developed some swelling along the right mandible and appeared to have an infection at the site of her previous surgery [Extraction site]. Therefore, a debridement was performed. Pathology from debridement identified a well-differentiated squamous cell carcinoma in September .... However, according to Mrs. ... the pathology result was not received until November ..."* [Formal diagnosis interval:210 days--Date of Initial Consultation Letter at head and neck oncology, February 28, …--Case 1:(deceased)].

" Mr. ... 38-year-old history began about one year ago [April] when he noticed a burning sensation on his tongue. He thought this might have been due to his inhalers for COPD. However, he began to notice a lump in the right side of his tongue about 8 to 9 months ago [July-August ...), and this has slowly grown in size. Four to five months ago [November to December ...], he developed lumps on the right side of his neck and under his mandible. By this point, he was also developing some otalgia, and was having difficulty with swallowing and with speech due to the size of the mass. He went to see his family doctor [January 2013] and was

*treated with **antibiotics**, but this did not have any effect…. As there was no improvement, the patient was subsequently referred to Dr. ….. . a biopsy was completed on April 4 …, confirming a moderately differentiated squamous cell carcinoma*. [Formal diagnosis interval:93 days--Date of Initial Consultation Letter at head and neck oncology, April 19, …--Case 20: (deceased)].

"Mr. … 49-year-old, …..who noticed a lump in his left neck last October . This was painless. This was gradually growing in size. He denies any changes in voice, swallowing …. His biopsy done in April 21, …, by Dr. A…. back with no evidence of dysplasia or malignancy. I will request Dr…. to take this patient back to the OR and do some deeper biopsies to rule out or confirm malignancy at the base of the tongue on the left side.

DATE Of CONSULTATION: JUL-….

Squamous cell carcinoma arising from the left tongue base. Diagnosis made on excisional biopsy from an ipsilateral neck node seen on PET/Ct. Biopsy from the neck revealed p16 positive disease." [Formal diagnosis interval:91days--Date of Initial Consultation Letter at head and neck oncology, May 22, ….--Case 30: (deceased)].

Lack of knowledge of early signs and symptoms of head and neck cancer, misdiagnosis of the condition resulting in inappropriate managements, and late referrals led to unnecessary long intervals for confirmation of the final diagnosis of cancer. Improper choice of interventions and medical tests also resulted in late diagnosis. In contrast, competent professionals with

accurate diagnostic and management abilities could make the diagnostic confirmation interval shorter **(Table 4.3).**

4.4.4 Pre-treatment interval

Our study revealed a substantially long interval from the formal diagnosis date to receiving first treatment. To achieve a better understanding of this interval, we looked at three periods including the total number of days from formal diagnosis date to the first oncologist consultation date; days from receiving a referral to the first oncologist consultation date; and days from formal diagnosis date to treatment initiation date. Of the 34 cases, in nine cases, the number of days from receiving a referral to the first oncologist consultation date was missing. **(Table 4.4)**.

Table 4.4 Pre-treatment interval related data

Cases: 34	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Days from formal Diagnosis to Oncologist visit Average: 88 Median: 50	154	30	28	102	56	111	50	520	18	49	7	39	57	45	16	36	119	703	85	15
Days from referral to first head and neck consultation Average: 49 Median: 15	NA	NA	2	51	NA	48	15	NA	3	21	NA	NA	17	15	3	NA	31	14	31	365
Days from formal diagnosis to treatment initiation Average: 92 Median: 56	105	109	34	129	50	96	81	23	-	-	39	27	68	77	91	56	124	769	-	53

Table 4.4 CONT: Pre-treatment interval related data

Table 4.4- Cont.	21	22	23	24	25	26	27	28	29	30	31	32	33	34
Days from formal Diagnosis to Oncologist visit Average: 88 Median: 50	21	67	63	91	44	36	99	185	15	-40	50	43	53	15
Days from referral to first head and neck consultation Average: 49 Median: 15	126	31	90	14	152	12	4	130	8	10	15	NA	NA	6
Days from formal diagnosis to treatment initiation Average: 92 Median: 56	54	85	32	-	61	41	159	125	53	2	51	49	-	35

NA: Not available; (-): No treatment; -40 (the diagnosis confirmed 40 days after first oncologist appointment)

4.4.5 Contributing factors

In addition to the four identified intervals, three other contributing factors that seemed to influence early detection of oral cancer included those related to the patient, providers and healthcare system, and tumor behavior.

Patient factors (biological, behavioural and sociodemographic): Our findings captured multiple risk factors reported by patients in this study. This risk factors are categorized as *biological*, such as having a past history or a family history of cancer along with comorbidities; *behavioural*, such as a long history of smoking tobacco/recreational drugs and alcohol consumption; and *sociodemographic*, such as older age, living alone, being divorced/never married, and low socioeconomic status. For example, case 2 was a male with a 37-year history of tobacco and alcohol consumption and his mother died of carcinoma of the stomach. These accumulated factors positioned him at high-risk for developing oral malignancy. Case 11, on the other hand, had a history of divorce and lived alone for 34 years. He also had asbestos exposure and his mother died of lung cancer. A combination of biological and sociodemographic factors increased his risk for cancer.

" Mr.…. is currently homeless, though he has been in Gunn, Alberta for alcohol detoxification. He is now an inpatient at the University Hospital under ENT. He has a history of alcohol abuse and continues to smoke one to a quarter pack daily." [Case 3- Deceased]

"The patient has a past medical history of celiac disease as well as prostate cancer treated with hormone therapy. The patient lives in Edmonton in a house with a friend. He was smoker quit two years ago. Prior to that he had a 50-pack-year smoking history. .... Patient states that he does drink approximately five drinks per week." [Case 7- Deceased]

"The patient is a 55-year-old who lives on his own in an apartment. He was previously a truck driver..... He has a 40-pack-year history of smoking. .... he does have a previous history of alcohol abuse. Previous history of radiation to the left side of the head. .... he has previously smoked crack and marijuana. [Case 9- Deceased]

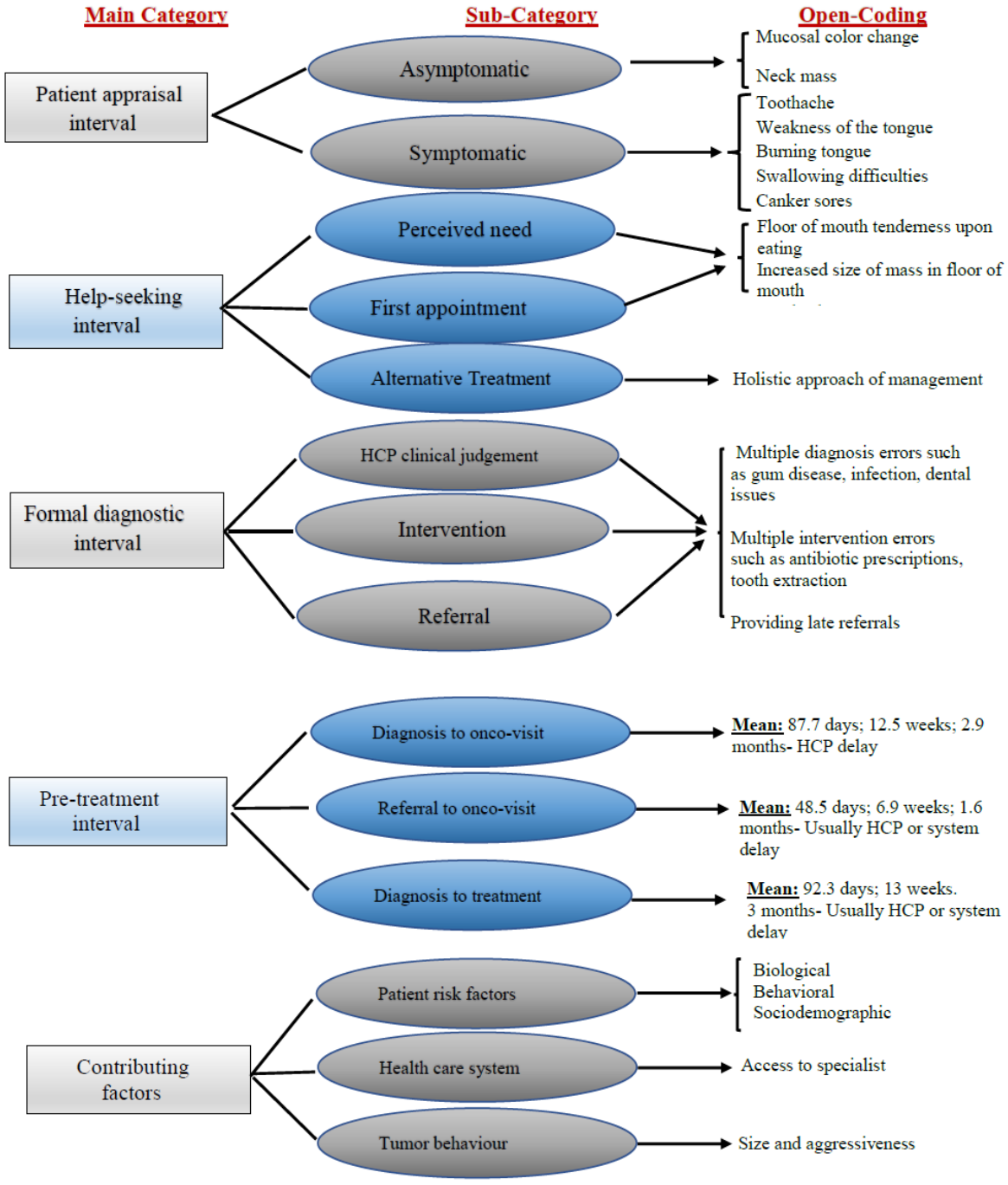
System Delay: Timely access to a healthcare provider was found to be extremely important for a better treatment outcome, survival, and quality of life in patients diagnosed with oral cancer. In addition to the already reported increased diagnostic and pre-treatment intervals, our findings identified only two specialists who were in charge of our study cohort, resulting in high patient loads and long waiting periods. **(Table 4.3)**

Tumor behavior: Tumor characteristics such as size, location, invasive behaviour and metastasis are important contributing factors to diagnosis and survival rate. As well, the aggressive behavior of certain malignancies might cause unwanted outcomes, even for cases that are diagnosed at an early stage and managed in a timely manner.

"[Her] husband recall that she admitted to the Royal Alexandra Hospital in May …, presenting with …. . At the time it was noted that she had "canker sores". At a subsequent dental visit, she was advised to seek medical attention for a suspicious tongue lesion. On June … she presented to the University of Alberta Hospital, and was admitted to the ENT ward….[three days after], a biopsy …performed demonstrating a p16 negative, moderately differentiated squamous cell carcinoma. Upper endoscopy on the same day demonstrated invading the entire right lateral tongue squamous cell carcinoma, extending into the palate, base of tongue, tonsil, right lateral pharynx, piriform, epiglottis, vallecula, and root of tongue, right lateral pharynx,… [Formal diagnosis interval:26 days--Date of Initial Consultation Letter at head and neck oncology, September 20,.. --Case 19: (Deceased- not eligible for curative treatment)].

" Mr. .. 48- year-old followed by a periodontist for a premalignant lesion of lichen planus of the maxillary gingiva and the premaxillary bone. This had been biopsied multiple times [for seven years]. The last biopsy in June … demonstrated squamous cell carcinoma. He was otherwise asymptomatic [in July …]. He does complain of some TMJ pain and some pain across the premaxilla and bleeding from his gums. Recently, periodontal work has revealed losing teeth of his premaxilla and also of the dental implant placed in his anterior teeth. [Pre-treatment interval: 8 days--Date of Initial Consultation Letter at head and neck oncology, July 30, … --Case 14: (deceased a few months later)].

Figure 4.3 Deductive coding data categorization matrix



4.5 Discussion

Using the modified Andersen model of "total patient delay for cancer diseases", we explored challenges experienced by patients and healthcare providers toward obtaining earlier detection of oral and oropharyngeal cancers in patients in Alberta (Walter et al., 2012). Our findings showed a remarkably prolonged average time of 350 days from the onset of symptoms until the patient perceived a need for a consultation with a healthcare professional (HCP) and the subsequent booking of an appointment. This average is far lengthier than the 31 to 90 days widely reported in the public health literature as the typical threshold, which itself has been criticized for being too long (Garbuglia, 2014; Lee, Dhepnorrarat, Nyhof-Young, & Witterick, 2016; U. A. Patel & Brennan, 2012) . The commonly reported average patient's delay for OC and OPC from first symptom to first HCP consultation is 105 to 165 days while three months is enough for squamous cell carcinoma to double in size (P. Stefanuto, J.-C. Doucet, & C. Robertson, 2014). However, the patients' Initial Consultation Notes lack an exact indication of the time from when a patient noticed the changes, the time they perceived the need to consult an HCP (*patient appraisal interval*), and when the actual care-seeking occurred (*help-seeking interval*).

Our data demonstrates transitional health-related behaviors by patients consisting of lack of attention at the asymptomatic stage to the symptomatic aspect of malignant changes, which ends at the first consultation. Similarly, Scott and colleagues in their systematic review reported that patient's delay was mostly due to not seeking care until the lesion became symptomatic (Scott, Grunfeld, Main, & McGurk, 2006). The literature supports the complexity and multifactorial reasons for what causes a longer *patient appraisal interval.* This includes the lack of symptoms associated with oral malignancies at early stages; the patient's lack of knowledge

about early manifestations of oral cancer; restricted access to HCPs; established health-related behaviour and self-treatment, with or without a pharmacy consultation; socioeconomic factors; and psychological factors such as individuals' symptom interpretation, disclosure of symptoms to others, and social priorities (Noonan, 2014; O'Connor, Papanikolaou, & Keogh, 2010; Simon N Rogers, Vedpathak, & Lowe, 2011; Peter Stefanuto et al., 2014).

Diagnosis delay and the interval from a patient's first consultation visit to the formal confirmation of the cancer diagnosis (*diagnostic interval*) has been studied by several researchers (Adrien, Bertolus, Gambotti, Mallet, & Baujat, 2014; Lee et al., 2016). In our study, the diagnostic interval range for our patients was 6 to 2,722 days (mean 183.5), which is considerably longer than the 14 -21 weeks (98-147 days) and 15.4 weeks (107.8 days) reported for diagnostic delay in two other reviews published in 2014 and 2016, respectively (Lee et al., 2016; Peter Stefanuto et al., 2014). Furthermore, we identified multiple diagnosis errors, inappropriate antibiotic prescriptions, extraction of teeth caused by clinical misjudgments and referral delays that led to several back and forth appointments and subsequent delays in cancer diagnosis. Other diagnostic delays were caused by the health care provider's recommendation of superficial/incisional biopsy rather than an in-depth/excisional biopsy. While there is considerable evidence in support of our findings for delay caused by professionals (Lee et al., 2016; Peter Stefanuto et al., 2014; Yu, Wood, Tenenbaum, & Perio, 2007), Rogers and colleagues, in their study conducted in the United Kingdom, reported that 78% of the cases were referred to specialists on the same day of the patient's first visit (S. N. Rogers et al., 2007).

In our study, 53% of patients approached a family physician for their first consultation as compared to 17.6% who visited a dentist. The cost for a dental visit could be a reasonable explanation for this choice. According to the literature, family physicians are less familiar with oral lesions, which can result in poorer screening, misdiagnosis, and delayed referrals to specialists, all of which would negatively affect early diagnosis of the lesion (Ford & Farah, 2013). Unlike family physicians, dentists have better training and more knowledge about oral lesions and oral pathology. However, it appeared from our study that oral examinations performed by dentists were not systematic and focused more on teeth or denture-related soft tissue rather than on high-risk anatomical areas such as floor of the mouth (Ford & Farah, 2013). Dentists' routine systematic examination of high-risk areas for malignancy might play an important role in the opportunistic screening of patients, particularly those who are in high-risk groups (Ford & Farah, 2013).

Long wait-times for treatment induces substantial anxiety and dissatisfaction in patients and supporting family members. Our study identified that patients waited an average of 13 weeks during the *pre-treatment interval* before starting treatment. According to the healthcare delivery practice guideline for head and neck cancer patients in Alberta, "… patients should be seen by a defined experienced surgeon with access to the necessary diagnostic tools within 2 weeks of referral… [and] patients undergoing primary surgical therapy should have surgery performed within 4 weeks of the ready-to-treat date" (Harris et al., 2014). Although our findings were calculated from the date of formal diagnosis rather than from the referral date (which was missing for almost 35% of cases [12 out of 34]), the 13-week average is much longer than the acceptable timeline based on the Alberta guideline. A study conducted in Brazil showed the similar 12-week waiting time for initial treatment of patients diagnosed with head and neck

cancers (A. W. Felippu, Freire, Silva Rde, Guimarães, & Dedivitis, 2016). In addition, the lack of availability and overbooking of experienced surgeons identified in our study raises additional concerns for meeting the guideline's recommendations.

Along with patient and professional factors, other factors also interfered with earlier diagnosis of oral and oropharyngeal cancers. This study has shown multiple behavioural, biological, and sociodemographic risk factors admitted by patients that highlight their vulnerability during clinical investigation **(Table 4.3).** Similarly, tumor size and invasive behaviour could result in negative outcomes even with early diagnosis and access to standard care, as has been seen in this study and is supported by the literature (Ford & Farah, 2013).

4.5.1 Study Limitation

There are some limitations inherent in retrospective studies using data from already recorded resources including potentially missing information (Sarkar & Seshadri, 2014). However, clinical chart reviews have considerable advantages, in that they are less time-consuming and are a relatively inexpensive way to generate hypotheses that could be tested prospectively(Gearing et al., 2006). Patients' consultation notes are unique resources to explore challenges faced by patients diagnosed in the late stages of disease, as many of these patients were deceased at the time of study. According to our preceding conducted study (Oral Cancer Surveillance and Control in Alberta: A Scoping Review), about half (47.9%) of total diagnosed OC and OPC patient cases were deceased at the time of our data collection.

In addition, the information provided through the Alberta Cancer Registry's Initial Consultation Notes of the patients did not follow a consistent format across several different

cases. Some of these cases were missing important data, such as the category of HCP at the first visit (physician, dentist, or specialist), and important dates, such as referral to the oncologist.

4.6 Conclusion

This study showed remarkably increased time intervals for five generated categories. The main contributors to total patient delay identified in this research were patients' general lack of awareness regarding early symptoms of oral cancer and high-risk anatomic areas, inaccurate clinical judgement of attending physicians and dentists, and lengthy access to care. A sustainable plan is needed for both public awareness interventions and the implementation of a solid curriculum for the training of medical and dental students in order to enhance their knowledge, clinical judgement competency, and treatment management. Additionally, a mandatory integration of opportunistic screening of oral lesions as part of routine practice.

5 Chapter Five: Discussion and Conclusions

In this chapter, a brief summary of the investigation outcomes within the conceptual framework of the research is presented. This is followed by the results of a mixed-method approach used to comprehensively collect and analyze oral cavity and oropharyngeal cancer (OCC, OPC) incidence, prevalence, management process and outcomes in Alberta. An interpretation and analysis of the triangulation multilevel results are also discussed in detail. Finally, the chapter ends with an overview of the study's conclusions and limitations, along with some considerations for future work.

5.1 Summary of Investigation Outcomes

This study comprehensively explored oral and oropharyngeal cancer surveillance and control in Alberta and created a multi-level overview of their current state and management that will contribute to a broader understanding of factors causing delays in diagnosis of oral cancer.

As a world-wide long-standing public health concern, late diagnosis of OCC and OPC and low survival rate are facts supported by extensive scientific evidence (C. W. LeHew et al., 2010; Steele & Meyers, 2011). However, the recognized diagnosis delay and deadly outcomes indicate both similarities and differences across different geographic locations, with the spectrum of results ranging from better (Western Pacific Region) to worse (India and Pakistan)(Gupta et al., 2016). Some globally well-known contributing factors associated with OCC and OPC are lifestyle, cultural practices, environment, diet, health-related behaviours, health system policies and practices, and genetic and biological traits.

Among the ten provinces and three territories in Canada, Alberta is currently ranked fourth for OCC and OPC prevalence, which justifies the urgent need for better understanding of the current status and development of evidenced-based future recommendations with regard to early diagnosis and management of the disease (Canadian Cancer Statistics Advisory Committee, 2019; C. C. Statistics, 2015). In the first phase, we conducted a comprehensive scoping review, gathered the accessible relevant information, and identified the knowledge gap associated with *oral and oropharyngeal cancer status in Alberta*. Subsequently, using a convergent mixed-method design, missing knowledge at the *population* level and *clinician-patient* level causing delays in OCC and OPC diagnosis and lack of timely management were explored. Our findings through a conceptual framework illustrated the demand for strategic health policy improvements within Alberta's existing high-tech technology and treatment facilities for cancers.

5.2 Conceptual Framework

Conceptual frameworks are mostly used in public health research to assist in displaying links between health exposures and outcomes (Paradies & Stevens, 2005). The conceptual framework constructed in this study was undertaken by triangulation of data through three phases **(Figure 5.1)**. Starting with a *Scoping Review* (SR), we launched a comprehensive search to identify accessible information connected to our study objectives. This information was scattered across multi-level resources. The SR identified the knowledge gap at patient, healthcare professional (HCP), and system levels and informed the convergent mixed-method design conducted in phases 2 and 3 concurrently.

In phase 2, a quantitative cross-sectional investigation detected the oral health status, prevalence of oral cancerous and precancerous lesions, and associated risk factors for these

diseases among the most underserved population in Edmonton as indicators of vulnerability for oral lesions and cancer. In phase 3, a retrospective qualitative study identified challenges faced by OCC and OPC patients, HCPs, and some contributing factors causing delay in diagnosis of oral and oropharyngeal in Alberta were identified. The synthesis and interpretation of results from the three phases generated conceptualized new knowledge which delineated our scope of inquiry towards a better understanding of OCC and OPC status in Alberta and any associative linkage to late diagnosis and undesired outcomes (Earp & Ennett, 1991). The developed conceptual framework in the present study could also play an important role in directing future research and translating generated knowledge to policy and practice (Paradies & Stevens, 2005) .

5.2.1 Summary of Scoping Review Results

The scoping review aimed to obtain fully accessible information in connection to oral and oropharyngeal cancer in Alberta and to identify potential related knowledge gaps. The identified available information included Alberta's OCC and OPC prevalence, patients' demographic characteristics, prevention strategies and funding, oral cancer management accessibility and quality, and published research and gray literature about oral and oropharyngeal cancers. We showed that OCC and OPC increased in prevalence between 2005 and 2017, and that 3,448 patients were diagnosed with OCC and OPC between 2005 and 2017, based on the Surveillance and Reporting and Alberta Cancer Registry.

Furthermore, over the course of a 12-year period, 1,763 (51%) patients were diagnosed with OCC and 1,685 (48.8 %) with OPC. The percentage of patients diagnosed with OCC and OPC was higher in urban (82.5%) versus rural (17.5%) locales, and survival was found to be lowest in rural and First Nations areas. This finding supports the idea of health inequity in

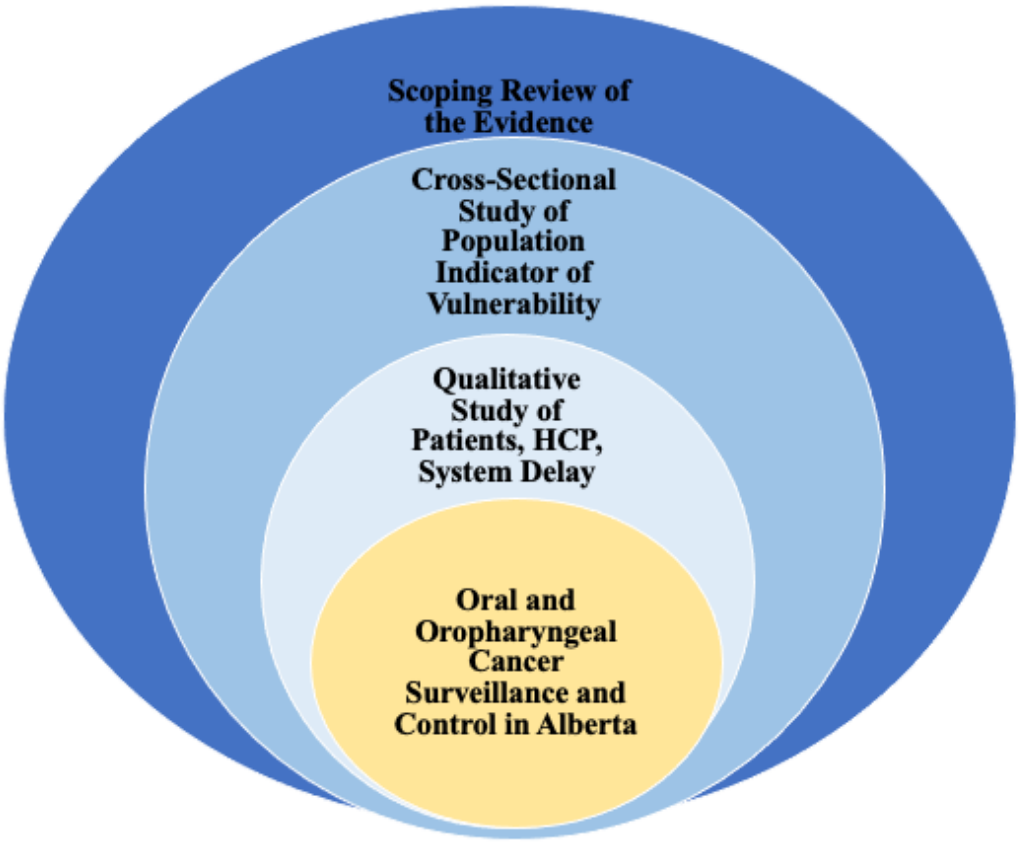
Alberta. Additionally, and in agreement with worldwide scientific evidence(Güneri & Epstein, 2014), our study identified that most of the OCC and OPC lesions were diagnosed at an advanced clinical stage, with a significantly high number of advanced OPC lesions in stage IV (OCC= 45.2%, OPC= 82.4%), of which 47.9% of the patients died. While a number of studies reported an increasing trend in incidence of oropharyngeal cancer globally including the United States and Canada, there are a few studies that explore OPC staging characteristics(Ajit Auluck et al., 2010; LeHew et al., 2017). A study conducted in five cancer centres in Alberta and Ontario reported a distinction between HPV p16 positive and HPV p16 negative oropharyngeal cancer associated with cancer stage at diagnosis (Raffle & Gray, 2019). p16 tumor positivity , younger age, male gender, having a tonsillar or base-of-tongue tumour, lack of smoking history and lower alcohol consumption were identified to be associated with lower tumour stage and higher nodal involvement at diagnosis.(Friedman, Stavas, & Cmelak, 2014; Raffle & Gray, 2019)

Our scoping review was unable to identify the causes of late-stage diagnosis in Alberta. However, we found that general practitioners/dentists referred patients to specialists, often with long waiting times for specialists to see the patients. The tonsils, tongue, and base of tongue were the main locations affected by cancer, and males younger than 45 years showed a higher incidence of HPV-associated oropharyngeal cancer. The province of Alberta has implemented HPV vaccinations for young men and women since 2008. The HPV-9 vaccine is up to 99% effective in preventing human papillomavirus-related disease from 9 HPV strains, including 25% of H&N cancers(Alberta Health Services: Immunization, 2018). We found multiple governmental and non-governmental online websites offering preventive information for OC and OPC and their associated risk factors, despite the lack of evidence for their scientific efficacy to promote population oral cancer knowledge and impact on cancer incidence. No solid preventive

strategies or any type of routine public oral/head & neck cancer screenings are currently in place in Alberta that we are aware of.

This review also identified that available funds are mainly allocated for research associated with treatment and therapy targeting quality of life improvement rather than disease prevention. As well, while there are published treatment algorithms presented by Alberta Health Services (AHS) providing clinical practice guideline for OCC and OPC treatment, there is a lack of an expected timeline for these clinical practice and treatment algorithm guidelines(Alberta Health Services, 2014, February; Services, 2019, February). Furthermore, the scoping review was unable to detect any substantial study at the population, patient, HCP or system levels in Alberta to help better understand the current outcomes. In fact, there was insufficient studies in this area that guided our present study toward proposing additional objectives and research questions to generate the missing knowledge through a convergent mixed-method design.

Figure 5.1 Conceptual Framework Oral and Oropharyngeal Cancer in Alberta



5.2.2 Convergent Mixed-Method Design

Investigating complex processes of systems in health and healthcare is facilitated by powerful tools offered by mixed method research (M. D. Fetters, L. A. Curry, & J. W. Creswell, 2013). A convergent mixed-method design allows for qualitative and quantitative data collection and analysis to occur parallel, with integration beginning upon the separate completion of the data collection and analysis (M. D. Fetters et al., 2013). Therefore, a convergent mixed-method approach informed by the conducted scoping review was designed to concurrently collect and analyze multi-level data. The merged quantitative and qualitative findings in this stage

conceptualized a broader understanding of multi-faceted OCC and OPC malignancies in Alberta and contributed to the assembly of our study's conceptual framework.

5.2.2.1 Summary of Quantitative Results

Employing multi-level questionnaires and comprehensive oral health clinical examinations including oral cancer and precancer screening enabled us to learn the extent of the oral health vulnerability of those in a well-known underserved population in Edmonton. The goal of this phase was to quantitatively assess the sociodemographic, health-related behaviour, oral and general health, and oral cancer and precancer status of the Boyle McCauley Street community as an indicator of vulnerability for these oral lesions at the population level. Our clinical screening found a striking number of 18.6% for oral cancerous/precancerous lesions and 54.7% for oral mucosal lesion/ inflammation. We also identified 61.5% with a high score DMFT index (mean=13.39; SD=7.20) ranging from zero to 28 for dental caries.

With respect to health-related behaviours, a large proportion (68.6%) of the participants used tobacco, 55.9% used recreational drugs, and 53.1% used alcohol. Moreover, participants had a better perception of their general health compared to their oral health. While about 63% perceived their oral health status as fair to poor, only 38.8% selected the option of fair to poor for their general health. Furthermore, 62.4% of the participants had no history of cancer screenings and 33.2% claimed they had no access to care when needed.

From our findings, we learned that the risk of cancerous/precancerous lesions was 1.68 times higher in participants living in shelters vs those living alone. This study also showed a significant correlation between oral mucosal lesion/ inflammation and cancerous/PMOL. In

addition, a higher point estimate for patients in the age range of 45-65 years and with education lower than tenth grade, history of tobacco smoking for more than 20 years, recreational drug usage, alcohol usage, fair to poor oral health perception, and with no knowledge of oral cancer was found among the cancerous/precancerous group compared to their counterpart cohort. The multi-level questionnaire instruments employed in our study were previously validated (A. Ross Kerr, 2010) .while validation of the clinical examination was further supported by the inter-examiner's inter-rater reliability measure (Cohen's kappa > 0.85). The quantitative study results were transferred to a conceptual framework for a full analysis and interpretation in combination with transferred results from the first, second and third study phases.

5.2.2.2 Summary of Qualitative Results

In the previous phase, the generated quantitative data were facilitated through numerical cross-population design. The qualitative data in the third phase, however, were emerged by using the Andersen model (Walter et al., 2012) refined for collecting and analysing the contents of OCC and OPC patients' initial consultation notes retrieved from the Alberta Cancer Registry. By employing the model, the data in the current study successfully described the delays that occurred in the detection, diagnosis, and treatment of OCC and OPC. The model incorporates four-time intervals whose summation accounts for the total time from the onset of signs and symptoms of the malignancy to the initiation of treatment (Walter et al., 2012). The four intervals are as follows: the "*appraisal"*, which is the period that starts with the patient noticing abnormal changes and ends with the patient's perceived need for medical attention; "*help-seeking"*, which is the period from the point of perceived need to consult with an HCP to scheduling the first consultation; *"diagnosis"*, which is the period from the first consultation

visit to formal confirmation of the malignancy; and "*pre-treatment"*, which is the period from the confirmation of diagnosis to the start of treatment.

We found that all four intervals not only exceeded the accepted range of delay based on the literature, but also exceeded the longest average delay globally (A. W. D. Felippu, Freire, de Arruda Silva, Guimarães, & Dedivitis, 2016; Harris et al., 2014; Murphy et al., 2016; Peter Stefanuto et al., 2014). In addition, our results showed that the main contributing factors for the lengthy delay were patients' risk factors, namely biological (genetic history of cancer), behavioural (history of tobacco, recreational drug, and alcohol consumption), healthcare system-related (such as limited access to skilled specialists), and tumour behaviour (size, site, and aggressiveness of tumours).

5.2.3 Interpretation of Study Results

The triangulation of data from the scoping review and the cross-sectional and qualitative studies enabled us to collect, assess and analyze the information to present a comprehensive overview of the OCC and OPC situation in Alberta. A realistic picture that adopts an evidence-based disease surveillance and control recommendation for policy and program development was thus made possible. Note that surveillance here refers to an early warning system for disease changes in incidence, the detection of high-risk groups, and the evaluation of the effectiveness of interventions (Hadden & O'Brien, 2001; Speechley et al., 2017).

The data from the first phase showed the impact of disease on population health, such as high OCC and OPC morbidity and mortality rates. We found Alberta was ranked fourth in Canada for new cases of oral cancer, with a steady annual increase of new cases, increasing

mortality rates, and more patients diagnosed at late stages. Irrespective of what caused the increase in new cases of OCC and OPC in the first place, the lack of any type of preventive strategy, as found by our scoping review, is concerning. Oral squamous cell carcinoma (OSCC) is recognized as an aggressive malignancy that requires early diagnosis for better survival and quality of life for patients.

Furthermore, in the third phase, we identified excessive patient delay in seeking medical attention for the first time. This health behaviour might be explained by the patients' general lack of awareness about OCC and OPC and the risk factors for these diseases. The implementation of a *primary prevention strategy for disease*, as introduced by the World Health Organization (WHO) (World Health Organization, 2020) , is an approved strategy for preventing our findings of patient appraisal interval delay. Such a strategy provides the general public with information on behavioural, medical risk, and oral care education. We also found increased oropharyngeal cancer with a high number of advanced OPC lesions in stage IV (82.4%), which were more prevalent in younger men. The evidence is supported by Shack *et al*.'s study that reported an annual increase of 3.4% in men versus 1.5% in women of HPV-associated OPC in Alberta (Lorraine Shack, Harold Y Lau, Longlong Huang, Corinne Doll, & Desirée Hao, 2014). Part of the *primary prevention strategy* calls for provincial cost coverage for an HPV vaccination for all ages. GARDASIL® it may still has benefit for already sexually active individuals. The vaccine is currently *the only known* effective preventive modality against HPV-associated OPC.

In addition, the identified high ranking (fourth position) of Alberta's OCC and OPC case numbers might be partly for the OCC explained by the province's large South Asian immigrant community. There is bold evidence showing that the South Asians population is known to have

the world's highest rate of morbidity and mortality caused by oral cancer (Gupta et al., 2016; Sankaranarayanan et al., 2015; Sankaranarayanan et al., 2010). Based on the province of Alberta's Focus on Geography Series 2016 Census, South Asians were reported as the largest visible population minority group (Statistics Canada, 2017).

Our scoping review did not, however, find evidence of any solid preventive oral cancer strategy in Alberta. This includes oral cancer screening of any type, not only for the general population but also for the at-risk communities in the province, such as South Asians. In the oral cancer context, screening would involve an oral examination or a test to identify changes which predict the high likelihood of developing oral cancer (Speight et al., 2017). Raffle and Gray stated that the type of screening program is based on the target population (Raffle & Gray, 2019). Since there is insufficient RCT evidence to support employing nationwide oral cancer screening (Speight et al., 2017), a *secondary prevention strategy* such as *targeted* and *opportunistic* screening programs would assist in the early detection of OCC and OPC and lead to positive health outcomes (World Health Organization, 2020).

Targeted oral cancer screening programs aim to employ full oral examinations for those at high-risk for developing oral cancer (Speechley et al., 2017). In Alberta, this could include the South Asian community, whose lifestyle predisposes them to oral cancer; the Boyle Street community, which we investigated in our cross-sectional study as an underserved population with high risk of exposure to tobacco, alcohol, and street drugs, and a compromised lifestyle; First Nation communities, identified in this study with lower socioeconomic status and having the lowest oral cancer survival rate; and people identified in our study as genetically at high risk

of developing cancer. All of these groups are suitable candidates for a targeted screening program.

Furthermore, opportunistic oral cancer screening has been proven to be highly effective in detecting asymptomatic early signs of oral cancer by employing a dentist-based clinical examination among the general population, for example when seeing a dentist or dental hygienist for routine checkups (Ford & Farah, 2013). By opportunistic oral cancer screening, we are referring to examinations for early detection of disease in people who visit HCPs for various other health conditions (Speechley et al., 2017).

Our descriptive data analysis in the second phase also detected substantial social determinants of health vulnerability and considerable higher risk of developing oral cancerous and precancerous compared to the general population among high-risk and undeserved population. Furthermore, logistic regressions within our study of at-risk populations showed that living in a shelter and oral mucosal lesion/ inflammation were associated with oral cancerous and precancerous conditions. An extreme delay at multi-level intervals at patient, HCP and system levels experienced by patients diagnosed with OCC and OPC was also found in our third phase. In addition to "primary and secondary disease prevention strategies" employing a health promotion policy through "*reinforcement of health professional competency*" for early detection and management of OCC and OPC, "*effective access to treatment system*" is recommended.

It has been proven globally that HCPs stand in the frontlines of early cancer detection and diagnosis. Despite this evidence, most physicians lack the necessary skills for detection and management of early signs and symptoms of suspicious oral lesions (Ford & Farah, 2013). Family physicians are particularly ill-equipped, from a knowledge perspective, to conduct

opportunistic oral cancer screening. This is unfortunate, as studies show that patients most at risk (e.g., lower socioeconomic classes) are more likely to visit a family physician on a regular basis than a dentist, due to the perceived expense (Ford & Farah, 2013; Macpherson, 2018). This study surprisingly identified the names of two expert medical specialists in a substantial proportion of initial consultation notes that raised the concern of longer waiting times experienced by OCC and OPC patients. More study is needed to better understand the cause of pre-treatment interval delays identified in our study in order to facilitate evidenced-based health promotion recommendations for effective and timely access to the treatment system.

The findings from this multilevel study have shown challenges and shortcomings for attaining earlier detection of OCC and OPC in Alberta at research-based evidence, population, healthcare provider, and system levels. However, since the identification of knowledge gaps is a key step toward finding the best resolution, the outcome of the present study could contribute to addressing the identified concerns through multifaceted health promotion strategies for a more effective OCC and OPC diagnosis at earlier stages.

Table 5.1 Study findings compared to the literature

Characteristics	Alberta Study Findings		Ontario	Quebec	British Columbia		Canada	The United States	South America/Brazil
Prevalence	**2005-2017:** **OCC:** 1763 (51%) **OPC:** 1685 (49 %)		**1993 2010[1]:** **OCC:** Average annual percentage change (AAPC):1.44% **OPC:** 4.56%		**1981-2010[2]:** **OCC:** 4319 (68%) **OCC:** 4319 (68%)		-	**2000-2010[3]** **OCC:** 38016 (50%) **OPC:** 37452 (50%	**Brazil[4]:** **2007-2016:** **OCC:** 52,799 (% 60) **OPC:**34,516 (40%)
Stage at diagnosis	**OCC:** IV 45.2%	**OPC:** IV 81.7%).	-		**OCC[5]:** Late 42.3%	**OPC:** Late 82.3%	-	-	**Brazil[6]: 2016** **OCC:** IV:55% **OPC:** IV:68%
Estimated incidence 2020[7] Both sexes	**OCC and OPC:** 500		**OCC and OPC[7]:** 2,067	**OCC and OPC[8]:** 1,310	**OCC and OPC[9]:** 680		**OCC[10]:** 2993 **OCC:** 1247	**OCC[11]: 24470 (66%)** **OPC:** 12775 (34%)	**South America:** **OCC[12]:** 14191 (66%) **OPC:** 7292 (34%)
Etiological Risk Factors	**OCC:** Male, age, 45->65, Tobacco and Alcohol consumption, Recreational drugs, lower education, low SES, Living in shelter, inherited genetic factors **OPC:** Male, age 45-65, higher SES, HPV infection		Head and Neck: Ottawa: Less than grade 8 education, Being born in Canada, Visit dentist less than once year[13]	-	**OCC[14]:** Male, deprived, Women with south Asian and Chinese background **OPC:** Male, lifetime never- smokers, HPV infection		**Hand[15] and Neck:** Male, Lowest level of education, Low income, Smoking tobacco, Drinking alcohol, Older age, HPV infection	**OCC[16,17]:** Male, older age 70+, alcohol, diet deficiency, smokeless tobacco, Heavy drinking, Processed meats, Socioeconomic deprivation **OPC:** Male, white, Age 60-69 yrs, HPV infection, Smokeless tobacco, heavy drinking	**Brazil: OCC[6]:** Male, Mate hot drinking, Tobacco and alcohol consumption, Low education
Anatomical location	**OCC:** tongue, Floor of mouth	**OPC:** Tonsil. Base of tongue	-	-	**OCC[14]:** Tongue, Floor of Mouth, Buccal mucosa	**OPC:** Tonsil, Base of tongue		Tonsil and Base of the tongue, oral tongue[17]	**OCC:** Tongue[6]
Patient Delay Accepted timeline: 2-3 weeks	11.6 Months	-	-	-	-	-	5.4 Months[18]	3.5 Months[19]	Patient appraisal[4] 10 Months Help seeking[4]: 4 Months
Professional Delay Accepted timeline: 30 days[25]	6.1 Months	-	-	-	-	-	2.8 Months[18]	3 Months[19]	4 Months[4]
Treatment Initiation Delay Accepted timeline: 30 days	3.0 Months	-	-	-	-	-	-	1.4-3.0 Months[19]	12 Months[4]

Table 5 CONT: Study findings for Alberta compared to the literature

Characteristics	Global	South/Southeast Asia	Europe	Africa	Southwestern Pacific-Oceania
Prevalence	**1998-2002[20]: Twenty-three countries:** **OCC:** 113144 (38%) **OPC:** 69592 (62%)	-	**UK:2016[21]** **OC:**3700 (51%) **OPC:**3500 (49%)	-	-
Stage at diagnosis	-	-	**Portugal[5]** **OCC:** IV:42% +- 3.89%	-	-
Estimated incidence <u>2020</u> Both sexes[12]	**OCC:** 377713 (79%) **OPC:** 98412 (21%)	**OCC:** 166900 (86%) **OPC:** 28233 (14%)	**OCC:** 69856 (70%) **OPC:** 30061 (30%)	**OCC:**14286 (83%) **OPC:**2913 (17%)	**OCC:** 60674 (83%) **OPC:** 12712 (17%)
Etiological Risk Factor	**OCC[22]:** Male, Tobacco use in any form, Excessive alcohol use, Dietary deficiency, Genetic factors **OPC:** Male, HPV infection, Oral sex practice	**OCC and OPC[23]:** Male, Age 45-64 years, Divorced, Betel nut chewing, Frequent drinking alcohol, long term smoking tobacco Low education, comorbidity, Low income, Diet deficiency, genetic factors, Poor oral health, HPV, bidi smoking	**OCC[24]:** Men, Smoking tobacco synergically with alcohol consumption, SES deprivation **OPC:** Male, oral sex practice, HPV Infection	-	**OCC[23]:** Betel quids with/out tobacco, areca nut chewing
Topographic location[24]	-	**OCC:** Buccal mucosa / **OPC:** Base of tongue	**OCC:** Tongue / **OPC:** Tonsil	**OCC:** Tongue and floor of mouth	-
Patient Delay Accepted timeline: Three weeks[25]	3.5-5.4 Months[18]	-	**Germany[26]:** 2 weeks (19.3%) 3-4 months (63.5%) >1 year (9.3%)	-	-
Professional Delay Accepted timeline: 30 days[25]	3.2-4.9 Months[18]	-	-	-	-
Treatment Initiation Delay Accepted timeline: 4-5 weeks[27]	-	-	**Netherlands[28]:** 1990-2011: 39 days	-	-

1.(Mifsud et al., 2017); 2.(A. Auluck et al., 2014);3.(Weatherspoon, Chattopadhyay, Boroumand, & Garcia, 2015); 4. (A. W. D. Felippu et al., 2016); 5. (Tavares, Guimarães, Lopes, Felino, & Coimbra, 2016); 6(Curado et al., 2016); 7.(Ontario, 2020); 8. (Society, 2020c); 9. (Society, 2020a); 10. (Society, 2020b); 11. (Net, 2020); 12. (World Health Organization: International Agency for Research on Cancer, 2020a); 13. (Stephanie Johnson et al., 2010); 14. (Ajit Auluck et al., 2010); 15. (E. Hwang et al., 2013); 16. (Javadi, Sharma, Zahnd, & Jenkins, 2017); 17. (LeHew et al., 2017); 18. (Peter Stefanuto et al., 2014); 19. (Murphy et al., 2016); 20.(Chaturvedi et al., 2013); 21. ;22. (Warnakulasuriya, 2009); 23. (Sankaranarayanan et al., 2015); 24. (D. Conway, M. Purkayastha, & I. Chestnutt, 2018); 25.(Lee et al., 2016) (X. Brouha et al., 2007) ; 26. (Friedrich, 2010) ;27. (Harris et al., 2014); 29.(van Harten et al., 2015).

The key characteristics of oral and oropharyngeal cancers found in Alberta in this study were compared with similar available data reported at the national and global level and are presented in **Table 5.1.**

5.3 Limitation

This study demonstrated several limitations in each phase that need to be acknowledged. During the first phase (i.e., conducting the scoping review), we found that relevant OCC and OPC information was distributed across a variety of resources. These included published peer-reviewed papers, websites, administration organizations, and unpublished gray literature. Using these resources was the only way we could obtain the desired "big picture" perspective of the phenomenon under study. However, in a scoping review, no quality assessment is provided, mostly due to the diversity of sources (Steven Habbous, Chu, Lau, Schorr, Belayneh, Ha, Murray, O'Sullivan, et al., 2017).

We also experienced a substantial challenge during the data collection period of our cross-sectional study. Our target population was hard to reach, which resulted in a longer data collection process and led to a later completion date than anticipated. Although our honest and professional interactions enabled us to develop a warm and trusting connection with the target organizations and centers within the community, initiating and building these connections was extremely time-consuming. The administrative representatives were very cautious around ensuring the participants' psychological, physical, and moral safety. Unfortunately, we found there is a generally negative impression about the mutual benefit intention of academic researchers; instead, concerns about researchers ignoring participants' health benefits and interests were repeatedly brought up by the organizations and administrators we engaged with.

There are some limitations inherent in retrospective studies using data from already recorded resources such as ICN including potentially missing information (Sarkar & Seshadri, 2014). However, clinical chart reviews have considerable advantages, in that they are less time-consuming and are a relatively inexpensive way for generating hypotheses that could be tested. Some additional deficiencies of information were identified that were associated with the patients' reasons for not seeking help on time. Furthermore, the exact dates of the delivery of some interventions or consultations were missing or difficult to detect through the context.

This study acknowledges that histopathological examination in the second phase and a focus on OCC and OPC treatment process in the first and third phases are considered outside the scope of the present work due to limitations in technical resources and were thus excluded from the study design.

5.4 Conclusions and Future Considerations

Alberta, like the rest of the world, has shown similar concerns about oral and oropharyngeal cancers as a deadly public health phenomenon. Our scoping review successfully gathered the information spread across numerous resources to provide a comprehensive picture of what we already knew while shedding light on dark and previously unseen corners of our provincial OCC and OPC challenges. Challenges, such as Alberta's high proportion of stage IV diagnosis, especially in OPC, and associated mortality rate, confirmation of cancer diagnosis and initiation of treatment in a longer timeframe compared to the proposed scientific consensus and the global trend and being the 4th among the ten Canadian provinces for oral cancer incidence and related death prevalence urges special attention and effective implementation of health promotion strategies as outlined in this work.

Further, in our cross-sectional study, we identified a high prevalence of oral mucosa lesions and cancerous/PMOL lesions among the underserved vulnerable population. This finding represents an additional serious concern that demands the immediate attention and intervention of the provincial public health authority. One easily applied and effective oral and oropharyngeal cancer prevention strategy is to improve cancer and associated risk factor literacy in lower socio-economically disadvantaged communities by providing information on available public health interventions.

Finally, our qualitative study indicated an increase in total delay in the processing of OCC and OPC patients from onset to the initiation of treatment. According to the evidence-based literature, such lengthy delays would have a negative impact on both survival rate and the quality of life of survivors. In the four intervals investigated in this study, we found long periods between a patient's appraisal of asymptomatic onset of cancerous changes in the area of neck and oral cavity to the point of patient interpretation of the need to seek medical consultation. While we did find missing information pertaining to what causes this delay, our data showed that seeking help was mostly accelerated by symptomatic presentation of the disease. This evidence suggests that strategies to enhance patients' awareness about risk factors of oral cancer and its early signs and symptoms should be at the centre of any health promotion initiatives.

We also found undesirable delays in confirmation of diagnosis following the patient's first medical consultation. Such delays should be seen within the framework of health professional incompetency, as dealing with the detection and management of OCC and OPC is crucial and needs to be considered a priority. Pre-treatment interval was also found to be

delayed. This needs to be addressed at the system level, while the HCP delay in providing a timely referral should be seen as a contributing factor.

5.4.1 Research Implications

In addition to displaying facts and challenges regarding OCC and OPC, such as significant evidence for late diagnosis of OCC and OPC (OCC= 45.2%, OPC= 82.4% stage IV) between 2005 and 2017 in Alberta, the developed conceptual framework in this study sheds light on unmet multilevel areas of research, policy, and practice that should be given special attention. To enhance our better understanding of how the additional factors identified in the present work impact late diagnosis, we need to consider investigating the following:

- Factors causing the delay in patients seeking health professional consultation after noticing early signs and symptoms of OCC and OPC.
- The ability of dentists and physicians in Alberta to confidently detect and diagnose premalignant and malignant oral lesions and then refer patients with these conditions to the appropriate specialists.
- The reason for a lack of dedicated research funding for oral cancer prevention or early-stage detection in the province.
- The effectiveness of online public awareness about oral and oropharyngeal cancers, especially among at-risk populations.

5.4.2 Policy Implications

The conceptual framework showed missing strategies at the population level that urged the following recommendations for improving OCC and OPC diagnoses at an earlier stage and with a better outcome:

- Employing solid, consistent, and periodic health promotion campaigns to increase OCC and OPC literacy at the public level, especially among at-risk and vulnerable groups.
- Introducing population-wide opportunistic OCC and OPC screening, which would facilitate evidence-based supported detection of asymptomatic precancers or cancers at an earlier stage.
- Implementing targeted OCC and OPC screening with a focus on at-risk groups, such as older patients, people with a biological predisposition for cancer, and users of tobacco, recreational drugs and alcohol.
- Providing HPV immunization cost coverage by public health for both sexes, with no age limitation.

5.4.3 Practice Implications

This study showed a remarkable increase in time for OCC and OPC diagnosis confirmation, pre-treatment time intervals, and structural barriers for patients with suspicious oral lesions to access proper care, including long distance and transportation issues. These challenges could be addressed through the following strategies:

- Mandatory and periodic continuing education for oral and oropharyngeal cancer detection and management for dentists and physicians, particularly those who are active in remote and rural areas.
- An evidence-based plan to integrate a sustainable curriculum for the training of medical and dental students in order to enhance their knowledge, clinical judgement competency, and treatment management.
- Prioritizing access to specialists based on the tumor aggressiveness. Patients suspected of having a squamous cell carcinoma (SCC) of any type should be prioritized for seeing an expert specialist, regardless of the stage of disease. Squamous cell carcinoma is well-known for its very invasive behaviour and fast transitioning from the early and generally survivable stages I and II (with about an 80% chance of survival) to the late and fatal stages III and IV (with a 50-60% chance of survival but with low quality of life).

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Appendices

APPENDIX 1: Ethics Approval

1/10/2021 Gmail - HERO: Ethics Application has been Approved Pro00060953

HERO: Ethics Application has been Approved Pro00060953

ID: Pro00060953

Title: A Comprehensive Oral Health Needs Assessment among Underprivileged Communities in Edmonton.

Study Investigator: Maryam Sharifzadeh-Amin

Description: This is to inform you that the above study has been approved.

Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta

Edmonton Alberta

Canada T6G 2E1

|

APPENDIX 2: Ethics Approval

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 4A7
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

Certification of Ethics Approval

This is to acknowledge that the following research has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) I am granting approval for your site's participation in the research.
Ethics ID: HREBA.CC-17-0370

Principal Investigator: Maryam Sharifzadeh-Amin
Co-Investigator(s): Vickie Baracos
Seema Ganatra
Student Co-Investigator(s): Parvaneh Badri

Study Title: Oral Cancer Surveillance and Control in Alberta: A Conceptual Framework

Sponsor:

Effective: September 8, 2017 Expires: September 7, 2018

Study reviewed by delegated review on 08 September 2017

The following documents have been approved:

Protocol-Oral Cancer Surveillance and Control in Alberta
1-HERO_ Ethics Application has been Approved Pro00060953
2- HERO_ An Amendment or Renewal has been Approved Pro00060953_REN1

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's Food and Drug Regulations (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Access to personal identifiable health information was requested in this ethics application. Upon review, the HREBA – Cancer Committee has waived consent as it was demonstrated to be impractical, unreasonable or not feasible to obtain.

As a requirement of the HIA, if your study uses health information a copy of this certification will be sent to the Office of the Information and Privacy Commissioner (OIPC).
Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This approval is subject to the following conditions:

1. It is being granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above. Failure to submit a request will result in the file entering into an expired state, whereby all research must cease.
5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

This approval does not guarantee that you will be able to access health records for research purposes. Other institutional or organizational requirements may be in place that you will be required to meet prior to initiating your research. These include approvals for the allocation of resources in support of your study. Inquiries regarding these additional approvals should be directed to the appropriate institutional or organizational body.

Please accept the Committee's best wishes for success in your research.

Approved on behalf of CC by	Date:
Peter Venner, HREBA-	September 11, 2017

APPENDIX 3: Community Support Letter

February 10, 2017

To whom it may concern:

I am writing this letter of support for Parvaneh Badri, DDS, MSc., who is participating in an oral cancer screening project. The project's principal investigator is Dr. Maryam Amin and co-investigator is Dr. Seema Ganatra both affiliated with the University of Alberta, Department of Dentistry.

The study is of great value to our clients and our organization. Boyle McCauley Health Centre provides relevant and accessible primary health care to some of the most vulnerable members of our community, including those experiencing poverty, homelessness, mental health and addiction issues and social isolation. Having the study operating in our Dental Clinic gives our clients excellent access in an environment that is welcoming and supportive. We can also provide timely follow up treatment and support for anyone requiring it. In addition, our outreach workers are able to transport clients to the clinic and can also help with reminders for future appointments. Outreach workers will also attend the appointments with the clients as their main support person.

We will provide the assistance of our dental receptionist and assistant as well as access to our sterilization equipment. We are also willing to provide any other logistical assistance that may come up over time.

As clients are already comfortable in this setting, they tend to trust any professionals we bring to our clinic. This provides ease of access to groups of clients in the inner city. Our staff has been introduced to the project team and are very excited to have their services on site on a regular basis.

Sincerely

Karin Frederiksen

Program Manager

Boyle McCauley Health Centre

Edmonton, AB

APPENDIX 4: Letter of Information

INFORMATION LETTER

Study Title: A Comprehensive Oral Health Needs Assessment among Underserved Communities in Edmonton.

Investigators:

Dr. Maryam Amin
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ADDRESS: 5-513 Edmonton Clinic Health Academy, University of Alberta, Edmonton, AB, T6G 1C9

Dr. Seema Ganatra
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Dr. Parvaneh Badri
EMAIL badri@ualberta.ca Phone number 780-965-8580
ADDRESS: 5-095 Edmonton Clinic Health Academy, University of Alberta, Edmonton, AB, T6G 1C9

Background:

- You are being invited to participate in this research study because you are age 18 or over and living in Boyle McCauley community.
- This study is a unique opportunity to find about the oral health needs of people living in your community to promote their oral health and facilitate their access to dental care services if needed.

Purpose:

- We are aware that residents of some communities, like yours, has a strong need for dental care. However, due to lack of observation, there is no objective information in dental and oral mucosa (skin in the mouth) health in this community.
- There is no information on how the residents use dental care services in this community.
- The purpose of this study is to collect information on dental, gum, and oral mucosal health conditions and how the dental care service is being utilized.

Procedures:

- You will be asked to complete a questionnaire about your age, ethnic background, education level, income level, habits in tobacco and alcohol use if any, general and oral health.
- We will also ask about your experience of using dental services.
- A Dentist or Certified Oral Pathologists, and Dental Hygienists will be providing the dental, gum, and mouth check-up. The check-up is simple, fast and painless. It takes about 10-15 minutes.
- The tissues inside the mouth will be looked at with the help of a white light. If abnormalities are detected, you will receive referral for a follow-up visit to the University of Alberta affiliated dental clinic in Edmonton.
- The estimate time required to complete the questionnaire will be 30 to 40 minutes.
- Should you have any questions concerning the procedures, please do not hesitate to ask.

Benefits:

- You benefit from a comprehensive free of charge mouth (Dental, Gum, Oral-mucosa) check-up by experts and receive referral to the University of Alberta affiliated dental clinic in Edmonton in case further follow-up or treatment is necessary.
- We also hope that the information that we learn from you as a result of this study, may improve health care programming for people in your community in the future.

Risks:

- Participating in this study does not carry any known risks or dangers associated with completing questionnaires and the mouth check-up.
- If you would like to speak to someone you may contact either the student or supervisors identified above.

Voluntary Participation:

- You have the right not to participate or to answer any of the questions if you do not want.
- You can withdraw from the study within 72 hours after completion of the questionnaire; your information will then be removed from the study if you decide to withdraw.
- If you choose not to participate in the study or not to answer some questions, your decision will not have any consequences for you.

Confidentiality:

- Your confidentiality will be respected. Your name will not be revealed in any reports such as research articles or presentations from this study.
- Documents from this study will be identified by code numbers and these code numbers will only be known to the researchers listed above.
- Data will be kept in a secure place for a minimum of 5 years following completion of research project and electronic data will be password protected and when appropriate destroyed in a way that ensures privacy and confidentiality.

- Your identity will not be used in any reports about the study.
- Research records and medical records identifying you may be inspected by representatives of Health Canada and the University of Alberta Research Ethics Board, for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the center. These organizations have policies of strict confidentiality and the individuals inspecting your records must sign a confidentiality form.
- Data, generated throughout the study, reports concerning your progress identified by a study code only.
- The information gathered from this study, with information identifying you removed, will be shared with the investigators who have conducted this study, sponsors of this study, the governmental regulatory agencies that oversee such research and other researchers throughout the world through publication of the results of this study.
- Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information.
- We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

Further Information:

- If you have any questions or concerns, please contact Dr. Amin at 780-492-7354**.**
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

This study is supported by the University of Alberta, School of Dentistry Oral Health Community Engagement Fun

APPENDIX 5: Consent Form

CONSENT FORM

Title of Project: A Comprehensive Oral Health Needs Assessment among Underprivileged Communities in Edmonton.

Investigators:
Dr. Maryam Amin
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ADDRESS: 5-095 Edmonton Clinic Health Academy, University of Alberta, Edmonton, AB, T6G 1C9

Part 2 (to be completed by the research subject):

	Yes	No
Do you understand that you have been asked to participate in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study within 72 hours after completion of the questionnaire without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access study data?	☐	☐

Who explained this study to you? _____

Your Name _____

I agree to take part in this study: YES ☐ NO ☐

Signature/Oral Consent: _____ Date & Time _____

(Printed Name) _____

Signature of Witness _____ Date & Time _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate in the research.

Signature of Investigator or Designee _____ Date & Time _____

A COPY OF THIS CONSENT FORM MUST BE GIVEN TO THE PARTICIPANT.

APPENDIX 6: Module I-IV

MODULE I. Demographic Characteristics

Gender: □ male □ female Date of Birth: _____ (YYYY/MM/DD)

In addition to being Canadian which of the following apply to you? Check all that apply.

□ Aboriginal, Status: □ No □ Yes

□ East or Southeast Asian (eg, China, Japan, Indonesia, Philippines, Vietnam)

□ South Asian (eg. India, Pakistan, Sri Lanka)

□ African

□ Other, (please Specify) _____

□ Decline to answer

What is your level of education?

□ Never attended School

□ Less than high school

□ High school diploma

□ College or Trade

□ University degree

What is your current marital status ? Check one box only

□ Married or Living Common Law

□ Divorced

□ Separated

□ Widowed

□ Never married

Who do you live with? Check one box only: Check one box only

□ Alone

□ With Family

□ With others

□ Not applicable

Including yourself, how many people usually live in this household?

□ Number of people age < 18 _____

□ Number of people aged 18-64_____

□ Number of people aged over age 65 _____

□ Not applicable

Currently what type of housing do you live in?

□ House

□ Apartment

□ Single room occupancy

□ Shelter

□ None of the above, please specify _____

Are you currently working in a paid position?

□ Yes

□ No

In the past 12 months, did you (or you family) receive income from any or the following assistance programs? please check all that apply

□ Child Tax Benefit

□ Guaranteed Income Supplement or Spouse's Allowance

□ Income Assistance or Welfare

□ Disability Insurance

□ Employment Insurance

□ Private Insurance

□ None of the above

What is your annual family income before taxes (Family is a group of individuals related by blood, marriage including common-law or adoption who current share a common dwelling unit) ? check one box only.

□ Less than $6,000

□ $6,000-$12,000

□ $12,001-$20,000

□ $20,001-$30,000

□ $30,001-$40,000

□ Greater than $40,000

□ Don’t know

□ Decline to answer

How long have you been living in Boyle McCauley community (If you have moved away from this community and then returned, please refer to your most recent return)?

□ Less than 3 months □ 3-6 months □ 6-12 months □ More than 12 months

MODULE II. Risk Factors

Study ID_____ Date: _____

1. Substance Use

	Do you currently use? (Y/N)	At what age did you start?	If stopped, at what age did you permanently stop?	Average number per day?	Do not wish to answer
Cigarettes					
Cigar					
Pipes					
Marijuana					
Chew Tobacco					
Betel nut					
Crack/Cocaine					
Crystal Meth					
Heroin					
Methadone					
Fentanyl					
Beer (cans)					
Wine (glasses)					
Liquor/ Shots					
Other					

MODULE III – ORAL HEALTH PERCEPTIONS AND BEHAVIOURS

Study ID_____ Date: _____

1. In general, would you say the health of your mouth is?

□ Excellent

□ Very good

□ Good

□ Fair

□ Poor

□ Do not know

2. When was your most recent dental visit?

□ Never

□ Within past year

□ 1-5 years ago

□ More than 5 years

3. In the past month, how often have you found it uncomfortable to eat or drink any food because of problems with your mouth or teeth?

□ Never

□ Once a week

□ More than once

□ Do not know

4. In the past month, how often have you had any other persistent or on-going pain anywhere in your mouth or teeth?

□ Never

□ Once a week

□ More than once a week

□ Do not know

5. In the past month, how often do you usually brush your teeth and/or dentures? (For example, twice a day, three times a week)

□ No, I do not have teeth or dentures

□ No, I do not brush my teeth or dentures

□ Yes, I brush _____times per (day, week, month – please circle)

□ Do not know

6. How often do you usually floss your teeth?

□ No, I do not have teeth or dentures

□ No, I do not floss my teeth or dentures

□ Yes, I floss _____times per (day, week, month – please circle)

7. What bother(s) you most about your mouth or teeth?

□ Nothing (You do not need to answer Q 8)

□ Eating

□ Talking/Speech

□ Aesthetics/appearance (i.e., impact on social interaction or job interview)

□ Others, please specify _____

8. If you checked any of the above except for 'nothing', what are the problems? (You can choose more than one option)?

□ Pain

□ Bleeding gum

□ Sharp teeth

□ Ill-fitting denture (unstable denture)

□ Bad breath

□ Missing teeth

9. Have you heard of oral (mouth) cancer before today?

□ Yes

□ No

□ I am not sure

10. Is there a family history of mouth or head and neck cancer?

□ Yes

□ No

11. Have you ever HAD an oral cancer examination before?

□Yes

□ No

□ I am not sure

12. During the past 3 months, how often you had problems with your teeth or gums that:

a) Affected your daily activities (Such as attending work)

□ □ All the time

□ Most of the time

□ Some of the time

□ Rarely

□ Never

b) Affected your social activities (Friends gathering or family gathering)

□ All the time

□ Most of the time

□ Some of the time

□ Rarely

□ Never

c) Caused avoidance of conversations? (Because of how your teeth look)

□ All the time

□ Most of the time

□ Some of the time

□ Rarely

□ Never

MODULE IV – Medical History & Health Care Utilization and Access

Study ID_____ Date: _____

1. In general, how would you say your health is?

□ Excellent

□ Very Good

□ Good

□ Fair

□ Poor

□ Do not know

2. Have you ever been told by a doctor or other health professional that you had cancer of any kind?

□ No

□ Yes: (Please specify type) _____

3. Medications:

□ No

□ Yes

_____

□ Anti-retroviral □ antidepressant □ anti-psychotics, □ pain medication □others

4. Hospitalization: □ No □ Yes; Reason: _____

□ Hepatitis C □ Hepatitis B carrier □TB □ Artificial joint (s)

□ Diabetes □ Heart problem □ STD

□ HIV □ HPV infection

□ Previous biopsy, site _____

□ Other

_____

_____

5. Drug Allergies?

□ No

□ Yes

Specify _____

6. In the past 12 months, have you seen any of the following health professionals?

	o.	Yes. How many times a month?	Do not know.	Do not want to answer.
Family doctor				
Eye doctor				
Surgeon				
Nurse/street nurse				
Social Worker				
Physiotherapist				
First Nation, Metis or Inuit Traditional healer				
Other				

7. Have you ever had cancer screening done? □ No □ Yes If yes, which of the following?

□ Mammogram □ Pap smear

□ Lung x-ray □ Colonoscopy

□ PSA for prostate cancer □ Rectal (prostate) examination

□ None of the above □ Other _____

8. Have you been a patient overnight in a hospital?

□ No

□ Yes, for what reason _____

□ Do not know

9. Was there ever a time you felt you needed health care and did not receive it?

□ No

□ Yes

MODULE V: ORAL HEALTH EXAMINATION

Examiner: _____ Date: _____

Extra-Oral & Mucosal Assessment:

1. Face: □ normal □ asymmetry □ pigmented lesion □ swelling

□ Other lesion_____

2. TMJ: □ normal □ clicking □ pain on mouth opening □ restricted mouth opening

□ Muscle tenderness □ other _____

3. Saliva: □ normal □ dry

4. Dentures: □ None □ URPD □ LRPD □ UCD □LCD

□ Other _____

5. Oral mucosal examination

Lesion characteristics:

Pain: □ No □ Yes

Location: _____

Colour: □ White □ red □ yellow □ other

Size: □ 0-0.5cm □ 0.5-1.0cm □ 1.0-1.5 cm □ 1.5-2.0cm □ larger than 2cm

If more than one lesion provide description: _____

/

6. Was an oral precancerous or cancer lesion or serious oral condition discovered during the oral examination that requires immediate attention?

□ No

□ Yes, please specify _____

Monitor □ No □ Yes Please specify_____

Refer □ No □ Yes Please specify_____

7. Recommend referral for dental or periodontal management?

□ No

□ Yes, please specify _____

8. Has this been discussed with the participant?

□ No □ Yes

HPV AS A RISK FACTOR QUESTIONS:

The reason why we are asking these questions is that HPV causes cancer-including oral cancer. This usually occurs via oral sex. We would like to know if you are predisposed to developing oral cancer. We understand that this topic may be uncomfortable for you to discuss but hope that you can provide valuable information. The information that you provide will be confidential.

9. Have you had oral sex without a protective barrier? □ No □ Yes

If "yes", how many partners? □1-5 □ 6-15 □ more than 15 □ Male? □ Female? □ Both?

Tooth conditions: DMFT INDEX: (Sound 0, Cavity 1, Missing 2, Filling 3)

~~8~~	7	6	5	4	3	2	1	1	2	3	4	5	6	7	~~8~~
~~8~~	7	6	5	4	3	2	1	1	2	3	4	5	6	7	~~8~~

Periodontal Health

Mobility			
Probing depth Buccal (3)			

//

Plaque score 1 6 21 24

Probing depth lingual (3)			
Mobility			
Probing depth Buccal (3)			

Plaque score 44 41 36

Probing depth lingual (3)			