Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences

By

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Abstract

Problem:

Treatment for head and neck cancer (HNC) can lead to experiences of intense symptom distress, particularly within the oral cavity and pharynx.

Methods:

Hermeneutic phenomenology as described by Max van Manen guided this study. 13 participants completed a semi-structured interview.

Results:

Treatment has a profound and sustained impact. During treatment, eating difficulties, pain, xerostomia, dysphagia, and weight loss were reported. Long-term, eating problems, dysphagia, xerostomia, and dental disease was described. Despite inadequate nutritional intake, a resistance to a feeding tube was expressed. This resistance was influenced by meanings of becoming and living as a cancer patient. The symbolic meaning of food and eating impacted the subjective concepts of self and illness.

Conclusion:

The participant experiences described suggest that there is a critical need to develop interventions that respond to living with symptoms in HNC. The participant experiences should inform and guide the development of clinical practice and recommendations.

Acknowledgment

I would like first to give thanks to the study participants. They have taught me not only about this research topic through sharing their perspectives and insights, but they also showed me a new way to live in this world. I have been honoured to hear their stories and will be forever grateful to each of them for their gift of time, and their courage.

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Dedication

I dedicate this thesis to the memory of my mom and to my partner and best friend, Orest.

Mom, although you are not with me, your strength, determination and convictions are what carry me through life and allow me to strive for my dreams. Always loved.

Orest, you are my rock, my constant source of unwavering support and encouragement. You believe in me, even when I do not believe in myself. Without your unconditional love and support, I would not have made it through this entire process.

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Chapter 1

Introduction

Hearing the words 'you have cancer' is life-changing, for both the person receiving the diagnosis, and their family members. Although the primary goal of cancer treatment is a cure, an important secondary goal is to address physical and psychological distress effectively. Persons with cancer of the head and neck region, do have unique needs. The teeth, the oral cavity, and the pharynx are central to speech, taste, eating, and swallowing.[1,2] Additionally, they play an essential role in body image, identity, social interactions and the ability to express oneself.[1-3]

Treatment of head and neck cancer can lead to intense symptom distress, particularly within the oral cavity and pharynx.[4] Consequently, health-related quality of life is reduced during treatment and in the long-term.[3,5,6] The most common lasting effects reported include deterioration in taste sensation,[7-11] xerostomia, sticky saliva,[7,12-15] dysphagia,[16,17] trismus,[7,18-21] and dental problems.[7,12-15,22] Therefore, for the person living with these effects and their partner they must learn to manage these complex treatment effects. Increased understanding of this impact could lead to improvements in family, and patient-centred care.

Oral and dental care represent an essential component across the trajectory of head and neck cancer.[23-27] Oral and dental care, along with individual patient concerns and needs, go beyond standard knowledge that can be acquired through formal dentist and dental hygienist education.[23] Numerous academics have noted that a specialized knowledge set is needed to provide the care for this patient population.[14,23-27] This care is said to only be accomplished through a collaborative approach by care providers.[14,23-27] Canada's health care system, for the most part, does not provide benefits for dental services.[28] As such, dental professionals are not routinely included in the team during the care of individuals with head and neck cancer.[29]

The purpose of this study was to develop an in-depth understanding of the individual diagnosed and their partners' oral and dental lived experiences in the context of head and neck cancer. Understanding the meaning of both the individual patient and partners' experience can provide insight for healthcare providers and decision makers to improve the quality of care provided, and to enhance the interactions between providers and patients and reduce barriers to high quality care. This study seeks to set the foundation of knowledge needed to help understand the family, and patient-centred issues in head and neck cancer in order to improve patient and family care and experiences. The meaning of these experiences will provide understanding that can enhancement the practice of family and patient-centred care. Furthermore, these meanings have the potential to inform clinical practice and the recommendations and protocols on dental health and disease for this patient population.

Chapter 2

Literature Review and the Research Process

Background

Head and neck cancer is an umbrella term commonly used to describe various neoplasms that arise from the mucosa of the upper aero-digestive tract. Head and neck cancer due to their anatomical location and the structures involved are typically within moist, mucosal lining which is made up of squamous cells. Therefore, most head and neck cancers are squamous cell carcinomas.[30] However, some head and neck cancer begin in the salivary glands or on the skin which contains many different types of cells. As such, the categorization of the tumor is according to the cell from which the cancer originates. It is common to classify head and neck cancer by their histological type and the anatomical structures from which the tumor arises. These broad categories include the oral cavity, pharynx, larynx, paranasal sinuses, nasal cavity and salivary glands.[31] The oral cavity would include the lips, the gingiva, the front two-thirds of the tongue, the lining of the inside of the cheeks and lips, the floor of the mouth and the hard palate. The pharynx would be further broken down to the nasopharynx, oropharynx and the hypopharynx.[31]

Risk Factors/Incidence and Prevalence

The most common risk factors attributed to head and neck cancer are alcohol and tobacco use.[32-37] More recently the human papillomavirus (HPV), specifically HPV-16 has also been identified as one of the most common risk factors for oropharyngeal cancer.[32,38-40] Additional risk factors include: sex (men more than women),[41] ancestry (Asian ancestry, mainly the Chinese for nasopharyngeal cancer,[42] and for esophageal cancer those from Asia, Africa and Latin

American[43]), age (45 years and older),[44,45] radiation exposure,[46,47] occupational exposure,[48-50] Epstein-Barr virus infections,[51-53] usage of paan (betel quid),[54,55] and consumption of maté.[54,56]

The demography of squamous cell carcinoma is changing. Squamous cell carcinomas typically occur in the middle-aged to older adults. However, due to HPV-16, there has been an increase in Oropharyngeal Squamous Cell Carcinoma (OSCC) in younger adults and predominantly males.[44,57,58] HPV-16 positive OSCC is typically located either at the base of the tongue, tonsils or soft palate.[44,57,58] OSCC HPV-16 positive cases tend to present with advanced disease. However, these cases respond better to treatment, and the prognosis is good.[59]

It is estimated that 4700 new cases of oral cancer (3200 males and 1450 females), and 1150 cancer of the larynx (970 males and 180 females) will be reported in 2017 in Canada.[60] In 2015, CancerCare Manitoba (CCMB) reported 204 new cases of head and neck cancer (149 males and 55 females).[61] Head and neck cancers are the fifth most common in the world by incidence.[38]

Treatment and the Acute and Long-term Side Effects of Treatment

Head and neck cancers, are typically diagnosed at a late stage.[15] Treatment may include a single modality or different combinations of surgery, radiation therapy and chemotherapy. However, due to the late stage of diagnosis, and the anatomical structures involved in the disease, treatment often includes multiple interventions.[6,45,62,63] Surgery and/or radiation therapy are essential modalities for any curative treatment.[64]

Surgery for the head and neck cancer patient may result in physical deformities, or functional impairments that may impede eating, talking and swallowing in the short and long term.[65] This, in combination with xerostomia, sticky or the absence of saliva and trismus can further hinder the ability to eat, talk and swallow.[64-65]As a result, social isolation, anxieties, and/or embarrassment or fear to eat or drink in front of others may occur.[1,65,66-68]

Mucositis and stomatitis are two of the most common effects experienced by individuals during head and neck cancer treatment.[4,6,23, 71] Mucositis and stomatitis are associated with severe pain in the oral cavity and orapharynx.[3,6,30,72,73] Cancer treatments break down the rapidly dividing epithelial cells lining the gastrointestinal tract.[74] Mucosal breakdown leaves the mucosal tissue open to an increased risk of ulceration.[74] If chemotherapy is used it can cause myelosuppression and a decreased immunity which may leave individuals vulnerable to severe complications, such as infections.[4,6,23,71] Ulceration and infections may lead to several additional complications including increased pain and restricted food and liquid intake. These further difficulties can contribute to interruptions of treatment and may lead to possible hospitalization.[3,4,23,30]

The most common lasting effects reported include deterioration in taste sensation,[7-11] xerostomia, sticky saliva,[7,12-15] dysphagia,[16,17] trismus,[7,18-21] and dental problems.[7,12-15,22] These result in long-term reduced HRQOL; with lasting physical, emotional, and psychosocial effects,[4-6] which means for both the person living with these effects and their partner they must learn to manage complex treatment effects.

Oral Health and Disease

The side effects of chemotherapy typically subside after treatment.[4,6] For some, the side effects of radiation therapy may diminish over time, while for others the side effects of radiation therapy may be permanent.[4,6,17] Xerostomia and reduced salivary output/or consistency are the most common lasting effects of radiation treatment [4,25-27,75-77] both of which increase the risk of dental caries, infection, and periodontal disease.[78]

Saliva, especially thin watery saliva, helps keep the oral cavity clean and healthy.[78] It accomplishes this by helping to clear the mouth of food and bacteria, fighting off bacteria, viruses, and fungi that enter the oral cavity and by helping maintain a neutral pH. A neutral pH is essential as an acidic mouth can cause dental caries. Radiation to the maxilla, mandible or both increase the lifetime risk of osteoradionecrosis (ORN).[79, 80]

The teeth, gums and their supporting structures are unique as they are the only area of the body that are under the direct care of oral health professionals. There is extensive literature describing the symptoms and the prevention of dental disease related to the treatment of head and neck cancer.[81-84] Despite this, many preventative measures are not followed. In a review the transdisciplinary management of treatment side effects, McClure notes that both non-dental and dental professionals may provide care or recommendations without consideration of the potential harmful effects to the oral dentition and their supporting structures.[23]

CancerCare Manitoba

At CCMB dental providers are not routinely included in the process of care provision during and after treatment for head and neck cancer.[29] However, a dentist is contracted to work one half day per week at CCMB, specifically for the head and neck cancer patient population. The dentist provides assessment and treatment recommendations only for dental services required before cancer treatment begins to prevent mouth and dental complications that may arise during and after treatment.[29] These recommendations may include but are not limited to having dental restorations, dental extraction(s), having custom fluoride mouth trays fabricated, and undergoing periodontal debridement.[81-84]The current recommendation for teeth with poor or questionable long-term prognosis is extraction.[4] This suggestion is to limit the future complication of ORN that could arise after radiation to the bone.[4,79,78] ORN is a lifetime risk of a long-term infection within bone that has been damaged by radiation. [4,79,78] The dental services recommended by the head and neck team dentist at CCMB are carried out by the individual's family dental team, or if needed, a referral to a dental group occurs.[29] All dental services recommended are at the financial expense of the patient.[29] Currently, continued or preventative dental care are not offered by any dental professional to the individuals with head and neck cancer during and after cancer treatment as part of the standard of care provided at CCMB.[29] Oral and dental care represent a critical component of the head and neck cancer treatment in preparation for, during treatment, and post-treatment.[14,23-27] Persons with a cancer of the head and neck region present with a lifetime risk of unique dental concerns and needs.[14,23-27]

Canada's universal health care system for the most part does not provide benefit for dental services.[28] As such, individuals bear the financial responsibility for dental care. An individual may forgo dental treatment because of the cost or prolong the time they are in pain until they can afford care. Further, as dental care typically occurs outside of the traditional healthcare system, the patient provides a conduit of information between the private and public healthcare system or between healthcare providers. All of these factors may negatively impact the individuals' quality of life, experiences and health outcomes.

Advances in Radiation Treatments

Radiation therapies have evolved significantly over time. Radiation therapy has advanced from a two-dimensional external beam to a 3-D conformal beam, to most currently, Intensity-Modulated Radiation Therapy (IMRT).[64] IMRT is a planned delivery system, which delivers a higher dose of radiation to the tumour site and a lower dose to the adjacent normal tissues at risk of unnecessary harmful radiation exposure.[64] These at-risk tissues may include the spinal cord, brain stem, parotid glands, optic pathway and the inner ear. Reduction of the overall dosage of radiation to these tissues has been suggested to be the reason for some improvements in HRQOL.[64,85-89] Reduction in the effects on the salivary glands in particular has been postulated to reduce some of the most common reported lasting adverse impacts in the HRQOL literature for certain head and neck cancer patients.[64,85-89]

Cancer treatment modalities are continually becoming more individually tailored and disease site-specific. As such, curative treatments or treatments to arrest the disease result in varying HRQOL outcomes both during and following treatment. Clinical practice, recommendations, and protocols should reflect these changes to match the individual patients' specific needs and expectations.

Moving Forward

Understanding the burden of cancer at a population and at a personal level are vital for future health policy, health planning and health decision-makers, particularly given the impact of the increasing cancer incidence on the healthcare system.

The impact of cancer is devastating regardless of age, gender, race or cultural background. However, those impacted with cancer earlier in life will be living with the outcomes of their disease and treatment for a greater number of years. When the diagnosis is head and neck cancer, this point is exemplified as noted previously in persons with HPV-16 positive cases of OSCC.

There are very few published studies that focus on the meaning of the oral/dental lived experiences of the head and neck cancer patients,[1,2,90-98] their partners,[99] or that of other family members. The meanings elucidated in these research approaches could help improve the care provided and patient/partner/ family member experiences.[1,2,90-99] This study will seek to set the foundation of knowledge needed to help understand the patient-centred issues to improve patient and family care and experiences. The meaning of these experiences will provide additional pieces of information that might lead to more family and patient-centred care. Furthermore, these meanings may lead to discussions to inform clinical practice and the recommendations and protocols on dental health and disease for this patient population.

Research Questions

To this end, a hermeneutic phenomenological qualitative study was conducted to address the following research questions:

1. What is the meaning of the lived oral/dental experience of the head and neck cancer patient along the continuum of their cancer care?
2. What is the meaning of the partner or other adult family members experiences of caring for and living with the oral/dental experiences in the context of head and neck cancer?
3. How can the meaning of these experiences help us understand the patient and family-centred issues to improve the healthcare provided and experiences?

The Research Process

Methodology and Method

This section will provide insight into the research methodology and method that was used to guide this study. Methodology is the philosophical framework that is used to guide the study from inception to analysis, where methods are the procedures and the techniques used in planning and performing the research.[100] This study's research design was qualitative and was guided by Max van Manan's hermeneutic phenomenological method.[100]

Methodology

Methodological approaches are situated within paradigms or the worldview of how truth and knowledge are perceived.[101] Hermeneutic phenomenological research is located within the interpretive constructivist paradigm as it is concerned with the understanding, rather than causality or explanation.[102] Edmond Husserl and Martin Heidegger were pivotal phenomenological philosophers.[103] Both Husserl's and Heidegger's philosophies form the foundation of phenomenological inquiry.[103] These founding philosophies have been reinterpreted throughout the years by many other philosophers.[102,104] Heidegger breaks down the Greek word *phenomenology* to its etymological meaning of *logos* "to let something be seen" [105] and *phenomenology* "that which shows itself in itself".[105] Phenomenology's aim is to gain a deeper understanding of the nature or meaning of everyday experiences or what it means to be human.[106] Phenomenology is not only a prescribed method, but a philosophy that guides the approach to research inquiry. [100,101,103,104,107] Phenomenology is a study of an individual's life world as experienced and not conceptualized, categorized or theorized.[100]

In phenomenological qualitative research, a strong emphasis is placed upon acknowledging the existence of multiple constructed realities.[100] Phenomenology is a human science which is a study of the "uniqueness of each human being".[101] Each person experiences his or her own unique "reality".[106] People may have shared experiences, however, individuals assign meaning to the lifeworld they are embedded.[106] The subjective experience and the objective world as conceptualized are inseparable or are one. Different perceptions of individuals will lead to different actions or understanding of reality. Meaning is assigned based on individual experience, history, and social customs. Without this context, Munhall states that data merely exist; for a situation to have meaning an individual must perceive it in a certain way.[106] A phenomenological researcher attempts to co-create a construction of the phenomenon through the interpretation of the words of the person who has experienced the phenomenon.[100]

Phenomenological research always questions the way the world is experienced as human beings. Phenomenology attempts to tell the difference between what is unique and what is the nature or essence of a phenomenon to better understand what the particular experience is like. The lived experience cannot be reflected on while living through it. Therefore, phenomenology is always retrospective or a recollection.[100]

Heidegger developed his own philosophy of phenomenology called hermeneutic phenomenology.[108] Within hermeneutic phenomenology the aim is to understand and interpret the phenomena.[103,108- 110] Heidegger's thoughts were founded on the theoretical question of uncovering the meaning of Being. 'Being' (human existence) or of the presence in the world as 'Dasein' (there-being) which is what it is to be human in the world.[108] To question the Being of something is to ask for the nature or meaning of the phenomenon. Heidegger used the phrase Being-in-the-world to refer to the way human beings exist, act or are involved in the world.[100] Dasein raises the questions of what it means to be, what existence is or what lived experience is.[108] Lived experience is shaped by the intimate interactions between self and the world. How humans experience the world are based on their situated context of the world, and because we are of the world we cannot be separated from the world that we live within. According to Heidegger, when one is existing as Dasein, the person is aware of one's own being and mortality.[100] Additionally, in this state the person is also aware that one is always with others. The average everyday life and this everyday life with others is central to Dasein. Dasein is the sense of familiarity, security or that of 'being home'.[100] Heidegger argues the hermeneutic phenomenological method captures this theoretical question of Being-in-the-world or shedding light on the experience of being human.[108]

Through Heidegger's approach researchers are advised to make explicit prior biases, knowledge, preconceptions as these contribute to the interpretation.[111] van Manan has argued that a challenge in phenomenological inquiry is "not always that we know too little about the phenomenon… we know too much".[100] This existing knowledge or assumptions may influence the researcher to interpret the nature of the phenomenon prior to coming to an understanding of the actual significance of the question sought.[100] Consequently, the researcher needs to continually reflect upon and articulate if, how, when they affected the inquiry and the interpretation process.[111] Hermeneutic phenomenology tries to be committed to both terms of its methodology.[100] As such, it is said to be both descriptive and interpretive: descriptive or phenomenological as it is attentive to how things appear or speak for themselves; and interpretive or hermeneutic because of its claim that there is no such thing as uninterrupted phenomena. [100] Heidegger believed it was impossible to consider in actuality that any description was without interpretation either in its telling, re-telling or recording.[103] van Manen argues that this contradiction can be explained or resolved if it is acknowledged that the phenomenological 'facts' of lived experience are always meaningfully or hermeneutically experienced.[100] Further, these 'facts' of lived experience are captured in language which are inevitably an interpretative process. Hermeneutic phenomenology encourages researchers to pay attention to the small details or what would seem trivial or otherwise be understood as the inconsequential of everyday life. The consequence in the inconsequential or the significance in the taken-for granted are made thoughtfully aware to the reader in the text of a hermeneutic phenomenological interpretation.[100]

The Appropriateness of Hermeneutic Phenomenology for This Study

There is minimal existing literature representing the head and neck cancer patients',[1,2,90-98] their partners,[99] or other adult family members narratives pertaining to the meaning of their lived oral and dental experiences or how these meanings can help bring understanding to the family, patient-centred issues to improve healthcare and experiences. Understanding the meaning of these experiences can help maintain and establish good clinical relationships with patients, their partners or other adult family members and allow the persons living with head and neck cancer to have the protection and space to speak reflectively and critically.

Munhall explains that understanding what a person experiences and the meaning attached to this experience is the best way to design patient care.[101] If patient education, interventions or directions are not based on this understanding or this meaning then we have missed an opportunity to be more effective in improving patient care and the patient experience.[103] Knowledge gained through understanding the meaning of patient and family experiences may lead to discussions to inform clinical practice, recommendations and protocols. Healthcare interventions to improve these experiences are best designed or considered from the perspective of their experiences and not from the healthcare providers assumptions.[101] Hermeneutic phenomenology shares the similar experiences of participants and the meaning attached to them but also highlights the particulars. Munhall argues that perhaps patient care made on assumptions or generalizations contributes to negative patient experiences or why a patient does not 'comply' with the education and directions provided during patient interactions.[101] By understanding the particular or the different meanings attached to the experiences, health care providers can better understand, and be more effective in providing family, patient centred care and improving this complex experience. As such, hermeneutic phenomenology is a highly appropriate methodology to answer the research questions of this study.

Lastly, van Manen states that researchers must have an interest in the topic area they take up, as this is what commits them to the world of the research.[100] I have interest in this topic area through prior experience with, and knowledge of the phenomenon. However, this experience and knowledge is limited. Consequently, as a dental hygienist and researcher this study allowed me to gain a better understanding of the meaning of the lived oral/dental experiences within the context of head and neck cancer along the continuum of cancer care and to better understand the family, patient-centred issues.

Method

Max van Manen's hermeneutic phenomenological method guided the design, data collection, analysis, interpretation and description of this study. van Manen's method is well represented in phenomenological literature by a variety of health professions, thus the method has demonstrated utility and flexibility to guide health research.[102] van Manen's approach identifies six methodological themes.[100] These six themes structured the research method for this study (See Table 1).[100]

Table 1: Structured Research Method Themes

van Manen's Methodological Themes	Study Research Activities
1. Turning to the phenomenon which seriously interests us and commits us to the world.	Conduction a literature review, research proposal, ethics approval, recruitment of study participants.
2. Investigating experiences as we live it rather than as we conceptualize it.	Interviews.
3. Reflecting on the essential themes which characterize the phenomenon.	Analysis
4. Describing the phenomenon through the art of writing and rewriting.	Interpretation of emerging themes and differences of the lived experiences. Writing and rewriting themes.
5. Maintaining a strong and oriented relation to the phenomenon.	Maintaining the studies research question(s) and purpose.

van Manen's Methodological Themes	Study Research Activities
6. Balancing the research context by considering the parts and whole.	Stepping back and between the themes to the entire transcripts and writing to measure the overall design of study/text against the significance these parts play to the total textural structures. Answers the 'what it is' and 'so what' questions.

1. **Turning to the phenomenon which seriously interests us and commits us to the world**. The study research activities involved within this theme include conduction of a literature review, research proposal, ethics approval and recruitment of study participants.[100]
2. **Investigating experiences as we live it rather than as we conceptualize it.** Within this theme, the research activity completed is the study participants interviews. This involved listening to the participants with which Munhull calls the "third ear".[106] Listening with a "third ear" is not only listening attentively but listening with an ear that is open to different possibilities and discoveries.[106]
3. **Reflection on the essential themes which characterize the phenomenon.** This is the analysis stage. Within this theme the researcher is reading and re-reading, dialoging and dwelling with the text. Through this process themes began to emerge that represent both the shared and individual nuances between the study participants. [100]
4. **Describing the phenomenon through the art of writing and rewriting.** As research study participants do not think or feel in themes or phenomena within this research activity the researcher is writing and rewriting in a process to interpret the emerging themes and the differences within the lived experience.[100]

5. **Maintaining a strong and oriented relation to the phenomenon.** Ensuring that the interpretation is maintaining the research question(s) and purpose. The researchers existing knowledge of the phenomenon may influence the interpretation prior to coming to an understanding of the actual nature of the phenomenon and the significance of the question sought.[105] van Manan describes this as not giving in to the temptations of being side-tracked. Examples of being side-tracked include "indulging in wishy-washy speculation, settling for preconceived opinions, self-indulgent preoccupations".[100]
6. **Balancing the research by considering the parts as a whole.** Within this activity the researcher is answering the "what it is" and "so what" questions or "what is this phenomenon in its whatness".[100] Within this process van Manan states the researcher needs to stop and step back from the process a few times to ensure they are considering the parts for the whole or more simply stated "not seeing the forest for the trees".[100] If this process is not completed the researcher can fall trap into writing them self into a hole and not knowing how to dig themselves out.[100]

Research Site

CancerCare Manitoba is the provincially mandated cancer agency for the province of Manitoba.[112] In the capital city, Winnipeg, CCMB has two tertiary sites. Of these two sites, the McDermot Avenue location at the Health Science Centre campus is considered the main cancer centre for the province. Additionally, within Winnipeg, CCMB works in partnership with the Winnipeg Regional Health Authority to provide services at six additional sites.[112] Outside of the city limits of Winnipeg, CCMB in collaboration with the regional health authorities offer community-based services throughout the province.[112] All study participants diagnosis and treated for a head and neck cancer received their cancer treatment at the main cancer centre in

Winnipeg. Meaning, regardless of their place of residence in the province, they all received their care at this site. Consequently, for ease of description, when I state, “CCMB”, I am referring to the main cancer centre located Winnipeg.

Ethics

This study received ethical approval from The Health Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CCMB (See Appendices A and B). All ethical guidelines for qualitative research as defined by the Tri-Council and HREB were followed. Further, I signed a Privacy Health Information Agreement (PHIA) with CCMB. All study participants signed the informed consent form prior to the initiation of this study. (See Appendix C) The study participant consent form provided information of the study description, purpose of the study, study procedures, risks, discomforts, benefits and payment for participation, how their confidentiality would be maintained, that their participation was voluntary, and that they could withdraw from the study at any time without any negative consequences. Study participants were told that I am not associated with or employed in any way with CCMB and were provided with my contact information.

The safety, anonymity and confidentiality of the research study participants from CCMB was my upper most priority. The incidence of head and neck cancer although substantial annually, when broken down by anatomical site, age and sex may require little effort for those at CCMB to identify the study participant.[61] As such, in reporting of the participants experiences, composite stories and/or generalization of age, place of residence was used in the reporting of the findings to protect the identity of the study participants. Study participants experiences were reported using pseudonyms to further protect the study participant’s anonymity. [101,113-114]

To ensure the study participants privacy and confidentiality was maintained the interviews collected where coded. The codes where kept separate from the data source and maintained within a password protected computer.[114] The data was encrypted for further security.[114] The interviews on the audio recorder were deleted once transcribed. The paper versions of the transcripts were stored in a locked cabinet.

Risk

An anticipated risk of participation for the study participants was potential emotional distress. [103,115,116] When study participants reflected on their oral/dental experiences it was possible that could have contributed to, or brought out new emotions, which could have potentially negatively affected their psychosocial well-being. [101,115] Consequently, psychosocial assistance was made available to all study participants. At the time of the interview, contact information was provided to study participants to psychosocial personnel at CCMB (See Appendix D). Study participants were provided two options to contact psychosocial personal; either directly themselves or at their request, I could refer them. To date, I have not been requested by any study participants to have psychosocial personal at CCMB contact them or have been made aware of any adverse events of participation in this study.

Benefits

For the study participants there was no real tangible benefit for participating in this study. However, it is well recognized that talking does have a therapeutic benefit.[101] In the sharing of their experience or putting a voice to the experience, the study participant could see this as a positive effect of participation. Relief may have come from the individual being able to express their feelings or ‘let out’ or to get their feelings ‘off their chest’.[101] It was anticipated that participants might feel validation in participating as their experiences were worth studying and may believe in telling their narrative that they were able to help others in the future.[101] It did appear for the study participants that sharing their experiences was positive. A prevailing narrative from the study participants was, it was nice to be able to have someone listen to them for an extended period as this was uncommon in our daily busy lives and health care system. Additionally, they hoped in sharing their experiences that they could help others diagnosed with a head and neck cancer. Although the potential for future benefit may occur it could not be guaranteed. Consequently, I made no false promises.

Study Participant Recruitment

The National Cancer Institute defines an index case as “a clinically affected individual through whom attention is first drawn to a genetic disorder in a family”.[117] This study included individuals diagnosed and treated for a head and neck cancer and their partner. Consequently, for ease in reference between these two individuals the person diagnosed and treated for a head and neck cancer will be referenced as the index participant as they were the individual who first drew me to this study and this partner relationship.

This study used purposive sampling to recruit the index participants.[114] To provide a rich description of individual experiences, index participants ranged in age and were at varying stages post-treatment. Index study participants were recruited through CCMB dieticians, speech-language pathologists, the psychosocial clinician, and the nurses of the head and neck disease site group. The latter healthcare providers provided potential study participants with a letter that offered a description of the study and its intent, and my contact information (See Appendix E). Additionally, posters were placed throughout CCMB clinics, and this same poster was advertised in the disease site group newsletter (See appendix F). Potential study participants were requested to contact me directly. This method was chosen as it was believed to be the best approach to provide the greatest exposure to potential index study participants while maintaining the study participants' anonymity. The inclusion criteria of index study participants include persons who:

- through their illness and recovery, had experienced oral/dental side effects of treatment;
- were able to recall and articulate their experiences;
- were over the age of 18;
- resided in Manitoba and received treatment for their head and neck cancer at CCMB;
- at the start of treatment either had natural teeth and/or a combination of natural teeth and partial denture(s) and/or complete denture(s) which they actively wore on a daily basis;
- received 4 or more weeks of radiation therapy to either one or more of the following anatomical structures:
    - the oral cavity, the oropharynx, the mandible, or the salivary glands as part of their cancer treatment;
- were at minimum 1-month post completion of treatment.

This study was conducted in English. The only exclusion criteria for this study were of persons who were not fluent in the English language as there were no interpreters present.

The initial focus of this study was on the person diagnosed with cancer (the index participant). As a dental hygienist, my day-to-day clinical focus is on the individual patient. Consequently, as I began this research, I believed it was the voice of the individual patient that I needed to hear. In Chapter 3, I offer a reflection about my growing understanding about the research topic, and my ultimate decision to return to the research ethics committee to amend this study to include the perspectives of the partners or other adult family members.

During the initial contact with the index participants, they were offered the opportunity to include their partner or other adult family member in the study. The participation of the index participants' partner or other adult family member had no bearing on the index participants' inclusion in this study. No honorarium was provided to the study participants for participation in the study.

Data Collection

As part of the interview questions the index participants age, sex, stage of cancer, diagnosis, prognosis, anatomical location of cancer and the treatment received (surgery, chemotherapy and/or radiation therapy) were self-reported. Oral/dental experiences were explored within a semi-structured in-depth narrative interview using an open-ended format. Guiding questions and probes were used to assist study participants and to enhance the depth of inquiry. See Appendices G and H for the original and amended interview guides.

Study participants were offered two locations to complete their interviews, either their home or within a private meeting space at CCMB. These locations were chosen to ensure privacy for the study participant. Interviews occurred at the location that was the most convenient for the study participants. Although no honorarium was provided for involvement in this study, if CCMB was chosen as the location for the interview, I reimbursed the study participant the cost of their parking. Interviews lasted between 41 to 142 minutes in duration. I transcribed the audio recorded interviews verbatim into a word processing software program.

A second follow-up meeting was offered to the study participants after a summary of their personal narrative and the interpretation of the study was complete. At this second meeting participants were asked if they agreed with the summary and the interpretation of the study and if they had anything further to add. Four index participants including two partners agreed to this second meeting. Of the remaining study participant, one index participant declined as he reported he was too weak and ill to meet, and the rest did not respond to invitations to participate in a follow-up interview. These follow-up meetings were between 30-60 minutes in duration and served as a member check which van Manan describes as an “interpretive conversation”.[100] During this conversation the researcher and the study participant discuss the appropriateness of each theme in asking “Is this what the experience is really like?”.[100] Additionally, at this second meeting study participants were asked if they would like a written copy of their initial interview. All participants who agreed to the second meeting requested and received a copy of their initial interview.

Rigour

Munhall states that to demonstrate rigour within qualitative research the reliability and validity of the research process must be established.[106] As such, the reliability and validity within this study was established through implementing verification strategies or a process of confirming the approaches that were used throughout the research process. The verification strategies employed included: ensuring methodological coherence, reflexive journaling (observations, ideas for analysis, researcher thoughts, writing and rewriting), member checking (to ensure accuracy and descriptive validity), and field notes (observations before, during, & after interviews to provide thick descriptions).[101]

Data Analysis and Interpretation

van Manen states that meaning is multi-dimensional and multi-layered.[100] No one definition can grasp the meaning of a phenomenon. The meaning as sought through this method can only be communicated textually through organized narratives and prose. As such, through this approach, the researcher becomes occupied in the reflective activity of working with the text. Within this analysis, the hermeneutic process of reading and re-reading, dwelling and dialoguing with the text was employed. This led to the development of themes that represent the shared and particular experiences of the participants.[100,101] In an effort to be as true to the meanings as possible, descriptions and stories were written and rewritten to include the meaningful themes within the context of the participants lived experience.[100] This writing was completed in the form of interpretive memos,[118] and was accompanied by an intensive process of ongoing dialogue about the text and evolving meaning with my thesis advisor. van Manen suggests that to come to the structured meaning of the text, it helps to think of the phenomenon described in terms of "meaning units, structures of meaning or themes".[100] Phenomenology's aim is not to be reductionist. Description and the meaning expressed through individual and group narratives were interpreted through "linguistic transformation" and by identifying the essence or themes.[100]

The writing and interpretive process that I followed within this analysis was guided by the specific methodological approaches described by van Manen.[100] This facilitated a detailed articulation of the thematic aspects of this phenomenon based on the text of the study participants.[100] Initially, the text was looked at as a whole and then was asked the following question: "what sententious phrase can capture the fundamental meaning or main significance of the text as a whole?" [100] Following this, I engaged in a selective or highlighting approach in which I listened to, and read the interview narratives several times. This included the asking of the following question: "what statement or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" [100] From there, I deeply engaged with the text by circling, highlighting and underlining pertinent statements or phrases. And lastly, I followed a detailed, line-by-line analysis of the text. Every single sentence or sentence cluster was looked at and I asked the question: "what does this sentence or sentence clusters reveal about the phenomena or experience being described".[100]

Research study participants do not think or feel in terms of phenomena, themes or essence.[103] Consequently, as the researcher my main task was to choose from the participants narratives the centrality of the meaning and then integrate this narrative into the life world of the person. To determine if a theme meets phenomenological textual description I needed to determine if the essence of the theme makes the phenomenon 'what it is' or without it the phenomena 'would not be what it is'.[100] To answer this question van Manen states the researcher may ask: "Is the phenomenon still the same if the theme is changed or deleted from the phenomena? Or does the phenomena lose its fundamental meaning without this theme?". [100] This is said to be the most challenging and controversial element of phenomenological human science.[100] It is the most challenged and controversial because of intersubjectivity.[101] I, as the researcher and each study participant are distinct human beings which each have their own situated context. As such, intersubjectivity is the verbal and non-verbal interplay between the researcher and the study participant's organized subjective worlds. The subjective world of anyone is represented by the organization of, but not limited to, the thoughts, feelings, ideas, principles, theories, illusions, distortions of that person.[101] Consequently, it must be recognized that with all interpretative phenomenological inquiries that no interpretation is ever complete, no explication of meaning is ever final and no insight is ever beyond challenge.[119]

Hermeneutics in essence is concerned with the process and the method of interpretation that brings out or reveals what is normally hidden in the human experience and relations.[103,110-112] In the human consciousness, the meanings of an experience may not always be apparent or accessible by the study participant as it is embedded within the experience.[105,108-110] The researcher captures the experience through the study participants narratives and then through the subsequent interpretation of the experience the meanings become apparent.[100]

My goal as the researcher was to try and understand another person by hearing and seeing that person through the lens of the person's situated context.[100] Phenomenological research is an exploration into the structures of the human lifeworld, or the lived world as experienced within the everyday relations and situations. van Manen argues that these fundamental themes spread through the lifeworld of all human beings, regardless of history, culture or the social situation.[100]

van Manen discusses that how the text is structured or presented within the research in its final form typically emerges organically.[100] Phenomenological research consists of exploring the essence of individuals' lived experience which cannot be predicted. Each persons' experience is unique, and is explained, felt and experienced individually. van Manen proposes that there are multiple ways to structure the final research text, each with its own challenges and benefits.[102] This study followed a combination of a thematic and analytical approach to structure the research text. A brief description of these two approaches include: Thematically: I used the emerging themes as a guide for writing the research. As such, the study is divided into chapters, parts or sections which elaborate on an essential aspect of the phenomena;[100] Analytically: writing to ground the phenomena.[100] Although van Manen describes many styles of writing analytically to ground the phenomena, examples used within this study include a composite narrative to exemplify the intensive treatment experience of the study participants, including study participants exemplar quotes weaved throughout. Additionally, I reflected throughout the text to describe how themes emerged from my participants' words, expression, experiential descriptions both in how they were similar and contrasting and related these to literary material and an anecdote intertwined throughout the text.

This chapter provided a literature review which offered insight into the current state understanding on the topic area. Additionally, within this chapter I outlined the methodology, method and research process used in this research study.

Chapter 3

Introduction to Study Participants

This chapter will introduce the individuals who have allowed me to use examples of their experiences of living with and through the continuum of head and neck cancer. These experiences allowed me to gain a deeper understanding about living with head and neck cancer and have informed the interpretation presented in this thesis. All names shared in these introductions are pseudonyms.

Over a seven-month period, the recruitment of ten index study participants occurred. Of these ten, five interviews included the index study participants partner and/or other adult family members. Eight of the ten research interviews ran very close to two-hours in duration. With the two remaining research interviews lasting fifty-nine minutes, and forty-one minutes.

Bill and Karen - the first index participant and his wife

Bill and Karen live outside of the city limits of Winnipeg. When booking this interview, Bill requested that his wife Karen be present for our interview. As a novice researcher and a person who had only completed one “mock-up” interview in my qualitative research methods course, I naively thought she would just be present in the room. Although Karen experienced this journey alongside Bill, at this point, I did not recognize the importance of her voice in this study. Bill signed the study participation consent form. However, at this point Karen did not as the consent form for inclusion in the study did not include the partner or other adult family members.

Bill invited me to their home to complete his interview. Our conversation occurred in the sunroom of his house on a sunny afternoon. Bill and I sat across from each other at a small table located in the corner of the room and Karen sat apart from us, across the room. Karen had a thick binder on her lap, which she referenced throughout the interview as it included notes, dates, and information about Bill's cancer treatment. Bill is a tall, thin man, who shared with me an extensive medical history. At the time of the interview, Bill and Karen were both retired, and they were living on a fixed income. Bill was in his sixties at the time of the interview and approximately seven years post-cancer treatment. When Bill received his cancer diagnosis, he was retired. I was left with the impression that Bill and Karen embraced traditional gender roles in their relationship when they shared the roles they played in meal preparation and maintenance of the family home. Bill prepared for our interview by printing two documents: *A Five-Year Action Plan to Address the Financial Hardship of Cancer in Canada, A Call for Action* authored by the Canadian Cancer Society[120] and *the Vision and Mission Statement* of Health, Seniors and Active Living department of the Government of Manitoba.[121] Bill referenced these two documents when he spoke about the financial strain related to uninsured health benefits for dental care. This financial burden was a vital perspective that Bill and Karen needed me to hear.

Throughout the interview, Karen kept giving her thoughts, experiences, and impressions related to Bill's cancer experience, and Bill often turned to Karen to answer questions. In response, she looked up pages within her binder. I was beginning to understand that perhaps my research focus was too narrow. I started to question myself about whose voice or voices were essential to hear.

Bill was diagnosed with stage IV, squamous cell carcinoma with two lymph nodes involved on one side of his neck. The primary location of Bill's cancer was unknown. Bill underwent a surgical neck dissection and thirty daily (Monday to Friday) radiation therapy treatments. When Bill's course of treatment was initially discussed, chemotherapy had also been planned. However, due to other health concerns, a decision was made with his oncologist, not to include chemotherapy in his treatment regimen. Bill and Karen commuted to the cancer centre daily for treatment.

Chris and Janice - the second index participant and his wife

When I first met Chris at his interview, he was in his sixties and approximately seven months post-cancer treatment. Chris invited me to his home to complete his interview. Chris lives in Winnipeg. Our interview took place in his living room. Janice, Chris's wife, was present at this meeting. Chris and I sat at opposite ends of their sectional couch, and Janice sat across the room from us in a chair. On the coffee table in front of us, Chris had displayed the large calendar that he used to keep track of all his treatment and doctor’s appointments. As I entered this conversation with my second participant, I had the intent to be careful not to ask Janice questions. This was necessary given that ethics approval had only been obtained for interviews with the individuals diagnosed with cancer.

At the beginning of our interview, I made it clear that I hoped to learn about Chris's experience. Despite my efforts to focus on Chris, the significance of what Janice had lived through made it essential for her to offer her unique perspective. Chris and Janice could be any couple I know. They both work full-time, have a home, a cottage, and a young adult son that still lives with them. Their world turned upside down with Chris's diagnosis. They were honest and bold in sharing the anger, tension, and the frustration that occurred between them as a couple throughout Chris's treatment. Despite this, their positivity and laughter stood out to me. Chris also expressed his anger about our healthcare system. He felt that the sole focus of the healthcare system and clinicians was focused on him, as he was the ‘patient’. He wished his wife and family had been included more in the process, as well as in the interventions and support offered.

Chris was diagnosed with a stage IV squamous cell carcinoma at the base of his tongue. He underwent thirty-five daily (Monday to Friday) radiation therapy treatments and seven chemotherapy treatments. The initial treatment plan included eight chemotherapy treatments, however, Chris missed his last chemotherapy treatment as he became ill (midway through radiation treatments). Chris had to go to the emergency department two days in a row with emesis, nausea, and constipation, which was the reason he did not receive his last chemotherapy treatment appointment. At the time of Chris's diagnosis, he was working full-time. Chris continued to work until two weeks into his radiation therapy. At that time, he took a medical leave of absence from work to complete treatment and for the post-treatment recovery period.

Frank, Sarah and Beth - the third index participant and his wife and daughter

Beth the daughter of Frank invited me to her dad's apartment to complete his interview. This interview occurred in the living room of Frank and Sarah’s (wife of index participant) suite. Beth requested that she and her mom be present for our research interview. I agreed to this request, however, at the beginning of our interview I made it clear that I hoped to learn about Frank’s experience. Yet again, despite this intention, the significance of what the family had lived through during cancer treatment seemed to compel them to offer their unique perspective during the interview. Beth was a professional who recently retired so that she could have the time to care for her aging parents. Frank and Sarah live in Winnipeg. By the end of the interview, I could no longer ignore that the lived experience of head and neck cancer needed to be understood from the perspective of the person diagnosed with cancer, as well as that of their partners/family members.

Unfortunately, during this family discussion, concerns with the cognition of Frank emerged. This meeting lasted forty-one minutes. After the transcription of the interview and its subsequent analysis, I determined that Frank did not meet the study inclusion criteria, as he was unable to recall and articulate his own cancer experience due to cognitive impairment. Consequently, I withdrew Frank from the study.

Reflection – Have I Completely Missed the Mark in my Research and Clinical Practice?

As a dental hygienist, my focus has always been on the patient. I believe my goal as a clinician is to provide interventions to treat or to prevent dental disease. My role as a clinician is to assess, diagnose, plan, implement and evaluate the outcomes of interventions. My understanding and the primary focus of my education led me to believe that the provision of patient-centred care meant including the patient in the decision-making process. As such, this understanding led me to focus my research on the perspective of individuals with head and neck cancer.

Within the process of conducting this research, I have been forced to ask myself the following question: do I really understand what patient-centred care is? The Institute of Medicine describes patient-centered care as care that "encompasses qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient". [122] This approach includes friends and families in the decision-making process, when the patient indicates this preference.[122] When I read this quote, I found myself asking: when was the last time I asked my patient what their goals, wants, or needs are? And if I do ask, do I actually listen? Or do I 'listen' and then respond with "Yeah, but…"? In our daily time-crunched clinical interactions, when the patient wants their family or friends included in the decision-making process, what does that look like, entail and how much time does that take? Have I given lip service to the concept without genuinely implementing or understanding it?

Throughout my first three interviews, it became apparent that this experience needed to be informed by not only the person diagnosed with cancer, but also from the perspective family members. There were family members who very much wanted to share their own unique experiences with head and neck cancer, and, although different, these perspectives are intimately connected to that of the index study participants. There was an apparent need for the family members to have their voice heard, to be included in the study, to inform my understanding of what 'the lived experience' means, not only for their loved one but also for themselves. If a dimension of patient-centred care is to include family and friends, how could I not have understood that the patient and partner/family member experience is intimately connected? Should the goal of healthcare be patient, family-centred care and not just patient-centred care?[123]

Before starting this research, when reading about hermeneutic phenomenology, I didn't fully grasp what it meant to understand the meaning of the lived experience.[100] For van Manen, "phenomenology asks the very nature of the phenomenon, for that which makes a some – "thing" what it is – and without which it could not be what it is".[100] I entered this research inquiry, I wanted to understand the patient experience, but it became essential for the partners to be heard and to offer their reflections during the interviews. I began to understand that the some- "thing" that is, that "could not be what it is,"[100] is this: the experience is relational and not just isolated to the patient, at least for some patients, for some participants.

Consequently, after a discussion with members of my committee, I amended my study protocol, research questions and ethics approval for the purpose of including the partners' or other adult family members of the index participants in the study. The inclusion of this additional person was presented as an option and did not preclude the index study participant alone from being part of the study.

The questions added to my interview guide (See Appendix H) as part of this study amendment came largely from the conversation I had with Karen and Bill (first family interviewed). Consequently, Karen had already answered the new questions added. As such, I did not interview Bill and Karen again. Following my ethics amendment, I had Bill and Karen sign my revised study consent form.

I contacted Chris and Janice (second family) to invite Janice to be part of the study based on the revised protocol. Since I had intentionally not asked Janice questions during my interview with Chris, a second interview was warranted. This provided the opportunity for Janice to share additional insights about her experience. Janice agreed to participate in the study, and we completed the second interview. Both Chris and Janice signed my revised study consent form.

Second Interview: Chris and Janice - the second index participant and his wife

This second interview occurred approximately six months after our first. Chris and Janice again invited me to their home to complete this interview. Our conversation happened in the living room of their house. Despite Janice offering her perspective during our first meeting, I had been careful not to ask her many probing or direct questions. As such, at this second interview, I intended to delve deeper into Janice's experiences, and to ask her more direct questions based on my amended interview guide. However, this interview became a combined discussion with Chris and Janice. As this interview began, Chris shared that his cancer had returned, and he recently completed a second course of treatment.

After a follow-up computed tomography scan (CT scan), Chris had received a diagnosis of recurrent cancer in a lymph node. At the time of this second interview, Chris was approximately two months post-cancer treatment. Chris took a medical absence from work for treatment and was still on this leave at the time of this interview. Chris had undergone a surgical neck dissection, two chemotherapy treatments, and twenty-eight daily (Monday to Friday) radiation therapy treatments.

During this period of relapse, Janice and Chris agreed to couple and individual counselling from the psychosocial clinician at CCMB. Although they both felt the counselling sessions helped them, they were particularly helpful for Janice. The sessions empowered her to be able to share her feelings, needs, and create common understanding with her husband. Chris did not appear to be as angry or frustrated this time when we discussed his treatment experience. The radiation therapy this round of treatment was very focused on the area of the one lymph node with recurrent cancer. Consequently, the radiation did not negatively impact Chris's fluid and nutrition intake as significantly as it did last round. Chris and Janice shared that Chris refused to use opioids this time for fear of what occurred the previous series of treatments (constipation and nausea) but had been using medicinal marijuana to relieve his pain. Janice attributed the marijuana to Chris being able to maintain his appetite. Chris was currently struggling more this round of treatment with the effects of his surgical neck dissection, as it limited his mobility and function.

John and Tracy - the fourth index participant and his wife

John and Tracy invited me to their home to complete our interview. They live outside the city limits of Winnipeg. Our conversation took place in the sunroom of their family home. John and Tracy sat beside each other, and I sat across from them. John was diagnosed with a stage IV cancer, which involved lymph nodes on one side of his neck. He was in his sixties at the time of his interview and approximately three months post-cancer treatment. The primary location of John's cancer was unknown. John underwent three chemotherapy treatments and thirty-five daily (Monday to Friday) radiation therapy treatments. Due to the distance needed to travel for his daily treatment, John stayed at a family friends' home close to CCMB. This meant that John was away from his family Monday to Friday but would return home on the weekends. Tracy and John had commitments at their home that prevented Tracy from going into the city with John for his treatments. John stopped working at the beginning of treatment because he had to re-locate to Winnipeg.

John is self-employed and does not have health benefits. He was proud of how physically fit he was going into his treatment and remained active throughout his cancer therapy. John was concerned that after his cancer treatment he did not have the same strength and energy he previously had. As a couple, Tracy and John are active in their community and manage many community projects. Tracy had previously cared for ill parents but felt this was entirely different because it was her husband. Given their commitments at home and the need for John to be away from his family, at the beginning of treatment Tracy questioned whether she would be able to maintain their home or if they could actually "do this". Tracy described John as a hard-working, tough individual who did not complain much.

Michael - the fifth index participant

Michael received a diagnosis of a stage IV cancer in his larynx. He underwent a total laryngectomy, which included the removal of his thyroid. He received thirty-three daily (Monday to Friday) radiation therapy treatments. Michael was retired and in his sixties at the time of the interview. He was approximately seven years post-cancer treatment. Michael lives outside of the city limits of Winnipeg. He invited me to his home for our interview, which took place at the kitchen table. Michael's granddaughter was at home with him that day as she was ill and could not go to school. Michael commuted daily to Winnipeg for treatment in a van run by the Canadian Cancer Society for a set daily cost.

Michael has a small body frame, he appeared frail, very thin and edentulous. He only wears his complete upper and lower dentures when out in public as they cause him pain when worn for an extended amount of time or when eating. Michael speaks through a voice prosthesis from a stoma in his neck. When talking to Michael on the telephone, I did not recognize his speech to be any different than if he was talking through his larynx. Michael was blunt, honest, and did not mince words. Many times, he would make me chuckle with his responses to the naivety of my questions. I have never directly talked to or provided care to anyone who had a stoma and voice prosthesis. Michael picked up on this right away and questioned me on this, but then put me at ease. Michael provided insight into matters relating to his stoma and voice prosthesis that I would have never thought of. This made me reflect on how I might have offered ill advice as a dental provider to clients who had a stoma. He was excited about sharing his experiences. Despite many negative experiences in the healthcare system, he was a positive, friendly man who saw the value in seeing one another as human beings, connecting as individuals and not just that of the 'patient' and the 'provider'.

Cheryl - the sixth index participant

Cheryl was the only female diagnosed with cancer in the head and neck region who volunteered to be in this study. We completed our interview in a private meeting room located in CCMB. At the time of this discussion, Cheryl was in her sixties and approximately five years post-cancer treatment. Cheryl lives in Winnipeg and was working at the time of her diagnosis but took a medical leave absence for treatment and a period of recovery post-treatment. Cheryl received a diagnosis of stage IV early advanced squamous cell carcinoma at the base of her tongue and underwent thirty-five daily (Monday to Friday) radiation therapy treatments and two chemotherapy treatments. Originally three chemotherapy treatments were scheduled, but she was only able to complete two as her complete blood count levels were too low.

Currently, Cheryl does not smoke, however she was a heavy smoker in the past, and also has a history of alcoholism. She spoke about the many ways she gives back to others recovering from alcohol addiction and the cancer community. Although the exact cause of Cheryl's cancer was unknown, she believes her previous addictions caused her cancer. Cheryl lives alone but had many friends that supported her during treatment. She was positive, well-spoken and well-dressed, thin and had an incredible sense of humour. At one point when Cheryl shared a story, we were laughing so hard together that tears rolled down our faces.

Without prompting within minutes into the interview, Cheryl shared that she felt her dentist dismissed a suspicious lesion in her mouth many years before her diagnosis. He had explained she had this lesion because "she was a smoker". To this day, this dismissal still bothers her. Cheryl shared her insights into how dentists or other health providers should handle these situations and was brutally honest about the role of health providers in the discussions with their patients surrounding smoking cessation and alcoholism.

Sam - the seventh index participant

Sam lives outside the city limits of Winnipeg and was the only individual I interviewed who continued to work throughout the entire course of treatment. He commuted daily to and from work to Winnipeg for his cancer treatment. Two days prior to receiving his cancer diagnosis he gave his termination notice to accept a new position, which he described as his "dream job". This new position had no health benefits, but Sam said he was miserable and had to leave his old career. He walked away from a full-time well-paying position that had significant health benefits and a pension. At the time of the interview, his family's finances were constrained, and this worried him. He was concerned about their financial stability, but also what the future would hold. Sam was concerned about his teeth, as he was aware of the possible side effects of xerostomia, and he worried about whether he would be able to afford dental treatment, if that was required. Additionally, he was currently struggling to manage the costs of products and appliances to help mitigate the effects of his xerostomia post-treatment. Sam recognized that both, during his cancer treatment and currently, his finances would have not been a concern if he had remained at his previous position. However, he felt that this choice had ensured his mental sanity and quality of life.

Sam considered himself a Christian and felt anger towards the insensitivities that some Christians express regarding illness and God's plan. He felt for the first time in his life he had a connection and conversations with God because it was on his terms and not in a church.

We completed our interview in a private office space at CCMB. Sam’s wife had hoped to join us but was unable to as they had their son with them. At the time of the interview, Sam was in his forties and approximately five-and-a-half months post-cancer treatment. Sam received a diagnosis of a stage IV, HPV positive cancer at the base of his tongue, with nodal involvement on one side of his neck. Sam underwent thirty-five daily (Monday to Friday) radiation therapy treatments and two chemotherapy treatments.

Cliff - the eighth index participant

Cliff received a diagnosis of stage III cancer, which involved three lymph nodes on one side of his neck. The primary location of Cliff's tumour was unknown. Cliff underwent thirty-five daily (Monday to Friday) radiation therapy treatments and two chemotherapy treatments. His initial treatment plan included four chemotherapy treatments, however Cliff became too ill to complete his last two chemotherapy treatments. Cliff was hospitalized and placed in the intensive care unit (ICU) two-thirds of the way through his treatment. This hospitalization occurred just after the placement of a percutaneous endoscopic gastrostomy, a PEG tube. After Cliff's hospital admission, he did not receive any additional chemotherapy treatments. However, once out of the ICU and stable, he completed his radiation therapy treatments as an inpatient while hospitalized.

Cliff resides in Winnipeg. He is married, and although I did not ask him directly about how many children he had, he did talk about his daughter, and a granddaughter. At the time of the interview, Cliff was in his seventies, retired, and eight-and-a-half years post-cancer treatment. Our conversation occurred in a private meeting room at CCMB. Cliff was working at the time of his diagnosis, but he took a medical leave of absence during his treatment and for a period of time post-treatment for recovery. He loved his profession and was excited to get back to work, and its close-knit community.

Leading up to my conversation with Cliff, for the most part, my interviews had followed the interview guide. Cliff came into our meeting with an agenda of what he wanted to say and in what order. In sharing his experiences, he would jump back and forth between different points of his cancer journey, which confused me. In addition to this, due to Cliff's parched mouth, dysphagia, and chest congestion, it was difficult to understand what he was saying. Initially, Cliff’s approach to sharing his story made me quite anxious, and at one point I didn't know how I was going to get back on track. However, by mid-conversation my panic had subsided, and I was able to recognize that Cliff was answering my questions, just not in the way that I had intended to ask them. I was mentally exhausted by the end of this interview. Additionally, Cliff's meeting was the most difficult and time-consuming to transcribe due to his garbled enunciation and the unpredictability of how he shared his story.

Jason and Patti - the ninth index participant and his wife

Jason received a diagnosis of stage IV, HPV positive, invasive squamous cell carcinoma at the base of his tongue. Jason underwent thirty-five daily (Monday to Friday) radiation therapy treatments and eight chemotherapy treatments. At the time of the interview, Jason was in his sixties and approximately three-and-a-half years post-cancer treatment. Jason and Patti's interview occurred in a private office space at CCMB. At diagnosis, Jason and Patti were retired, and live in Winnipeg.

Jason appeared to be a very organized and analytical individual. He came into our interview with his iPad, which provided detailed information about his cancer experience. Patti joked that he is “anal” about that kind of stuff and that this bothered her. To me, they seemed to be two opposites that attract. Patti and Jason are a lovely couple who readily poked fun at each other. Patti shared her fears of caring for Jason throughout his treatment and her frustrations post-treatment when preparing meals for him. Jason accredited Patti for the support and care she provided and for getting him through his cancer experience. What struck me most about Patti was how she had become empowered during Jason’s cancer treatment. Patti had been empowered by her ability to care for Jason throughout his treatment and extended period of recovery. Shortly after Jason completed his cancer treatment he needed a tracheostomy as his airway became severely restricted due to the effects of his radiation therapy. Consequently, Patti needed to suction the secretions from his trachea tube frequently. Patti had been very uncomfortable with caring for “sick people” and wasn’t sure she would be able to care for Jason. However, throughout the experience, she learned that she was more resilient than she knew she could be.

Kevin - the tenth index participant

Kevin was diagnosed with stage IV cancer, that included lymph node involvement on one side of his neck. The primary location of Kevin's tumour was unknown, but it was suspected to be at the base of his tongue, and HPV positive. Kevin underwent forty daily (Monday to Friday) radiation therapy treatments and three chemotherapy treatments. At the time of the interview, Kevin was in his forties and approximately two years post-cancer treatment. We completed our conversation in a private meeting room at CCMB. Kevin resides outside of the city limits of Winnipeg. He took a medical leave of absence from work for his cancer treatment and a period of post-treatment recovery.

Due to the distance Kevin travelled for his daily cancer treatments, he stayed at a family members' home located in Winnipeg. Kevin's original plan was to stay in Winnipeg Monday to Friday and then return home on the weekends. However, shortly into treatment, Kevin was too ill to return home on the weekends. Both Kevin and his wife have professional careers, and two very young children. At Kevin's request, his wife maintained their family life at home. This meant Kevin was away from his wife and children for most of his treatment. He received limited support from his two brothers and his parents are deceased. Kevin had struggled with depression throughout his life and had sought therapy in the past. He spoke about his fears and pre-occupation with his cancer returning and was worried about how his young children would be impacted, if he should die. I have never met a man who was able to share his emotions and feelings with as much ease and comfort. Perhaps this was due to his time in therapy or just his personality, but it was engrossing.

Kevin's experience resonated with me the most because we are close in age. Although my partner and I do not have children, his cancer journey could have easily been ours. The reality of

Kevin's and the other study participants' experiences scared me and made me reflect on what is truly important in life and how quickly life can change. Additionally, as a healthcare provider, I now am more aware of the impact of my words and how I make my patients feel. Up to this point in my interviews, all participants had shared their feelings and experiences about the impact healthcare professionals had on their cancer and survivorship experience. However, the way Kevin shared his experience, brought me to tears. I needed to take a few moments in the interview to collect myself as his words made this real and tangible. The experiences that he shared with me summarized that of all the others. I will describe this further in the discussion chapter.

Concluding Thoughts

I have introduced my study participants in this chapter. For ease in future reference a summary these introductions have been included as Appendix I which includes the:

- Approximate age at the time of interview;
- Inclusion of partner or other adult family member;
- Stage of cancer, diagnosis, and the location of cancer;
- Cancer treatment received;
- Time elapsed post-treatment to interview;
- Location of residence: Winnipeg or outside of the city limits;
- Residence during treatment; and
- Employment status

In the following chapters, I will present the interpretation of the meaning of lived oral/dental experience of the person diagnosed with a head and neck cancer as well as their partners along the trajectory of cancer care.

Chapter 4

Pre-treatment: Warning Signs, Triggers and the Complexity of Prognosis

Persons with a cancer of the head and neck region have needs that are different to other cancer patients. The teeth, oral cavity, and pharynx are central to speech, taste, eating, and swallowing,[1,2] and also play an essential role in appearance, self-identity, social interactions and the ability to express oneself.[1-3] Treatment of head and neck cancer can lead to intense symptom distress, particularly within the oral cavity and pharynx.[4] Consequently, health-related quality of life experienced by head and neck cancer patients can be significantly reduced during and following treatment.[3,6,124]

This was my superficial understanding of head and neck cancer as I approached this study. This perspective came from a final project that I completed as part of my Bachelor of Dental Science (Dental Hygiene) degree. The goal for that project was to create a plain language document that provided oral/dental recommendations for individuals diagnosed with cancer in the head and neck region at CCMB (before, during, and following treatment). For that project, I completed a literature review, observed, questioned and talked to various interdisciplinary members within the head and neck disease site group, and had limited interactions with patients. I also attended the weekly disease site case conferences for approximately two months.

Initially, the intent for this document was for it to be handed out by the dentists at CCMB who are contracted to provide pre-treatment dental exams. However, by coincidence, the Head and Neck Disease Group were in the process of updating their patient information handbook, a comprehensive document of information and recommendations used to help patients manage treatment effects. The patient handbook had been created by an interdisciplinary group of health care professionals. The first edition of the handbook contained very few pages about oral and dental information. I worked collaboratively with the team to incorporate the plain language document for my BDSc(DH) project into the second edition of the Head and Neck Disease Site Group's Patient Guide.

I am very proud of the accomplishments of this final project. Oral and dental information now represent a more substantial part of the patient guide. Despite this accomplishment, I recognized the recommendations represented a 'one-size-fits-all' approach, which is concerning, as patients do not fit into a standard template. Although my experiences with the individuals with cancer was limited in this project, those interactions made me realize I had no real understanding of what it is like to live through head and neck cancer, and I was left with a desire to understand this more fully.

This is what brought me to my Master of Science and this research study. What does a reduced health-related quality of life during and after treatment look like, and what is the meaning of this for the individual living through it? This research study aims to provide an interpretation of the meaning of this experience, while simultaneously describing the nuances of individualized experiences.[100] Additionally, given that many of the long-term effects of treatment are dental related, I was interested in understanding how to assist patients' in living with those oral and dental side effects.

The Continuum of Cancer Care

As I entered this research project, I perceived the continuum of cancer care to have three distinct phases: pre-diagnosis, cancer treatment, and post-treatment. As such, the questions within my interview guide (Appendices G and H) were purposely developed around these treatment phases. Within this study, the participants' experiences did support the conceptualization of treatment into these distinct phases. However, on reflection, participants' reports of these stages might have been influenced by the way I structured the research interviews or could have occurred without prompting. Nonetheless, the findings from this study indicate that there are crucial time frames within the head and neck cancer trajectory, and that each phase raises unique questions about clinical care and the lived experience of patients and their partners.

Diagnosis: "Your World Starts to Fall Away from You"

Receiving a referral to a cancer centre is life-changing, not only for the person receiving this diagnosis, but also for family members. The initial referral was a "red flag" (Bill), there was a sudden realization about the seriousness of the situation. The experience of diagnosis was akin to being caught in the beginning of a slow growing snow avalanche. When you think of an avalanche, you imagine a violent, unrelenting cascade of snow that is out of control. However, before an avalanche gains this kind of momentum, there is almost always warning signs of a slow, growing movement of snow that eventually leads to the rupture of the snow pack.[125] For the study participants, the period during which they suspected they may be ill, and their subsequent referral to CCMB, were two distinct experiences. The period of investigation prior to referral to CCMB was like the slow building movement of snow, the warning signs prior to the avalanche; and upon hearing the news that they had been referred to CCMB, index participants and family members experiences were akin to the sudden, unexpected rupture of the snow pack. At the point of rupture, each participant felt their world fall away from them. The world they had once known and lived, no longer existed. It was as if all that they knew, the very ground beneath them suddenly fell away.

Warning Signs

The index participants experienced similar symptoms leading up to their diagnosis (see Appendix J). These symptoms included one or more of the following: pain or what was described as a very sore throat, pain in one ear, difficulties with swallowing, feelings of a lump in the throat or mouth, change in voice, or a unilateral neck mass. For different index participants, their experience and the course of time from symptom to referral varied. For Bill and Cheryl, the time from the emergence of symptoms, family doctor consultation, to their subsequent CCMB referral did not include any delays or setbacks.

For Chris, Michael, and Sam, the time leading up to referral was a prolonged process of repeated visits to the doctor's office; they experienced not being heard or, believed, and they felt physicians had minimized their concerns and worries. Chris, Michael, and Sam were angry and frustrated, and also saw this as a loss of precious time. This time could have focused on treatment but was wasted because they had not been listened to. They believed the inaction and dismissal of their worries resulted in the progression of their cancer.

> Sam: I got mad (at the doctor) …I said…It's not a cold…and it's not strep throat…and it's not an infection…there is something wrong with me…Stop sending me away…it's not getting better…I'm tired of feeling this way…I would have probably only been stage one cancer…and I would not have had this radical treatment.

Michael felt he was "pumped full of antibiotics" for a full year, while his physician failed to see the need to pursue additional investigations. It was only when he started to lose his voice that his doctor took further action. Chris's family doctor did act on his symptoms with a referral to see an ear, nose, and throat specialist (ENT). However, the ENT dismissed his earache, attributing it to an unknown cause, and failed to complete any further follow-up. After an extended period of time, Chris returned to his family doctor as there was no resolution in his persistent earache. At that time, Chris's family doctor sent him for a CT scan, which subsequently identified his tumour. Cliff, similarly described this period as a "long process", however, he did not seem upset or angry about it. He attributed this wait to a limit of resources (specialty doctors and advanced imaging technologies) in the community that he was working in at the time.

Kevin shared that he has always gone to the doctor easily, and that he was not a "typical male who won't go to the doctor". He described caring for his health as he would a car, he believed in preventative maintenance. He believed prevention was a quick and easy fix that prevents expensive and extensive repairs in the future. Despite this belief, Kevin did share that he had been aware of signs that something was not right in his throat and swallowing over a prolonged period of time. When Kevin first presented his symptoms, they were dismissed by his family doctor, and he was told with more time, the symptoms would clear up on their own. Kevin firmly responded that his symptoms did not feel "typical" and that he wanted to see a specialist. The doctor then referred Kevin to see an ENT specialist. Two weeks later, before the appointment with the ENT specialist, Kevin developed a large unilateral neck mass. Kevin returned to his family doctor, but also went to see his periodontist who had placed his dental implants many years before. He asked for another opinion and found himself thinking "maybe it's not cancer.... or anything nasty like that…. Maybe it's… maybe I have a deep-seated infection or jaw infection".

It is Like Grass Growing or Paint Drying

John was the sole participant that stated that he had ignored his symptoms for a period of time.

> John: it was there for a while (neck mass) and I was ignoring it… you know, I would complain… I said to you (wife) one day, I'm really getting concerned about this lump.

Additionally, when presented with his treatment options, John was the sole individual who initially declined treatment. Tracy (partner) felt this was almost an act of defiance and shock.

> Tracy: He was like 'I'm not doing that… there's no way… I'm doing that'… he was almost being defiant.

John initially explored alternative treatment, but with some time to re-organize family life and to process the information and following discussions with his oncologists, he agreed to have treatment.

Jason, also recognized that he had overlooked his symptoms:

> Jason: in hindsight… I realized it'd probably been there and developing for a while… but it's like grass growing or paint drying and all that stuff.

For Jason, the trigger that something may be wrong was his inability to swallow his bagel one morning. The symptoms for John and Jason that once had been boring and apparently inconsequential, created feelings of panic once the referral to CCMB occurred. Despite how participants moved through the process of symptom emergence to referral, the examples shared reiterated a sentiment that each and every participants' experience was unique. As health care professionals, we may think that we understand what people are thinking or feeling but completing this analysis has helped me to realize that, we really cannot understand what each person experiences. It is important to recognize that how individuals deal with and process information is vastly different.

The Trigger

When Kevin heard his doctor say he was being referred to CCMB, he was very shocked. As noted earlier, this experience was like the sudden rupture of the snowpack in an avalanche. This was the trigger, the moment when the world once known, life itself, fell away:

> Kevin: I'm…trying not to panic…like, holy shit… literally…your world just starts to fall away from you.

What does it mean to have your world fall away from you? For each of the participants the referral point was a profound, remembered marker on their cancer trajectory; time stopped, at least time as they had previously known it. Once the participants were seen at CCMB everything moved very quickly, and the reality that they had cancer began to set in, it could no longer be kept at bay. At this point, the snow engulfed participants, they fell uncontrollably into a world they did not know, into a world they did not want to be a part of.

> Bill: When you're told of cancer it's a big rush…You're going through a lot of stuff, especially when you start going to the CancerCare…Reality sets in that you actually got this… you're going to have to deal with it.

Prognosis

Prognosis, what the future will hold for the index participant, is a central area of concern not only for health care professionals, but also for each individual receiving treatment, and their family. And yet, what does prognosis really mean? How do we understand that word, how do patients and their families live with that word? One definition for prognosis is "the prospect of recovery as anticipated from the usual course of disease".[126] The etymological meaning of prognosis is "forecast of the probable course of a disease" and from Greek origins meaning "foreknowledge".[127] These definitions highlight that the simple word 'prognosis' is fraught with possibilities and uncertainties. Before I started these research interviews, the word prognosis was simply a word on paper, it did not engage me more than the other words I had chosen to use in the questions I would ask. I believed that when I asked my participants about their prognosis, they would respond with a number or percentage provided to them by their oncology team. I did not see that this would ask much more of me, and the participants than I expected, that this was a complex, haunted question to find your way around.

When I actually had to ***say these words,*** and ***ask this question to a human being face-to-face, I choked***. I was naive or ignorant about what I was really asking my participants. I was not just asking for information, context, or for them to provide me with a percentage. I was asking each of these participants if they believed they were going to live or die. Through the process of conducting these interviews I came to understand that my detachment from this word at the beginning of this study is baffling. In reflection, I realized that, if I, an interviewer choked and struggled to ask this question, then how do cancer professionals deal with this in their everyday practice? Does the term prognosis function to allow us (the person diagnosed, family, friends, strangers, healthcare providers) to detach from the emotion, the weight of what this topic carries in our lives, what it means to live in the midst of these statistical numbers?

All but one index study participant received a stage IV cancer diagnosis. When I asked them about their prognosis I initially experienced confusion and felt conflicted upon hearing their positive responses. I believed that stage IV cancer meant death and a poor prognosis. After my eighth interview and repeatedly hearing from most participants that their prognosis was "positive", I increasingly questioned my own understanding about prognosis of Stage IV head and neck cancer. I found myself asking "is CCMB lying to them?", "Why are they not telling them to get their affairs in order… they are going to die!”. I was angry, confused, emotionally upset and utterly shocked as I tried to understand these responses.

Given this, I went to talk with a member of the disease site group, who is also a member of my thesis advisory committee. He described the TNM Staging System and explained that for each cell type and organ this can equate to different prognosis and outcomes or stated more simply that for each “kind of cancer” the staging equates to various outcomes. Additionally, he explained that for the most part, he and his colleagues frame prognostic information in a positive way, at least in most situations. They provide hope for the individual unless there is no doubt that the prognosis is terminal. He shared with me that “no one knows what side of the statistics the patient will fall on”. He reiterated how each body, cell, or individual will react and respond to treatment is unpredictable, and in some respects, is uncontrollable. As such, there is no need to be negative. There is a need to be realistic and honest about the possibility of death, but the standard approach is to stay positive. This approach was reflected in the voices of the participants in this study:

> Tracy (partner): I mean from the onset… they told us that it was a good prognosis… which I think made it different… for us in the whole process.

> Chris: I never worried about not making it… because they gave me those odds… I felt good at 70 or 80 and I, I kind of hung on to that by saying…. Well that’s pretty good odds and all.

While most participants perceived health care professionals’ efforts to stay positive as favourable, some recognized that healthcare providers are very cautious with the language they chose to use. This careful approach did create worry and anxiety for some participants. I found myself wondering who was most served by this language of protection and positivity: the patient or the healthcare provider. This language of positivity/protection did leave participants with pressing, unanswered questions:

> Kevin: But they don't… nobody really talks about… 'I think…you're going to be fine' or 'I think you're cured'… that's just not reality…. I've recognized that in some of the, the careful wording or behaviour (of the doctor) … that they're careful not to promise… things like that and I, I often went in wanting reassurance… Like, I'm going to live, right? … Like, I'm going to be okay, right?

What patients hear or most want to hear from those caring for them, may be different between individuals and cannot be standardized. Kevin stated this well:

> Kevin: how do you talk to a patient about the realities … without scaring the hell out of them, right?

To reduce anxiety and doubt, it may be most important to ask patients and family members what they believe their future will hold, what their fears are, what are the questions that they most need answered.

Chapter 5

Treatment - Like Being Hit by A "Sledgehammer" or a "Nuclear Bomb"

Cancer treatment has a profound and sustained impact on individuals diagnosed with cancer of the head and neck region and their partners. All index participants in this study received radiation therapy as part of their cancer treatment. Additionally, seven had chemotherapy, and three underwent a surgical intervention as summarized in Chapter 3 and Appendix J.

As the index participants entered cancer treatment, they understood that the acute effects of radiation therapy and chemotherapy treatment would be intense, painful and for some individuals, so difficult to endure, that they may decide to quit treatment before completion. Prior to the initiation of Kevin's cancer therapy, his oncologist told him it would be like being hit by a "sledgehammer", a "nuclear bomb", and that they were going to "hit him hard". Despite these types of descriptions and preparation, each of the participants felt that regardless of how prepared one thought they were, the treatment experience was far more intense and painful, and side-effects progressed quicker and lasted longer, than could ever be imaged or fathomed.

"Just hang on…and grit your teeth"

Despite having lived with pre-diagnosis symptoms for weeks or months, and finally having received a cancer diagnosis, when participants entered treatment, the prevailing sentiment was: "I wasn't sick", "I didn't feel any worse… I was still healthy", "I felt good", "I felt no illness at all" or "I was feeling excellent". As treatment began, participants' routine day-to-day life felt normal and there were minimal to no apparent side effects from cancer treatment. The main difference they perceived in life were the daily trips to CCMB for treatment. However, two-weeks into treatment marked a distinct point in time: this was when life began to suddenly change. It was at this time that participants no longer saw themselves as healthy and normal; they suddenly were forced to experience a new way of being in the world, they were ill, very ill.

> Cliff: the first 2-weeks of radiation I was feeling excellent… But then all of the sudden with the accumulation of radiation… it was like BOOM!

The first recognized side effects of cancer treatment were loss of taste, followed by the changing texture of how food felt in the mouth. These moments of facing the sudden, severe impacts that come with treatment, were not small events, they represented significant, persistent experiences of loss for these individuals, and their partners. Kevin shared his particular distress about the changes he experienced eating cheese, which had always been one of his favourite foods. He thought of cheese as an "old friend", his go-to food:

> Kevin: eating cheese…was a miserable experience because it didn't taste… like anything. And, the texture was… it's hard to remember… how it was, but it was…it was **SO** different it was kind of distressing, you know…It's like, I cannot even trust you……my old friend (chuckle)… but it was really…like granular… and odd…. my tongue was like…. it was totally off.

Soon after the loss of taste and the changing texture of food was perceived, extreme xerostomia, thick oral secretions, severe pain from mucositis and stomatitis were experienced. The oral cavity, pharynx and the skin in the field of radiation felt like they had been burnt, these treatment effects were similar to having experienced third-degree burns in these fragile tissues. Due to these effects, swallowing rapidly progressed from being challenging to a complete loss of the ability to swallow.

> Chris: the pillows would be full of blood, and some skin would come off and … it was like being burnt…. your throat is on fire… it hurts…constantly…. 24/7 and… you don't

> want to put anything down it because every time… just… the simple fact of swallowing… hurt…Now put something in that… you know, cold/hot whatever… and it hurts even more.

To help explore the participants experiences a composite narrative will now be described. Imagine the pain you might have experienced from strep throat. Your throat is burning, it is raw, you grasp your throat in an attempt to limit the pain as you try to swallow saliva. The act of swallowing, instead of being unnoticeable, taken for granted, feels like a razor blade ripping through tissue with each muscle contraction. The watery saliva that naturally occurs in the mouth, that usually acts as a lubricant for this delicate tissue is gone, and you are left with a thick paste that fills your mouth and throat. The thickness of this paste makes you feel with every breath, every attempt to swallow, at any moment your throat will be blocked, and the paste will choke you. Day after day, week after week, the cumulative effects of radiation feel like the tissues are being burnt deeper, and the pain in your mouth and pharynx became more unbearable as the days progress. The oral and pharyngeal mucosa becomes friable, raw, and ulcerated. There are sheets of tissue hanging from the roof of your mouth and the tissues of the pharynx feel as if you have a growing lump lodged in your throat, blocking anything from going down. This lump cannot be dislodged, despite your efforts. Further, your ability to swallow, to clear the thick paste in your pharynx, is increasingly becoming more difficult as each day passes, and as the pain intensifies with each muscle contraction.

You smell your foul breathe, and all that can be tasted in the back of your throat is dry blood, dead tissue and open sores. The skin that had been in the field of the radiation (neck, back) feels “nuked” (Chris). Your skin is peeling off; sore, fragile blisters and pustule are present. Your skin is burnt and feels far worse than any excruciating sunburn you have experienced. The heat that radiates from your skin instantly dries the damp gauze used to clean your wounds. Imagine living through this for four to six weeks, as the pain consumes each moment of your life, and it feels as if there is no escape.

> John: my throat was getting really sore…when I…looked in the mirror and looked down… if you've ever had a canker sore…. well the whole back of my throat was one big white mass…. So, it hurt…. It hurt like **hell** to swallow…I'd be foaming at the mouth…endless slime coming out of your mouth… the radiation was burning… to the point where there was…. I could feel…skin hanging…. off the back of your throat.

The thick oral paste that accumulated in the participants' oral cavity caused frustration, anger, and for Sam, sheer panic. Sam shared that the quantity and thickness of the oral secretions caused him to panic. He feared he would choke or not be able to breath when he was lying down. Due to this panic, Sam was provided with a portable dental suction machine to help extract the secretions. Eventually, near the end treatment, he resorted to rinsing his mouth with Coke or Pepsi, as this was the only way he felt he could break-up the thick oral secretions.

> Sam: in the end, I was actually gargling with, ah… Coke and Pepsi…it was so bad that…I got one of those machines to suck the spit out…it was a lifesaver because…I ended up…having some panic…at night time when you're lying there and…you're trying to swallow, and you can't swallow…you just feel like you're going to choke…you have all this stuff in your throat… I…felt like it was restricting my breathing…I'm not going to be able to breathe…It was…so bad that the machine wouldn't actually suck anything out because it was so thick….so, then I would gargle with Coke, and it would break it all up… and then I would suck it out.

As a dental hygienist, this set off alarm bells! I found myself wondering how I would have reacted if Sam had shared this with me as his dental hygienist. What would I have said, or done? Would he have ever revealed this kind of information? I am unsure of the answer to those questions, however, my growing understanding of the horrendous experiences of these acute effects of treatment, and the severe impact of this thick oral paste in the oral cavity, has made me grapple with these important questions.

Chapter 6

A Persistent Resistance to Surrendering to the World of Cancer

Cancer is the abnormal, highly invasive growth of cells in the human body. Despite this, each participant described cancer in the third person, cancer was consistently described as foreign to the self. The disease that lived within each of the index participants was spoken about as a “thing” or “it”. In relation to his initial appointments at CCMB, Chris stated the following about his cancer:

> Chris: You got to deal with this thing…We are going to beat this thing.

John struggled significantly with whether he would actually consent to cancer treatment. John and Tracy (partner) had a vivid memory of how the oncologist had described cancer as a ‘monster’ during this period of time.

> Tracy: Dr. (oncologist) said…Well, I certainly hope you that you change your mind... because we can beat this monster…That was his exact words… We can stay ahead of this monster.

The etymological definition of monster is a “malformed animal or human”.[128] Historically, strange animals and humans are seen as “signs or omens of impending evil”, or “inhuman cruelty and wickedness”.[128] In Latin, monstrum is defined as “divine omen, portent, sign, abnormal shape, monster” or figuratively as a “repulsive character, object of dread… an abomination”.[128] The ‘monster’ scared many of us during childhood, but we learnt that when the lights go on the monster subsides, and eventually, that the monster is not real. I found myself questioning the meaning of this use of language, why did participants repeatedly refer to cancer as being separate from themselves? Is this conceptualization of cancer as a monster part of why participants did not speak about their disease as part of themselves, part of their bodies? What is at play in speaking and thinking about cancer as living outside of you? Cancer, if represented as separate to self, may again work to facilitate a detachment from the emotion, from the weight of what this topic carries in human life, what it may one day mean in our lives, what it will mean for both the participants and the professionals who care for the person diagnosed with cancer.

Drink Your Poison

When John began treatment, he struggled intensely with surrendering to a treatment process that would make him so ill. What made this surrender to treatment particularly difficult was that he still felt well. This ‘monster’ that had been described to him, the reason he needed cancer treatment, remained largely invisible at this point. He felt well and although he understood this was what needed to happen, he also felt a deep-seated resistance to surrendering himself, his life, to this new world of cancer treatment. He resisted what he knew he must do. He knew that this would mean he would become horribly ill, and with that, the ‘monster’ inside could no longer remain at a distance.

> John: Drink my poison…. Like, it doesn't make any sense…I feel fantastic… but now I've got to go and… go and kill myself, so I can live… To me, that sounds wrong.

Participants described chemotherapy treatments as leaving them feeling like they were “sucking wind” (John), their energy levels were dragged down further and further with each successive treatment cycle.

> Kevin: think of your worst hangover…coupled with your worst flu…and then double that…that’s what chemo is like.

Chemotherapy was described by Chris as “nasty shit”, it made the nerves in his hands and feet tremble. Participants who received chemotherapy treatments also experienced nausea and felt an ever present ‘brain fog’, and with each treatment it took longer and longer to recover physically.

Weight Loss

Weight loss and the inability to meet nutritional needs with an oral diet are frequently experienced in the treatment of head and neck cancers.[129]As such, there are many interventions offered to help support the patient's ability to meet their daily nutritional needs. All index participants met with a registered dietician at CCMB and were well versed in dietary recommendations to increase daily caloric intake, how to make food more palatable given the symptoms experienced, and options for liquid meal replacements such as Resource, Boost and Ensure.

Additionally, to help minimalize the pain experienced with the ingestion of food and liquids, and to treat or help prevent opportunistic infections within the oral cavity and pharynx, the oncologist often prescribed a compounded mouth rinse, which was referenced by participants using various terms, such as, 'pink lady' or 'magic mouthwash'. These preventative rinses are typically compounded in varying combinations and concentrations that include a topical analgesic agent, a steroid, an antifungal agent, an antibacterial agent and a mucosal coating agent.[130] For the index participants of this study, the effectiveness of these rinses ranged from very beneficial to having no benefit at all.

Lastly, when individuals are not able to meet their daily nutritional intake, a feeding tube is suggested. The feeding tube may be a nasogastric tube (NG tube), or a surgically placed percutaneous endoscopic gastrostomy, what is commonly called a 'PEG tube'. Placement of a feeding tube may be recommended prophylactically, if the oncologist is concerned that the side effects of treatment will result in challenges with eating, swallowing and weight loss. In this case, before treatment begins, the feeding tube is placed. Therefore, if or when the side effects of treatment make eating and swallowing too challenging, the PEG tube is in place to help support body weight and daily nutrition needs.[29,131] In other cases, if in the midst of or initially following cancer treatment, an individual is not able to meet their daily nutritional intake and their body weight cannot be maintained, a reactive feeding tube may be recommended.[131]

Four of the nine index participants received a recommendation to have a feeding tube inserted before the initiation of treatment; two agreed to the placement, and two declined. Five participants, including the two that refused the prophylactic feeding tube, were encouraged to have a reactive feeding tube placed during treatment, by the oncology team. Three participants, including the two participants that initially declined the feeding tube, had a reactive feeding tube placed. See Appendix K for details pertaining to the placement or discussion of a feeding tube for each index participant. Index participants who received chemotherapy, also received intravenous hydration as part of their treatment. Additionally, both Bill and Kevin needed additional sessions of intravenous hydration due to dehydration.

You Must Eat to Survive

Each of us knows that we must eat to survive. As an individual who has struggled with weight my entire life, I appreciate the internal mental torment, the battle one has with one's self surrounding food restrictions and food choices. As I began this study, I categorized food or beverages as being either 'good' or 'bad'. Further, I recognized that holiday celebrations, social gatherings, and most social interactions typically revolve around some form of eating and drinking. I understood that eating and drinking are a central part of our social life and interactions. However, I did not grasp the complex relationship that exists between food, life, and the meaning-filled rituals that exist in our everyday lives.

Guided by my prior work in this area, which involved participating in the development of the second edition of the CCMB Patient Guide, I entered this inquiry with an expectation that some individuals might experience ‘challenges’ with eating or experience a loss of appetite due to nausea during treatment. I believed these difficulties could be mitigated through support from dieticians, who would provide eating tips to make food more palatable, information about liquid meal replacements, and suggestions to encourage frequent snacking/eating and multiple mini meals. I was naïve in this regard, I had no understanding of the complexity of the decision-making process surrounding the placement of a feeding tube during cancer treatment. I thought a feeding tube was primarily recommended for individuals following a surgery when eating or drinking through the mouth would impede healing. I did not fully grasp the severity of the treatment effects of radiation therapy or chemo-radiation therapy, I did not understand the intense assault that would occur on the oral cavity and pharynx, or the frequency that patients struggle with maintaining their body weight and daily nutritional intake. Upon entering this study, I did not think too deeply about the symbolic meaning that food and beverages have for individuals living with head and neck cancer. I was mistaken in assuming that their sole meaning is related to sustaining life and giving energy. I misunderstood the recommendation for the insertion of a feeding tube, and the intricacies and complexities involved when a person with cancer wrestles with whether or not to accept a feeding tube into their body, their self, the life they are now forced to live.

“One of Those Guys”

As a result of the acute side-effects experienced in the oral cavity and pharynx region, index participants’ ability to tolerate an oral diet ranged from severe restriction to the complete inability to ingest anything by mouth. Further, index participants purposely consumed less fluid or food to control the severe pain they experienced. Eating was described by Chris as a “pain in the ass” and that “meals were…dreadful times…. they went from something you enjoyed to…something you avoid or tried to avoid”. Consequently, during treatment and through the initial stages of recovery, despite the individual nuances between index participants, all experienced dehydration, malnutrition, and weight loss. And for some, an extreme loss of weight occurred (See Table 2).

Table 2: Index Participant Weigh Loss

Index Participant	Weight Loss	Index Participant	Weight Loss
Bill	44 pounds	Cheryl	20 pounds
Chris (initial interview)	55 pounds	Sam	40 pounds
Chris (second interview)	5 pounds	Cliff	40 pounds
John	37 pounds	Jason	20 pounds
Michael	20 pounds	Kevin	60-65 pounds

Due to this weight loss and the ongoing challenges with eating and drinking across cancer treatment, there was a significant, and enduring impact on the lives of the index participants, as well as their partners.

> Kevin: I think, after 3 weeks… I really, really stopped eating. Then, I think…. 4 weeks in… I was physically unable… to eat. Like, I just couldn't eat because my throat was just… impossible to get anything down…and even drinking water … was a challenge. And then probably about 5 weeks…. I don't think I was drinking water.

Both Jason and Cheryl agreed to the placement of a prophylactic PEG tube. Jason decided to have a PEG tube placed because he felt that if his oncology team recommended this to him, he needed to trust their recommendations, as he believed they knew what would be best for him. Additionally, it was explained to Jason that if he became too ill, the surgical placement of a

PEG tube might not be possible, and then he would need to have an NG tube inserted. For Jason, the NG tube was a "much less attractive" alternative to the PEG tube. Cheryl felt she did not have a choice about receiving a feeding tube; she did not think she was allowed to refuse the PEG tube placement. She later found out that she could have declined this intervention. Cheryl wished she had not proceeded with the insertion of a PEG tube due to the pain associated with its placement. She understood the benefits and risks of the PEG tube but did regret its placement due to the pain she experienced.

> Cheryl: A couple of the guys… that I know pretty well, who had the same as me…. refused the tube…. and I remember saying to them… that I didn't know I could refuse it… and they said 'Oh, yeah… you can refuse it'.

For Cliff and Kevin, when a prophylactic feeding tube was discussed, they refused placement because they believed they could manage treatment without it and resisted what the tube symbolized. Cliff felt very strongly that he did not want to be "one of those guys".

> Cliff: Before when I was healthy… I was like 'I don't need that!'…I don't want to be one of those guys.

When Cliff said he didn't want to become "one of those guys," I found myself wondering who it was that he didn't want to become, what was he resisting in that moment? The sick guy? The cancer patient? If you were to wave to a neighbour from afar, a neighbour that you had not talked to for a while, and you recognized that they had an NG tube, what would you think? If your friend shares that their aunt is reliant on a PEG tube, what assumptions would you have about this aunt? Sick people in hospital have feeding tubes. People with feeding tubes must then be ill, seriously ill. Do you ask about their illness? Do you want to know the answer? Or is the answer so obvious, asking the question seems irrelevant?

The title of this study is “Understanding the Meaning of the Head and Neck Cancer Patients’ Oral/Dental Lived Experiences”. Upon entering this study, I broadly defined all individuals living with cancer together, under one singular label, the ‘cancer patient’. In listening and transcribing the interviews of this study, I recognized that I would reference the index participants or talk of others living with cancer as the ‘patient’ or ‘other cancer patients’. This label, these words, the ‘cancer patient’, symbolized or was connected in some way to this notion, to the resistance expressed by the participants in this study. I came to understand that the index participants held a deep resistance to becoming a ‘cancer patient’, to surrendering themselves to this new, unwanted identity, to having their lives consumed and identified by the illness they had been diagnosed with. How do you remain a unique individual, maintain your human identity, be recognized for who you are as a dad, a mom, a sister, a brother, an artist, or engineer? These participants struggled with having their identity, their sense of who they are in the world limited to that of a ‘cancer patient’. Further, this was an identity they did not want to take on, they did not want to surrender to being known as a ‘cancer patient’.

Due to the participants’ ongoing eating/weight challenges, their weight was frequently monitored by CCMB staff. Due to persistent weight loss, the inability to maintain an oral diet, and failed attempts of encouragement and assistance from the dieticians to eat, the placement of a reactive feeding tube was discussed with Chris, John, Sam, Cliff, and Kevin, but this recommendation was forcefully rejected.

> Kevin: I resisted (a feeding tube) …the whole time. Because…getting a…feeding tube through my nose…I was like, I'm not…walking around with a tube…hanging out my nose. There’s no way I’m going to do that…I'll be fine, right…. I’ll manage… I certainly don't need to have a…tube hanging out of my nose…tape on my face…certainly didn't

> want, ah… hole poked into my gut …I didn't…feel that I needed it.

This resistance was so strong in the participants, that for some, they resisted placement of a tube to the point where they came close to collapsing, even to the point where they felt close to death. It was only here, in coming close to death, that they became willing to surrender to assistance with eating, to maintaining their nutritional needs through a PEG tube.

Close to Death

Two-thirds of the way through treatment, Cliff needed to have a reactive PEG tube placed as he was frail, constipated, and very ill. Before he agreed to the placement of a PEG tube, he spent multiple nights in the emergency department trying to get relief from severe constipation. He received a "tiny bit" of relief from constipation during these visits, but essentially, intervention efforts were unsuccessful. Due to Cliff's state of declining health, his radiation oncologist ordered a PEG tube. There was a two-week delay before the placement of the PEG tube, which Cliff felt contributed to a "wearing down" of his health. Cliff's state of health declined so significantly, that very shortly after the PEG tube was inserted, he was hospitalized and admitted to the intensive care unit. When he finally entered the hospital, he was "close to death". Cliff felt that it was receiving some "tender love and care" from fabulous nurses, that helped him start to feel better, his constipation resolved, and he slowly began to regain some of his energy. He attributes this turn in his health to receiving the much-needed nutrients through his PEG tube and although limited, a minimal quantity of very soft foods (pudding, mash potatoes, yogurt) by mouth. Cliff described what it was like to be fed through his PEG tube:

> Cliff: It's like a baby…as soon as you put the stomach feed… Oh, you feel **sooooooo** resourced!

Kevin had a similar experience. As described previously, Kevin had to travel a significant distance for treatment in Winnipeg. As such, he stayed in Winnipeg away from his family and was alone for most of his treatment. Kevin's motivation to get through each day was to return to his family. When Kevin recalled the day that he returned home at the end of his treatment, he became emotional. His children had made a sign for him that said, "Welcome Home Dad". After his last cancer treatment in Winnipeg, Kevin remembers getting into his car, he was starving and barely conscious, he questioned his ability to drive but did anyway as he wanted to return home so desperately.

> Kevin: I just had my last radiation treatment…pardon the French, but I was ready (chuckle) to get the…. "F" home…You know…. I was starving… I remember driving home and I thought, you know…. I'm barely conscious, and…I'm doing this… I really shouldn't be doing this, but I just want to get home, right. I was so… anxious to get home.

Despite starving, Kevin made it through treatment and returned home without the placement of a feeding tube. Throughout treatment he did occasionally receive intravenous fluids for dehydration. Kevin said that by the end of treatment he was essentially starving, very sick and frail. Once home, Kevin was still unable to eat or drink. He was so weak that throughout the day the only tasks he was able to accomplish were sleeping and showering, and even showering was a challenge.

> Kevin: I would go….and have a shower, but I …couldn't even stand… in the shower. (snicker) I had to sit…I don't know why I didn't have a bath… (chuckle) but, I would sit on the…on the floor of the…. And I would sit…and I would…. want to get out of the shower but I was, like…. I was too weak to stand up…and turn off the shower and to

> towel off…So, I would just sit in the shower for like an…. hour.

For Kevin, despite anorexia, and being so weak he could not stand up, he remained resistant to the placement of a feeding tube. After admission to the hospital, Kevin's doctor suggested a feeding tube. After failed attempts at placing an NG tube, he had a PEG tube surgically inserted. Kevin could not recall what brought him to the hospital or why he went, but he remembers he remained resistant to the placement of a feeding tube the whole time.

Chris, John, and Sam also lost excessive amounts of weight during their treatment. Due to their extreme weight loss, there were discussions about the placement of a reactive PEG tube. However, they all declined and resisted placement. When describing the dialogue about the PEG tube, Chris, John, and Sam described it as threatening. Such that, if they did not start eating they would be forced to accept a feeding tube.

> Chris: And you realize you got to eat, right.…Because they're… going to put a feeding tube in you…and you don't want that… No.

John described how the dietician "gave him the gears… big time" on his eating and his weight loss and the possible need for a reactive PEG tube, if he did not start eating. Sam also described a continual harassing or pestering about his eating and the PEG tube. For John, the description of the placement of the PEG tube, the possible adverse complications, how restrictive it would make his life, and the thought of pouring food into the tube, was enough for him to start trying to eat and drink. Sam also spoke about how the threat of PEG tube placement forced him to eat a bit more.

> Sam: My routine…I would do that (rinse with Magic Mouthwash) …usually about 15 minutes before I would eat… and then I would just... it hurt like crazy, but I would just…. they were threatening to put a feeding tube in me, so…. I wasn't going to have

that.

Sam also felt the PEG tube would significantly restrict his mobility and that it would affect his ability to work. Additionally, he did not like the idea of having something hanging outside of his body. Sam questioned what he would be eating with a PEG tube: “what am I eating? I’m not really eating anything”.

In hindsight, Chris, Cliff, and Kevin felt that if they knew what they eventually came to understand about the treatment experience, they would have or should have had a prophylactic PEG tube placed. They felt if they had one, that they would have been much stronger and healthier throughout their treatment, and that their recovery would have moved forward more quickly.

Additionally, for all participants the treatment side effects experienced lasted much longer post-treatment than was anticipated. There was a misconception that once treatment was completed, the ability to eat and drink would suddenly return; this was not what happened. The participants believed that after treatment ended, their lives would return to what they once were, that they would be able to eat, enjoy eating in a similar manner to before treatment. They didn’t know, were not aware, that many of these side effects would continue for months, and in some cases, would involve permanent, life-altering changes.

> Kevin: I didn’t know… that I was… that my throat was going to be, like…. you know, closed for business for two months after treatment.

You Are What You Eat

In this study, the symbolic meaning of food and eating had a profound impact on the participants' subjective concepts of self and illness. Ludwig Feuerbach, a German philosopher coined the phrase “Man is what he eats” or “Des Mensch ist was er isst”.[132] What Feuerbach actually meant by this phrase remains debated.[132] However, what remains inferred by a variety of disciplines and academic perspectives (nutritional sciences, anthropology, sociology, biology, medicine) is that essentially “we become what we eat”.[133] For each of us, with this common everyday knowledge we might find ourselves saying ‘you are what you eat’. The act of eating and drinking is taken for granted, we do not think about this consciously as we move through our lives.

In her book *Food, the Body and the Self*, Deborah Lupton captures the complexities of food and eating through a discussion about how the banality of eating in everyday life is deceptive. [133] Food often is classified into binary categories such as: “good or bad, masculine or feminine, healthy or non-healthy, a comfort or a punishment, a sin or a virtue, self or other” and these binary oppositions shape food choice, food preferences, and beliefs. [133] Control over the body can be symbolized and established by dietary habits. [133] Lupton states, “food and eating are central to our subjectivity or sense of self, and our experience of embodiment, or the ways that we live in and through our bodies, which itself is inextricably linked with subjectivity”.[133]

We wrap our sense of self, who we are, the control over the body into the connotations embedded in the phrase, ‘we are what we eat’, so it is not unexpected that when participants in this study were faced with the placement of a feeding tube, they expressed deep resistance. This resistance occurred, despite participants being armed with the knowledge of possible starvation, or experiences of becoming so weak from starvation that they could not stand up. This resistance embodied much more meaning than what I initially understood. Food and eating, and specifically, their place in our lives, is not as simple as I originally thought. Food does not simply exist just for alleviating hunger or providing fuel to stay alive.[133]

Being fed through a feeding tube meant giving in or giving oneself over to the cancer world. Kleinman states cancer reminds us of the unpredictability and injustice of the human condition.[134] In hearing the words that you or a loved one 'has cancer', we are confronted with the reality that we lack control over our own or the others' death.[134] Cancer highlights that regardless of how much we know about the world, we still lack the understanding of many things. Kleinman states most notably that "cancer symbolizes our need to make moral sense of 'why me?' that scientific explanation cannot provide".[134]

The feeding tube, or the loss of eating through the mouth, symbolized becoming the 'cancer patient', the 'sick' person. Receiving nutritional sustenance through a feeding tube means losing one more piece of yourself to illness. Think about it, yes, we eat when we are hungry, and drink when we are thirsty, but we also eat when we are happy, when we are sad, and we celebrate and mourn with food and beverages. Our very lives are framed around events of eating (breakfast, lunch, dinner): we socialize, and connect in these important moments. Meals and food consumption are a ritual activity; their predictable structures can create order out of potential disorder.[135] Most of us freely choose what we consume into our bodies, as well as how and when that occurs. Take all that away, then what is left?

Food, and the rituals that surround it also are embedded with emotional meaning, which embody and mix with emotions and sensations along a spectrum from "disgust, hate, fear and anger to pleasure, a satisfaction to desire" and act to define us from others.[133] Homo sapiens are omnivores, and as human omnivores, we are very particular, almost fussy about what food we chose to include in our diet.[137] Humans eat a variety of food groups, but also eat based on symbols, myths and fantasies.[137] Food selection is not only made according to "physiological requirements, perceptual and cognitive mechanisms, but also on the basis of culture and social representation which results in additional constraints on what can and cannot be eaten, what is liked and is disliked".[137] Food is center of our identity, what an individual or any given group eats highlights both their closeness to or distance from those with different eating practices.[138, 139] By refusing to surrender 'eating', Chris, John, Sam, Cliff, and Kevin were grasping to hold onto the life they once knew, to remain in control of eating, and to have control over their lives. They resisted being defined by the illness world they quickly found themselves plummeting into.

"You don't understand…. Leave Me Alone"

Karen, Janice, and Tracy (partners) felt it was their 'job' or 'duty' to ensure their husbands received adequate daily nutrition. As a result, they admitted they were constantly on their husbands' case to eat or drink. They each were persistent in offering liquid meal replacements or alternatively, they would offer to prepare their partners a variety of foods.

> Janice: I would be… getting up on Friday or Saturday morning or whatever… and I'd be "Do you want?" … I'd make poached eggs … and then he would try and eat it… and the odd time he did, you know. "How about I make you pancakes?" …And I would be on his case (to consume liquid meal replacement) … on his case all the time, okay… "I'll make you some soup… you'd like that". No…. he didn't want anything.

The duty of ensuring the index participants ate, was almost communicated through interactions with the health care professionals on the oncology team. An example of the way that this role was reinforced is described in Janice's experience of attending dietician appointments with her husband Chris:

> Janice: I went to the dietician appointments with him… and she's looking at me saying… he's gotta eat… he's gotta eat! …. You got to do this, you got to do that…. now I'm on a mission, right… and I didn't under…. Well I understood it, but I was just… remembering

> what the dietician kept saying… it seemed like that was my mission…. Was to do it! Make him do it!

Both Chris, and John experienced relational conflict and anger with their partners surrounding their eating and drinking. Due to their pain and how sick they felt during treatment, they just wanted to be left alone. They felt their wives did not understand what they were experiencing as a result of treatment. Chris also experienced anger towards his healthcare providers at CCMB.

> Chris: I mean…they don't understand… …they would just turn around and say… "yeah, yeah, I understand…but do this, you know…so do it" … You know; you can't do it…the whole conversation was "you're not eating enough or you're not doing this enough… or you're not doing that, so" … Everybody means well.

Chris described remorse for how he treated his wife throughout treatment but shared that when he was in the middle of the experience, it was difficult to have a different perspective about how to manage his emotions.

> Chris: You are sick… people…telling you to do this, telling you to do that… It's just when you're in the middle of it… it's, it's hard to… get a different perspective… people are trying to help you… But son of a bitch…I'm not feeling good. You know, so….

Leave me alone.

When Kevin, who was alone for treatment, reflected on whether having his wife with him during treatment would have made the treatment experience more tolerable, he did not know the answer. Kevin believed that due to how sick he was feeling he did not know if he could tolerate anyone doting over him or being with his family. He recalled that during the one time he was able to return home on the weekend, the noise of his girls playing irritated him. By the end of treatment, the smallest things, such as the noise or light from the television made him irritable.

Kevin believed it was probably better that he was alone because if his family had been around, he would worry about being a “jerk” or feel even worse if he told them to leave him alone.

> Kevin: I would’ve worried about being a jerk…. to her, right. Like, that I was being a…. an asshole by telling her to leave me alone or get away or …. I know that she would've understood, as I would've understood… if, if it was her right…it’s the sickness talking…right. But I think I couldn't have necessarily tolerated somebody… doting on me.

Tracy shared the helplessness she felt when John left for Winnipeg the first time. Prior to John leaving home, Tracy researched, obtained recipe books, and prepared supplies for John, which she hoped would help maintain his dietary intake while he was in Winnipeg.

> Tracy: You felt a little helpless because you wanted to …you know, he had a cooler… and I’d… done all this reading… we bought a blender and juicer and everything…. but he couldn’t… he was not eating properly.

As John could only return home on the weekends from treatment, Tracy described the weekends as not fun. John was not eating and was looking very gray and gaunt. Tracy was very concerned that while John was in Winnipeg, he was suffering needlessly. She felt he was not the type of guy that would ask for help, he would not want to bother anyone. Tracy was very stressed during this time and expressed that while John was losing weight, to deal with her stress, she gained weight.

If we must eat to survive, and our loved one stops eating, what thoughts or fears could this bring up? Not eating might exacerbate fears that your partner may die or is dying. The partners were helpless and lacked control in this situation. For Karen, Janice, and Tracy, witnessing their partners not eating and losing weight day after day made them very anxious, scared and upset.

> Karen: I watched him…. with some of these treatments (became emotional – teary) …it wasn't very nice. (expressed through tears) … And they both (dieticians) saw him…. I mean, they were very concerned… every time he went in there he was another 5 pounds lighter…. I mean he just kept losing….and they were very concerned, but he couldn't eat anyway… he couldn't chew anything that's for-sure.

For Janice seeing Chris lose extreme amounts of weight over such a short period of time made her feel as if she was letting her husband down, that she was not fulfilling her 'duty' to him as his wife to take care of him.

> Janice: Oh, yeah… that was scary (seeing the weight loss) …it was unbelievable…. Just how…. it just kind of (snapped fingers) dropped right off…... every week and it was like another 5 pounds…6 pounds down… I felt then I wasn't doing my job properly… I felt like I… let him down …he wouldn't listen to me… I got anxious and I had…. stress… I didn't feel angry with him; you know… not depressed but, just…. I don't know how to describe it…. I didn't feel positive, NO!

For the partners included in this study, witnessing the index participants' extreme weight loss, experiencing the resistance to their food offerings, and observing their spouses' inability to consume adequate food and fluid, was very distressing. Participants experienced frustration and conflict as love, care, and life-giving qualities are intimately related to nutritional sustenance.[133] Food held significant relational meaning, and this led to impacts on the relationships shared by index participants and their partners. In all societies, food sharing is an important component of kinship. [133] Love has been persistently been linked with food, "particularly maternal love, romantic love and wifely concern for the well-being of one's husband". [133] Sitting down for a "family meal" at the "dinner table" symbolizes the family itself. [133] When one prepares food for another person, that person and their preferences are in your mind, therefore by doing so, "the food is stamped with both the identity of the giver and the receiver". [133] Charles and Kerr interviewed two-hundred British women and found that preparing and giving of food from a wife to a husband was seen by the wives as a means of sharing affection and ensuring the happiness of their husbands.[140] Furthermore, these British women felt rejection and hurt when the food they prepared was rejected by their husbands.[140] Food holds a very important place in relationships: it has been shown to be a way to express love and bind families together.[133] Similarly, in this study, the losses associated with eating, weight, and the profound changes to food and eating rituals led to relational and emotional distress for the index study participants and their partners.

Chapter 7

Settling into a New Life: A Transformed Landscape

Regardless of how horrible cancer treatment made the index participants feel, once they surrendered to this new world, treatment became their life purpose, their reason to get up and out of bed each morning. As such, following cancer treatment, the initial recovery period was a time of mixed feelings. Over time, CCMB, a place that once had evoked panic, fear, and their world falling away, had become a place of safety that was intensely missed once treatment ended.

> Cheryl: You do your last treatment that day… you miss coming here (CCMB)…it was a safe place to come.

Post-treatment, the index participants felt ill, were still suffering from the acute side-effects of treatment, and yet, very abruptly, these participants were expected to go from intensive daily interactions with members of their oncology team to very limited interactions or none at all. Treatment, which was their purpose, their drive to get up and out of bed each morning was suddenly gone. Tracy (partner) described the time initially after treatment as a "hole".

> Tracy: You feel crappy… people have difficult things in their lives… when it ends there's a hole… even though they want it to end there's still that… emptiness there…. It's pretty intense…. 7 weeks is a long time… and its very purpose-driven …focused on treatment… and this is what I have to do every single day… and suddenly BOOM… now I'm just sick… now I feel like crap… I don't have any reason, right…. to get out of bed.

For Bill, John, Jason, and Kevin the sudden transition into this post-treatment period was described as one of their lowest times. Shortly after Bill completed treatment he experienced a hemorrhage within his pharynx. He went to the emergency department many times: the bleeding was stopped, but the bleeding quickly recurred once he returned home. Consequently, he was hospitalized for thirty days and required an NG tube.

Jason described the initial time post-treatment as “bleak”; this was the period when he was most down and depressed. Jason's PEG tube was placed prophylactically and remained in place for almost one year after placement. Following treatment, Jason went to the emergency room five-times due to restriction in his breathing before he felt anyone took his symptoms seriously. During his first four visits to the emergency room, the restriction in his breathing was attributed to a panic attack. This experience of having his symptoms dismissed caused frustration and annoyance. After finally being examined by the ENT specialist during his last visit to the emergency room, he was admitted to the hospital and had a tracheal tube inserted. Due to residual effects of radiation therapy on his pharynx, Jason’s airway had been reduced to ten to fifteen percent of normal capacity, leading to the breathing difficulties he experienced. Jason’s tracheal tube remained in place for three months. During this period Jason rarely left his house.

For Kevin, the initial post-treatment period was also his lowest. Once discharged from the hospital with his PEG tube in place, Kevin recalls not leaving the house very often. The sight of the feeding tube disgusted Kevin; he described the initial recovery as a time where he sat around the house, pouring “brown/grey glop into his gut”.

Food Porn

Kevin, who was using his PEG tube for nutrition, and John, who could only consume porridge and liquid meal replacements, both described a fixation on food images during the early recovery period. Despite having every television and movie channel at his fingertips, all day, every day, Kevin watched the Food Network, which became his “food porn”.

> Kevin: I just sat at home…. and I watched…the Food Network. I couldn't eat (chuckle)…. I couldn't swallow water. All I watched was Chopped…and every cooking show Gordon Ramsey…...every show, ever… I couldn't eat or drink… and yet here I am on watching all this… gorgeous food, right…. It's just like food porn, right… bet that tastes good.

John's 'food porn' was cooking, then watching and hearing others speak of the food he had prepared. John purchased the barbeque he had always wanted and started to do most of the cooking and barbequing, which was not typical. He described various food items he prepared such as making fried green tomatoes, pickling beets, and canning tomatoes and carrots. John would cook large family meals and then sit and watch his family eat. He would ask his family how the food items tasted, as he could not eat any of the food himself.

> John: So, I'd ask everybody…how do these taste … because I can't taste them (started laughing) Are they any good?... So, I'd watch…I'd cook these big meals…I'd sit down and… and eat my, ah… cream of wheat and drink some… Resource with a glass of milk…. and watch everybody eat (chuckle).

The palatability of food relates to its appearance and presentation.[133] Food in cookbooks, magazines, television, and cooking shows are presented with great care so that the food looks perfect.[133] Rosalind Coward coined the term 'food pornography,' which she defined as "a simulacrum of food in which pleasure is derived from its aesthetic form and consequent evocation of emotional states rather than its taste or texture".[140]

The mouth symbolizes both consumption and control as it combines the tongue and taste buds with the organ of speech.[133] Halligan described a link between talking and eating as "words fill the mouth as food does, they have their own savour and texture".[141] Through watching others eat, hearing the description of how food tasted, John and Kevin received pleasure and excitement in the context of a painful, sustained loss of pleasure from their lives.

The New Normal: A Transformed Oral Landscape

The period following the end of treatment was a time of settling in. If we return to the metaphor of a snow avalanche, this time was akin to the settling in of the rocks and material into the new area of land at the bottom of the mountainside, after the avalanche broke way and sent them hurling down. At the time of the initial interview, the index participants ranged between two months to eight-and-a-half years into survivorship. In survivorship, altered taste sensation, dysphagia, and xerostomia persisted. Although the impact of these post-treatment effects will be described separately, they were interconnected and multidimensional.

Once the index participants started to feel better, they began to eat more. However, due to altered taste sensation, eating was portrayed as having "lost all of its magic" and "not really that much fun anymore". Altered taste sensation and xerostomia were the two treatment side-effects that had the most lasting impact and were the treatment outcomes that caused the most distress.

> Chris: You smell it (food)… It smells the same and it smells good. It creates an appetite; you really have an appetite. You… can see it prepared and it looks great…And you put in in your mouth… and, it's… a total, total let down. You go to the movie and it's a piece of garbage… That's what it's like, every time you sit down to a meal…. I don't… want to jump off of a bridge because of it, but it's such a letdown…. it's not what it was, you know before…it's a disappointment.

In survivorship, the index participants were aware that their altered taste sensation could take months to years to return to what was previously experienced, or this may become a permanent alteration. Food that was once favoured now ranged from having some or no taste, to an altered taste sensation. Additionally, some items were inconsumable due to oral and pharyngeal pain. Food that had any spice (i.e., Mexican, Thai, Indian, wasabi with sushi) or was acidic (i.e., fruits, sauces, ketchup, mustard, salad dressings) made the oral cavity and pharynx tingle, hurt, and burn. However, this burning was atypical, it felt like an "acid" (Bill), a chemical, or a "chemical reaction". Bill compared eating acidic foods to consuming gasoline. For Bill, putting anything in the mouth that was acidic was like when he swallowed syphoned gasoline when he was younger. Kevin and Chris shared their old love of sriracha, hot sauce and spicy foods, which they no longer could tolerate.

> Kevin: The biggest tragedy, that has come out of this is…. I can't tolerate…. spice…I used to go and eat… food that… it was so hot…that, it literally would have you crying…Yup…your nose would be running… Your eyes are weakened, **but you're in heaven, right**… **This is awesome!** But I can't… the mildest… the lamest…. hot and spicy food….

For most, sweet or sugary foods were tolerable and were one the few foods that could be tasted. However, Sam felt his mouth "rejected" sugary food.

> Sam: If I eat sugar, then my sores flare up… my throat gets all stingy…it's like… my mouth is rejecting bad food…. And it's almost like it's an immediate rejection…. Like I get immediate reaction to it and my mouth gets very… mucousy and… it's just not clean… It feels dirty.

Despite the index participants ranging in months to years into survivorship, it was a prevailing sentiment that their taste sensations would most likely not return to what they had experienced prior to treatment but would evolve into a 'new normal'. This new normal of eating would not come from regaining their taste sensations, but from a lowered expectation of the enjoyment of food. Chris described eating as mundane as brushing he teeth.

> Chris: It's like brushing your teeth; you got to do it. Well, you got to eat, so... And it's not going to be that.... great big experience that it used to be.

Michael described eating from memory during this initial adjustment period.

> Michael: You have to remember how things taste… and you liked it in your mind… in order for you to eat because… you don't taste… It's horrible….

Smell, taste, and memory have an active link with the emotional dimension of the human experiences.[133] Food can stir emotions because of its emotional and social meanings.[133] Your memory is "embodied, often recalled via the sensation of taste and smell". [133] Think of a time when food brought you intense pleasure or comfort, such as at your favourite restaurant, a family meal, or romantic experience. Can you taste that food without actually having it in front of you? Do you vividly remember who you were with, who prepared the food, or why you prepared that food or meal for that certain person? What emotions does this conjure up now and at that time?

Regarding food, the act of "touching it, smelling it, preparing it, taking it into the mouth, chewing and swallowing it, are all sensual experiences that may evoke particular emotions on both the conscious and unconscious levels".[133] For many individuals the daily pleasure gained from food is the highest point of their everyday sensual experiences.[133] For the participants of this study, as a result of treatment side-effects, these daily pleasurable experiences were partially or completely lost. Again, during the post-treatment period, food and eating practices were highlighted as being far more complex than just nutrition and sustenance.

Xerostomia – "Never without a bottle of water"

Xerostomia also had a profound and sustained impact on participants' lives. Along with altered taste sensation, xerostomia affected food choices, swallowing of food, dental caries, and the frequency of eating and sleeping patterns. Index participants spoke about how they were never without a bottle of water or some form of liquid by their side, day and night. To assist with swallowing, all food consumed needed to be accompanied by a beverage or added moisture which was obtained through the addition of gravies, creams, sauces or butter.

> Jason: I can't create enough saliva; you know… to eat anything particularly dry… The amount of saliva that's in my mouth…Will very quickly… dissipate… as I start to chew on something… I find myself eating less and less meat… for that reason… I need to have gravy with it…. or sauce with it or something…. If I want to eat bread…. I layer on… what most people would perceive it to be a…a ridiculous amount of butter or margarine.

Xerostomia, affected the tolerability of certain foods. The palatability and ability to eat particular foods was established by trial and error. Participants made many attempts to prepare food in new ways. The palatability of food changed daily: one day food tasted alright or was tolerable but on other days, it was not. For Bill and Cliff, the description of food they could and could not eat was in absolutes and sounded ritualistic.

Xerostomia had two notable effects on sleeping patterns. Participants no longer experienced a restful or full night sleep. All index participants awoke at night due to the dryness of their mouth, and Chris, Jason and Cliff experienced more frequent urination due to the increased liquid intake. Index participants experienced a complete absence of saliva during sleep and needed to wake every one-to-three hours to moisturize their mouth. Kevin described having to "pry" his mouth open due to how dry it is some mornings.

The index participants experimented with a variety of products or devises to help mitigate xerostomia. Examples included a humidifier in their bedroom while sleeping, xylitol gums, mints or patches, and over-the-counter mouth moisturizers. When queried, participants noted that all products provided varying degrees of benefit, with very individual responses. Again, as with food choices, a trial and error method was used. Financial burden was an unfortunate consequence experienced with these trial and error attempts. Other than the humidifier, these products sell in dental offices, natural food stores, over the internet, or as specialty items over-the-counter. This typically increased the cost and made them unaffordable in certain situations.

Although each index participant described the effects of xerostomia on their lives, they struggled to express in words how very dry their mouth felt. There was a prevailing sentiment that until experienced, this treatment effect was far worse than could be understood or imagined.

"Radiation…a Lovely Gift that Just Keeps on Giving"

Oral and dental care represents a vital component of each treatment phase of head and neck cancer (pre-treatment, treatment, and post-treatment). As such, and as a dental hygienist, I believed the discussion with the participants would revolve around their teeth, xerostomia, and dental caries. Teeth and the effects of xerostomia on dental caries and eating were part of their shared experiences. However, it was not until many years post-treatment that dental caries and disease and severe dysphagia once again became a prominent part of the cancer experience.

It is current practice for individuals entering treatment for cancer of the head and neck region to have a pre-treatment dental examination. If during this exam a dental extraction is recommended, a period of ten to fourteen days of healing prior to the initiation of cancer treatment is recommended.[29] Except for Michael, all index participants received a pre-treatment dental exam. When questioned about this, Michael did not recall being offered or having this examination. All index participants completed the recommended dental procedures within the specified time for healing before starting their radiation or chemo-radiation therapy except for Chris.

Before the initiation of Chris's first course of treatment, there was a recommendation pre-treatment to have a mandibular wisdom tooth extracted. Chris's family dentist subsequently decided against extraction as he believed it would be appropriate to forego this treatment. Chris went through two-rounds of cancer treatment. Due to the amendment of my study, I was able to talk with Chris and Janice (partner) twice. This second discussion provided me with the opportunity to ask Chris if he received a pre-treatment exam before the initiation of his second round of cancer treatment and to follow-up about his wisdom tooth. Chris did not have a pre-treatment dental exam before his second round of treatment. And at the time of our second interview, Chris had completed the second round of radiation therapy to the same area of the location of the wisdom tooth. At that time of our second discussion he was experiencing discomfort and localized periodontal disease around this wisdom tooth and he was awaiting a referral to an oral surgeon for extraction.

During treatment, the teeth, gums and oral hygiene were discussed, but much to my surprise, this only occurred because I purposefully raised it within the interview. The pain experienced from mucositis and stomatitis dominated the treatment experiences for the index participants. During treatment, index participants' teeth felt unpleasant, sticky or "welded together" (Sam) due to the thick oral secretions, lack of saliva, and dry blood. Tooth brushing and gently brushing of the tongue did offer some relief from the "grossness" (Kevin) experienced and would help break up the thick oral secretions within the oral cavity. However, oral care was approached gingerly due to the pain suffered from mucositis and stomatitis. Participants were fearful of triggering the gag reflex, as each muscle contraction exacerbated the pain they experienced.

Post-treatment, the participants were well aware of the importance of daily oral care, and the recommendation for an increased concentration of daily fluoride due to the increased risk of dental caries due to xerostomia. Despite this awareness, at the time of the interview, Jason was the sole individual interviewed who was still following the recommended daily use of an increased concentration of fluoride gel in custom dental trays. The other index participants, shared varying reasons for why they did not follow the recommended daily use of fluoride gel in their custom dental trays. When questioned, two index participants were not aware of this recommendation. For the others, they were aware of the recommendation and had custom dental trays made and did use the trays initially, but subsequently stopped. Again, there were varying reasons why, including: the gel felt as if it was burning the tissues of the oral cavity, unable to tolerate holding the dental trays in his mouth for an extended period, they made him gag, a feeling it was just time to stop, concerns with the toxicity of fluoride, unsure why he was not using, other than he was not, and lastly experimenting with various other products within the custom trays.

Bill, and Cliff who were seven and eight-and-a-half years respectively into survivorship, described their on-going struggle with maintaining an oral diet. For both Bill and Cliff, a significant portion of their day was spent trying to swallow their food. They described the extended amount of time it took to consume meals. They attributed their struggles to the sequela of the effect of the radiation therapy to their saliva glands (xerostomia), dental caries, tooth loss, dysphagia, and the formation a scar tissue in the pharynx, muscles and ligaments in the field of radiation. Obtaining enough daily nutrition had become their whole life. Cliff described eating meals as a “big event”. Bill joked that if you spend five plus hours sitting around the dinner table eating, you burn more calories trying to eat than you receive.

> Bill: Takes me… an hour to eat breakfast minimum… 2 hours to eat lunch and…sometimes 2 or 3 hours to eat supper.

Karen (partner) described how Bill's eating struggles had negatively affected their ability to socialize. At social events or even during the day when Bill is home alone, for him, "sometimes it is easier not to eat". To be able to maintain an oral diet, Bill had been undergoing throat dilations every two months to support his ability to swallow.

For Cliff, for the two years prior to our interview, he was on antibiotics sixty to seventy percent of the time due to lung congestion attributed to choking, xerostomia, pulmonary aspiration, and dysphagia. As a result of Bill and Cliff's ongoing struggles with maintaining their oral diet, it has been recommended for them to consider a permanent PEG tube. Karen (partner) is quite adamant that everything needs to be done to help Bill maintain an oral diet, as he will **"NOT"** be living off of a PEG tube.

Cliff, with the assistance of the speech-language pathologist (SLP) at CCMB, was able to clear most of his lung congestion. This was accomplished through ongoing support of the SLP by increasing the frequency of follow-up appointments and encouragement to complete daily mouth, throat and neck exercises. Cliff shared that the SLP stated that he had severe dysphagia and if he did not start doing his exercises that he would have to live with a PEG tube. For Cliff, the discussion of the PEG tube "put the fear in" him as it did for Chris, John, and Sam during treatment to start following the SLP's recommendations.

> Cliff: Live off of a stomach tube… So that put the fear in me… If I live to 95… I could be on a stomach tube… I don't want… I want to avoid that… It just… who needs that!

For Bill, Karen and Cliff, despite living through a time when the feeding tube provided the nutrients needed to help regain weight and energy, in survivorship they were particularly resistant to this intervention. It seems that once again, as described in the last chapter, food and eating are much more than nutrients and linked to the connotation of becoming “one of those guys”.

“On the Verge of Fending for Myself”

Bill, Michael, Cheryl, and Cliff experienced substantial financial burden as a result of their dental disease, which they related to xerostomia. Under Canadian universal health care coverage, there are very limited insured dental benefits. Consequently, most dental care is covered by third-party dental insurance or paid out-of-pocket.

Cheryl had dental coverage through work initially, however now that she is retired she has no coverage. Unfortunately, for Cheryl, the costly dental work she required occurred after her coverage ended. At the time of the interview, Cheryl has spent upwards to $4000 on dental bills. Cliff cannot keep up with the costs of his dental treatment needs. Despite having four dental insurance plans, he does not have enough coverage for all the dental treatment required. Consequently, following dental procedures Cliff distributes outstanding costs over seven different credit cards. At the time of his study participation, Cliff had seen a dentist at the Health Science Centre (HSC) who recommended that he have all of his teeth extracted due to dental caries in each tooth. Cliff was considering his options.

Bill and Michael live on a fixed income as they are retired. Michael did not have dental insurance until recently, as his wife has limited dental coverage through her employment. Bill currently does not have any dental insurance. At the time of Bill's retirement, Bill described his process of decision-making when he was forced between choosing prescription drug versus dental coverage.

> Bill: Is it my fault that I don’t have dental insurance? Probably, but that was the choice I made when I had my heart attack...Was it drugs that I needed to sustain my life or…was it going to be dental that I might need in the future… So, I choose what I needed right then.

Due to the extensive dental work required, both Bill and Michael had dental extractions completed in the hospital covered under *The Health Services Insurance Act* of the province of Manitoba.[28] Additionally, Bill has had ongoing dental treatment completed in a private dental office under the financial assistance of the Fund of Last Resort program at CCMB. These are funds that have been allocated for use by individuals who need financial assistance for dental treatment as a result of head and neck cancer.

Bill estimates he has spent over $10, 000 personally on his teeth thus far, which does not include the coverage through MB Health and the Fund of Last Resort, which he states has put his family in a less stable financial position. When asked how this made him feel, he said: “it doesn't make me feel like a good provider”. For Karen, Bill's cancer diagnosis, his post-treatment doctors’ appointments, and the dental costs have made them realize that their plans for retirement will never materialize.

Prior to their dental extractions, both Bill and Michael struggled with eating because of the fragility of their teeth due to circumferential dental caries. Food choices and eating were approached cautiously because there was a risk their teeth would break off at the gum line. Bill, Karen and Michael believe the dental care required is directly related to the cancer treatment, and therefore should be part of their ongoing healthcare. As such, they do not believe they should have to beg for help to pay. They feel our healthcare system has failed them.

> Bill: If they were made available (dental treatment) …to us then we wouldn't have to beg, borrow and steal money in order to pay ...or go on welfare.

Michael lived many years with teeth that were increasing becoming "loose", broken at the gum line or that had cusp fractures. I questioned why he had not gone to the dentist, and Michael stated he could not afford it. Consequently, Michael was living for many years with sharp jagged teeth or root tips present in his mouth. When I asked how he managed with the discomfort from his broken teeth, Michael response stunned me. I am not proud of how I responded in those moments. However, my response illustrates that I had no understanding what individuals experience or undertake when they have no dental coverage:

> Michael: Sometimes I had to break off a little piece…… With a pair of tweezers…… Just so there wasn't a sharp edge…I couldn't go run to the dentist every time…
>
> Deanna: How come?
>
> Michael: It's expensive… And I'm not covered under a dental plan
>
> Deanna: Uh, huh…. Ah [pause]…do you think that it is normal?
>
> Michael: A lot of people will not go to the dentist because of financial reasons… it's not a cheap proposition.

For Michael, after repeated times of mentioning his teeth at follow-up appointments at CCMB, in talking to his SLP he was referred to see a dentist at HSC, who recommended all his teeth be extracted due to dental caries in every tooth. Michael shared that he told the receptionist at HSC that he could not afford the dental surgery. Consequently, the receptionist "check into" coverage for him and he was able to have the surgery covered under *The Health Services Insurance Act*.[28] It was important to Michael that I understand receiving this coverage did not occur without a fight. When I asked Michael how this made him feel, his answer was disheartening.

> Michael: I was just about on the verge of fending for myself to get them cut out… It is hard to fathom that, ah…. they'd leave you out to hang… high and dry… but they do.

Historically, and to date, the debate continues regarding oral and dental treatments being included as part of the insured benefits of our single-payer healthcare system in Canada. The answer is complex and multidimensional. The complexity of this debate is highlighted in these participants' experiences of helplessness, distress, and lack of control.

For the Rest of Your Life

Post-treatment, the routine of day-to-day life, although notably different, became ordinary again. Although there was always a concern that 'it' may return, cancer was pushed to the back of the mind. When Chris sarcastically stated "radiation…the lovely gift that keeps on giving", he exemplified the understanding of all the participants: although radiation therapy helped saved his life, it's latent effects would affect him for the "rest of his life". For the participants of the study, the cancer experience did not end when treatment was completed. Despite experiences of ongoing, sustained latent effects from radiation therapy, Bill, Michael, Cheryl, Cliff, Jason and Kevin did not consistently maintain daily preventative measures to assist with swallowing, neck and jaw stiffness, or dental caries. When participants started to feel 'normal', they wanted to simplify their lives. Preventative measures complicated day-to-day life and were reminders that life would never be as it once was and a cue to the looming question of what the future would hold.

I will end as I began, with the metaphor of the avalanche. The American poet Quincy Troupe published a book titled, *Avalanche*, one of many books that include a collection of his poetry.[142] Troupe develops his writing through three distinct sections. Within these three parts, he hopes to describe the three stages of an avalanche within the language and form of his writing. Troupe's explanation of the third scene of an avalanche exquisitely illustrates head and neck cancer survivorship.

> "After the settling has become permanent and everything has died down, the landscape is changed into a new one containing different scenes and still lifes than what existed before. And if one were to fly over this new scene --- after the avalanche has occurred and settled --- that person would perhaps think of this picture as pristine, even peaceful, and would not be mindful of the complete transformation that has occurred and has produced these new still lifes" [142]

Chapter 8: Discussion

The purpose of this study was to develop an in-depth understanding of the oral/dental lived experience of individuals with head and neck cancer and their partners. To this end, a hermeneutic phenomenological qualitative study was conducted to address the following research questions:

1. What is the meaning of the lived oral/dental experiences of the head and neck cancer patient along the continuum of their cancer care?
2. What is the meaning of the partner or other family members experiences of caring for and living with the oral/dental experiences in the context of head and neck cancer?
3. How can the meaning of these experiences help us understand the patient and family issues to improve the healthcare provided and experiences?

Within this final chapter, I will discuss research questions #1 and #2 separately based on this research findings and in relation to existing academic literature. I will address Question #3 within the clinical implications and future research sections of this chapter. I then present the limitations of this study and conclude with a discussion about the most significant lesson I learned as I conducted this study.

The Meaning of the Patient Experience

The first research question sought to explore the meaning of the lived oral/dental experience of the patient along the continuum of cancer care, which consisted of three distinct phases: pre-diagnosis, cancer treatment, and post-treatment. However, before addressing this question, I will revisit my growing understanding of the term 'cancer patient' as it relates to what I learned over the course of this study. When I entered this research inquiry, I broadly defined all individuals living with cancer under one single label: the ‘cancer patient’. Consequently, the title of this study and the research questions included this term. Through this interpretation, I grew to understand that this label, these words, the ‘patient’, the ‘cancer patient’ symbolized and held a more profound meaning than I had previously understood. The term ‘patient’ remains within my study protocol, the title of this section, and the research questions submitted, despite the emerging knowledge that the label, the words ‘cancer patient’, symbolized or were connected to the deep resistance that participants had to surrendering to the world of cancer, to becoming a ‘cancer patient’.

Cancer is the abnormal, highly invasive growth of cells in the human body. What was particularly intriguing in this study is that despite this, each participant described cancer in the third person: cancer was consistently described as foreign to the self. This specific way of speaking of cancer, as separate to self, may have worked to facilitate a detachment from the emotion, from the weight of this lived experience in human life, the meaning of the presence of ‘cancer’ in the life of the study participants. The index participants held a deep resistance to becoming a ‘cancer patient’, to surrendering themselves to this new, unwanted identity, to having their lives consumed and identified by the illness they had been diagnosed with. The index participants struggled with having their identity, their sense of who they are in the world limited to that of a ‘cancer patient’.

This aspect of the interpretation raises important questions about how the nature of clinicians’ interactions with those they care for may be framing the patients’ experience in a way that is very painful to live with. Are there approaches that would better acknowledge the full life of the ‘cancer patient’, that would prevent us from leaving patients with the perspective that their lives have been reduced to the disease they have been diagnosed with.

Continuum of Cancer Care: Pre-Diagnosis

Hearing the words ‘you have cancer’ was life-changing for the participants of this study. For each of the participants, the referral point to the cancer centre was a profound, remembered marker on their cancer trajectory; time stopped, at least time as they had previously known it. The initial referral to CCMB brought a sudden realization about the seriousness of the participants’ situation. The world they had once known and lived, no longer existed. It was as if all that they knew, the very ground beneath them suddenly fell away. This experience of feeling the ground beneath you fall away is consistent with previous research.[2,93]

Once a ‘patient’ of CCMB, the process of events leading up to treatment occurred quickly for index participants. They were suddenly assimilated into a world they did not know or want to be part of. Participants faced the realization that they had cancer, and they were now forced to make a life-changing decision in a brief period of time relative to the enormity of their illness. At first glance, this life changing question and answer may seem simple, to treat or not to treat. If the answer is yes, treatment may provide a longer life; if the answer is no, with time, cancer would take over their body, and they would ultimately succumb to the disease. These findings have shown that the gruelling side-effects of treatment in head and neck cancer make this question and answer a far more complex matter which is layered with meaning.

This study revealed that treatment for head and neck cancer has a profound and sustained impact on the index participant and their partner. Although the partner experience is described separately in this discussion, through the process of this study, the partners who agreed to be part of this study wanted to have their voice heard. They wanted to inform my understanding of what ‘the lived experience’ means, not only for their husbands, but also for themselves. They wanted to share their own unique experience and perspective, and, although different from their husband's experience, these perspectives were intimately connected. The lived experience of the individual with cancer and patient-centred care are relational, at least for some individuals.

Despite having lived with pre-diagnosis symptoms for weeks or months, and finally having received a cancer diagnosis, when entering treatment, the prevailing sentiment of the index participants was that they were not sick and felt healthy. And yet, all index participants of this study reported advanced stage cancer. This staging is consistent with previous results, with more than fifty percent of individuals with a head and neck cancer presenting with advanced-stage disease.[164] Before being referred to CCMB, seven of the nine index participants described various delays leading up to their diagnosis and referral to CCMB. Diagnostic delays fall into two categories: patient delay (time from when an individual first notices a symptom to the time they contact a healthcare professional about the symptom), and provider/professional delay (time from initial contact with a healthcare professional about a symptom to definitive pathological diagnosis).[165] Combined, these represent the overall (or total) diagnostic delay.[165] The reason for patient delay is poorly understood.[166]

Continuum of Cancer Care: Treatment

The acute and lasting functional oral and dental side-effects experienced by individuals treated for a head and neck cancer are well described within the academic literature.[4,13,14,25,26,75,81,143,144-148] Additionally, reduced health-related quality of life during treatment and survivorship are well described.[27,63,149] However, the individual experiences and meanings attributed to these side effects are not yet well represented or understood.

Regardless of how prepared index participants thought they were for treatment, it was far more intense and painful, and side-effects progressed quicker and lasted longer than they could have every imaged or fathomed. This finding is consistent with other qualitative research studies.[1,90, 92,93,97] The composite narrative described on pages 55 and 56 provides insight into the intensity of treatment and the extreme pain experienced due to mucositis, as well as stomatitis, xerostomia, dysphagia, thick ropey saliva, burnt skin, and mucosa. Due to these side-effects the index participants experienced weight loss, decreased nutritional intake, and anorexia. During head and neck cancer treatment, it is frequent to experience weight loss and the inability to meet nutritional needs with an oral diet.[129] The description of these experiences has been portrayed in other qualitative literature as negative, described as a physical loss, [97] and distressing due to disrupted expectations of what life could be. They also acted as a marked, ongoing reminder of cancer treatment.[90,93] Ottosson described how weight loss was initially experienced as frightening and uncontrollable, however post-treatment weight loss was seen as a positive consequence of treatment.[92]

During treatment, if an individual is not able to meet their daily nutritional intake, the placement of a feeding tube is suggested.[29] PEG tube feeding is an established way of delivering adequate dietary nutrients to an individual unable to maintain an oral diet when treated for a head and neck cancer.[150] However, the insertion of a feeding tube (PEG or NG) is not without medical risks and possible complications.[150] Ongoing debates related to improving long and short term outcomes associated with dysphagia, weight loss and gain from the placement of a prophylactic or reactive feeding tube are well established in the academic literature.[131,151-157] Additionally, there are ethical and moral debates about when a healthcare professional or family can or should step in concerning this decision. This emerges when a patient is comatose, at the end of life, or at times of diminished mental capacity.[158-163] For individuals treated for a head and neck cancer, despite the understanding of the acute and lasting eating difficulties and the knowledge that the establishment of a feeding tube is an effective approach to providing dietary nutrients, what has not been reported is the extreme resistance experience in relation to accepting feeding tube placement. A highly unique finding in this study was the symbolic meaning ascribed to food and eating, and the elucidation of meaning related to patients' resistance to placement of a feeding tube.

In this study, the symbolic meaning of food and eating had a profound impact on participants' subjective concepts of self and illness. The feeding tube represented giving oneself over to the cancer world, losing ones' identity, and becoming the 'cancer patient'. This resistance was so strong, that for some, they resisted, even forcefully rejected the placement of a feeding tube to the point where they came close to collapsing, and even death. It was only then, that they were willing to surrender to assistance with eating, to maintain their nutritional needs through a PEG tube.

This intense resistance highlights the deceptive nature of the banality of food and eating in our everyday life.[133] Our subjectivity, our sense of self is centred on food and eating.[133] Food is the center of our identity. What an individual or any given group eats highlights both their closeness or distance from those who are similar or different from them. [138,139] Our sense of self, who we are, the control over the body is wrapped, at least partly, around connotations embedded in the phrase, 'we are what we eat'. Food and eating, and more accurately, their place in our lives, is not simple, this is a deeply complex phenomenon. We frame our very lives around events of eating (breakfast, lunch, dinner): we socialize and connect in these crucial moments. Meals and food consumption act as a ritual; their predictable structures can create order out of potential disorder.[135] Most of us freely choose what we consume into our bodies, as well as how and when that occurs. Therefore, when the participants in this study were faced with the decision of whether or not to accept the placement of a feeding tube, the resistance they expressed embodied much more meaning than what I initially understood. Food does not merely exist to just alleviate hunger or providing fuel to stay alive.[133]

Being fed through a feeding tube meant giving in or giving oneself over to the cancer world. Cancer is a reminder of the unpredictability and injustice of the human condition.[134] In hearing the words that you or a loved one 'has cancer,' we are confronted with the reality that we lack control over our own or others' death.[134] Cancer is a painful reminder that regardless of how much we know about the world, we still lack the understanding of many things, specifically the need to make sense of the question "why me?".[134]

Continuum of Cancer Care: Post-treatment

Post-treatment, the index participants described a loss of enjoyment and the inability to eat certain foods or beverages due to sustained xerostomia, dysphagia, altered taste sensation and mucosal sensitivities. Participants also experienced distress related to the increased time that was needed to complete the act of chewing and swallowing, which has been previously described by others.[1,2,90-98,167] For many of us the daily pleasure gained from food is the highest point of our daily sensual experiences.[133] The sensual experience gained through the act of touching, smelling, preparing, and taking the food into the mouth, chewing and swallowing it, may evoke particular emotions on both the conscious and unconscious levels.[133] Smell, taste, and memory have an active link with the emotional dimension of human experiences.[133] Food can stir emotions because of its emotional and social meanings.[133] Memories are "embodied, often recalled via the sensation of taste and smell". [133] Take that all away, what is left?

Following treatment, the daily pleasure of eating and tasting food was partially or entirely lost. Once the index participants started to feel better, they began to eat more. However, due to altered taste sensation, eating was portrayed as mundane as brushing their teeth, it had lost its magic, and was not much fun anymore. A ‘new normal’ of eating was described, which did not come from participants regaining taste sensations, but from a lowered expectation of the enjoyment of food. Altered taste sensation and xerostomia were the two treatment side-effects that had the most lasting impact and caused the most distress. Again, post-treatment, the complexity of food and eating practices were shown to be far more complex than just meeting nutritional needs and sustenance.

The Impact of Dental Disease

An additional unique finding from this study was the meaning of the impact of dental disease. Oral and dental care represents a vital component of each treatment phase of head and neck cancer. An extensive body of literature has previously described the effects of xerostomia[168-170] on dental caries[146,171] periodontal disease, [172,173,174] mucosal tissues, [175,176] and associated symptom management for those treated for a head and neck cancer. Further, there are many recommendations for preventative measures aimed at reducing dental caries; these are important oral and dental recommendations for patients preparing for, undergoing, and post-treatment. [22,143,144,177,178] The financial cost of dental treatment and the effects of xerostomia on dental caries and eating were part of the experiences described in this study. However, it was not until many years into survivorship that dental caries/disease became a prominent part of the cancer experience described. Post-treatment, the routine of day-to-day life, although notably different, became ordinary again. However, it is important to note that despite experiencing ongoing, sustained lasting effects from radiation therapy, the daily preventative measures to assist with dental caries were, for the most part, not maintained.

As a dental professional, the description of xerostomia, dysphagia, the increased time needed to chew, and swallow food described appears to be a recipe or 'perfect storm' for the development of dental caries in the future. The impact of cancer is devastating regardless of age, gender, race or cultural background. However, those impacted with cancer earlier in life will be living with the outcomes of their disease and treatment for a greater number of years. When the diagnosis is head and neck cancer, this point is exemplified because, as noted previously, in the context of HPV-16 positive cases of OSCC, younger people are receiving a head and neck cancer diagnosis.[59]

The dental disease described by the index participants caused a substantial financial burden. As such, necessary dental treatment was postponed and avoided as it was not affordable. Under Canadian universal health care coverage, there are insufficient insured dental benefits, which become particularly evident in the context of head and neck cancer treatment. Consequently, the payment for dental care either came by third-party dental insurance or was paid out-of-pocket. The participants believed that the extensive dental treatment they required was directly related to the cancer treatment, and therefore should have been a part of their ongoing health care. Since this was not the case, they felt they had to beg for financial assistance and that the healthcare system had failed them. The National Cancer Institute defines survivorship as the:

> In cancer, survivorship focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.[179]

Oral and dental care, along with individual patient concerns and needs, go beyond the standard knowledge that well patients acquire through involvement with a dentist, and dental hygienist;[23] numerous academics have noted that a specialized knowledge set is needed to provide the care for this patient population.[14,23-27] This care is said to only be accomplished most effectively through a collaborative approach by care providers.[14,23-27] For the participants of this study, the inclusion of a dental professional was not part of their healthcare team across the trajectory of their cancer care. Individuals living post-cancer treatment with medical and psychological unmet needs have been shown to have a greater reduction in their quality of life than those who have their needs met.[180] Historically, and to date, there has been ongoing debate about whether or not to include oral and dental treatments as part of the insured benefits of our single-payer healthcare system in Canada. This debate is complex and multidimensional, with no clear answers currently available. However, the depth of the complexity related to this issue in the context of head and neck cancer treatment is highlighted in participants' experiences of helplessness, distress, and lack of control regarding their current and future dental concerns and needs.

The Meaning of the Partner Experience

The second research question sought to understand the meaning of the partner or other family members oral/dental experiences of caring for and living in the context of head and neck cancer. As previously discussed, within the process of developing this interpretation, I came to understand that the lived experience and patient-centred care is a relational phenomenon and is not just isolated to the index participant, at least for some individuals. This study revealed that treatment for head and neck cancer has a profound and sustained impact on the index participant and their partner.

For the partners in this study, witnessing the index participants rapid, persistent, and extreme weight loss made them anxious, scared and upset. In the context of the index participant's extreme weight loss, they felt it was their 'job' or 'duty' to ensure their husband received adequate daily nutrition. The duty of ensuring the index participants ate was strongly communicated through the interactions that partners had with the dieticians on the oncology team. Consequently, the partners were constantly on their husbands' case to eat or drink, or they would continuously offer to prepare a variety of foods. Furthermore, partners were intensely aware that eating was connected to survival, and with this knowledge, they experienced intense fear, and had recurring thoughts about the possibility of their partner's death. The partners felt helpless and lacked control in this situation.

Due to severe pain and how sick the index participants felt during treatment, they wanted to be left alone. They felt their wives did not understand what they were experiencing. Therefore, the persistent offering of food and encouragement to eat resulted in relational conflict and anger. Food held significant relational meaning, and this led to impacts on the relationships shared by index participants and their partners. In society, food sharing is an essential component of kinship.[133] Love has been persistently linked with food, "particularly maternal love, romantic love and wifely concern for the well-being of one's husband".[133] The preparation and giving of food from a wife to a husband has been shown to be a means of sharing affection and ensuring the happiness of their husbands and that women felt rejection and hurt when their husbands rejected the food they prepared.[140] Food holds a very important place in relationships: it has been shown to be a way to express love and bind families together.[133] Similarly, in this study, the losses associated with eating, weight, and the profound changes to food and eating rituals led to relational and emotional distress for the index study participants and their partners.

Previous studies on couple dyads in advanced cancer relating to food and eating have primarily focused on cancer cachexia syndrome and terminal cancer. [181,182] Although this syndrome was not self-reported by the study participants, anorexia was present. Within these studies, similar narratives regarding relational conflict and anxiety of the caregivers to the index participants were reported. Specifically, two research studies had similar descriptions to those articulated in this interpretation about eating, the offering of food, focus on symptoms, relational conflict, and reactions to food refusal. [181,182]

Clinical Implications

The primary goal of cancer treatment is a cure; an important secondary goal is to effectively address physical and psychological distress. As described in this study persons with cancer of the head and neck region, do have unique needs. The teeth, the oral cavity, and the pharynx are central to speech, taste, eating, and swallowing.[1,2] Additionally, they play an essential role in body image, identity, social interactions and the ability to express oneself.[1-3] Consequently, understanding the meanings attributed to the lived experience of head and neck cancer patients and their partners is critical in ensuring the delivery of high quality family and patient centred care.[123]

Prognosis, or what the future will hold is a central area of concern not only for health care professionals, but also for each individual receiving treatment, and their family members. As I conducted this study, it became apparent that the word ‘prognosis’ is complex, and fraught with possibilities and uncertainties. This study revealed that while most participants perceived health care professionals’ efforts to stay positive within prognosis discussions as favourable, some recognized that healthcare providers are very cautious with the language they chose to use. This careful approach to these conversations created worry and anxiety for some participants. The language of positivity/protection did leave participants with pressing, unanswered questions. Understanding the depth and the manner in which prognosis information is shared with individuals has implications related to the well-being of patients and their families, and is also central to providing responsive, high-quality care.[183] Consequently, in the future, to reduce anxiety and doubt, it may be important to ask the individual and their family members what they believe their future will hold, what their fears are, and what questions they most need answered.

Other scholars have described weight loss, eating issues and the changed meaning of food. However, this study has offered a 'new' perspective, connecting the marked resistance to a feeding tube to the acceptance of underlying meanings of becoming a 'cancer patient'. The exemplars shared by the participants have given voice to the many meanings and the complexity of decisions about placing a feeding tube. As healthcare professionals, the goal is to provide the best care for our patients. However, well-intended advice may negatively impact individuals. An example of this was in the interactions between the partners and the dietician. The dietician's recommendation for the wife to encourage the index participant to eat reinforced the wife perceptions that they had failed what they saw as one of their most important responsibilities as a partner: ensuring the index participants' nutritional needs were met. This was particularly difficult for partners as their husbands lost more and more weight, week after week. These findings suggest that different approaches in clinical care are needed in the discussion of this key intervention, not only with the individual with cancer, but also with their family members.

Dental Hygienist Implications

Post-treatment the ill effects of reduced saliva production increases the risk for dental caries and disease.[184-186] Additionally, given that radiation to the maxilla, mandible or both increase the lifetime risk of ORN,[79, 80] reducing post-radiation dental extraction due to dental disease could reduce future complications post-treatment. The extend of dental disease described by participants provides insight into the degree and the challenges faced by individuals about dental disease and its related cost. These findings indicate that the current approach to preventative dental interventions in our public healthcare system may be inadequate for this specialized population. Healthcare providers at CCMB have very limited, or no solutions to offer their patients regarding oral and dental restorative and preventative care. Dental hygienists are the only healthcare professional trained specifically in oral health promotion and oral disease prevention, therefore they are well positioned for inclusion within the transdisciplinary team for this patient population and may provide a partial solution to this problem.

Future Research

The findings from this study indicate that each phase of head and neck cancer treatment raises different questions about clinical care and the meaning of lived experience of patients and their families. Understanding these questions, concerns, and worries from various perspectives and different qualitative research approaches are essential in order to better care for individuals and families living with head and neck cancer. Consequently, the list of areas of future research are vast.

Understanding the meaning of these experiences can help maintain and establish good family and patient-centred care and high quality clinical care. Studies like the current one provides those living with the experience the protection and space to speak reflectively and critically. If patient education, interventions or directions are not based on this understanding or this meaning, then it may be a missed opportunity to improve family and patient care and experiences.[103] The knowledge gained through understanding the meaning of the lived experience may lead to discussions that inform clinical practice, recommendations and protocols.

Healthcare interventions to improve these experiences are best designed or considered from the perspective of those experiencing them and not only from the assumptions of healthcare providers.[101]

Examples of future research questions may include exploring the understanding of why individuals eventually diagnosed with a head and neck cancer dismiss or normalize their cancer symptoms prior to diagnosis. Could this understanding tie into the deeper meaning of not wanting to become the ‘cancer patient’? These delays in seeking treatment may also be related to feelings of shame, guilt, or stigmatism related to the risk factors or side effects of head and neck cancer.

Previous studies on couple dyads in advanced cancer have reported relational conflict related to food and eating, but those studies pertain to cancer cachexia syndrome and terminal cancer. [179,180] Much of the discussion within the academic literature focuses on the moral and ethical debate on the placement of a feeding tube for individuals who are terminal, comatose or have diminished mental capacity.[158-163] For the participants of this study their prognosis for survival was not terminal for the immediate future; therefore, the debate and clinical implications of the recommendation and acceptance of feeding tube placement are unique and interwoven with the symbolic meaning of the feeding tube itself and food and eating in human life, as elucidated in this study. [133,134]

This lived experience is complex and full of deeper meanings, which are embedded in the context of each individuals’ life experience and interactions with the healthcare system. This highlights the need to consider individualized and tailored approaches to care with each patient and family, rather than standardized protocols, which can act to limit the voices of patients and families in the context of cancer care. [180,187,188] At the very least, these protocols need to be individualized, and be inclusive of patient and family voices and preferences.

Interactions with healthcare providers and within the healthcare system can impact the family and patient experience, quality of care, and quality of life of all individuals involved in these interactions. Future studies exploring the interactions between healthcare providers and individuals could provide additional insight to improve the family and patient experiences. These studies could include interviewing healthcare providers, decision makers or various other key informants. To broaden this understanding field observations within varying ethnographic approaches could add a different perspective of this lived experience. Additionally, the ideologies, and cultures within the healthcare system and their influence on the lived experience of head and neck cancer might be better elucidated. This example and other qualitative research studies, questions and approaches could provide further knowledge that may have been missed or not captured within quantitative research approaches.

Research Study Limitations

Sample size, generalizability and the subjectivity of qualitative research may be a perceived limitation of this study. In qualitative research, no statistical formula exists to determine the number of study participants required. The number of participants required is emergent. [100,101] Phenomenology aims to increase the understanding of a particular phenomenon and the meanings attributed to these phenomena. In this study, and other phenomenological hermeneutic studies a small number are participants are recruited, as there is an in-depth exploration of the research topic. Therefore, achieving the number of study participants for this study was guided by the richness within the examples shared. [100,101]

Phenomenology does not attempt to predict, generalize or generate theories. [100,101] In phenomenological qualitative research, a strong emphasis is placed upon acknowledging the existence of multiple constructed realities.[100] van Manen states that meaning is multi-dimensional and multi-layered.[100] No one definition can grasp the meaning of a phenomenon. The meaning as sought through this research approach can only be communicated textually through organized narratives and prose. The lived experience of humans in the midst of living it is never neutral. There is an acknowledgement that objectivity cannot be detached from subjectivity as they are not separate but always intertwined with the humans who produce it.[113] Subjectivity is a component of understanding human experiences, therefore is essential for understanding humans. [100,101]

With all interpretative phenomenological questions, no interpretation is ever complete, no explication of meaning is ever final, and no insight is ever beyond challenge.[119] Hermeneutics, in essence, is concerned with the process of interpretation that brings out or reveals what is typically hidden in the human experience.[103,110-112] In the human consciousness, the meanings of experience may not always be apparent or accessible by the study participant as it is embedded within the experience.[105,108-110] Many research topics, irrespective of whether qualitative or quantitative methods are employed, are self-driven by the researcher. As such, within the research, the personal concepts, worldview, and experiences of the researcher are embedded. Individuals, researchers, theorists continually rethink, deconstruct and invent, as such always trying to catch-up or make sense of situations and research findings.[113] I, as the researcher and each study participant are distinct human beings, with each having their own situated context. My existing knowledge or assumptions may have influenced the interpretation of the phenomenon.[100] Consequently, I continually reflected upon and articulate if, how, when my previous experience and assumptions may have affected the inquiry and the interpretation process. Transferability is an important measure of rigor and credibility in qualitative research.[101] It is a measure of the extent to which qualitative findings are transferable to specific clinical contexts, or similar clinical situations.[101] The transferability in this study was addressed by making an effort to fully inform the reader of the processes that I used to arrive at the interpretation of findings, as well as through thick, detailed descriptions within the research findings. I acknowledge that there will be some judgment required by the reader in relation to how, and in what context the findings of this study can be applied.[118]

Conclusion: The Most Important Lesson I Learned

To conclude, I return to the questions that brought me to this study: what does a reduced health-related quality of life during and after treatment for head and neck cancer look like, and what is the meaning of this for the individual living through it?

If we return to the metaphor of the avalanche, the stages of an avalanche were akin the continuum of cancer care as described in this study. An avalanche, once it gains momentum, is violent, an unrelenting cascade of snow that falls down a mountain out of control. The period of investigation before referral to CCMB was like the slow building movement of snow, the warning signs before the avalanche. When participants heard the news that they were being referred to CCMB, this experience was akin to the sudden, unexpected rupture of the snowpack. At that point of separation, each participant felt their world fall away; the world they had once known and lived, no longer existed. It was as if all that they knew, the very ground beneath them suddenly fell away.

Two weeks into treatment marked a distinct point in time: this was when life began to suddenly change. It was at this time that participants no longer saw themselves as healthy; they suddenly were forced to experience a new way of being in the world, they were ill, very ill. They were a cancer patient. The snow of the avalanche had wholly engulfed them; they were now hurling uncontrollably down the mountainside. The treatment experience was far more intense and painful, and side-effects progressed quicker and lasted longer, than could ever be imaged or fathomed. Further, for the participants of this study, the symbolic meaning of food and eating had a profound and sustained impact on their subjective concepts of self and illness, which may not be recognized in day to day clinical care.

The period initially following the end of treatment was a time of settling in. Within the snow avalanche, this time was akin to the settling in of the rocks and material into the new area of land at the bottom of the mountainside. Post treatment, life began to return to normal. The participants started to settle into a new life: the new normal, a transformed landscape of living in the world. The lasting effects of treatment, xerostomia, dysphagia and dental disease were the price they paid for survivorship. Thus, although as Troupe explains in his poem, if one was to capture a still life of participants' lives everything may look pristine and tranquil.[142] However, what lay beneath the surface represents a complete transformation of what life once was.[142]

I was particularly interested in this topic as so many of the long-term effects of treatment are dental related. I wanted to understand how to assist individuals living with oral and dental side effects. However, within the process of conducting this research, I have been forced to ask myself the following question: do I understand what patient-centred care is?

Throughout the participant interviews, all participants shared their perspectives on the positive and negative impacts that healthcare professionals had on their cancer and survivorship experience. As a healthcare provider, I am now more aware of the effect of my words and how I make individuals feel. Maya Angelou's famous quote speaks to what I now will carry forward about the importance and value of how we interact with patients and family members in the context of head and neck cancer: “people will forget what you said, people will forget what you did, but people will never forget how you made them feel”.[189] This quote resonated with me and with the exemplars generated in this study, particularly when Kevin described the profound, enduring impact that health care professionals had during his treatment. His words summarized the experiences of all the other participants of this study.

> Kevin: But if you're talking to somebody like, Dr. (oncologist) who will… relate it to you… to their own human experiences… Real people, right…Who… give a real shit…. I think that's an important aspect of it (patient care) …. human touch… Will be able to look you in the eye and say that… to me, that's the most important kind of support that a person… can get, right. It just like… trust us... we are going to do the best we can for you… We're fighting for you, right. Because of what I don't remember… are the stats and the facts… and the… procedures and the medical names… but I remember the expression or… the eyes… the pat on the shoulder. Like, those are the things I remember… from everybody…that they actually… care about the people that they're sitting across from.

Simple eye contact, a hug, recognition that the person sitting across from you is an individual, is unique and is not just a ‘patient’ or your 10:15 a.m. appointment resonated deeply with the participants. The participants of this study have voiced how deeply the words and intentions of health care providers matter to them.

This interpretation aimed to understand the meaning of the lived experience of head and neck cancer patients and their partners, while simultaneously describing the nuances of individualized experiences. Through my growing understanding, I have gained and shared insights within this interpretation. However, I realize I will never fully understand this experience. This study's findings have shown that the side-effects of treatment make the question and answer to whether or not to treat someone a far more complex matter than we would originally assume it to be. What does having a dry mouth mean to the life of the participants when they have never experienced xerostomia 24/7? Despite all participants being able to provide examples of the impact of their xerostomia, none could put into words just how dry their mouths felt. Can the worth of saliva in our daily lives compared to living or dying ever be fully described? Would understanding this meaning help make the decision between agreeing to treatment or not? Is knowing ever possible, and if so, enough? In retrospect, the participants of this study can provide insight, however, when faced with a life or death question what information matters? The answer is, I do not know. Although this study may add to this decision process, until one is faced with this question, the answer cannot be known. Throughout the interpretation of this study, these are the questions I pondered.

This knowledge of not knowing, I believe is one of the important meanings we need to understand. As a novice researcher, each study participant taught me not only about this research topic through sharing their perspectives and insights, but they also taught me a new way to live in this world. I have been honoured to hear their stories and will be forever grateful to each of them for their gift of time, and their courage. As described previously, as healthcare professionals, we may think that we know what people are thinking, experiencing or feeling. Though, in completing this analysis, I have realized that, we really cannot understand what each person experiences if we don’t remember there is an individual in the individualized care we are trying to provide.

References

1. Larsson M, Hedelin B, Athlin E. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. J Clin Nurs. 2003;12(4):562–70.

2. Röing M, Hirsch JM, Holmström I. The uncanny mouth-A phenomenological approach to oral cancer. Patient Educ Couns. 2007;67(3 SPEC. ISS.):301–6.

3. Semple, Cherith, Killough S. Quality of Life in Head and Neck Cancer. Dent Update. 2014; 41:346–53.

4. Epstein JB, Thariat J, Bensadoun R-J, Barasch A, Murphy B a., Kolnick L, et al. Oral Complications of Cancer and Cancer Therapy: From Cancer Treatment to Survivorship. A Cancer J Clin. 2012;62(6):400–22.

5. Chandu A, Smith ACH, Rogers SN. Health-related quality of life in oral cancer: A review. J Oral Maxillofac Surg. 2006;64(3):495–502.

6. Klein J, Livergant J, Ringash J. Health related quality of life in head and neck cancer treated with radiation therapy with or without chemotherapy: A systematic review. Oral Oncol. 2014;50(4):254–62.

7. Rogers SN, Ahad SA, Murphy AP. A structured review and theme analysis of papers published on "quality of life" in head and neck cancer: 2000-2005. Oral Oncol. 2007;43(9):843–68.

8. Irune E, Dwivedi RC, Nutting CM, Harrington KJ. Treatment-related dysgeusia in head and neck cancer patients. Cancer Treat Rev. 2014;40(9):1106–17.

9. McLaughlin L, Mahon S. A Meta-Analysis of the Relationship Among Impaired Taste and Treatment, Treatment Type, and Tumor Site in Head and Neck Cancer Treatment Survivors. Oncol Nurs Forum. 2014;41(3): E194–202.

10. Porter SR, Fedele S, Habbab KM. Taste dysfunction in head and neck malignancy. Oral Oncol. 2010;46(6):457–9.

11. Epstein JB, Barasch A. Taste disorders in cancer patients: Pathogenesis, and approach to assessment and management. Oral Oncol. 2010;46(2):77–81.

12. Duke RL, Campbell BH, Indresano AT, Eaton DJ, Marbella AM, Myers KB, Layde PM. Dental Status and Quality of Life in Long-Term Head and Neck Cancer Survivors. Laryngoscope. 2005;115(4):678–83.

13. Sciubba JJ, Goldenberg D. Oral complications of radiotherapy. Lancet Oncol. 2006;7(2):175–83.

14. Meurman JH, Grönroos L. Oral and dental health care of oral cancer patients: hyposalivation, caries and infections. Oral Oncol. 2010;46(6):464–7.

15. Nordgren M, Hammerlid E, Bjordal K, Ahlner-Elmqvist M, Boysen M, Jannert M. Quality of life in oral carcinoma: a 5-year prospective study. Head Neck 2008; 30:461-470.

16. Wall LR, Ward EC, Cartmill B, Hill AJ. Physiological changes to the swallowing mechanism following (chemo)radiotherapy for head and neck cancer: a systematic review. Dysphagia 2013; 28:481-493.

17. Murphy BA, Gilbert J. Dysphagia in head and neck cancer patients treated with radiation: assessment, sequelea, and rehabilitation. Semin Radiat Oncol 2009; 19:35-42.

18. Dijkstra PU, Kalk WWI, Roodenburg JLN. Trismus in head and neck oncology: a systematic review. Oral Oncology 2004;40: 879-889.

19. Lee L-Y, Chen S-C, Chen W-C, Huang B-S, Lin C-Y. Postradiation trismus and its impact on quality of life in patients with head and neck cancer. Oral Surg Oral Med Oral Pathol Oral Radiol 2015; 119:187-195.

20. Weber C, Dommerich S, Pau HW, Kramp B. Limited mouth opening after primary therapy of head and neck cancer. Oral Maxillofac Surg 2010; 14:169–173

21. Satheeshkumar PS, Mohan MP, Jacobs J. Restricted mouth opening and trismus in oral oncology. Oral Surg Oral Med Oral Pathol Oral Radiol 2014; 117:709-715

22. Lieshout HFJ, Bots CP. The effect of radiotherapy on dental hard tissue—a systematic review. Clin Oral Invest 2014; 18:17–24.

23. McClure D, Essary D, Gurenlian JR. A collaborative team approach for symptom management for head and neck cancer patients. Grand Rounds Oral-Sys Med. 2007; 1:43-51.

24. Mahmood R, Butterworth C, Lowe D, Rogers SN. Characteristics and referral of head and neck cancer patients who report chewing and dental issues on patient concern inventory. British Dental Journal 2014; 216: E25.

25. Hong CHL, Napenas JJ, Hodgson BD, Stokman MA, Mathers-Stauffer V, Elting LS, Spijkervet FKL, Brennan MT, Dental Disease Section, Oral Care Study Group, Multi-national Association of Supportive Cancer, International Society of Oral Oncology. A systematic review of dental disease in patients undergoing cancer therapy. Support Care Cancer 2010;18: 1007-1021.

26. Jham BC, Reis PM, Miranda EL, Lopes RC, Carvalho AL, Scheper MA, Freire AR. Oral health status of 207 head and neck cancer patients before, during and after radiotherapy. Clin Oral Invest 2008;12: 19-24.

27. Moore KA, Ford PJ, Farah CS. Support needs and quality of life in oral cancer: a systematic review. Int J Dent Hygiene 2014;12: 36-47.

28. Manitoba. The Health Services Insurance Act. [Online]. 1993 Mar 19 [cited 2018 Mar 05]; Available from:URL:http://web2.gov.mb.ca/laws/regs/pdf/h035-048.93.pdf.

29. CancerCare Manitoba. Head and neck disease site group. head and neck cancer patient guide. 2nd ed. [Online] 2013. [cited 2018 Mar 05]; Available from:URL: http://www.cancercare.mb.ca/resource/File/Radiation_Therapy/Radiation_Therapy_Head_Neck_Cancer_Patient_Guide_Oct13.pdf.

30. Davies AN, Epstein JB. Oral complications of cancer and its management. New York: Oxford University Press; 2010.

31. National Cancer Institute. Head and Neck Cancers. [Online]. 2013 Jan 02 [cited 2018 Mar 06]; Available from: URL:http://www.cancer.gov/cancertopics/factsheet/Sites-Types/head-and-neck.

32. Johnson-Obaseki S, McDonald JT, Corsten M, Rourke R. Head and neck cancer in Canada: Trends 1992 to 2007. Otolaryngology - Head and Neck Surgery (United States) 2012;147(1):74-78.

33. Gandini S, Botteri E, Iodice S, Boniol M, Lowenfels AB, Maisonneuve P, Boyle P. Tobacco smoking and cancer: a meta-analysis. Int J Cancer. 2008 Jan 1;122(1):155-64.

34. Hashibe M, Boffetta P, Zaridze D, Shangina O, Szeszenia-Dabrowska N, Mates D, Janout V, Fabiánová E, Bencko V, Moullan N, Chabrier A, Hung R, Hall J, Canzian F, Brennan P. Evidence for an important role of alcohol- and aldehyde-metabolizing genes in cancers of the upper aerodigestive tract.Cancer Epidemiol Biomarkers Prev. 2006 Apr;15(4):696-703.

35. Hashibe M, Brennan P, Benhamou S, Castellsague X, Chen C, Curado MP, Dal Maso L, Daudt AW, Fabianova E, Fernandez L, Wünsch-Filho V, Franceschi S, Hayes RB, Herrero R, Koifman S, La Vecchia C, Lazarus P, Levi F, Mates D, Matos E, Menezes A, Muscat J, Eluf-Neto J, Olshan AF, Rudnai P, Schwartz SM, Smith E, Sturgis EM, Szeszenia-Dabrowska N, Talamini R, Wei Q, Winn DM, Zaridze D, Zatonski W, Zhang ZF, Berthiller J, Boffetta P. Alcohol drinking in never users of tobacco, cigarette smoking in never drinkers, and the risk of head and neck cancer: pooled analysis in the International Head and Neck Cancer Epidemiology Consortium. J Natl Cancer Inst. 2007 May 16;99(10):777-89.

36. Hashibe M, Brennan P, Chuang SC, Boccia S, Castellsague X, Chen C, Curado MP, Dal Maso L, Daudt AW, Fabianova E, Fernandez L, Wünsch-Filho V, Franceschi S, Hayes RB, Herrero R, Kelsey K, Koifman S, La Vecchia C, Lazarus P, Levi F, Lence JJ, Mates D, Matos E, Menezes A, McClean MD, Muscat J, Eluf-Neto J, Olshan AF, Purdue M, Rudnai P, Schwartz SM, Smith E, Sturgis EM, Szeszenia-Dabrowska N, Talamini R, Wei Q, Winn DM, Shangina O, Pilarska A, Zhang ZF, Ferro G, Berthiller J, Boffetta P. Interaction between tobacco and alcohol use and the risk of head and neck cancer: pooled analysis in the International Head and Neck Cancer Epidemiology Consortium. Cancer Epidemiol Biomarkers Prev. 2009 Feb;18(2):541-50.

37. Boffetta P, Hecht S, Gray N, Gupta P, Straif K. Smokeless tobacco and cancer. Lancet Oncol. 2008 Jul;9(7):667-75.

38. Friedman JM, Stavas MJ, Cmelak AJ. Clinical and scientific impact of human papillomavirus on head and neck cancer. World J Clin Oncol 2014 October 10; 5(4): 781-791

39. Chaturvedi AK, Engels EA, Anderson WF, Gillison ML.Incidence trends for human papillomavirus-related and -unrelated oral squamous cell carcinomas in the United States.J Clin Oncol. 2008;26(4):612-9.

40. Chaturvedi AK, Engels EA, Pfeiffer RM, Hernandez BY, Xiao W, Kim E, Jiang B, Goodman MT, Sibug-Saber M, Cozen W, Liu L, Lynch CF, Wentzensen N, Jordan RC, Altekruse S, Anderson WF, Rosenberg PS, Gillison ML. Human papillomavirus and rising oropharyngeal cancer incidence in the United States. J Clin Oncol. 2011;29(32):4294-301.

41. Health Canada. Oral Cancer. [Online]. 2009 Oct 19 [cited 2018 Mar 05]; Available from: URL:http://www.hc-sc.gc.ca/hl-vs/oral-bucco/disease-maladie/cancer-eng.php.

42. Yu MC, Yuan JM. Epidemiology of nasopharyngeal carcinoma. Seminars in Cancer Biology 2002;12(6): 421–429.

43. Day NE, Varghese C. Oesophageal cancer. Cancer Survey 1994;19/20:43-54.

44. Majchrzak E. Szybiak B, Wegner A, Pienkowski P, Pazdrowski J, Luczewski L, Sowka M, Golusinski P, Malicki J, Golusinski W. Oral cavity and oropharyngeal squamous cell carcinoma in young adults: a review of the literature. Radiol Oncol 2014; 48(1): 1-10.

45. Scully C, Bagan J. Oral squamous cell carcinoma overview. Oral Oncology 2009;45: 201-308.

46. Preston-Martin S, Thomas DC, White SC, Cohen D. Prior exposure to medical and dental x-rays related to tumors of the parotid gland. Journal of the National Cancer Institute 1988; 80(12):943–949.

47. Horn-Ross PL, Ljung BM, Morrow M. Environmental factors and the risk of salivary gland cancer. Epidemiology 1997;8(4):414–429.

48. Boffetta P, Richiardi L, Berrino F, Estève J, Pisani P, Crosignani P, Raymond L, Zubiri L, Del Moral A, Lehmann W, Donato F, Terracini B, Tuyns A, Merletti F. Occupation and larynx and hypopharynxcancer: an international case-control study in France, Italy, Spain, and Switzerland. Cancer Causes and Control 2003;14(3):203–212.

49. Luce D, Gérin M, Leclerc A, Morcet JF, Brugère J, Goldberg M. Sinonasal cancer and occupational exposure to formaldehyde and other substances. International Journal of Cancer 1993;53(2):2 24–231.

50. Luce D, Leclerc A, Bégin D, Demers PA, Gérin M, Orlowski E, Kogevinas M, Belli S, Bugel I, Bolm-Audorff U, Brinton LA, Comba P, Hardell L, Hayes RB, Magnani C, Merler E, Preston-Martin S, Vaughan TL, Zheng W, Boffetta P. Sinonasal cancer and occupational exposures: a pooled analysis of 12 case-control studies. Cancer Causes and Control 2002;13(2):147–157.

51. Chien YC, Chen JY, Liu MY, Yang HI, Hsu MM, Chen CJ, Yang CS. Serologic markers of Epstein Barr virus infection and nasopharyngeal carcinoma in Taiwanese men.New England Journal of Medicine 2001;345(26):1877–1882.

52. Hamilton-Dutoit SJ1, Therkildsen MH, Neilsen NH, Jensen H, Hansen JP, Pallesen G. Undifferentiated carcinoma of the salivary gland in Greenlandic Eskimos: demonstration of Epstein-Barr virus DNA by in situ nucleic acid hybridization. HumanPathology1991;22(8):811–815.

53. Chan JK1, Yip TT, Tsang WY, Poon YF, Wong CS, Ma VW. Specific association of Epstein-Barr virus with lymphoepithelial carcinoma among tumors and tumorlike lesions of the salivary gland. Arch Pathol Lab Med 1994;118(10):994–997.

54. Goldenberg D, Lee J, Koch WM, Kim MM, Trink B, Sidransky D, Moon CS. Habitual risk factors for head and neck cancer. Otolaryngol Head Neck Surg.2004;131(6):986–993.

55. Ho PS, Ko YC, Yang YH, Shieh TY, Tsai CC. The incidence of oropharyngeal cancer in Taiwan: an endemic betel quid chewing area. Journal of Oral Pathology and Medicine 2002; 31(4):213–219.

56. Goldenberg D, Golz A, Joachims HZ. The beverage maté: a risk factor for cancer of the head and neck. Head and Neck 2003;25(7):595–601.

57. Chaturvedi AK, Graubard B, Broutian T, Pickard RK, Tong ZY, Xiao W, Kahle L, Gillison ML. NHANES 2009-2012 findings: association of sexual behaviors with higher prevalence of oral oncogenic human papillomavirus infections in U.S. men. Cancer Res. 2015 Apr 14.

58. Freidman JM, Stavas MJ, Cmelak. Clinical and scientific impact of human papillomavirus on head and neck cancer. World J Clin Oncol 2014; 5(4): 781-791.

59. Lydiatt WM, Patel SG, O'Sullivan B, Brandwein MS, Ridge JA, Migliacci JC, Loomis AM, Shar JP. Head and neck cancers – major changes in the American Joint Committee on Cancer eight edition cancer staging manual. CA Cancer J Clin 2017: 67: 122-137.

60. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Society. Cancer Statistics 2017. [Online]. 2017 June [cited 2018 Mar 05]; Available from: URL: http://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2017-EN.pdf?la=en

61. CancerCare Manitoba. Cancer in Manitoba. department of epidemiology & cancer registry 2015 annual statistical report. [Online]. 2017 [cited 2018 Mar 05]; Available from:URL:http: http://www.cancercare.mb.ca/resource/File/Epi-Cancer_Registry/CCMB_2015_Annual_Statistical_Report_Oct17.pdf

62. Marur S, Forastiere AA. Head and neck cancer: changing epidemiology, diagnosis, and treatment. Mayo Clin Proc 2008;83(4): 489-501.

63. Murphy BA, Ridner S, Wells N, Dietrich M. Quality of life research in head and neck cancer: a review of the current state of the science. Critical Reviews in Oncology/Hematology 2007; 62: 251–267.

64. Tribius S, Bergelt C. Intensity-modulated radiotherapy versus conventional and 3D conformal radiotherapy in patients with head and neck cancer: Is there a worthwhile quality of life gain? Cancer Treat Rev 2011;37(7):511-519.

65. Schliephake H, Jamil MU. Prospective evaluation of quality of life after oncologic surgery for oral cancer. Int. J. Oral Maxillofac. Surg. 2002; 31: 427–433

66. Cousins N, MacAulay F, Lang H, MacGillivray S, Wells M. A systematic review of interventions for eating and drinking problems following treatment for head and neck cancer suggests a need to look beyond swallowing and trismus. Oral Oncology 2013;49: 387–400.

67. Manikantan K, Khode S, Sayed SI, Roe J, Nutting CM, Rhys-Evan P, Harrington KJ, Kazi R. Dysphagia in head and neck cancer. Cancer Treatment Reviews 2009; 35: 724–732.

68. Abendstein H, Nordgren M, Boysen M, Jannert M, Silander E, Ahlner-Elmqvist M, Hammerlid E, Bjordal K. Quality of life and head and neck cancer: a 5 year prospective study. Laryngoscope 2005; 115: 2183-2192.

69. Hammerlid E, Silander E, Hornestam L, Sullivan M. Health-related quality of life three years after diagnosis of head of neck cancer-a longitudinal study. Head Neck 2001; 23:113-125.

70. Chaukar DA, Walvekar RR, Das AK, Deshpande MS, Pai PS, Chaturvedi P, Kakade A, Cruz AK. Quality of life in head and neck cancer survivors: a cross-sectional survey. Am J Otolaryngol 2009; 30:176-180.

71. van der Molen L, van Rossum MA, Burkhead LM, Smeele LE, Hilgers FJM. Functional outcomes and rehabilitation strategies in patients treated with chemotherapy for advanced head and neck cancer: a systematic review. Eur Arch Otorhinolaryngol 2009;266: 889–900

72. Bhishamjit CS, Eisbruch A, Murphy BA, Ridge JA, Gavin P, Reeve BB, Burner DW, Movsas B. Recommended patient-reported core set of symptoms to measure in head and neck cancer treatment trails. JNCI J Natl Cancer Inst (2014) 106(7): dju127 doi:10.1093/jnci/dju127

73. Worthington HV, Clarkson JE, Eden OB. Interventions for treating oral mucositis for patients with cancer receiving treatment. Cochrane Database Syst Rev 2007; (2): CD001973.

74. Keefe DMK. Mucositis Management in patients with cancer. Support Cancer Ther 2006;3(3):154-157.

75. Turner L, Mapparapu M, Akintoye SO. Review of complications associated with treatment of oropharyngeal cancer: A guide for dental practitioners. Quintessence Int 2013; 44:267–279.

76. Pace-Balzan A, Rogers SN. Dental rehabilitation after surgery for oral cancer. Curr Opin Otolaryngol Head Neck Surg 2012, 20:109 –113.

77. Siddall K, Rogers SN, Butterworth CJ. The prosthodontic pathway of the oral cancer patient. Dent Update 2012;39: 98–106.

78. Brosky ME. The role of saliva in oral health: strategies for prevention and management of xerostomia. J Support Oncol 2007;5(5):215-225.

79. Nabil S, Samman N. Incidence and prevention of osteoradionecrosis after dental extraction in irradiated patients: a systematic review. Int. J. Oral Maxillofac. Surg. 2011;40: 229–243.

80. Nabil S, Samman N. Risk factors for osteoradionecrosis after head and neck radiation: a systemic review. Oral Surg Oral Med Oral Pathol Oral Radiol 2012; 113:54-69.

81. Fischer DJ, Epstein JB. Management of patients who have undergone head and neck cancer therapy. Dent Clin N Am 2008; 52:39-60.

82. Epstein JB, Chow AW. Oral complications associated with immunosuppression and cancer therapies. Infect Dis Clin North Am 1999; 13(4):901-923.

83. Miller EH, Quinn AI. Dental considerations in the management of head and neck cancer patients. Otolaryngol Clin N Am 2006; 39:319-329.

84. Eades M, Chasen M, Bhargava R. Rehabilitation: long-term physical and functional changes following treatment. Semin Oncol Nurs 2009; 25(3):222-230.

85. Chen AM, Farwell DG, Luu Q, Vazquez EG, Lau DH, Purdy JA. Intensity-modulated radiotherapy is associated with improved global quality of life among long-term survivors of head-and-neck cancer. International Journal of Radiation Oncology Biology Physics 2012;84(1):170-175.

86. Graff P, Lapeyre M, Desandes E, Ortholan C, Bensadoun R-, Alfonsi M, Maingon P, Giraud P, Bourhis J, Marchesi V, Mege A, Peiffert D. Impact of Intensity-Modulated Radiotherapy on Health-Related Quality of Life for Head and Neck Cancer Patients: Matched-Pair Comparison with Conventional Radiotherapy. International Journal of Radiation Oncology Biology Physics 2007;67(5):1309-1317.

87. Meirovitz A, Murdoch-Kinch CA, Schipper M, Pan C, Eisbruch A. Grading xerostomia by physicians or by patients after intensity-modulated radiotherapy of head-and-neck cancer. International Journal of Radiation Oncology Biology Physics 2006;66(2):445-453.

88. Scott-Brown M, Miah A, Harrington K, Nutting C. Evidence-based review: Quality of life following head and neck intensity-modulated radiotherapy. Radiotherapy and Oncology 2010;97(2):249-257.

89. Yao M, Karnell LH, Funk GF, Lu H, Dornfeld K, Buatti JM. Health-Related Quality-of-Life Outcomes Following IMRT Versus Conventional Radiotherapy for Oropharyngeal Squamous Cell Carcinoma. International Journal of Radiation Oncology Biology Physics 2007;69(5):1354-1360.

90. Larsson M, Hedelin B, Athlin E. Needing a hand to hold. Lived experience during the trajectory of care for patients with head and neck cancer treated for radiotherapy. Cancer Nurs 2007; 30(4):324-334.

91. Charalambous A. Hermeneutic phenomenological interpretations of patients with head and neck neoplasm experiences living with radiation-induced xerostomia: the price to pay? Eur J Oncol Nurs 2014; 18: 512-520.

92. Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. J Clin Nurs 2013; 22: 1034-1043.

93. McQuestion M, Fitch MI. Patients, experience of receiving radiation treatment for head and neck cancer: before, during and after treatment. Can Oncol Nurs J / Rev Can soins Infirm en Oncol. 1991;26(4):325–35.

94. Nund RL, Ward EC, Scarinci NA, Cartmill B, Kuiper P, Porceddu SV. The lived experience of dysphagia following non-surgical treatment of head and neck cancer. Int J of Speech-Language Path 2014; 156(3): 282-289.

95. McLaughlin L, Mahon SM. Taste dsyfuntion and eating behaviours in survivors of head and neck cancer treatment. MedSurg Nurs 2014;23(3): 165-184.

96. Molassiotis A, Rogers M. Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: a qualitative longitudinal study. Palliat Support Care 2012; 10:197-204.

97. McQuestion M, Fitch M, Howell D. The changed meaning of food: physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. Eur J Oncol Nurs 2011;15:145-151.

98. Röing M, Hirsch JM, Holmström I, Schuster M. Making new meanings of being in the world after treatment for oral cancer. Qual Health Res. 2009;19(8):1076–86.

99. Röing M, Hirshe JM, Holmström. Living in a state of suspence - a phenomenological approach to the spouce's experience of oral cancer. Scand J Care Sciences 2008; 22(1):40-47.

100. van Manen M. Researching lived experiences. human science for action sensitive pedagogy, London Ontario: The Althouse Press; 1990.

101. Munhall PL. Nursing research. 5th ed. Mississauga: Jones and Bartlett Learning; 2012.

102. Dowling M. From Hurrerl to van Manan. a review of different phenomenological approaches. International Journal of Nursing 2007;44: 131-142.

103. Mackey S. Phenomenological nursing research: methodological insights from heidegger's interpretive phenomenology. International Journal of Nursing Studies 2005; 42(1): 179-186.

104. Phillips-Pula L, Strunk J, & Pickler RH. Understanding phenomenological approaches to data analysis. Journal of Pediatric Health Care 2011; 25(1): 67-71.

105. Pringle J, Hendry C, McLafferty E. Phenomenological approaches: challenges and choices. Nurse Research 2011;18(2): 7-18.

106. Munhall PL. Revisioning phenomenology: nursing and health science research. New York: National League for Nursing; 1994.

107. Creswell JW. Qualitative inquiry and research design: Choosing among the five approaches. 3rd ed. Thousand Oaks: Sage; 2013

108. Miles M, Chapman Y, Francis K, Taylor B. Exploring Heideggerian hermeneutic phenomenology: a perfect fit for midwifery research. Women and Birth 2013; 26:273-276.

109. Wojnar DM, Swanson KM. Phenomenology. an exploration. Journal of Holistic Nursing 2007;25(3): 172-180.

110. Todres L, Wheeler S. A complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. International Journal of Nursing 2001;38: 1-8.

111. Annells M. Hermeneutic phenomenology: philosophical perspectives and current use in nursing research. Journal of Advanced Nursing 1996;23(4),705-713.

112. CancerCare Manitoba. About us. [Online] 2017 [2018 Mar 05]; Available from: URL: http://www.cancercare.mb.ca/home/about_us/

113. Denzin NK, Lincoln YS. The SAGE handbook of qualitative research. 4th ed. California: SAGE Publications; 2011.p.245

114. Liamputtong P. Research methods in health. foundations for evidence-based practice. 2nd ed. Australia: Oxford University Press; 2013.

115. Johnson B, Clark JM. Collecting sensitive data: the impact on researchers. Qualitative Health Research 2003;13(3): 421-434.

116. Allmark P, Boote J, Chambers E, Clarke A, McDonnell A, Thompson A, Tod AM. Ethical issues in the use of in-depth interviews: literature review and discussion. Res Ethics 2009; 5(2):48-54.

117. National Cancer Institute. Index case. [Online] 2018 [cited 2018 Mar 5]; Available from: URL: https://www.cancer.gov/publications/dictionaries/genetics-dictionary/def/index-case.

118. Moules NJ, McCaffrey G, Field JC, Laing CM. Conduction hermeneutic research. New York: Peter Lang Publishing; 2015. p. 126, 171-181

119. van Manen M. Writing in the dark. phenomenological studies in interpretative inquiry. London, ON: The Althouse Press; 1997.

120. Canadian Cancer Society Manitoba Division. Five-year action plan to address the financial hardship of cancer in Canada a call for action. [Online] 2012 Oct [cited 2018 Mar 05]; Available from: URL: http://www.cancer.ca/~/media/cancer.ca/MB/get%20involved/take%20action/financial%20hardship%20of%20cancer%20in%20canada/financialhardshipofcancer-MB-EN.pdf?la=en

121. Government of Manitoba. Health, seniors and active living department. Vision and Mission. [Online] 2016 May [cited 2018 Mar 05]; Available from: URL: https://www.gov.mb.ca/health/documents/priorities_goals.pdf

122. Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century, Washington, D.C: National Academy Press; 2001. pg. 48-49.

123. Mitchell ML, Coyer F, Kean S, Stone R, Murfield J, Dwan T. Patient, family-centred care interventions within the adult ICU setting: an integrative review. Aust Crit Care. 2016; 29: 179-193

124. Rogers SN. Quality of life perspectives in patients with oral cancer. Oral Oncol 2010; 46: 445-447.

125. National Geographic. Avalanche. [Online] 2017 [2018 Mar 05]; Available from: URL:http://www.nationalgeographic.com/environment/natural-disasters/avalanches/

126. Webster Merriam. Prognosis. [Online] 2017 [2018 Mar 05]; Available from: https://www.merriam-webster.com/dictionary/prognosis?src=search-dict-hed

127. Online Etymology Dictionary. Prognosis. [Online] 2017 [2018 Mar 05]; Available from: URL: https://www.etymonline.com/search?q=prognosis

128. Online Etymology Dictionary. Monster. [Online] 2018 [cited 2018 Mar 05]; Available from: URL: https://www.etymonline.com/search?q=monster

129. Dechaphunkul T, Martin L, Alberda C, Olson K, Baracos V, Gramlich L. Malnutrition assessment in patients with cancers of the head and neck: A call to action and consensus. Crit Rev Oncol Hematol 2013;88(2):459-476.

130. BC Cancer Agency, Hovan A. "Magic" mouthwash explained. [Online] 2014 Fall [cited 2018 Mar 05]; Available from: URL: http://www.bccancer.bc.ca/managing-symptoms-site/Documents/magic%20mouthwash%20excerpt%20from%202014%20Fall%20FPON%20journal.pdf.

131. Shaw SM, Flowers H, O'Sullivan B, Hope A, Lui LWC, Martino R. The effect of prophylactic percutaneous endoscopic gastronomy (PEG) tube placement on swallowing and swallowing-related outcomes in patients undergoing radiotherapy for head and neck cancer: a systematic review. Dysphagia 2015; 30:152-175.

132. Cherno M. Feuerbach's "man is what he eats": a rectification. J Hist Ideas 1963; 24(3): 397-406.

133. Lupton D. Food, the body and the self. London: Sage Publications Ltd; 1996. p. 1, 2, 6-8, 12, 13, 15,16, 25, 48, 68, 75

134. Kleinman A. The illness narrative. New York: Basic Books Inc.;1988. p. 20.

135. Douglas M. Implicit meanings: essays in anthropology. London: Routledge and Kegan Paul;1975. p.273.

136. Fischler, C. Food habits, social change and nature/culture dilemma. Social Science Information 1980; 19(6):937-953.

137. Fischler, C. Food, self and identity. Social Science information 1988;27(2):275-292.

138. Rozin P, Zeller D. The role of pavlovian conditioning in the acquisition of food likes and dislikes. Annals of the New York Academy of Sciences 1985; 443:189-202.

139. Charles N, Kerr M. Women, Food and Families. Manchester: Manchester University Press; 1988. p. 65 -70

140. Coward R. Female desire: women's sexuality today. London: Paladin; 1984. p. 101.

141. Halligan M. Eat my words. Sydney: Angus and Robertson; 1990. p. 124-125.

142. Troupe Q. Avalanche. Minneapolis: Coffee House Press; 1996. p. 13.

143. Joshi VK. Dental treatment planning and management for the mouth cancer patient. Oral Oncol. 2010;46(6):475–9.

144. McCaul LK. Oral and dental management for head and neck cancer patients treated by chemotherapy and radiotherapy. Dent Update. 2012;39(2):135–8, 140.

145. Tolentino EDS, Centurion BS, Ferreira LHC, Souza AP De, Damante JH, Rubira-Bullen IRF. Oral adverse effects of head and neck radiotherapy: literature review and suggestion of a clinical oral care guideline for irradiated patients. J Appl Oral Sci. 2011;19(5):448–54.

146. Speksnijder CM, van der Glas HW, van der Bilt A, van Es RJJ, van der Rijt E, Koole R. Oral Function After Oncological Intervention in the Oral Cavity: A Retrospective Study. J Oral Maxillofac Surg. 2010;68(6):1231–7.

147. Lieshout HFJ, Bots CP. The effect of radiotherapy on dental hard tissue-a systematic review. Clin Oral Investig. 2014;18(1):17–24.

148. Schoen PJ, Reintsema H, Bouma J, Roodenburg JLN, Vissink A, Raghoebar GM. Quality of life related to oral function in edentulous head and neck cancer patients posttreatment. Int J Prosthodont. 2007;20(5):469–77.

149. Verdonck-De Leeuw IM, Buffart LM, Heymans MW, Rietveld DH, Doornaert P, De Bree R, et al. The course of health-related quality of life in head and neck cancer patients treated with chemoradiation: A prospective cohort study. Radiother Oncol. 2014;110(3):422–8.

150. Hucl T, Spicak J. Complications of percutaneous endoscopic gastrostomy. Best Pract Res Clin Gastroenterol 2016;30: 769-781.

151. Jack DR, Dawson FR, Reilly JE, Shoaib T. Guideline for prophylactic feeding tube insertion in patients undergoing resection of head and neck cancers. J Plast Reconstr Aesthetic Surg. 2012;65(5):610–5.

152. Chen AM, Li BQ, Lau DH, Farwell DG, Luu Q, Stuart K, et al. Evaluating the role of prophylactic gastrostomy tube placement prior to definitive chemoradiotherapy for head and neck cancer. Int J Radiat Oncol Biol Phys. 2010;78(4):1026–32.

153. van der Linden NC, Kok A, Leermakers-Vermeer MJ, de Roos NM, de Bree R, van Cruijsen H, et al. Indicators for Enteral Nutrition Use and Prophylactic Percutaneous Endoscopic Gastrostomy Placement in Patients With Head and Neck Cancer Undergoing Chemoradiotherapy. Nutr Clin Pract. 2017;32(2):225–32.

154. VAN BOKHORST-DE VAN DER SCHUEREN MAE, LANGENDOEN SI, VONDELING H, KUIK DJ, QUAK JJ, VAN LEEUWEN PAM. Perioperative enteral nutrition and quality of life of severely malnourished head and neck cancer patients: a randomized clinical trial. Clin Nutr. 2000;19(6):437–44.

155. Salas S, Baumstarck-Barrau K, Alfonsi M, Digue L, Bagarry D, Feham N, et al. Impact of the prophylactic gastrostomy for unresectable squamous cell head and neck carcinomas treated with radio-chemotherapy on quality of life: Prospective randomized trial. Radiother Oncol. 2009;93(3):503–9.

156. Nguyen NP, North D, Smith HJ, Dutta S, Alfieri A, Karlsson U, et al. Safety and effectiveness of prophylactic gastrostomy tubes for head and neck cancer patients undergoing chemoradiation. Surg Oncol. 2006;15(4):199–203.

157. Moor JW, Patterson J, Kelly C, Paleri V. Prophylactic gastrostomy before chemoradiation in advanced head and neck cancer: A multiprofessional web-based survey to identify current practice and to analyse decision Making. Clin Oncol. 2010;22(3):192–8.

158. van de Vathorst S. Artificial nutrition at the end of life: Ethical issues. Best Pract Res Clin Gastroenterol. 2014;28(2):247–53.

159. O'Sullivan Maillet J, Baird Schwartz D, Posthauer ME. Position of the academy of nutrition and dietetics: Ethical and legal issues in feeding and hydration. J Acad Nutr Diet. 2013;113(6):828–33.

160. Macfie J, McNaught C. The ethics of artificial nutrition. Med (United Kingdom). 2015;43(2):124–6.

161. Geppert C, Andrews M, Druyan ME. Ethical Issues in Artificial Nutrition and Hydration: A Review. J Parenter Enter Nutr. 2010;34(1):79–88.

162. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. Clin Nutr. 2016;35(3):545–56.

163. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. Clin Nutr. 2016;35(3):545–56.

164. Scott SE, Grunfeld EA, McGurk M. The idiosyncratic relationship between diagnostic delay and stage of oral squamous cell carcinoma. Oral Oncol. 2005;41(4):396–403.

165. Seoane J, Takkouche B, Varela-Centelles P, Tomás I, Seoane-Romero JM. Impact of delay in diagnosis on survival to head and neck carcinomas: A systematic review with meta-analysis. Clin Otolaryngol. 2012;37(2):99–106.

166. Scott SE, Grunfeld EA, McGurk M. Patient's delay in oral cancer: A systematic review. Community Dent Oral Epidemiol. 2006;34(5):337–43.

167. Ganzer H, Rothpletz-Puglia P, Byham-Gray L, Murphy BA, Touger-Decker R. The eating experience in long-term survivors of head and neck cancer: a mixed-methods study. Support Care Cancer. 2015;23(11):3257–68.

168. Bruce SD. Radiation-induced xerostomia: how dry is your patient? Vol. 8, Clinical journal of oncology nursing. 2004. p. 61–7.

169. Vissink A, Mitchell JB, Baum BJ, Limesand KH, Jensen SB, Fox PC, et al. Clinical management of salivary gland hypofunction and xerostomia in head-and-neck cancer patients: Successes and barriers. Int J Radiat Oncol Biol Phys. 2010;78(4):983–91.

170. Bomeli SR, Desai SC, Johnson JT, Walvekar RR. Management of salivary flow in head and neck cancer patients - A systematic review. Oral Oncol. 2008;44(11):1000–8.

171. Jones DL, Rankin KV. Management of the oral sequelae of cancer therapy. Tex Dent J. 2012;129(5):461–8.

172. Epstein JB, Lunn R, Le N, Moore PS. Periodontal Attachment Loss in Patients after Head and Neck Radiation Therapy. Oral Surgery, Oral Med Oral Pathol. 1998;86(6):4–6.

173. Epstein JB, Stevenson-Moore P. Periodontal disease and periodontal management in patients with cancer. Oral Oncol. 2001;37(8):613–9.

174. Rodríguez-Caballero A, Torres-Lagares D, Robles-García M, Pachón-Ibáñez J, González-Padilla D, Gutiérrez-Pérez JL. Cancer treatment-induced oral mucositis: A critical review. Int J Oral Maxillofac Surg. 2012;41(2):225–38.

175. Napenas JJ., Shetty KV SC. Oral Mucositis: Review of pathogenesis, diagnosis, prevention, and managment. 2007.

176. Epstein JB, Schubert MM. Managing pain in mucositis. Semin Oncol Nurs. 2004;20(1):30–7.

177. Tschoppe P, Zandim DL, Sampaio JEC, Kielbassa AM. Saliva substitute in combination with high-concentrated fluoride toothpaste: Effects on demineralised dentin in vitro. J Dent. 2010;38(3):207–13.

178. Epstein JB, Chin EA, Jacobson JJ, Rishiraj B, Le N. The relationships among fluoride, cariogenic oral flora, and salivary flow rate during radiation therapy. Oral Surg Oral Med Oral Pathol Oral Radiol Endod. 1998;86(3):286–92.

179. National Cancer Institute. NCI dictionary of cancer terms: survivorship [Online] 2017 Oct 4 [cited 2018 Mar 22]; Available from: URL: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship

180. Mayer DK, Nasso SF, Earp JA. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. Lancet Oncol 2017;18: e11–18.

181. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting Over Food: Patient and Family Understanding of Cancer Cachexia. Oncol Nurs Forum. 2009;36(4):439–45.

182. Holden CM. Anorexia in the terminally ill cancer patient: the emotional impact on the patient and the family. Hosp J. 1991;7(3):73–84.

183. Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. Palliat Med 2009; 23: 29-39.

184. Vissink A, Jansma J, Spijkervet FKL, Burlage FR, Coppes RP. Oral Sequelae of head and neck radiotherapy. Crit Rev Oral Biol Med 2003; 14(3):199-212.

185. Han P, Suarez-Durall P, Mulligan R. Dry mouth: a critical topic for older adult patients. J Prostho Res 2015; 59:6-19.

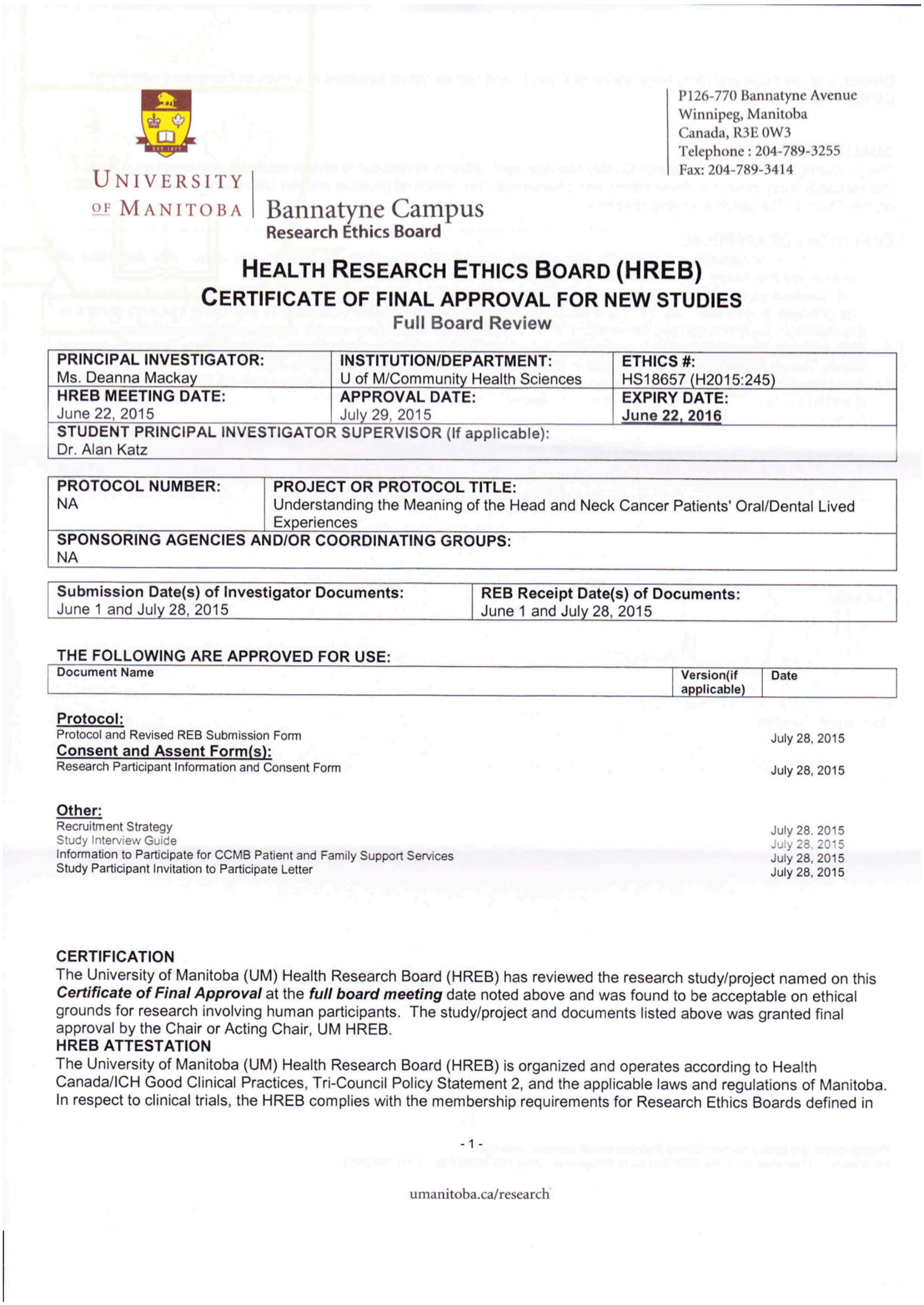
186. Epstein JB, Thariat J, Bensadoun R, Barasch A, Murphy B, Kolnick L, Popplewell L, Maghami E. Oral complications of cancer and cancer therapy. From cancer treatment to survivorship. CA Cancer J Clin 2012;62: 400-422.

187. Burg M, Adorno G, Lopex EDS, Loerzel V, Stein K, Wallace C, Sharma DKB. Current unmet needs of cancer survivors: analysis of open-ended responses to the American cancer society study of cancer survivors II. Cancer 2015; 121:623-630.

188. Hewitt M, Greenfield S, Stovall E, eds. From cancer patient to cancer survivor: lost in transition. Washington, DC: The National Academies Press, 2005.

189. Angelou M. Brainy Quote [Online] 2018 [cited 2018 Mar 5]; Available from: URL: https://www.brainyquote.com/search_results?q=forget+how+you+feel

Appendix A: Part 1, Initial University of Manitoba Health Research Ethic Board Approval



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UNIVERSITY OF MANITOBA | Bannatyne Campus
Research Ethics Board

HEALTH RESEARCH ETHICS BOARD (HREB)
CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES
Full Board Review

PRINCIPAL INVESTIGATOR: Ms. Deanna Mackay	**INSTITUTION/DEPARTMENT:** U of M/Community Health Sciences	**ETHICS #:** HS18657 (H2015:245)
HREB MEETING DATE: June 22, 2015	**APPROVAL DATE:** July 29, 2015	**EXPIRY DATE:** **June 22, 2016**
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable): Dr. Alan Katz		

PROTOCOL NUMBER: NA	**PROJECT OR PROTOCOL TITLE:** Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: NA	

Submission Date(s) of Investigator Documents: June 1 and July 28, 2015	**REB Receipt Date(s) of Documents:** June 1 and July 28, 2015

THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
Protocol:		
Protocol and Revised REB Submission Form		July 28, 2015
Consent and Assent Form(s):		
Research Participant Information and Consent Form		July 28, 2015
Other:		
Recruitment Strategy		July 28, 2015
Study Interview Guide		July 28, 2015
Information to Participate for CCMB Patient and Family Support Services		July 28, 2015
Study Participant Invitation to Participate Letter		July 28, 2015

CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this ***Certificate of Final Approval*** at the ***full board meeting*** date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

HREB ATTESTATION

The University of Manitoba (UM) Health Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulations of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in

- 1 -

umanitoba.ca/research

Division 5 of the Food and Drug Regulations of Canada and carries out its functions in a manner consistent with Good Clinical Practices.

QUALITY ASSURANCE
The University of Manitoba Research Quality Management Office may request to review research documentation from this research study/project to demonstrate compliance with this approved protocol and the University of Manitoba Policy on the Ethics of Research Involving Humans.

CONDITIONS OF APPROVAL:

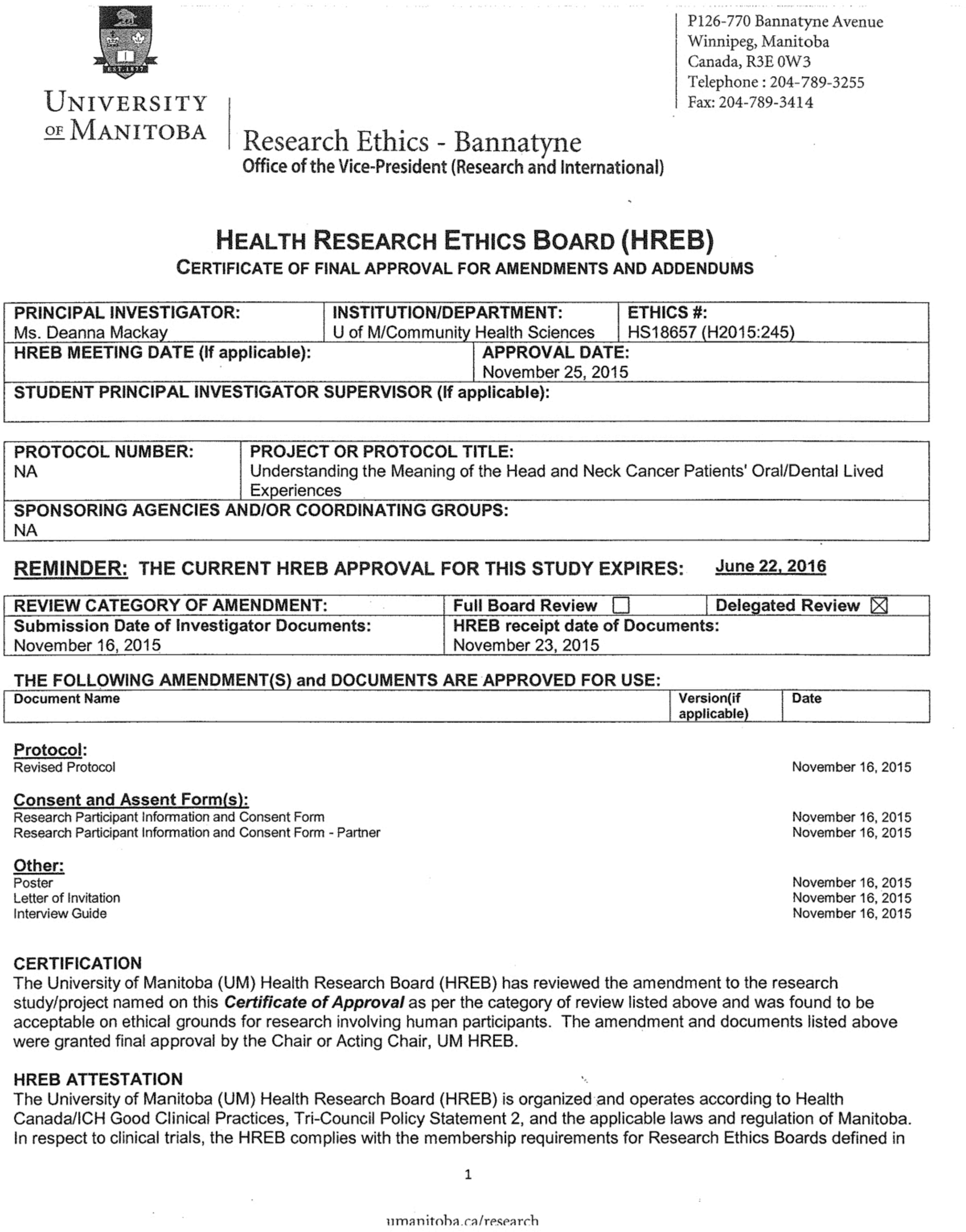
1. The study is acceptable on scientific and ethical grounds for the ethics of human use only. ***For logistics of performing the study, approval must be sought from the relevant institution(s).***
2. This research study/project is to be conducted by the local principal investigator listed on this certificate of approval.
3. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to the research study/project, and for ensuring that the authorized research is carried out according to governing law.
4. **This approval is valid until the expiry date noted on this certificate of approval. A Bannatyne Campus Annual Study Status Report** must be submitted to the REB within 15-30 days of this expiry date.
5. Any changes of the protocol (including recruitment procedures, etc.), informed consent form(s) or documents must be reported to the HREB for consideration in advance of implementation of such changes on the **Bannatyne Campus Research Amendment Form.**
6. Adverse events and unanticipated problems must be reported to the REB as per Bannatyne Campus Research Boards Standard Operating procedures.
7. The UM HREB must be notified regarding discontinuation or study/project closure on the **Bannatyne Campus Final Study Status Report**.

Sincerely, [redacted]

[redacted]

John, Arnett, PhD., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Appendix A: Part 2, Study Amendment University of Manitoba Health Research Ethic Board Approval



UNIVERSITY OF MANITOBA | Research Ethics - Bannatyne
Office of the Vice-President (Research and International)

P126-770 Bannatyne Avenue
Winnipeg, Manitoba
Canada, R3E 0W3
Telephone : 204-789-3255
Fax: 204-789-3414

HEALTH RESEARCH ETHICS BOARD (HREB)

CERTIFICATE OF FINAL APPROVAL FOR AMENDMENTS AND ADDENDUMS

PRINCIPAL INVESTIGATOR: Ms. Deanna Mackay	**INSTITUTION/DEPARTMENT:** U of M/Community Health Sciences	**ETHICS #:** HS18657 (H2015:245)
HREB MEETING DATE (If applicable):	**APPROVAL DATE:** November 25, 2015	
STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable):		

PROTOCOL NUMBER: NA	**PROJECT OR PROTOCOL TITLE:** Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences
SPONSORING AGENCIES AND/OR COORDINATING GROUPS: NA	

REMINDER: **THE CURRENT HREB APPROVAL FOR THIS STUDY EXPIRES:** **June 22, 2016**

REVIEW CATEGORY OF AMENDMENT:	**Full Board Review** ☐	**Delegated Review** ☒
Submission Date of Investigator Documents: November 16, 2015	**HREB receipt date of Documents:** November 23, 2015	

THE FOLLOWING AMENDMENT(S) and DOCUMENTS ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
Protocol:		
Revised Protocol		November 16, 2015
Consent and Assent Form(s):		
Research Participant Information and Consent Form		November 16, 2015
Research Participant Information and Consent Form - Partner		November 16, 2015
Other:		
Poster		November 16, 2015
Letter of Invitation		November 16, 2015
Interview Guide		November 16, 2015

CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the amendment to the research study/project named on this ***Certificate of Approval*** as per the category of review listed above and was found to be acceptable on ethical grounds for research involving human participants. The amendment and documents listed above were granted final approval by the Chair or Acting Chair, UM HREB.

HREB ATTESTATION

The University of Manitoba (UM) Health Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulation of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in

Division 5 of the Food and Drug Regulations of Canada and carries out its functions in a manner consistent with Good Clinical Practices.

QUALITY ASSURANCE
The University of Manitoba Research Quality Management Office may request to review research documentation from this research study/project to demonstrate compliance with this approved protocol and the University of Manitoba Policy on the Ethics of Research Involving Humans.

CONDITIONS OF APPROVAL:

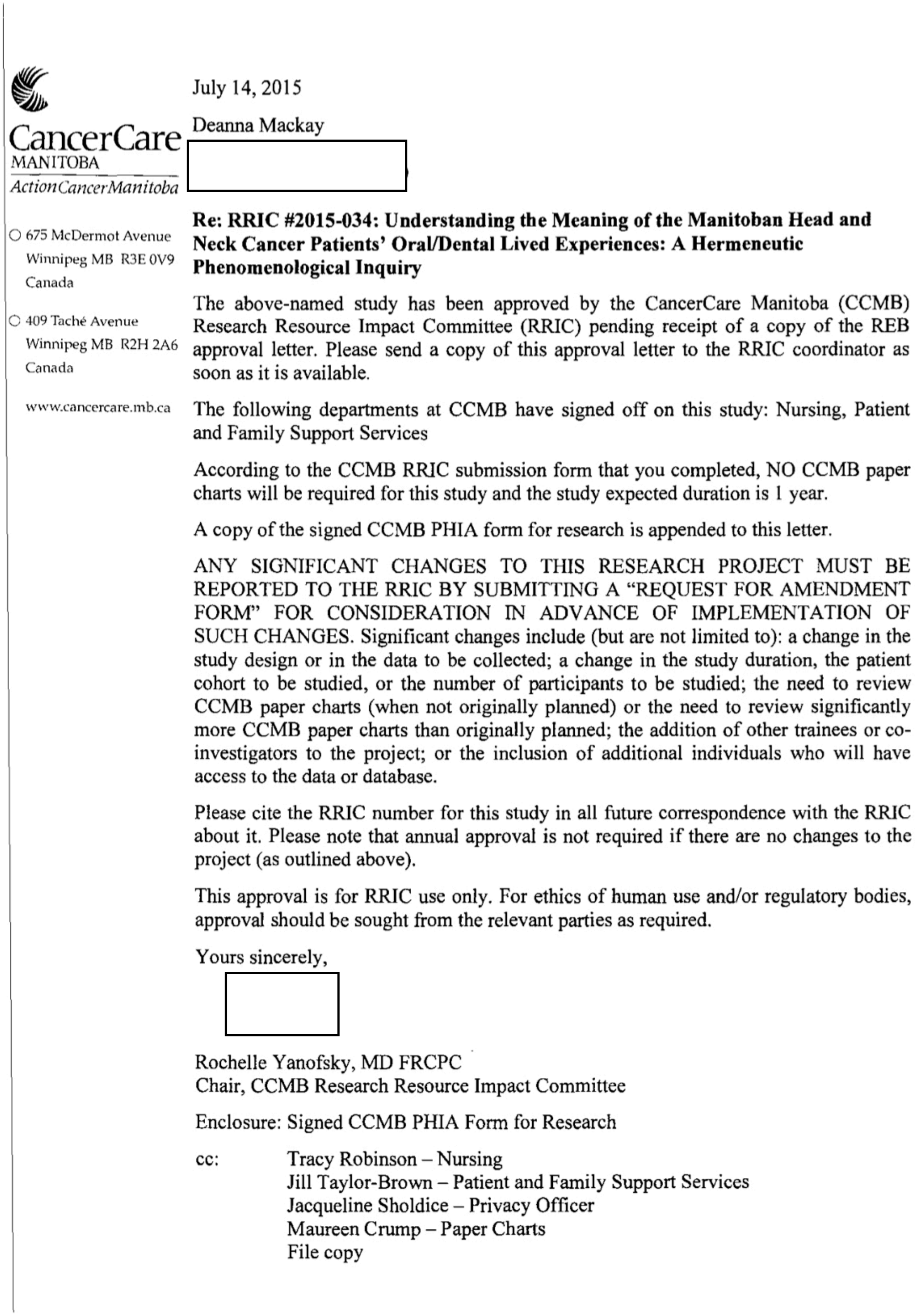
1. This amendment is acceptable on scientific and ethical grounds for the ethics of human use only. ***For logistics of performing the study, approval must be sought from the relevant institution(s).***
2. This research study/project is to be conducted by the local principal investigator listed on this certificate of approval.
3. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to the research study/project, and for ensuring that the authorized research is carried out according to governing law.
4. **<u>This approval is valid until the expiry date noted on this certificate of approval.</u> A Bannatyne Campus Annual Study Status Report** must be submitted to the HREB within 15-30 days of this expiry date.
5. Any changes of the protocol (including recruitment procedures, etc.), informed consent form(s) or documents must be reported to the HREB for consideration in advance of implementation of such changes on the **Bannatyne Campus Research Amendment Form.**
6. Adverse events and unanticipated problems must be reported to the HREB as per Bannatyne Campus Research Boards Standard Operating procedures.
7. The UM HREB must be notified regarding discontinuation or study/project closure on the **Bannatyne Campus Final Study Status Report**.

Sincerely,

[redacted]

John Arnett, PhD. C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Appendix B: Part 1, Initial CancerCare Manitoba Research Recourse Impact Committee Approval Form



CancerCare
MANITOBA
ActionCancerManitoba

○ 675 McDermot Avenue
Winnipeg MB R3E 0V9
Canada

○ 409 Taché Avenue
Winnipeg MB R2H 2A6
Canada

www.cancercare.mb.ca

July 14, 2015

Deanna Mackay
[redacted]

Re: RRIC #2015-034: Understanding the Meaning of the Manitoban Head and Neck Cancer Patients' Oral/Dental Lived Experiences: A Hermeneutic Phenomenological Inquiry

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC) pending receipt of a copy of the REB approval letter. Please send a copy of this approval letter to the RRIC coordinator as soon as it is available.

The following departments at CCMB have signed off on this study: Nursing, Patient and Family Support Services

According to the CCMB RRIC submission form that you completed, NO CCMB paper charts will be required for this study and the study expected duration is 1 year.

A copy of the signed CCMB PHIA form for research is appended to this letter.

ANY SIGNIFICANT CHANGES TO THIS RESEARCH PROJECT MUST BE REPORTED TO THE RRIC BY SUBMITTING A "REQUEST FOR AMENDMENT FORM" FOR CONSIDERATION IN ADVANCE OF IMPLEMENTATION OF SUCH CHANGES. Significant changes include (but are not limited to): a change in the study design or in the data to be collected; a change in the study duration, the patient cohort to be studied, or the number of participants to be studied; the need to review CCMB paper charts (when not originally planned) or the need to review significantly more CCMB paper charts than originally planned; the addition of other trainees or co-investigators to the project; or the inclusion of additional individuals who will have access to the data or database.

Please cite the RRIC number for this study in all future correspondence with the RRIC about it. Please note that annual approval is not required if there are no changes to the project (as outlined above).

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,

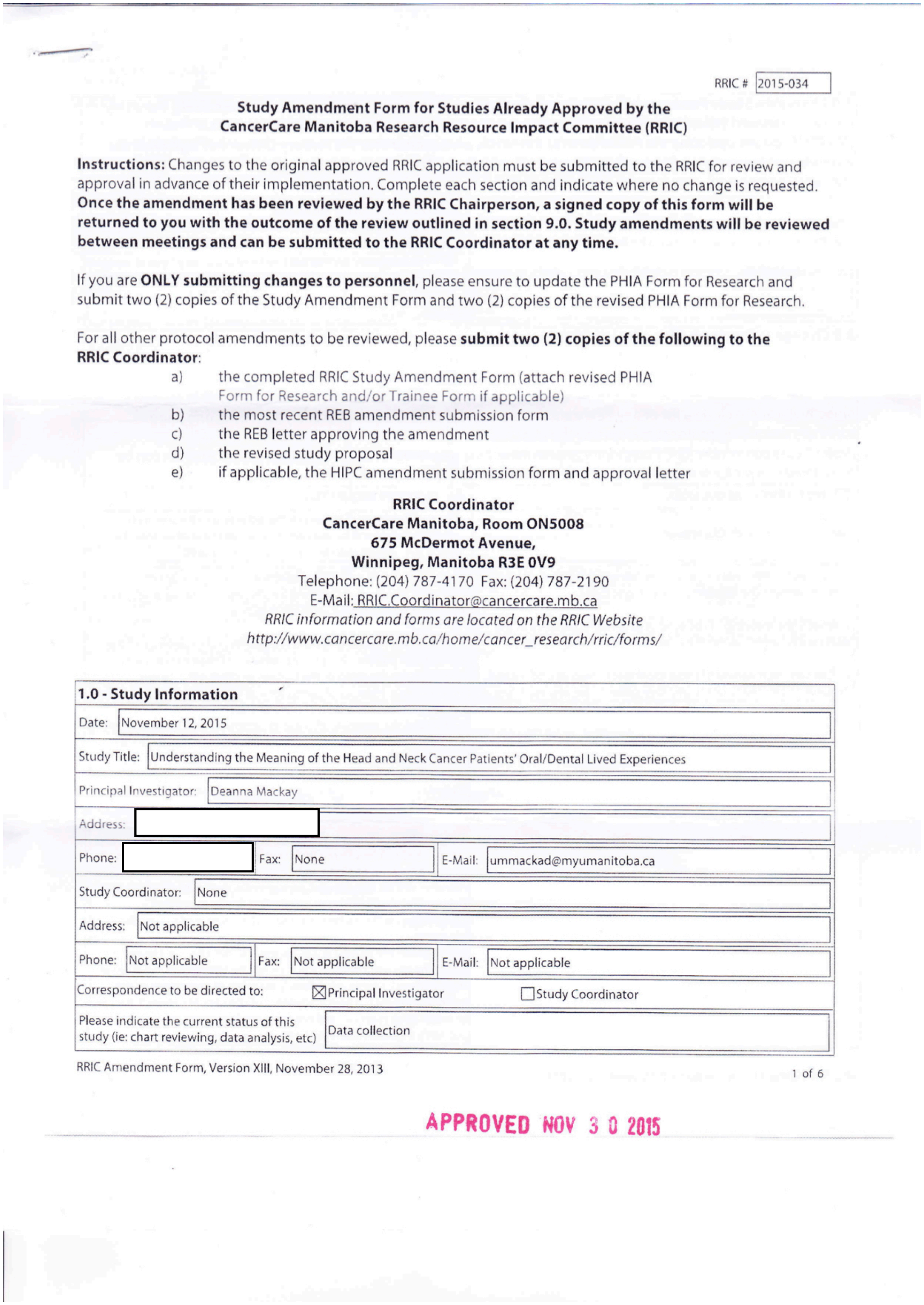
[redacted]

Rochelle Yanofsky, MD FRCPC
Chair, CCMB Research Resource Impact Committee

Enclosure: Signed CCMB PHIA Form for Research

cc: Tracy Robinson – Nursing
Jill Taylor-Brown – Patient and Family Support Services
Jacqueline Sholdice – Privacy Officer
Maureen Crump – Paper Charts
File copy

Appendix B: Part 2, Study Amendment CancerCare Manitoba Research Recourse Impact Committee Approval Form



RRIC # 2015-034

Study Amendment Form for Studies Already Approved by the CancerCare Manitoba Research Resource Impact Committee (RRIC)

Instructions: Changes to the original approved RRIC application must be submitted to the RRIC for review and approval in advance of their implementation. Complete each section and indicate where no change is requested. **Once the amendment has been reviewed by the RRIC Chairperson, a signed copy of this form will be returned to you with the outcome of the review outlined in section 9.0. Study amendments will be reviewed between meetings and can be submitted to the RRIC Coordinator at any time.**

If you are **ONLY submitting changes to personnel**, please ensure to update the PHIA Form for Research and submit two (2) copies of the Study Amendment Form and two (2) copies of the revised PHIA Form for Research.

For all other protocol amendments to be reviewed, please **submit two (2) copies of the following to the RRIC Coordinator**:

a) the completed RRIC Study Amendment Form (attach revised PHIA Form for Research and/or Trainee Form if applicable)
b) the most recent REB amendment submission form
c) the REB letter approving the amendment
d) the revised study proposal
e) if applicable, the HIPC amendment submission form and approval letter

RRIC Coordinator
CancerCare Manitoba, Room ON5008
675 McDermot Avenue,
Winnipeg, Manitoba R3E 0V9
Telephone: (204) 787-4170 Fax: (204) 787-2190
E-Mail: RRIC.Coordinator@cancercare.mb.ca
RRIC information and forms are located on the RRIC Website
http://www.cancercare.mb.ca/home/cancer_research/rric/forms/

1.0 - Study Information

Date: November 12, 2015

Study Title: Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences

Principal Investigator: Deanna Mackay

Address: [redacted]

Phone: [redacted] Fax: None E-Mail: ummackad@myumanitoba.ca

Study Coordinator: None

Address: Not applicable

Phone: Not applicable Fax: Not applicable E-Mail: Not applicable

Correspondence to be directed to: ☒ Principal Investigator ☐ Study Coordinator

Please indicate the current status of this study (ie: chart reviewing, data analysis, etc): Data collection

RRIC Amendment Form, Version XIII, November 28, 2013 1 of 6

APPROVED NOV 3 0 2015

RRIC # 2015-034

2.0 Change in Study Personnel: The RRIC must be notified of those individuals who will be accessing the study data and a revised CCMB PHIA Form for Research must be submitted with this amendment form.
(NOTE: If you are updating the PHIA Form for Research, please note that the Privacy Officer will sign once the amendment is approved. Please do not contact Health Records to obtain this signature.)

☒ **NO CHANGES REQUESTED**	☐ **CHANGES REQUESTED**
Original List of Study Personnel (as listed on the original PHIA Form for Research)	**Revised List of Study Personnel** (please specify the names and roles of all individuals who will have access to study data. A Trainee Form must be submitted for each trainee added to the study personnel list.)

3.0 Change in Research Objective(s): Often through the course of research, a supplementary research question or hypothesis must be explored that was not considered at the time of preparing the original submission. If this additional research question, hypothesis or analysis falls within the scope of the approved project, it may be considered an amendment to the original approval. Please provide a description of the additional or revised study objective(s) and include a list of any new data that is required for this additional analysis. A brief one page summary describing protocol changes can be attached.
(Note: Please contact the RRIC Coordinator to determine if the new research objective, hypothesis, or analysis can be considered as a protocol amendment or if a new submission is required.)

☐ **NO CHANGES REQUESTED**	☒ **CHANGES REQUESTED**
Approved Research Objectives	**Change/Additional Research Objectives** (please specify if additional data will be required to analyze these objectives by listing the information and years of data required.)
The proposed hermeneutic phenomenological qualitative study seeks to answer the following research questions: 1. What is the meaning of the lived oral/dental experience of the H&N cancer patient along the continuum of their cancer care? 2. How can the meaning of these experiences help us understand the patient-centred issues to improve patient care and experience?	A slight change to the study objectives is being proposed. The proposed hermeneutic phenomenological qualitative study seeks to answer the following research questions: 1. What is the meaning of the lived oral/dental experience of the H&N cancer patient along the continuum of their cancer care? 2. What is the meaning of the partner or other adult family members' experiences of caring for and living with the oral/dental experiences in the context of H&N cancer? 3. How can the meaning of these experiences help us understand the patient and family-centred issues to improve the healthcare provided and experiences? As such a slight modification to the study protocol is being proposed: The partner or other adult family member (if they choose to participate) will be offered inclusion into this study. The head and neck cancer patient along with their partner or other adult family member will be interviewed concurrently. Both individuals (cancer patient and their partner or other adult family members) perspectives will now be explored in the context of this study. The recruitment of the cancer patient will not change. However, when the patient contacts me they will be offered the inclusion of their partner or other adult family member to participate in the interview process . The participation of the cancer patient's partner or other adult member will not have any baring on the cancer patient's inclusion into this study.

RRIC # 2015-034

4.0 Change in Study Design and/or Data Collection: Please indicate the type of study and source of data collection, including years for which access was originally approved. In the adjacent column, list any changes to the type of study, the data collection, and/or years required. Note that it is important to describe why the originally approved data were insufficient.

(Note: If a new research question or hypothesis is being tested, this may be considered a new project. Please contact the RRIC Coordinator to determine if a new submission is required.)

(Note: If you are making changes to the "Years Requested" please also complete section 5.0)

☐ **NO CHANGES REQUESTED**			☒ **CHANGES REQUESTED**		
Original Study Type, Data Source, and/or Years Requested (as listed in the original RRIC submission)			**Changes to Study Type, Data Source, and/or Years Requested**		
Study Type	Data Source	Years	Study Type	Data Source	Years
☒ Qualitative	☐ Survey		☒ Qualitative	☐ Survey	
☐ Quantitative	☐ Electronic Chart Audit		☐ Quantitative	☐ Electronic Chart Audit	
☐ Retrospective Record Review	☐ Paper Chart Audit		☐ Retrospective Record Review	☐ Paper Chart Audit	
☐ Other (specify):	☐ Cancer Registry		☐ Other (specify):	☐ Cancer Registry	
	☐ Existing Database			☐ Existing Database	
	☒ Other (specify):			☒ Other (specify):	
	Head and neck cancer patient			Head and neck cancer patient and potentially their partner or other adult family member who lived and cared for the patient during this proposed study experiences.	

Reason for change(s):

At each of the three interviews conducted thus far a family member has been present (at the request of the cancer patient) and they have had variable contributions at each interview. It has become apparent through the interviews done thus far that the partners of the cancer patients have an important perspective to share about living with the oral/dental experiences in the context of head and neck cancer. Currently, the interview questions are not directed to the partner or other adult family member of the cancer patient. However, it is believed to gain a better understanding of the oral/dental experiences in the context of head and neck cancer it appears that the partner/adult family member needs to be offered inclusion and their perspective explored.

As such, developing an understanding of the meaning of the lived oral/dental experiences during cancer treatment completely, it is proposed that the partner or other adult family member of the cancer patient be offered inclusion into the study.

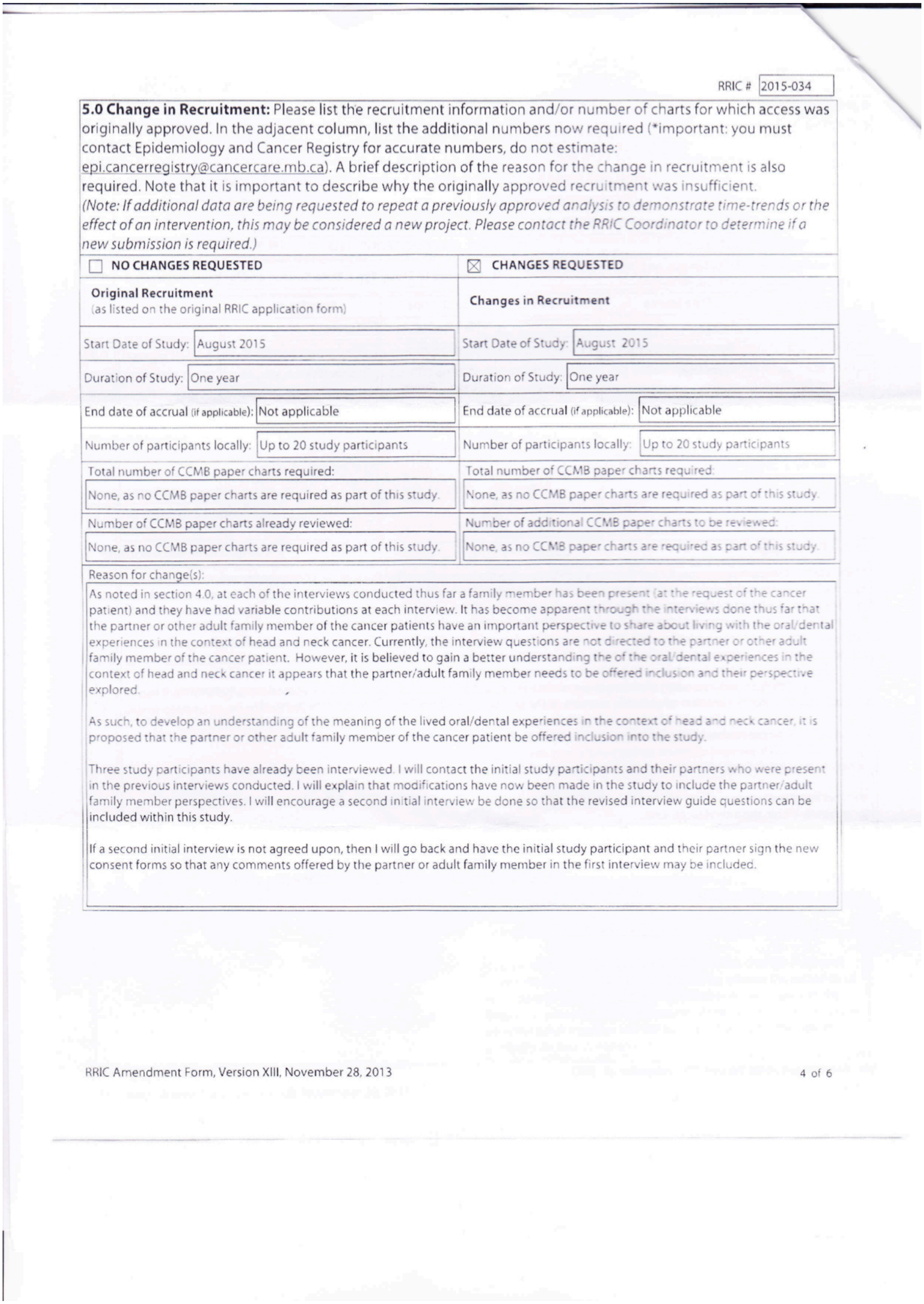
Because of this proposed change the following modifications to documents are needed for approval:

- a new partner/adult family member consent form has been drafted. As such this is included as a document for approval.

-the cancer patient's consent form needed to be modified to include the offer of the partner/adult family member's participation concurrently within the interview process.

- the interview guide needed to be altered slightly for the potential inclusion of the partner/adult family member of the cancer patient.

- the letter of invitation for participation and the recruitment poster needed to be modified to include the offer of participation of the partner or other adult family member into the study.



RRIC # 2015-034

5.0 Change in Recruitment: Please list the recruitment information and/or number of charts for which access was originally approved. In the adjacent column, list the additional numbers now required (*important: you must contact Epidemiology and Cancer Registry for accurate numbers, do not estimate: epi.cancerregistry@cancercare.mb.ca). A brief description of the reason for the change in recruitment is also required. Note that it is important to describe why the originally approved recruitment was insufficient. *(Note: If additional data are being requested to repeat a previously approved analysis to demonstrate time-trends or the effect of an intervention, this may be considered a new project. Please contact the RRIC Coordinator to determine if a new submission is required.)*

☐ **NO CHANGES REQUESTED**	☒ **CHANGES REQUESTED**
Original Recruitment (as listed on the original RRIC application form)	**Changes in Recruitment**
Start Date of Study: August 2015	Start Date of Study: August 2015
Duration of Study: One year	Duration of Study: One year
End date of accrual (if applicable): Not applicable	End date of accrual (if applicable): Not applicable
Number of participants locally: Up to 20 study participants	Number of participants locally: Up to 20 study participants
Total number of CCMB paper charts required: None, as no CCMB paper charts are required as part of this study.	Total number of CCMB paper charts required: None, as no CCMB paper charts are required as part of this study.
Number of CCMB paper charts already reviewed: None, as no CCMB paper charts are required as part of this study.	Number of additional CCMB paper charts to be reviewed: None, as no CCMB paper charts are required as part of this study.

Reason for change(s):

As noted in section 4.0, at each of the interviews conducted thus far a family member has been present (at the request of the cancer patient) and they have had variable contributions at each interview. It has become apparent through the interviews done thus far that the partner or other adult family member of the cancer patients have an important perspective to share about living with the oral/dental experiences in the context of head and neck cancer. Currently, the interview questions are not directed to the partner or other adult family member of the cancer patient. However, it is believed to gain a better understanding the of the oral/dental experiences in the context of head and neck cancer it appears that the partner/adult family member needs to be offered inclusion and their perspective explored.

As such, to develop an understanding of the meaning of the lived oral/dental experiences in the context of head and neck cancer, it is proposed that the partner or other adult family member of the cancer patient be offered inclusion into the study.

Three study participants have already been interviewed. I will contact the initial study participants and their partners who were present in the previous interviews conducted. I will explain that modifications have now been made in the study to include the partner/adult family member perspectives. I will encourage a second initial interview be done so that the revised interview guide questions can be included within this study.

If a second initial interview is not agreed upon, then I will go back and have the initial study participant and their partner sign the new consent forms so that any comments offered by the partner or adult family member in the first interview may be included.

RRIC # 2015-034

6.0 Change in Location of Data Storage and/or Analysis: The RRIC and PHIA office must be notified if data will be stored or analyzed at a location other than that which was originally approved. A complete description of the data security procedures at the new location must be included. A revised CCMB PHIA Form for Research must be completed and submitted.

☒ **NO CHANGES REQUESTED**	☐ **CHANGES REQUESTED**
Approved Location of Data Storage/Access	**New or Additional Data Storage/Access Location** (Please include a description of the security measures in place to protect the confidentiality of the data.)

7.0 Other: Please outline requested changes not described above.

☒ **NO CHANGES REQUESTED**	☐ **CHANGES REQUESTED**
Approved process/procedure	**Requested changes**

RRIC # 2015-034

8.0 Signatures

Deanna Mackay
Name of Principal Investigator

[redacted]
Signature of Principal Investigator

Nov 17/15
Date

Dr. Alan Katz and Dr. Christina West
Name of Supervisor (if PI is a Trainee)

[redacted]
Signature of Supervisor

Nov. 12/2015
Date

9.0 For RRIC Use Only:

Departments Impacted by Change:	Contact:	Signature:	Date:
☐ Cancer Registry	Ms Gail Noonan (204) 787-2157		
☐ Epidemiology	Dr. Jane Griffith (204) 235-3277		
☐ Health Information/Health Records	Ms Jacqueline Sholdice (204) 787-2266		
☐ Privacy Officer	Ms Jacqueline Sholdice (204) 787-2266		
☐ Clinical Investigations Office	Ms Kathryn Dyck (204) 787-2127		
☒ Other: Nursing PFSS	Tracy Robinson Jill Taylor-Brown	[redacted]	30 Nov 2015

Approved:

☑ Yes

[redacted]
Signature of RRIC Chairperson

Nov 30/15
Date

Approved:

☐ No

Reason for not approving:

☐ Requires Full Committee Review

☐ Information Missing:

☐ Other:

Save Completed Form

Appendix C: Part 1, Initial Study Participant Consent Form

University of Manitoba
Faculty of Health Sciences

College of Medicine
Department of
Community Health Sciences
750 Bannatyne Avenue
Winnipeg, Manitoba,
Canada, R3E 0W2
Telephone 204-789-3714
Fax 204-789-3905

Title of Study: Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences.

Principal Investigator: Deanna Mackay
[redacted]
Email: ummackad@myumanitoba.ca

Co-Supervisors:
Dr Alan Katz
Professor, Department of Community Health Sciences
Phone 204-789-3442
Email: akatz@cpe.umanitoba.ca

Dr. Christina West
Assistant Professor, College of Nursing
Phone 204-474-8001
Email: christina.West@umanitoba.ca

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to develop an understanding of the experiences of patients with head and neck cancer in Manitoba. We are particularly interested in oral and dental experiences in relation to your cancer treatment (in preparation for, during and after). Understanding the meaning of the patient experience provides insight for healthcare providers and decision makers to improve the quality of care provided, and to enhance the interactions and reduce barriers within the patient experience.

Up to 20 study participants will participate in this study.

Study Procedures

If you take part in this study, you will be interviewed two (2) times. Both interviews will be audio recorded. The recorded audio of the interview will be written down exactly into a word processing program document.

At the beginning of the first interview you will be asked to share your age, sex, stage of cancer, cancer prognosis, anatomical location of your cancer and the treatment you received (surgery, chemotherapy and/or radiation therapy). Following that, your oral and dental experiences in relation to your cancer treatment will be explored through a 60 to 120 minute conversational interview.

After your interview has been printed, the researcher will then review your personal narrative and summarize it by identify the emerging themes that capture the meaning of your oral and dental experiences. This process is also called thematic analysis.

At the second interview you will be asked to review the summary of your narrative. You will be asked if you agree with the summary and if you have anything else that you would like add.

Within the final analysis of the findings the researcher will review the study participants narratives individually and as a group to identify the central themes that emerge that provide understanding to the meaning of the head and neck cancer patient's oral and dental experiences in relation to their cancer treatment (in preparation for, during and after).

Your participation in this study will be complete after your second interview or when you agree with the summary and themes that emerged from your personal narrative. The researcher may decide to take you out of this study if it is felt that in recalling your experiences that you are experiencing emotional distress.

You can stop participating in this study at any time. However, if you decide to stop participating in the study, it is encouraged that you to talk to the principle investigator first.

At the end of the study, you will be asked if you would like a written copy of your interviews. If yes, this document will be hand delivered by the researcher at a location of convenience to you.

Risks and Discomforts

An anticipated risk to you for your participation in this study may be emotional distress. For some study participants reflecting on their oral/dental experiences may be upsetting or distressing as you recall your own illness experience, or the experience of your family member(s). If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Therefore, in anticipation of this potential risk, contact information will be readily available to you to Patient and Family Support Service staff at CancerCare Manitoba.

Benefits

There may or may not be direct benefit to you from participating in this study. It is hoped that the information learned from this study will benefit other people with a cancer to the head and neck region in the future.

Payment for participation

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Your individual information will be de-identified. All study related documents will bear only your assigned study number. Only the primary investigator will know which assigned study number matches which study participant. Direct quotations that can be directly attributed to you will not be used. Further, combined or mixed stories and/or generalization of age, sex and anatomical site of cancer may be necessary in the reporting of the study findings to protect the identity of the study participants. Your experience will be reported using a false name to further protect your anonymity. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

Your interviews will be entered into the principle investigators laptop computer. Audio recordings will be retained on the audio devise for up to one year. Once your audio recordings have been transcribed they will be deleted from the hard drive of the audio device. The laptop computer will be password protected and the data will be encrypted for further security.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

The principle investigator will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, contact the principle investigator Deanna Mackay at [redacted].

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Deanna Mackay. I have had my questions answered by Deanna in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature ______________________________________ Date________________
(day/month/year)

Participant printed name: ____

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed name ____ Date _________________
(day/month/year)

Signature: ____

Role in the study: Principle investigator

Appendix C: Part 2, Amended Study Participant Consent Form

UNIVERSITY OF MANITOBA | Faculty of Health Sciences

College of Medicine
Department of
Community Health Sciences
750 Bannatyne Avenue
Winnipeg, Manitoba,
Canada, R3E 0W2
Telephone 204-789-3714
Fax 204-789-3905

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences.

Principal Investigator: Deanna Mackay
[redacted]
Email: ummackad@myumanitoba.ca

Co-Supervisors:
Dr Alan Katz
Professor, Department of Community Health Sciences
Phone 204-789-3442
Email: akatz@cpe.umanitoba.ca

Dr. Christina West
Assistant Professor, College of Nursing
Phone 204-474-8001
Email: christina.West@umanitoba.ca

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to develop an understanding of the experiences of patients with head and neck cancer. We are particularly interested in oral and dental experiences in relation to your cancer treatment (in preparation for, during and after). In addition, if your partner or other adult family member would like to be included in this study they will be invited to share their perspective of living with and caring for you. Understanding the meaning of the patient experience (and that of your partner or other adult family member if they choose to be included) provides insight for healthcare providers and decision makers to improve the quality of care provided, and to enhance the interactions and reduce barriers within the patient (and their partner or other adult family member) experience(s). Up to 20 study participants will participate in this study.

Study Procedures

If you take part in this study, you will be interviewed two (2) times (with your partner or other adult family member if they decide to be included). Both interviews will be audio recorded. The recorded audio of the interview will be written down exactly into a word processing program document.

At the beginning of the first interview you will be asked to share your age, sex, stage of cancer, cancer prognosis, anatomical location of your cancer and the treatment you received (surgery, chemotherapy and/or radiation therapy). Following that, your oral and dental experiences in relation to your cancer treatment will be explored through a 60 to 120 minute conversational interview.

After your interview has been printed, the researcher will then review your personal narrative and summarize it by identifying the emerging themes that capture the meaning of your oral and dental experiences. This process is also called thematic analysis.

At the second interview you will be asked to review the summary of your narrative. You will be asked if you agree with the summary and if you have anything else that you would like to add.

Within the final analysis of the findings the researcher will review the study participants narratives individually and as a group to identify the central themes that emerge that provide understanding to the meaning of the head and neck cancer patient's oral and dental experiences in relation to their cancer treatment (in preparation for, during and after).

Your participation in this study will be complete after your second interview or when you agree with the summary and themes that emerged from your personal narrative. The researcher may decide to take you out of this study if it is felt that in recalling your experiences that you are experiencing emotional distress.

You can stop participating in this study at any time. However, if you decide to stop participating in the study, it is encouraged that you to talk to the principle investigator first.

At the end of the study, you will be asked if you would like a written copy of your interviews. If yes, this document will be hand delivered by the principle investigator at a location of convenience to you.

Risks and Discomforts

An anticipated risk to you for your participation in this study may be emotional distress. For some study participants reflecting on their oral/dental experiences may be upsetting or distressing as you recall your own illness experience, or the experience of your partner, or family member(s). If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Therefore, in anticipation of this potential risk, contact information will be readily available to you to Patient and Family Support Service staff at CancerCare Manitoba.

Benefits

There may or may not be direct benefit to you from participating in this study. It is hoped that the information learned from this study will benefit other people with a cancer to the head and neck region in the future.

Payment for participation

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Your individual information will be de-identified. All study related documents will bear only your assigned study number. Only the principle investigator will know which assigned study number matches which study participant. Direct quotations that can be directly attributed to you will not be used. Further, combined or mixed stories and/or generalization of age, sex and anatomical site of cancer and/or your relationship status to your partner or other adult family member (if they choose to participate) may be necessary in the reporting of the study findings to protect the identity of the study participants. Your experience will be reported using a false name to further protect your anonymity. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

Your interviews will be entered into the principle investigators laptop computer. Audio recordings will be retained on the audio devise for up to one year. Once your audio recordings have been transcribed they will be deleted from the hard drive of the audio device. The laptop computer will be password protected and the data will be encrypted for further security.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care, (your partner or other adult family members) receive from CancerCare Manitoba. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

The principle investigator will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, contact the principle investigator Deanna Mackay at [redacted].

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Deanna Mackay. I have had my questions answered by Deanna in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature ______________________________________ Date_________________
(day/month/year)

Participant printed name: ____

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed name ____ Date ________________
(day/month/year)

Signature: ____

Role in the study: Principle investigator

Appendix C: Part 3, Partner or Other Adult Family Member Study Consent Form

University of Manitoba | Faculty of Health Sciences

College of Medicine
Department of
Community Health Sciences
750 Bannatyne Avenue
Winnipeg, Manitoba,
Canada, R3E 0W2
Telephone 204-789-3714
Fax 204-789-3905

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Title of Study: Understanding the Meaning of the Head and Neck Cancer Patients' Oral/Dental Lived Experiences.

Principal Investigator: Deanna Mackay
[redacted]
Email: ummackad@myumanitoba.ca

Co-Supervisors:
Dr Alan Katz
Professor, Department of Community Health Sciences
Phone 204-789-3442
Email: akatz@cpe.umanitoba.ca

Dr. Christina West
Assistant Professor, College of Nursing
Phone 204-474-8001
Email: christina.West@umanitoba.ca

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research study is being conducted to develop an understanding of the experiences of patients with head and neck cancer. We are particularly interested in oral and dental experiences in relation to your partner's or family member's cancer treatment (in preparation for, during and after). Additionally, we are interested in your perspective of living with and caring for your partner or family member during these experiences. Understanding the meaning of the patient and their partner or other adult family member's experiences provides insight for healthcare providers and decision makers to improve the quality of care provided, and to enhance the interactions and reduce barriers within the patient, their partner or other adult family member's experiences. Up to 20 study participants will participate in this study.

Study Procedures

If you take part in this study, you will be interviewed two (2) times along with your partner or other adult family member. Both interviews will be audio recorded. The recorded audio of the interview will be written down exactly into a word processing program document.

At the beginning of the first interview you will be asked to share your relationship status to the patient with a cancer of the head and neck region. Following that, your experience of living with and caring for your partner or family member during their oral and dental experiences in relation to their cancer treatment will be explored through a 60 to 120 minute conversational interview.

After your interview has been printed, the researcher will then review your personal narrative and summarize it by identifying the emerging themes that capture the meaning of your experience of living with and caring for your partner or family member during their oral and dental experiences with treatment. This process is also called thematic analysis.

At the second interview you will be asked to review the summary of your narrative. You will be asked if you agree with the summary and if you have anything else that you would like to add.

Within the final analysis of the findings the researcher will review the study participants narratives individually and as a group to identify the central themes that emerge that provide understanding to the meaning of your experiences of living with and caring for your partner or adult family member during their oral and dental experiences in relation to their treatment (in preparation for, during and after).

Your participation in this study will be complete after your second interview or when you agree with the summary and themes that emerged from your personal narrative. The researcher may decide to take you out of this study if it is felt that in recalling your experiences that you are experiencing emotional distress.

You can stop participating in this study at any time. However, if you decide to stop participating in the study, it is encouraged that you to talk to the principle investigator first.

At the end of the study, you will be asked if you would like a written copy of your interviews. If yes, this document will be hand delivered by the principle investigator at a location of convenience to you.

Risks and Discomforts

An anticipated risk to you for your participation in this study may be emotional distress. For some study participants reflecting on their experiences may be upsetting or distressing as you recall your own experiences, or the experiences of your partner, or family member(s). If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Therefore, in anticipation of this potential risk, contact information will be readily available to you to Patient and Family Support Service staff at CancerCare Manitoba.

Benefits

There may or may not be direct benefit to you from participating in this study. It is hoped that the information learned from this study will benefit other people with a cancer to the head and neck region in the future, as well as their partners or adult family members.

Payment for participation

You will receive no payment or reimbursement for any expenses related to taking part in this study.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Your individual information will be de-identified. All study related documents will bear only your assigned study number. Only the principle investigator will know which assigned study number matches which study participant. Direct quotations that can be directly attributed to you will not be used. Further, combined or mixed stories and/or generalization of age, sex and anatomical site of your partner or family member's cancer and/or your relationship status to your partner may be necessary in the reporting of the study findings to protect the identity of the study participants. Your experience will be reported using a false name to further protect your anonymity. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

Your interviews will be entered into the principle investigators laptop computer. Audio recordings will be retained on the audio devise for up to one year. Once your audio recordings have been transcribed they will be deleted from the hard drive of the audio device. The laptop computer will be password protected and the data will be encrypted for further security.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect the care you, your partner or adult family member receive from CancerCare Manitoba. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent.

The principle investigator will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, contact the principle investigator Deanna Mackay at [redacted].

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Deanna Mackay. I have had my questions answered by Deanna in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature ______________________________________ Date________________
(day/month/year)

Participant printed name: ____

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed name ____ Date _________________
(day/month/year)

Signature: ____

Role in the study: Principle investigator

Appendix D: CCMB Patient and Family Support Services Contact Information

Participation in this study may be upsetting or distressing to you as you recall your own illness experience, or the experience of your family member. If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Please call 204-787-2109 or toll free 1-800-561-1026, or if you would like I can refer you to them.

Appendix E: Recruitment Letter

UNIVERSITY OF MANITOBA | Faculty of Health Sciences

College of Medicine
Department of
Community Health Sciences
750 Bannatyne Avenue
Winnipeg, Manitoba,
Canada, R3E 0W2
Telephone 204-789-3714
Fax 204-789-3905

Dear potential study participant:

My name is Deanna Mackay. I am a dental hygienist and a student in the Master's of Science Program in the Department of Community Health Sciences within the College of Medicine at the University of Manitoba. My study supervisors are Dr. Alan Katz, Professor in the Department of Community Health Sciences and Dr. Christina West, Assistant Professor in the College of Nursing.

This research study is being conducted to develop an understanding of the experiences of patients with head and neck cancer. We are particularly interested in oral and dental experiences in relation to your cancer treatment (in preparation for, during and after). In addition, if your partner or other adult family member would like to be included in this study, we are inviting them to also share their perspective of living with and caring for you during these experiences.

If you (and your partner or other adult family member) agree to participate in the study you will be interviewed twice by myself. Your interviews will occur at a location of convenience to you. The first interview will take approximately 1 to 2 hours and the second interview will take approximately 1 hour.

If you (and your partner or other adult family member) would like to be part of this study or would like more information, please contact Deanna Mackay directly by email at ummackad@myumanitoba.ca or call .

Sincerely,

Deanna Mackay, BDSc (DH), RDH

Appendix F: Recruitment Poster

Did you experience oral and dental side effects during your cancer treatment?

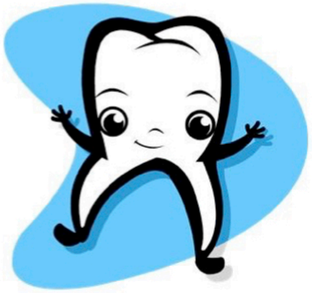
- Have you been diagnosed with a cancer in your mouth, throat or saliva (spit) glands?
- Did you receive more than 4 weeks of radiation therapy?
- During your recovery from your cancer treatment did you or are you still experiencing any oral or dental side effects to your cancer treatments?

If you answered YES to these questions then we would like to hear from you!

Researchers from the University of Manitoba are conducting a study to develop an understanding of the head and neck cancer patient's oral and dental experiences in relation to their cancer treatment.

You will be asked to share your:

- oral and dental experiences in relation to your cancer treatment (in getting ready for, during and after);
- age;
- location of cancer;
- stage of cancer;
- prognosis of cancer; and
- the cancer treatment that you received (surgery, chemotherapy and/or radiation therapy)



If your partner or other adult family member would like to be included in this study we invite them to also share their perspective of living with and caring for you during these experiences.

If you would like to be part of this study or would like more information, please contact:

University of Manitoba **Deanna Mackay by email at ummackad@myumanitoba.ca or call** [redacted]

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Deanna Mackay
Oral and dental experiences
ummackad@myumanitoba.ca
[redacted] after 6 p.m.

Appendix G: Original Interview Guide

Thank you for agreeing to meet with me. I appreciate the time that you have set aside for me to do this interview. As mentioned in the consent form you signed, I will be audio recording our discussion. I just want to confirm your approval that I can audio record our discussion. Do you approve that I audio record our discussion?

I understand that sharing your experiences with me might be difficult or upsetting to you. At any time, if you want to stop this interview we can. Or if you do not want to answer one or more of the questions please feel comfortable to tell me so as you do not have to answer anything that you are not comfortable with sharing. We will only talk about what you are comfortable with so please feel no pressure. Also, if you need to 'take a break' we can do so whenever or how many times you want to.

I am not employed by or have any ties to CancerCare Manitoba. All the information that you share with me will be kept confidential. No specific information from this interview will be shared with your care providers at CCMB. You can leave this study at any time and there will be no negative consequence from myself or in the care you are receiving at CCMB.

Participation in this study may be upsetting or distressing to you as you recall your own illness experience, or the experience of your family member. If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Please call 204-787-2109 or toll free 1-800-561-1026, or if you would like I can refer you to them. I have written this information down for you (provide participant with this document).

I would like to learn about your cancer experience especially about what happened with your mouth and teeth before, during and after your treatment

4. 1. What was it like?

5. 2. What was it like to prepare your mouth and teeth to start your cancer treatment?

6. 3. What did you experience in your mouth and with your teeth during your cancer treatment?

7. 4. What is it like now in your mouth and with your teeth?

8. 5. What were and are some of your challenges?

9. 6. If you could change anything about what you experienced with your mouth and teeth what would it be?

10. 7. What advice would you give to health care professionals about how they can best support you?

    A. The dental team?
    B. Your CCMB team?

8. What would you like to see in regard to resources that could assist you in your care?

9. What advice would you give to other patients about what you experience with your mouth and teeth?

10. Is there anything else that you would like to talk about that we did not talk about today?

Note: Probes will be used as necessary to further or enrich the discussion.

Possible probes:

- What were you feeling?
- How does that make you feel?
- Do you remember how that made you feel?
- What were you thinking?
- Can you give me some examples?
- Could you give me an example of that?
- Can you describe that to me?
- What did that do for you?
- Go on……. Could you elaborate more on that?
- (After a period of silence, ask) Can you tell me what you are thinking about?

I will not say:

Don't you think…….?

Did you find that…...?

Do you think it was because they were…….?

Appendix H: Amended Interview Guide

Thank you for agreeing to meet with me. I appreciate the time that you have set aside for me to do this interview. As mentioned in the consent form you signed, I will be audio recording our discussion. I just want to confirm your approval that I can audio record our discussion. Do you approve that I audio record our discussion?

I understand that sharing your experiences with me might be difficult or upsetting to you (or to the both of you). At any time, if you want to stop this interview we can. Or if you do not want to answer one or more of the questions please feel comfortable to tell me so as you do not have to answer anything that you are not comfortable with sharing. We will only talk about what you are comfortable with, so please feel no pressure. Also, if you need to 'take a break' we can do so whenever or how many times you want to.

I am not employed by or have any ties to CancerCare Manitoba. All the information that you share with me will be kept confidential. No specific information from this interview will be shared with your care providers at CCMB. You can leave this study at any time and there will be no negative consequence from myself or in the care you are receiving at CCMB.

Participation in this study may be upsetting or distressing to you as you recall your own illness experience, or that of your partner or family member. If you would like to talk to someone about this, there is support available through CancerCare Manitoba Patient and Family Support Services. Please call 204-787-2109 or toll free 1-800-561-1026, or if you would like I can refer you to them. I have written this information down for you (both) (provide participant(s) with this document).

Addressed to the patient: I would like to learn about your cancer experience especially about what happened with your mouth and teeth before, during and after your treatment.

Addressed to the partner of patient: And your experience of living with and caring for your partner during these experiences.

11. **1. To both participants:** What was it like?

2. To the cancer patient: What was it like to prepare your mouth and teeth to start your cancer treatment?

To the partner or other adult family member: From your perspective what was this experience like?

3. To the cancer patient: What did you experience in your mouth and with your teeth during your cancer treatment?

To the partner or other adult family member: What was your experience of living and caring for your partner/family member during cancer treatment?

4. **To the cancer patient**: What is it like now in your mouth and with your teeth?

   To the partner or other adult family member: From your perspective what has changed with your partner/family member's teeth or mouth since their treatment is complete?

5. **To both participants:** What were and are some of your challenges?

6. **To the cancer patient**: If you could change anything about what you experienced with your mouth and teeth what would it be?

   To the partner or other adult family member: When you think back to living with and caring for ________ during his/her oral/dental experience in cancer treatment, what one thing would you most want to change? For ______? For yourself?

7. **To both participants:** What advice would you give to health care professionals about how they can best support you?

A. The dental team?

B. Your CCMB team?

8. **To both participants:** What would you like to see in regard to resources that could assist you in your care? (to the patient) …to you as the patient's caregiver? (to the partner/family member).

9. **To the cancer patient:** What advice would you give to other patients based on what you experienced with your mouth and teeth? ….and to the patient's caregiver? (partner or family member)

   To the partner or other adult family member: What advice would you give to other patients based on what you experienced with your partner/family member's mouth and teeth? …and to the patient's caregiver? (partner or family member)

10. **To both participants:** Is there anything else that you would like to talk about that we did not talk about today?

<u>Note: Probes will be used as necessary to further or enrich the discussion.</u>

Possible probes:

- What do you think about what "x" is saying? Tell me more. What would be your perspective?
- I hear "X" saying this, what is your perspective?
- What effect did that have on you?
- In thinking back to _____ (eg. husband not eating b/c of mouth pain), what do you feel is most important for me to understand about what that experience was like for you?

- What were you feeling?
- How does that make you feel?
- Do you remember how that made you feel?
- What were you thinking?
- Can you give me some examples?
- Could you give me an example of that?
- Can you describe that to me?
- What did that do for you?
- Go on……. Could you elaborate more on that?
- (After a period of silence, ask) Can you tell me what you are thinking about?

<u>I will not say:</u>

Don't you think…….?

Did you find that…...?

Do you think it was because they were…….?

Appendix I: Summary Table of Study Participants

Index participant **Age at the time of interview**	**Partner or adult family member included in interview**	**Stage of cancer, diagnosis, and the location of cancer**	**Cancer treatment received** **Retired, worked through or went on a medical leave during cancer treatment?**	**Time elapsed post-treatment to interview**	**Resides in Winnipeg or outside of city limits** **Residence during treatment**
Bill Age: In his sixties	Yes, wife Karen	Stage 4 - Squamous cell carcinoma with two lymph nodes involved on right side of neck Location: Unknown primary	- 30 daily radiation therapy treatments - Surgery: neck dissection - Retired	~ 7 years post cancer treatment	Resides outside of the city limits of Winnipeg Commuted daily to/from home for daily treatment
Chris (initial interview) Age: In his sixties	Yes, wife Janice	Stage 4 - Squamous cell carcinoma Location: Base of tongue	- 35 daily radiation therapy treatments - 7 of 8 chemotherapy treatments completed - Medical leave of absence	~ 7 months post cancer treatment	Lives in Winnipeg
Chris (second interview) Age: In his sixties	Yes, wife Janice	Recurrent Location: lymph node on one side of neck	- 28 localized daily radiation therapy treatments - Surgery: neck dissection - 2 chemotherapy treatments - Medical leave of absence	~ 2 months post cancer treatment	Lives in Winnipeg

Index participant **Age at the time of interview**	**Partner or adult family member included in interview**	**Stage of cancer, diagnosis, and the location of cancer**	**Cancer treatment received** **Retired, worked through or went on a medical leave during cancer treatment?**	**Time elapsed post-treatment to interview**	**Resides in Winnipeg or outside of city limits** **Residence during treatment**
John Age: In his sixties	Yes, wife Tracy	Stage 4 - Unknown primary Location: lymph nodes on one side of neck	- 35 daily radiation therapy treatments - 3 chemotherapy treatments - Medical leave of absence (self-employed)	~ 3 months post cancer treatment	Resides outside of the city limits of Winnipeg Monday to Friday stayed at a family friends home alone close to urban cancer centre and returned home to family on weekends
Michael Age: In his sixties	No	Stage 4 - Cancer in throat involving vocal chords Location: Larynx	- 33 daily radiation therapy treatments - Surgery: Total laryngectomy and thyroid removal - Retired	~ 7 years post cancer treatment	Resides outside of the city limits of Winnipeg Commuted daily to and from home with the Canadian Cancer Society Drivers Program

Index participant **Age at the time of interview**	**Partner or adult family member included in interview**	**Stage of cancer, diagnosis, and the location of cancer**	**Cancer treatment received** **Retired, worked through or went on a medical leave during cancer treatment?**	**Time elapsed post-treatment to interview**	**Resides in Winnipeg or outside of city limits** **Residence during treatment**
Cheryl Age: In her sixties	No	Stage 4 - early advanced squamous cell carcinoma Location: base of tongue	- 35 daily radiation therapy treatments - 2 of 3 chemotherapy treatments completed - Medical leave of absence	~ 5 years post cancer treatment	Lives in Winnipeg
Sam Age: In his forties	No	Stage 4 - HPV positive Location: base of tongue with node involved on one side of neck	- 35 daily radiation therapy treatments - 2 chemotherapy treatments - Worked throughout his entire course of cancer treatment	~ 5.5 months post cancer treatment	Resides outside the city limits of Winnipeg Commuted daily to/from home for daily treatment
Cliff Age: In his seventies	No	Stage 3 - Unknown primary Location: 3 lymph nodes on one side of neck	- 35 daily radiation therapy treatments - 2 chemotherapy treatments completed, 4 treatments planned - Medical leave of absence	~ 8.5 years post cancer treatment	Lives in Winnipeg

Index participant **Age at the time of interview**	**Partner or adult family member included in interview**	**Stage of cancer, diagnosis, and the location of cancer**	**Cancer treatment received** **Retired, worked through or went on a medical leave during cancer treatment?**	**Time elapsed post-treatment to interview**	**Resides in Winnipeg or outside of city limits** **Residence during treatment**
Jason Age: In his sixties	Yes, wife Patti	Stage 4 - HPV positive, invasive squamous cell carcinoma Location: base of tongue	- 35 daily radiation therapy treatments - 8 chemotherapy treatments - Retired	~ 3.5 years post cancer treatment	Lives in Winnipeg
Kevin Age: In his forties	No	Stage 4 - Unknown Primary, assumed to be HPV positive Location: - Suspected to be the base of tongue, with nodes involved on one side of neck	- 40 daily radiation therapy treatments - 3 chemotherapy treatments - Medical leave of absence	~ 2 years post cancer treatment	Resides outside of the city limits of Winnipeg Original plan was to stay Monday to Friday at a family member home alone in the city of the urban cancer centre and returned home on the weekends. However, he was too ill to drive home shortly into treatments. Therefore, he stayed in the city alone for most of his cancer treatments

*All names are pseudonyms

Appendix J – Summary Table of Symptoms/Referral Pre-Diagnosis

Index Participant	Symptoms & Referral
Bill	• Bill presented to his family doctor with pain and concerns in his throat and ear. • His family doctor made a referral to the Ear, Nose, and Throat (ENT) Specialist. • Unilateral neck mass. I am unsure of the exact timing of when appeared as I didn't follow-up on this statement by Bill, but it was sometime after referral made to ENT, but before treatment at CCMB. • ENT did exam and referred Bill to CCMB for diagnosis
Chris (first interview)	• Chris went to a family doctor complaining of an earache. Family doctor referred Chris to ENT. • The ENT did a visual exam (no scans) and said he could not see a reason for his earache. • Chris returned to family doctor after some time (not defined) because his earache persisted. • After this second appointment with his family doctor because of persistent ear ache, his doctor sent him for a CT scan which revealed that he had tumour present. • Family doctor then made a referral to CCMB for definitive diagnosis.
Chris (second interview)	• At post-treatment follow up CT scan at CCMB and it revealed his cancer had returned in a lymph node
John	• Sizeable unilateral neck mass which John states he had been ignoring for awhile • He went to a new family doctor and was given antibiotic first to rule out an infection. • At follow-up appointment post antibiotics with the family doctor, the neck mass was still present, so the family doctor sent John to have a CT scan. • After CT scan two additional smaller masses appeared on the same side as the large mass. • Referral to a general surgeon after CT scan, reports surgeon did a needle biopsy on the neck mass. • After a "clear" or cancer-free result from the needle biopsy, the surgeon asked John if he wanted to leave the masses or if wanted his to removed them for cosmetic reasons • John had the masses surgically removed for cosmetic purposes, which were sent out for pathology and they came back cancerous. • A referral was made to CCMB for treatment.

Index Participant	**Symptoms & Referral**
Michael	• Reports he went to a family doctor for over a year complaining of a sore throat. • Family doctor gave him antibiotics multiple times, which would subside the symptoms a little bit but then symptoms would return. • Over the course of the year, Michael voice started disappearing. • After a year, his family doctor referred him to an oral surgeon in the capital city of the province. • The oral surgeon did an exam and suspected a tumour in his throat and referred Michael to CCMB for diagnosis.
Cheryl	• Cheryl noticed a lump on one side of her neck, so she went to her family doctor in July. She reported her family doctor suspected it was a swollen lymph node. • Family doctor referred Cheryl to CCMB in October. I did not follow-up with Cheryl what transpired between July and October.
Sam	• Sam went to his family doctor complaining of an irritated throat and pain in his ear. • Over an extended period (not defined in the interview) and multiple visits to the doctor who provided numerous diagnoses (a cold, a sore throat, post-nasal drip, hard time getting over cold) and medications with no resolution, Sam got angry with the doctor and said he wanted something more done. • Sam reports his family doctor (after he got angry with doctor) sent him for an MRI and to see an ENT • ENT made the referral to CCMB
Cliff	• Cliff noticed minor lumps under his tongue which didn't bother him, but they just felt different, so he went to the health centre to have it examined. • Then seen a specialist after exam at health centre • Specialist sent him for a CT Scan • After CT Scan specialist referred him to CCMB
Jason	• Jason went to his family doctor complaining of a really sore throat. • Jason reports family doctor gave him some medication for a sore throat which didn't really work. • After some time (not defined), on top of his sore throat he noticed he was having a hard time swallowing, so he returned to see his family doctor. • After Jason's swallowing difficulties, his family doctor referred him to the ENT (1.5 month wait to see ENT) • ENT referred Jason to CCMB • Jason’s family doctor noticed at a follow-up appointment after Jason’s ENT appointment that Jason’s voice was changing.

Index Participant	**Symptoms & Referral**
Kevin	• Kevin reports persistent trouble swallowing that felt like he had a sore throat. This sore throat progressed to the feeling that there was an actual lump in his throat. • When he went to see his family doctor with these symptoms his doctor told him to give it some time to clear up on their own. However, Kevin was firm with his family doctor that his symptoms did not feel like a typical throat thing, as such he did not want to give it some additional time to resolve. Kevin made it clear that he wanted to see a specialist about this concern. • After this, family doctor referred to ENT. • There was a four week wait period for the appointment with ENT from referral date. Two weeks into this waiting period a unilateral neck presented on Kevin's neck. • ENT referred Kevin to CCMB

*All names are pseudonyms

Appendix K: Summary Table of Feed Tube

Index Participant	Percutaneous endoscopic gastrostomy (PEG tube) or Nasogastric Tube (NG Tube)
Bill	Hospitalized post-treatment and required a NG tube placed for the acute recovery time period Progressive severity of dysphagia in survivorship, resulting in discussions of a PEG tube At second interview, Bill is now living with a PEG tube
Chris (initial interview)	PEG tube discussed due to weight loss during treatment, however resisted placement
Chris (second interview)	Stated to wife at end of first round of treatment if he had to go through treatment again, he would have a PEG tube placed prophylactically Discussed with wife at initiation of second round of treatment that he wanted to try treatment without a PEG tube
John	PEG tube discussed due to weight loss during treatment, however resisted placement
Michael	Reports not discussed
Cheryl	PEG tube offered and agreed to the placement prior to the initiation of treatment. PEG tube remained in during the acute recovery phase post-treatment
Sam	PEG tube discussed due to weight loss during treatment, however resisted placement
Cliff	PEG offered and declined placement prior to the initiation of treatment Hospitalized during treatment - PEG tube placed just prior to hospitalization and remained in during acute recovery phase post-treatment Progressive severity of dysphagia in survivorship, resulting in discussions of a placement of PEG tube

Jason	PEG tube offered and agreed to have one placed prior to the initiation of treatment PEG tube remained in for one year as post-treatment breathing become severely restricted, resulting in a trachea tube being placed for 3 months
Kevin	PEG tube discussed due to weight loss during treatment, however resisted placement Hospitalized post-treatment and required a PEG tube placed, which remained in during the acute recovery phase post-treatment

*All names are pseudonyms