PERCEIVED ORAL CARE NEEDS OF TERMINALLY ILL ADULTS – A QUALITATIVE INVESTIGATION

by

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Thesis Supervisor: Associate Professor Dr. Xi Chen
This thesis is dedicated to my beloved niece, Stasia Aranha
who left us in the summer of 2018
There is an end to cure; there is no end to care  
(M. Verma)

Dr. Violet D’Souza

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ABSTRACT

Individuals with advance-stage illnesses frequently face illness or treatment-related adverse effects in the mouth. These adverse effects can have serious consequences. Despite that, the importance of oral care in this population is often overlooked and there are no definitive guidelines as to what kind of oral care should be provided to these individuals. Given that, our study aims were to explore and better understand the oral health-related concerns, perceived oral care needs of palliative care patients and the barriers that face in accessing dental care services. We conducted a qualitative description study by recruiting a purposive sample of 11 participants with advanced stage health conditions from the outpatient palliative care services of the University of Iowa Hospitals and Clinics. Data were collected using in-depth, semi-structured interviews using an interview guide. All interviews were fully transcribed, with the data managed with Atlas.ti software to facilitate the analysis. All participants had oral concerns although they varied widely from person to person and their illness statuses. The most significant concerns were related to dry mouth, loose dentures, and eating difficulties. Among those who stated that they would seek dental care if required, they were not planning on seeking dental care even though they had treatable oral problems, suggesting a mismatch between their oral health status and their perceived needs. The frequently observed barriers that prevented them from seeking dental care were their illness and illness related priorities, finances, feeling discriminated against by the dentist, and a dislike towards the dentist. Providing information to the palliative care clinicians about the significance of oral health and its impact, incorporating a dental care provider in palliative care team, and providing timely information to individuals with advanced health conditions may enhance the understanding of their oral health problems and help them better manage their oral health and may enhance their dental care seeking behavior.
PUBLIC ABSTRACT

Individuals with advance-stage illnesses frequently face illness or treatment-related adverse effects in the mouth. These adverse effects can have serious local and systemic consequences. Despite that, the importance of oral care in this population is often overlooked and there are no definitive guidelines as to what kind of oral care should be provided to these individuals. Given that, our study aims were to explore and better understand the oral health-related concerns, perceived oral care needs of palliative care patients and the barriers that face in accessing dental care services. We conducted a qualitative description study by recruiting 11 participants with advanced stage health conditions from the outpatient palliative care services of the University of Iowa Hospitals and Clinics. We conducted in-depth, semi-structured interviews and audiotaped all the interviews. All interviews were fully transcribed verbatim. All participants had oral concerns although they varied widely from person to person and their illness statuses. The most significant concerns were related to dry mouth, loose dentures, and eating difficulties. Among those who stated that they would seek dental care if required, they were not planning on seeking dental care even though they had treatable oral problems. Also, some of them faced significant barriers in accessing dental care. The frequently observed barriers were their illness and illness related priorities, finances, feeling discriminated against by the dentist, and a dislike towards the dentist. Providing oral health related information to the palliative care clinicians about the significance of oral health and its impact, incorporating a dental care provider in palliative care team, and providing timely information to individuals with advanced health conditions may enhance the understanding of their oral health problems and help them better manage their oral health and also, may help them in seeking the needed oral care.
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CHAPTER 1: INTRODUCTION

Palliative care is a type of specialized medical care for people with life-threatening illnesses (1-3). In addition to medical treatment, palliative care extends to meet the patients’ psychological, social, and spiritual needs. World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (4). Palliative care includes early identification, assessment, and effective control of symptoms, and effective communication with the patients and their significant others and providing psychosocial, spiritual and practical support to both patients and their caregivers (5). A care team of doctors, nurses, and other specialists provide palliative care alongside curative medical treatment (2, 3). Rather than curing the disease, palliative care focuses on providing comfort and improving the quality of life of patients. It can be provided at any age or at any stage of a life-limiting illness. Palliative care is often provided at an outpatient setting or at the hospital with short-term admissions.

When palliative care is provided to people who are nearing death, it is called end-of-life care. Unlike palliative care, end-of-life care focuses on individuals whose illness is unlikely to be cured, and often they are in the last few months of their life (6). Although palliative care and hospice care are not the same, these terms are frequently used interchangeably. Both provide compassionate care to patients with life-limiting illnesses. However, palliative care provides active treatment while hospice care does not (7, 8). Also, hospice does not provide a full-time caregiver and requires a willing, able and available caregiver in the homes of the patients.
Palliative care patients may often have competing illnesses/conditions. Also, they may experience physical and cognitive decline (9, 10). Both functional and cognitive decline, together with debility, may affect or interfere with their activities of daily living (ADL), such as self-care, walking, eating, bathing, dressing, toileting, and tooth brushing. Palliative care patients often depend on informal caregivers to help them with the ADLs. Despite that, poor oral hygiene is frequently observed in palliative care patients (11-14). This could be because of the patients’ illness taking priority (15), patients’ and caregivers’ lack of oral health awareness, not understanding the value of oral health and its consequences, patient and caregiver’s educational level, time constraints, or other challenges (16). Also, those with cognitive decline seem to resist or do not cooperate in performing oral hygiene (17).

Oral health is a major component of general health and well-being (18). It is much more than healthy teeth. In fact, the mouth is both a cause and a reflection of health and well-being. Inadequate oral hygiene can lead to a wide range of oral problems. It has been observed that elderly, care-dependent patients often have high amounts of plaque on their teeth and/or denture surfaces (19-21), severe gingival inflammation (19), periodontal disease (22), and dental caries (23-25). Also, these care dependent elderly individuals are susceptible to a range of oral complications including oromucosal infections, hypofunction or dysfunction of the salivary glands, and difficulty in swallowing (26, 27). Often individuals at the end of their life experience xerostomia and denture-related problems such as broken denture teeth, fungal infections, and denture sores resulting from poorly-fitting dentures (28). These conditions can limit the affected individuals’ ability to chew and speak as well as their food choices, leading malnutrition. The consequences of poor oral health are not restricted to the mouth alone but can lead to many life-threatening health conditions like bacteremia (29), brain abscesses (30-32), endocarditis (29) and
aspiration pneumonia (33-35). Aspiration pneumonia is one among the most common causes of death among long-term care residents and individuals who are seriously ill, especially, those with neurologic diseases such as stroke, Parkinson’s disease, and dementia (34, 36-45). Furthermore, poor oral health can affect a person’s quality of life and their physical and psychological well being.

Although a vast majority of the palliative care patients may have compromised oral health, they seldom receive oral care services (16, 46-48). This could be because of the seriousness of their medical conditions, their illness taking the priority, medical care providers primarily focusing on their general health with little or no emphasis on their oral health, a lack of dental insurance, high dental treatment costs, not understanding the importance of oral health, a lack of access to the dental care services, unwillingness on behalf of dental service providers to provide care to these individuals, and a lack of specialized dental training to treat these individuals (49-52). Often, the importance of dental care is overlooked and dentists are not included in the palliative care teams. (53). Although it has been repeatedly observed that cognitive decline can affect one’s care seeking behavior (54-57), those with cognitive decline seem to utilize dental services more than their cognitively intact counterparts (58). It is possible that caregivers sought help for these individuals and the patients had no say in such decisions. On the other hand, when presenting in dental offices, individuals at the end of life are likely to receive comprehensive care as their healthy counterparts do. One study reported that some of the treatment that was provided to care-dependent, cognitively impaired elderly individuals during their last year of life was costly and futile (59) and some of these individuals may have gone through long appointments increasing their physical and emotional stress.
In summary, the consequences of poor oral health are significant for individuals receiving palliative care. Therefore, oral care should be an integral component of palliative care to prevent oral diseases or conditions that cause pain, suffering and medical complications. Although dental treatment should be essential for palliative care patients, it is not clear as to how the treatment decisions are made for them, whether the treatment decisions meet their needs, expectations, and values, and what challenges the care-dependent palliative care patients face while making treatment decisions. In such situations, it is imperative to understand the perceived oral care needs of these individuals and their preferences, so that these can be included in their care plans as a part of person-centered holistic care.
CHAPTER 2- LITERATURE REVIEW

2.1 Palliative care

Palliative care is a multidisciplinary care approach provided by a care team of doctors, nurses and other specialists to individuals with life-threatening illnesses (1-3). The overarching goal of this care is to address the patients’ needs and provide an extra layer of support to them while focusing on the quality of life (QoL) of both the patient and their family members (1). Palliative care focuses on managing the pain and distress of patients in addition to their curative medical treatments. Thus, it prevents and relieves their suffering through the early identification and assessment of their symptoms and accommodates for their physical, psychosocial, or spiritual pain and suffering (7, 60). Palliative care has no age limit, and is provided at any age or any stage in a life-limiting illness. Hospice care is similar to palliative care and is provided to terminally ill patients who no longer seek curative or life-prolonging treatments. Also, hospice is restricted to those with a life expectancy of six months or less and is delivered at homes, nursing homes, and hospitals or stand-alone facilities (61).

2.1.1 Origin and Growth of Palliative Care

Palliative care has been a rapidly growing medical specialty during the past decade in the United States (62). Although Dr. Cicely Saunders introduced the concept of palliative care as care for the dying in 1950, surgical oncologist Dr. Balfour M. Mount coined the actual term “palliative care” in 1974 at Royal Victoria Hospital affiliated with McGill University in Montreal Canada (63). He introduced Dr. Saunders’ innovations and demonstrated the importance of providing holistic care for relieving physical, psychological, social and spiritual distress in people with chronic and life-limiting diseases. Later, in 1997, the Institute of Medicine published the report
“Approaching Death: Improving Care at the End of Life,” documenting the gaps in end-of-life care in the United States (64). Later, with the support of the Robert Wood Johnson Foundation and George Soros’ Open Society Institute, significant efforts were taken to bring palliative care into mainstream medicine and nursing.

In 2004, for the first time, the Clinical Practice Guidelines for Quality Palliative Care were released (65), and based on them, the focus of palliative care expanded to include dying patients and those diagnosed with life-limiting illnesses or conditions (63). By 2006, there were about 57 palliative medicine fellowships and about 100 trainees in palliative care. In the same year, both the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education recognized Hospice and Palliative Medicine as a subspecialty of Medicine, and in 2008, for the first time, the ABMS certification examination was conducted (63). Currently, palliative care is a subspecialty of medicine that aims to fulfill a promise to patients and families not to abandon those with life-limiting illnesses and to relieve their suffering when their treatments fail (63). In recent years, the palliative care field has grown exponentially. According to a 2014 Center for Palliative Care report, more than 1,700 hospitals in the US have palliative care teams and are providing palliative care, and about 61% of all hospitals with more than 50 beds have palliative care services (66).

Palliative care comes in three types: primary, secondary, and tertiary (67, 68). Primary palliative care is delivered every day in the medical office and it includes symptom assessment, spiritual assessment, effective communication, and discussion of advance care planning with transition prompts to end-of-life care. Palliative care can be provided by clinicians other than palliative care specialists including internists, family physicians, cardiologists, oncologists, and many other clinicians. Such care is called as “primary” or “basic palliative care” (68, 69).
Secondary palliative care is delivered at specialized programs or inpatient units using an interdisciplinary team approach by palliative care specialists (70). It is provided alongside the patients’ primary care and is called “subspecialty palliative care” (68, 69). Although this type of care is available in high-income countries, its availability in low-income countries is very limited (68, 69). Tertiary palliative care is delivered by specialized teams with expertise in advanced pain and symptom management, which may include palliative sedation or advanced delirium management (71).

### 2.1.2 Who Can Receive Palliative Care?

The established philosophy of palliative care is to help people “living with” rather than “dying from” advanced illnesses, and it focuses on the whole person rather than a disease. Also, palliative care is needs-based, not a discipline-based (72). It is provided for patients with a wide range of diseases or conditions, especially when the disease is life-threatening. Thus, anyone suffering from a life-threatening illness or condition can receive palliative care (66). It can be given from the time of diagnoses and is not dependent on the prognosis of the illness.

Palliative care include eight domains: 1) structure and processes of care, 2) physical aspects of care, 3) psychological aspects of care, 4) social aspects of care, 5) spiritual aspects of care, 6) cultural aspects of care, 7) care of the imminently dying, and 8) ethical & legal aspects of care. The overall goal of palliative care is to improve the quality of life of both patients and their family members irrespective of the diagnosis and prognosis of the illness. Thus, it primarily focuses on aggressive symptom management and psychosocial support. Thus, palliative care includes providing support and resources for a wide range of physical and emotional symptoms, including anxiety, depression, fatigue, sleep-related challenges, nausea, loss of appetite, and shortness of
breath. In addition, it extends to helping the patients and their families in understanding the nature of illness, prognosis, and the treatment options that match their treatment expectations; gaining or maintaining their self-efficacy to carry on with daily life; enhancing the patients’ ability to tolerate medical treatments, and providing support for the family caregivers (66). Furthermore, in some cases, it may include establishing the need for a medical proxy and advance directives at the end of life (73, 74), helping patients and their family better address the difficult situations such as whether to receive cardiopulmonary resuscitation (CPR) or other life-sustaining therapies if that person’s heart stops beating.

A large majority of palliative care patients have serious diseases/conditions such as terminal stages of cancer, cardiac diseases, respiratory diseases, organ failure, and cognitive decline. According to a 2017 WHO fact sheet, the highest proportion of individuals who receive palliative care (38.5%) are those with cardiovascular diseases, the second highest population (34%) have cancer, 10% have chronic respiratory diseases, 6% have AIDS, and 5% have diabetes (60). In addition, many conditions such as terminal kidney and liver diseases, multiple sclerosis, congenital abnormalities, rheumatoid arthritis, neurological disease, dementia, congenital anomalies, Parkinson’s disease, and drug-resistant tuberculosis may require palliative care (60).

2.1.3 The Significance of Palliative Care

The main goal of palliative care is to enhance the quality of life of terminally ill patients (1). To achieve this goal, the care focuses on preventing suffering through the identification of the problems that are associated with life-threatening illnesses and their treatments, such as pain and distress, whether they be physical, psychological, social and/or spiritual in origin. A significant part of palliative care focuses on pain relief. Palliative care is not intended to hasten or postpone
death. On the contrary, it offers a support system to help patients live as actively as possible whatever the outcome may be. It also integrates the psychological and spiritual needs of patients and provides support to families and caregivers so that they can cope with the patients’ illness and later with bereavement (1).

Providing care to a person with multiple illnesses is very complex and it requires the attention of and coordination between a team of healthcare specialists. Frequently, such patients are managed by multiple providers with little or no coordination (75, 76). Such situations necessitate palliative care. Palliative care develops strategies for providing care that is aligned with the patients’ needs, values and expectations (61). Thus, palliative care is holistic care that addresses the physical, emotional, social and spiritual needs of the patients (61).

Palliative care is highly desired by patients and is most effective when considered early in the course of an illness. When palliative care is given early in the course of a life-limiting illness, it can improve the quality of life of the patients; decrease their overall health care utilization, intensive care service utilization and hospitalization; (62, 77, 78); shorten their hospital stay; and reduce the need for nonbeneficial life-sustaining therapies (79-81). Although palliative care is not meant to hasten or postpone death, it has been observed that palliative care increases the use of hospice care and improves the quality of life and survival of the patients (82). Palliative care intervention can significantly reduce total healthcare costs in patients with advanced cancers (77, 83, 84). Morrison et al. (2008) examined the hospital administrative data from 2002-2004 from eight diverse hospitals in the U.S. and estimated the effect of palliative care on hospital costs by comparing the costs of palliative care vs usual care (85). They found that palliative care was associated with a reduction in direct hospital costs. According to another report, a 400-bed hospital
equipped with an interdisciplinary palliative care team who provide palliative care to 500 patients a year could expect to have a net savings of $1.3 million a year (86).

2.1.4 Access to Palliative Care Service

Access to palliative care is uneven and limited worldwide. In 2011, Lynch et al. mapped palliative care development throughout the world, country by country (86). Of the total 234 countries that they explored, 58% (136 countries) had at least one palliative care service; 42% had no palliative services at all; 32% had some kind of isolated services; while 20 countries had advanced integration of palliative care. There is a paucity of literature concerning what proportion of people need palliative care and what proportion of them receive it. When reported, there appears a discrepancy in the projected numbers. For instance, according to 2017 WHO Fact Sheet, every year, over 40 million people need palliative care services worldwide and only 14% receive it. (60). Among the 40 million who need palliative care, 78% live in low or middle-income countries, and 98% of the children who need palliative care live in low or middle-income countries. According to the Center for Advance Palliative Care report 2014, 6 million people in the U.S could benefit from palliative care (66).

Although palliative care is a rapidly growing medical specialty field, access to it is limited mostly to hospitals, and only to those who are dying. Ideally, palliative care should be available at nursing homes as many of the nursing home residents suffer from multiple, chronic life-limiting conditions. It is unclear as to what proportion of nursing home residents who require palliative care receive it. Stumpf et al. (2008) reported that 40% of nursing home residents are transferred to hospitals during the last month of their lives (87). However, they did not specify the source of this information and also whether such hospitalization included any palliative care. Another study
reported that 20% of the US population die in intensive care units (88). In addition to mortality, those who are in intensive care units often suffer severe symptom burdens, including pain, dyspnea, delirium, and psychological distress (89-91) which could be better managed with palliative care services (88, 92).

Palliative medicine has become the fastest-growing medical specialty in the US, and this is because the payers, providers and the policymakers have understood the significance of palliative care as well as its cost-effectiveness. Morrison et al. (2011) reported that 90% of the large hospitals in the US with 300 beds or more, now have palliative care programs (77). Hospitals that are for-profit and those with fewer than 50 beds are less likely to provide palliative care (61). According to the 2015 State-by-State Report Card, from 2008-2015, the number of hospitals with palliative care teams is increasing (61). For instance, in 2008, 53% of hospitals with 50 or more beds had palliative care teams, and this number raised to 67% in 2015. Despite this increase, millions of Americans with serious illnesses who require palliative care still do not receive it (61, 93). This could be because one-third of the hospitals do not have palliative services of any kind. Also, it may not be available for those who are not actively dying. Availability of palliative care services is highly varied from region to region and state to state (61, 66). Only a small proportion of the patients receive palliative care even in those hospitals that have palliative care services. Also, many programs are understaffed and under-resourced to meet the growing needs of the patients (61, 66). Based on the data from the National Palliative Care Registry, the need for palliative care is 7.5-8% of admissions, but only 3.4% of admissions receive it. This means that 1 to 1.8 million patients who are admitted to U.S. hospitals each year could benefit from palliative care, but unfortunately, they do not receive it (93).
2.1.5 Barriers to Accessing Palliative Care Services

As mentioned earlier, among many who require palliative care, only a small number of them receive it. The major barriers that prevent patients from receiving palliative care include workforce, research, and payment models (61, 94). The other important barriers include: limited availability of services for those individuals with life-threatening conditions; knowledge and training of healthcare providers who are unsure about which patients to refer and when to refer them to palliative care services; limited number of palliative care health professionals; a lack of awareness among policy-makers, health professionals and the public about palliative care and its benefits; cultural and social barriers (beliefs about death and dying); misconceptions about palliative care (it is only for patients with cancer, or for the last weeks of life); inadequate access to opioid pain relief; and misconceptions that improving access to opioid analgesia will lead to increased substance abuse (60). In addition to the above, there are other barriers that prevent patients from benefiting from palliative care due to inaccurate physician prognostication (95); the existing prognostic scoring systems (96-98), patients undermining its use in clinical decision making (99); clinicians in the intensive care units not considering the patients’ potential life expectancy beyond their hospitalization for acute conditions (100) and/or simply insufficiently prioritizing the delivery of palliative care (101). When compared to other illnesses, cancer patients are more likely to receive palliative care (102). It has been reported that doctors rarely refer heart patients to receive palliative care services although these patients experience significant symptom burdens that are similar or even greater than those dying from cancer (103). This could be because the palliative care evidence base for heart disease is not as robust as it is in oncology (102, 104-106). Also, the cardiologists’ behavior (105), the view of heart disease as a chronic, manageable disease (107, 108), the unpredictability of the heart disease trajectory (107), limited resources and
shortage of palliative care specialists (94) and patient and caregiver confusion regarding prognosis (109, 110) seem to prevent heart patients being referred to palliative care services.

2.1.6 Palliative Dentistry

Palliative dentistry is defined as the management of patients with active, progressive, or advanced disease, with compromised oral health because of the disease itself or its treatment, focusing on their quality of life (53). In many terminally ill patients, traditional oral hygiene practice may not be feasible due to their illness status or declined daily function (111, 112). In such situations, maintaining their oral health is extremely important for maintaining their mouth comfort and quality of life. Thus, the oral health goals of palliative care patients should include maintaining the mouth free of pain, infection, and dryness, as well as oral cleanliness through the elimination of dental plaque, calculus and food debris (50).

Good oral health is important for one’s functional, emotional and social well-being (12, 113-116). Oral care is essential in the management of patients with advanced life-threatening diseases or conditions for improving and also maintaining the quality of life of the affected individuals (50). Thus, individuals receiving palliative care may require special dental attention which could include procedures that vary from preventive to operative. Dentists may be able to mitigate some of the oral problems faced by these individuals by performing oral prophylaxis and providing other necessary preventive, corrective and restorative dental treatments. These may alleviate some of their oral symptoms; reduce their risk for mouth sores, denture sores, periodontal and oral infections; and decrease the risk of sepsis, aspiration pneumonia, cervical cellulites and mediastinitis and other life-threatening systemic complications (117). However, dentists seldom interact with dying patients. In fact, oral care has been overlooked by both palliative and hospice
patients, and dentists are not part of palliative care teams (50, 53, 118, 119). In fact, the National Hospice and Palliative Care Organization does not list “dentist” in their care teams (Figure 1) (120).

Although oral health maintenance is an integral part of basic nursing care, especially while care for cancer patients, there is limited evidence of regular assessment of mouth or implementation of the oral protocol in the wards or hospice (121). Gillam and Gillam (2006) examined the published literature from 1995-1999 concerning mouthcare assessment and implementation in palliative care setting, and they reported a lack of training and education among nurses of mouthcare (121). They also reported that palliative care did not apply mouthcare routinely with a few notable exceptions indicating oral care may not be adequate in palliative care settings as required.

Also, it seems like adequate training in the assessment and implantation of mouthcare is lacking in the general nursing training (121). Also, there appears a number of inconsistencies in the knowledge of mouth care and its implementation by nursing staff in palliative care (121). It was observed that palliative care practice does not apply mouthcare with a few notable exceptions. Therefore, to provide quality palliative care services, a dental professional should be included in the palliative and hospice care. In addition to addressing the dental emergencies that could be occurring in these patients, dentists can perform routine oral assessments and identify potential sources of infections in the mouth which could cause systemic complications; provide timely interventions for treating or managing dental diseases such as caries, periodontal disease, oral mucosal problems and prosthetic needs; and provide tailored education that is necessary for the day-to-day oral care management to these patients and their caregivers (118). In addition, the dentists can make significant contributions for ensuring pain management, eliminating sites of
infection or potential infections, understanding the patient's preferences for enhancing oral functions, and maintaining esthetic balance for protecting self-esteem in terminally ill patients (117). Dentists have the potential to make significant contributions of high relevance in palliative care and address the oral symptoms of the patients to enhance their comfort and quality of life (12, 117). Although the dentists cannot prevent some of the treatment-induced oral symptoms such as oral mucositis, they can provide meticulous oral care that is necessary for preventing infections that cause systemic complications such as sepsis, aspiration pneumonia which could interfere with the medical management of the illnesses of these individuals (122).

2.1.7 Dental Care Utilization During End-of-life

Although there is not much literature concerning the dental care utilization pattern in palliative patients, Chen et al. (2013b) retrospectively examined and reported dental care utilization in elderly patients during their last year of life (59). To accomplish this, they linked the dental records from a university-affiliated community-based geriatric dental clinic in Minnesota from Oct. 1999 to Dec. 2006 with the records from the National Death Index (59). Participants of this study were elderly individuals 65 years of age or older, living in assisted living facilities or nursing homes and were in the last year of their lives. Based on the level of dental treatment that they received, the investigators categorized the total 199 participants into three groups i) No-Care group, n=100; ii) limited-care group, n=36; and iii) usual care groups, n=63. The No-Care group did not receive any dental treatment after the initial exam; the Limited-Care group received dental care for providing comfort and eliminating pain and infection, and the Usual-Care group received comprehensive dental treatment. The mean survival length of the participants was 189.4 days. Overall, their oral health was poor; 34% were edentulous; and among the dentate patients, the mean number of caries teeth was 6.3 at the time of new patient examination. The No-Care group
did not have any dental insurance, while both of the other groups had dental insurance through the Medicaid program (p=0.02). The mean number of visits to the study dental clinic by the Limited-Care group was 2.2 with a mean dental treatment cost of $172 while the average number of visits to the dental clinic by the Usual-Care group was 5.9 with a mean dental treatment cost of $857, ranging from $52- $2,855/person (59). The number of visits and the treatment costs in the Usual-Care group indicates that some individuals received a lot of dental care in the last year of their life.

In a similar study, Chen and his associates (2013b) retrospectively investigated the self-rated oral health and oral health behaviors in 810 community dwelling older adults in North Carolina (123). They found that those who were in the last year of life were more likely to rate their oral health 2.94 (odds ratio [OR = 2.94, 95% confidence interval [CI] and general health (OR = 2.35, 95% CI: 1.12, 4.91) as bad, less likely to utilize dental services (OR = 0.66; 95% CI: 0.36–1.19) and were more likely to see dentists only when they had problems (OR = 1.53; 95% CI: 0.75–3.13) when compared with those who were not in the last year of life (123).

2.1.8 Summary

In summary, palliative care is specialized care given to individuals with serious, life-threatening illnesses/conditions. The overarching focus of palliative care is to alleviate pain and distress and improve the quality of life of individuals and their family members. It is given both in patient’s homes or nursing homes and at any time during the course of treatment. Although needed, its availability is limited worldwide, more so in developing countries. Palliative care has shown to lessen patients’ burdens in a variety of ways. Furthermore, it has shown to be cost-effective. In fact, palliative care has shown to significantly decrease healthcare spending. Currently, palliative dentistry is only a concept and is at the very early stage of its development. Although oral health
is essential in individuals with life-limiting illnesses, dentists are not part of palliative care teams. Very little is understood about what prompts individuals with advanced health conditions to seek dental care. Including dental professionals in palliative care teams could be extremely beneficial in enhancing dental care utilization in this population, which is required for improving the quality of life of the affected individuals while reducing the healthcare cost.

2.2 Oral Health Issues in Terminally Ill Individuals

2.2.1 Dental Diseases That Affect Palliative Care/Hospice Patients

Oral health is essential for one’s general well-being. Compromised oral health increases the pain and suffering of affected individuals. Oral diseases will not be resolved when left untreated, but they can cause pain and can effect the quality of life profoundly (124, 125). In addition, compromised oral health can lead to serious consequences such as local abscesses, bacteremia (29), brain abscesses (30-32), endocarditis (29), and aspiration pneumonia (33-35). Aspiration pneumonia, a condition that is associated with poor oral hygiene, is one of the major reasons for transferring patients to acute-care facilities and causes death in frail older adults (126). Given that palliative care is provided to individuals with different types of illnesses, there are no studies that have descriptively explored oral disease in palliative care patients. Exploring oral health statuses in this population group can be extremely challenging, especially when large samples are required to explore multiple outcomes. Therefore, very little is understood concerning the oral health status of palliative care patients.

2.2.1.1 Dental Caries

As mentioned earlier, individuals who receive palliative care often take multiple medications. As an adverse effect, these individuals frequently experience xerostomia and oral
pain. Xerostomia affects the self-cleaning ability, salivary clearance, and buffering action of saliva, thereby increases the caries risk (127-129). Pain can interfere with one’s routine oral hygiene practices, leading to poor oral hygiene. Thus, affected individuals may have increased plaque accumulation harboring cariogenic bacteria, increasing their risk for dental caries.

A limited number of studies have examined dental caries in palliative care patients. Hong et al. (2010) conducted a systematic review for examining the prevalence of dental caries in different types of cancer patients receiving different modalities of cancer treatment (130). In that review, the prevalence of dental caries was highest in cancer survivors who underwent chemotherapy alone when compared to those who received radiotherapy or a combination of radiotherapy and chemotherapy (130). The authors of this review argued that the observed difference could be attributed to several factors. First, those who receive radiation treatment in the head and neck region are systematically evaluated and provided the necessary care, including a preventive regimen prior to commencing radiation treatment. This might have led to underestimating caries prevalence in those who underwent radiotherapy or a combination of radiotherapy and chemotherapy. Second, of the total 19 studies that examined dental caries prevalence, 12 were conducted in children. A high proportion of these children had hematological malignancies and received curative chemotherapy (130). It is possible that these children might have been ill for a very long time and for the weight maintenance purposes they might have consumed a highly cariogenic diet. Finally, the caregivers of these children might have been overwhelmed by their child’s medical diagnoses and thus might have neglected the oral health component (130). The literacy levels of the caregivers or their perceptions about oral health might have played a significant role as well.
Wilberg et al. (2012) conducted a cross-section study in Norway investigating the prevalence of oral and dental problems in 99 advanced-stage cancer patients (excluding head and neck cancer patients) receiving palliative treatment (27). All participants underwent an oral examination. In addition, they determined oral morbidity by asking the participants to respond (yes/no) to the dichotomous question: “Do you suffer from discomfort or pain from the oral cavity at present? (27)” The mean age of the participants was 64 years, and 47% were males. Gastrointestinal cancer was the most prevalent cancer among the participants (21%), followed by lung cancer (19%) and prostate cancer (11%). All patients had either locally advanced, metastatic, or generalized disease and 73% had the estimated life expectancy of less than 3 months, and 73% of the patients died within 3 months of examination (27). About 48% had dental caries, 66% had xerostomia, 68% had altered taste, 86% had microbial evidence for Candida carriage, 34% had oral candidiasis, and only 9% received antifungal treatment. Xerostomia (p<0.001) and taste alterations (p=0.03) were significantly associated with oral morbidity. There was no association between the total number of drugs taken and patients’ self-reporting of oral morbidity, xerostomia, or taste alterations (27).

In another study, Chen et al. (2013c) linked the dental records from a university-affiliated community-based geriatric dental clinic in Minnesota with the National Death Index (NDI) and investigated the severity of dental caries in older adults during their last year of life (131). They examined the dental records and radiographs for 1,216 patients. Those who died within the 1st year of life were categorized as the “End of life” group (n=168), and the remaining records were used as the “Comparison” group (n= 1,048). They observed that the “End-of-life” group had a higher rate of edentulism (p=0.02) and had more carious teeth (P = 0.009), especially among those who were between he ages 75 to 84-years (P =0.007). They also found that being in the last year of life
(P =0.03), reduced oral self care capacity (P < 0.001) and impaired oral care function were associated with greater numbers of caries teeth [Incidence density ratio (IDR)=1.57; 95% confidence interval (CI): 1.14–2.16] (131). Interestingly, caries was less severe in individuals from the “End of life” group in whom the oral care functions were not impaired (IDR = 0.53, 95% CI = 0.30–0.92). Those participants who depended on the caregivers for maintaining their oral hygiene were at a slightly increased risk for caries (adjusted IDR= 1.12, 95% CI=0.85–1.48) (131).

Oral disease pattern seems to vary in individuals with different types of illnesses. Several studies have explored dental caries in individuals with chronic kidney disease and the results appear to be inconclusive (132-136). Some studies observed no difference in the prevalence of dental caries in individuals with kidney disease (134-136), one study reported a higher number of caries (137) while others reported fewer decayed and missing teeth in individuals with kidney disease (132, 133, 138, 139). The low caries risk in these individuals is assumed to be because any of the following mechanisms or their combined effect: in individuals with kidney disease, the salivary urea splits to form ammonia and carbon dioxide, leading to the highly buffered alkaline saliva with the pH above the critical level for demineralization (140); the phosphate concentrations associated with disease (138, 139); the antibacterial effect of the urea (141); or the salivary phosphate concentration that is found in patients with uremia may lead to the remineralization of the incipient carious lesions (138, 139, 142). However, these individuals with kidney disease could have a higher risk for caries if their oral hygiene is poor and they consume a carbohydrate rich diet. Also, having hypoplastic enamel, low salivary flow, long-term medication use, and disease-related debilitation may increase the risk for caries (138, 139). An association between chronic liver disease and compromised oral health has been observed (143, 144). It is possible that those with alcoholic liver diseases are more likely to smoke and smoking increases the risk for
periodontal disease and tooth loss (145). Also, a large majority of individuals with liver disease receive antidiuretic treatment which lead to xerostomia, and thus increases their risk for caries (145). Therefore, individuals with liver disease may be benefited with routine dental treatment. Bajaj et al. (2018) reported that systematic periodontal therapy when performed for individuals with cirrhotic liver, it lessens their risk for systemic inflammation (143).

COPD and asthma are common respiratory diseases (146). Although they differ in their etiology and pathophysiological characteristics, they do share similar functional characteristics such as limited air passage (147). Also, both conditions are frequently treated using beta-2 agonists, anticholinergic bronchodilators, and inhaled corticosteroids (148). A large portion of the inhaled drug can be retained in the oral cavity and oropharynx, which can interfere in the normal physiology of oral tissues (148). Also, the medications used in treating these conditions can reduce the salivary flow rate, increasing the risk for carries in the affected individuals (149).

Studies have reported that individuals with greater cognitive decline have more coronal caries when compared with individuals who have mild cognitive decline (23, 150). Cognitively declined individuals have poorer oral hygiene when compared with their cognitively intact counterparts (19, 20). Cognitive decline affects the prospective memory of the affected individual and thus interferes in executing the activities of daily living, (54) including dentally related functions such as oral hygiene routines and oral hygiene procedures like brushing and flossing (57, 151). Additionally, those with cognitive decline are often disinclined to maintain oral hygiene practices (152) and may lack the required dexterity or self-efficacy to perform routine oral hygiene practices (153).
2.2.1.2 Periodontal Diseases

A limited amount of literature is available concerning the periodontal status of patients receiving palliative or hospice care. Individuals receiving palliative care may have comorbidities. The illnesses, comorbidities, and the adverse effects of their treatments may affect the physical functioning of these individuals, thereby affecting their selfcare ability. Thus, many of them depend on caregivers for their activities of daily living (154). Performing and maintaining good oral hygiene can be a great challenge for these individuals despite having caregivers’ assistance. In addition, due to the seriousness of the other symptoms, less emphasis might be placed on oral health (47). This may result in plaque accumulation, leading to gingivitis and periodontitis.

Periodontal disease is highly prevalent in individuals with diabetes mellitus (155-158), chronic kidney failure (133, 139, 159-161) and coronary heart disease and stroke (162-164). Individuals with chronic kidney disease seem to have more supragingival plaque, calculus, periodontal disease and related tooth loss (133) and those undergoing hemodialysis seem to be at a higher risk for calculus formation (165, 166). Diabetes has shown be significantly associated with periodontitis (155-157) and this association is stronger for those with poor glycemic control or uncontrolled diabetes patients (167, 168). The other diseases that periodontal disease is associated with include cardiovascular diseases (164), oral (169-172), gastric (173-176), pancreatic (171, 175, 177-179) and colorectal (180-182) cancers, and dementia (183-186).

Studies have shown that the individuals with cognitive decline have poorer oral hygiene and a greater amount of plaque accumulation (19, 20, 57), are at a greater risk for gingivitis (19), alveolar bone loss (22) leading to tooth loss. Cognitive decline seems to affect procedural memory, which allows an individual to complete the daily procedures without requiring to be consciously
aware of it (187). When impaired, it can affect an individual’s ability to selfcare, a skill that they learnt and practiced early in their life, such as self-care ability (188) including oral selfcare (23). Also, oral selfcare requires abstract reasoning, judgment, and planning (189) and executing goal-directed behaviors (190, 191). Individuals with cognitive decline may loose their ability to selfcare, resulting in compromised oral and dental hygiene (23).

2.2.1.3 Summary

Although oral health is essential for one’s general wellbeing, it is often overlooked in individuals with chronic conditions. Individuals with life-limiting illnesses are frequently on multiple medications. The adverse side effects of these medications, emotional distress, compromised oral health due to both neglect and inadequate support from the caregivers can increase the risk for oral diseases such as dental caries and periodontal disease. These can increase pain and suffering in the affected individuals. Furthermore, these oral diseases can lead to fatal systemic complications. For example, aspiration pneumonia is common in patients with poor oral hygiene and is one of the most common causes of death in frail older adults. Maintaining good oral health hygiene can decrease the risk of systemic complications in these individuals, lessen their pain and suffering and contribute to reducing healthcare utilization and healthcare costs.

2.2.2 Oral Symptoms Experienced by Terminally Ill Individuals

Treatments of many life-threatening illnesses have serious adverse effects on the oral cavity. These adverse effects frequently cause pain and distress and impair the oral functions of the affected individuals. Patients receiving palliative care often present multiple oral symptoms due to the disease, its treatment, and comorbidities (83, 85, 192). The most common oral adverse
effects such as oral pain, mucositis, xerostomia, candidiasis, pain and dysphagia, and other significant oral-health-related problems are described below in detail.

2.2.2.1 Pain

Oral pain is one of the most severe and frequent symptoms experienced by patients in need of palliative care (193). Opioid analgesics are frequently used for treating the pain associated with advanced progressive conditions. It has been observed that 80% of the individuals with AIDS or cancer, and 67% of individuals with cardiovascular disease or chronic obstructive pulmonary disease experience moderate to severe pain at the end of their lives (60). Opioids are frequently used drugs for pain management in palliative care (194), and these can cause dry mouth (195).

Although pain management plays a vital role in palliative care, unfortunately, many barriers interfere in the process of effective pain management. The barriers can be patient-related, provider-related, or system-related (196). Frequently observed patient-related barriers are the complexity of the symptoms, reluctance to report pain, fears, and concerns about pain medications and their adverse effects, and misconceptions about pain and its treatments (197). In addition, cognitive impairment can prevent affected individuals from communicating their pain with their care providers and getting the required attention (198). The provider-related barriers are lack of providers’ knowledge about the symptoms, pain medications, and their adverse effects; skills of the provider; and time for adequate pain and symptom management (199). The system-related barriers include low priority given for pain management, access, and restrictive regulations for some treatments (200). The other barriers to pain management include knowledge gaps concerning pain and symptoms experienced by palliative and end of life patients and health disparity in palliative care (196).
2.2.2.2 Oral Mucositis

The mouth is very susceptible to both the direct and indirect effects of harsh treatments. The pathophysiology of oral mucositis is a complex process. Oral mucositis frequently occurs in cancer patients, especially, those who undergo radiotherapy, bone marrow transplantation, and chemotherapies (201). It can result from the epithelial injury caused by cytotoxic chemotherapy and radiation treatment (202). Oral mucositis more commonly affects the non-keratinized mucosa (203). The toxic effects of chemotherapy and radiation treatments have shown to cause the oral mucous membrane to become thin and denuded, leading to ulceration (201, 204). Evidence suggests that, before the epithelial damage, injury occurs in the blood vessels and connective tissue of the submucosa (205). Also, the damaged tissue provides an entry point for the normal flora microorganisms that exist in the patient's mouth to enter the body and travel through the bloodstream (206).

As mentioned earlier, frequently, oral mucositis occurs an adverse effect of a variety of medications and treatments used in many of illnesses, although its signs, symptoms, and degree of severity vary (207). Signs of oral mucositis include: a red, shiny or swollen mouth; soft, white patches in the mouth or pus in the mouth; blood in the mouth; sores in the mouth (tongue, gums, palate) and/or throat; burning sensation in the mouth; pain when eating; xerostomia; and thick saliva with increased mucous (207). The signs and symptoms of oral may vary from pain and discomfort to an inability to tolerate food or fluids. Mucositis may also limit the patient’s ability to tolerate either chemotherapy or radiotherapy.

As mentioned earlier, oral mucositis is very common in cancer patients (203, 208-210). Past studies have shown that 40-80% of those who undergo chemotherapy (201, 204, 206, 209, 210), 80% of those who receive radiation in the head and neck region (211) and 75% of those who
receive bone marrow transplantation experience oral mucositis (210, 212-214). Oral mucositis is a multifaceted problem with pain and debilitation. As it is associated with acute pain, it has a significant impact on the affected individuals’ wellbeing. About 80% of the people who have oral mucositis experience acute pain (215, 216). In addition, it compromises the affected individual’s ability to eat, leading to nutritional problems, open sores, increasing the risk of infection; and poor quality of life (214, 217). Also, oral mucositis can lead to hypovolemia, electrolyte abnormalities, malnutrition and neutropenia increasing the affected individuals’ risk infections leading to septicemia and death (218). Also, it may affect their treatment compliance and increase healthcare utilization. For example, a person with severe mucositis may not be able to continue to receive regular chemotherapy and thus, his/her doses may have to be reduced or altered due to the severe symptoms. Vera-Lionch and associates (2007) conducted a chart review for 281 patients with hematologic malignancies receiving allogeneic hematopoietic stem-cell transplantation (214). In this investigation, severe oral mucositis was significantly associated with an increased number of days requiring parenteral narcotics and parenteral nutrition, increased time at the hospital and increased inpatient charges (214).

In summary, oral mucositis is the most common, debilitating complication of cancer treatments. More specifically, those who receive radiation treatment in the head and neck region frequently experience extremely severe oral mucositis. Oral mucositis often causes pain, affects esting and nutrional intake, and it also increases the risk for infection due to open sores in the mouth. Moreover, oral mucositis has a significant effect on the patient’s quality of life. Consequences of oral mucositis can range from mild to very severe. In severe cases, it can restrict oral intake, interrupt treatment, increase antibiotics or narcotics use, increase the length of hospitalization, and increase treatment cost.
Xerostomia is very common in palliative care patients (27, 192, 219, 220). It may result from radiation treatment in the head and neck region, chemotherapy, and polypharmacy (27), especially when it included the anticholinergic medications (221) and opioids (195). A large majority of palliative care patients have multiple chronic illnesses/conditions and receive multiple medications (222-224) including opioids for pain relief which are known to cause xerostomia (194, 195). Xerostomia affects 30-77% of palliative care cancer patients (220). Also, it is very common in patients with end-stage kidney failure, affecting 28-59% of them (225). Individuals with kidney failure experience polyuria as an adverse effect due to an inability to reabsorb sodium, which can lead to xerostomia (225, 226). The other factors that are associated with xerostomia include dehydration and metabolic imbalance (227).

Saliva has many important functions in the mouth. It not only mechanically cleanses the teeth but also neutralizes the acidic environment of the oral cavity through the buffering action (228). Reduced salivary flow has numerous negative effects on oral-dental tissues (219). Xerostomia can a) increase their risk for oral infections and stomatitis (27, 224); b) impair the salivary antimicrobial properties and increase the risk for caries (229); c) affect ingestion, affect swallowing, and speech articulation (230, 231); d) affect the lubrication of the oral tissues, increase the risk for abrasion and ulcerations of the oral mucosa, e) affect the denture retention in denture wearers (127-129), and f) cause pain and distress (232). It has been observed that those with xerostomia avoid certain foods, which may reduce the dietary quality of the patient (233, 234).
2.2.2.4 Oral Candidiasis

Oral candidiasis is an opportunistic infection that frequently affects the mouth. It is caused by an overgrowth of the most common Candida species, Candida albicans. Although C. albicans is the more frequently isolated yeast in the mouth (235). The prevalence of candidiasis in terminally ill patients ranges from 8-94% (236, 237). The risk factors include immunosuppression, cancers, hypofunctions of the salivary gland, drugs, dentures, smoking, and diabetes mellitus (238-241). Oral candidiasis is very common in cancer patients undergoing chemotherapy and radiation treatments (238, 242). In fact, it is a significant cause of morbidity for them. Also, it frequently observed in individuals with the following diseases such as AIDS (126), diabetes (243, 244), asthma (245, 246), cognitive decline (247). Oral candidiasis causes pain and distress and poses a significant burden for advanced cancer patients (248, 249).

2.2.2.5 Taste Alteration

Taste alteration can frequently occur in palliative care patients, especially those with cancers (219, 250, 251). In fact, 25-50% of advanced cancer patients experience taste alterations (250). Although taste alteration can affect all types of cancer patients, it is a very common side effect of head and neck cancer treatment (251). A study that was conducted with 101 non-head and neck cancer patients reported that 78% of their participants experienced taste disturbances (252). Also, taste alterations have been associated with many other illnesses. Individuals who are treated for rheumatoid arthritis (253), and patients with kidney failure (166, 226), neurodegenerative disorders and cognitive decline seem to have taste alterations (254). Taste alteration has a significant impact on the quality of life of the affected individuals, as it can
decrease the appetite, affect the nutritional intake and lead to unwanted weight loss at a critical
time. Thus, it can indirectly affect the treatment and treatment outcomes.

2.2.2.6 Petechiae, Bruises and Gingival Bleeding

Individuals with chronic renal failure, liver diseases, and cancers suffer from petechiae, bruises and spontaneous gingival bleeding (255-257). Bacterial toxins seem to cause platelet dysfunction, which can cause bleeding (258). Also, several other factors aggravate the condition, including renal anemia, the use of anticoagulants, and the dysfunction of the endothelial cells, leading to vessel fragility (259). In addition, endothelial dysfunction due to hyperlipidemia is associated with calcium and oxalate precipitation in the blood vessels, leading to the formation of petechiae in the oral cavity.

2.2.2.7 Halitosis

Halitosis can be a significant problem in patients receiving palliative and Hospice care. Microbial degradation in the oral cavity results in volatile sulfur compounds such as hydrogen sulfide, methyl mercaptan, and dimethyl sulfide (260). These are primarily involved in halitosis produced by Gram-negative anaerobic oral bacteria (260). Frequently, halitosis can occur due to compromised oral health and oral hygiene, oral infections, xerostomia, tongue coating, dental caries, and periodontitis (261, 262). The other individuals who experience halitosis include those with ear, nose, and throat infections (263) and higher levels of urea nitrogen in their blood, especially when it reaches >55 mg/dL (264). Patients with chronic renal failure have high levels of urea nitrogen in the blood and saliva, which seem to may cause halitosis (160, 226, 265).
2.2.2.8 Dysphagia

Dysphagia is a medical term for describing a swallowing disorder, often associated with many neuromuscular conditions or as a consequence of systemic weakness (192). It can result in food sticking in the throat, or food or fluid entering the airway. Patients with dysphagia range from having minimum difficulty swallowing to a full-on disability. There are numerous causes of dysphagia and they include: a) achalasia, failure of the lower esophageal sphincter to relax properly, causing a food back-up into the throat; (b) diffuse spasm of the muscles in the esophageal wall; c) esophageal stricture (narrowed esophagus); (d) tumors; e) foreign bodies; f) allergy (eosinophilic esophagitis; g) radiation therapy leading to inflammation and scarring of the esophagus (266).

Dysphagia is associated with increased morbidity (267). Although its exact prevalence is not fully known, it can occur in association with many diseases and age groups (268). Dysphagia is more common in older individuals, and its prevalence seems to increase with age (269). The highest prevalence is observed in those individuals with neurological diseases affecting up to 64% of those with stroke and over 80% those who with dementia (270). Also, it is a common complication of head and neck cancer patients (271), affecting 75-95% of the head and neck cancer patients during cancer treatment and 24% during post-treatment periods (272, 273).

Regardless of the cause, dysphagia has a significant impact on the affected individuals’ life (274). It can compromise their caloric and oral medication intake requiring alternative routes of food and medication administrations (192). Also, eating and drinking is an integral part of one’s life. Thus, dysphagia can increase social anxiety and may lead to social withdrawal and reduce the quality of life of the affected individuals (275). Severe forms of dysphagia can impair liquid and nutritional intake, and thereby increase the risk of developing malnutrition and dehydration, and
also aspiration pneumonia (276-278). In elderly patients, oropharyngeal dysphagia is a significant risk factor for hospital readmission (276, 279). Cabré et al. (2013) conducted a cohort study (2002-2010) in Barcelona, Spain, in which they followed 2,358 elderly individuals discharged from the geriatric unit until death (276). In this study, they observed that oropharyngeal dysphagia has a significant effect on the risk of readmission due to its associations with pneumonia, non-aspiration pneumonia, and aspiration pneumonia.

2.2.2.9 Denture-related Issues

Although the incidence of tooth loss and the prevalence of edentulism has decreased, individuals who are completely or partially edentulous will continue to receive conventional prosthodontic treatments (280). Masticatory performance decreases with tooth loss, age, and denture-wearing. However, the perceived masticatory ability seems to be associated with dental status, denture quality, general health and a variety of personal, physiologic, social, economic, and psychological factors (281, 282). A poor-quality denture can cause chewing/eating difficulties, increase discomfort and may limit food choices (281, 283).

Studies have reported that nearly half of the denture wearers experience mucosal lesions such as angular cheilitis, denture stomatitis, or traumatic ulcers (284-286). Angular cheilitis is an inflammatory condition that affects the corners of the mouth (287). Studies have reported about angular cheilitis in 28% of the hospitalized dentures wearers (285, 288, 289). Reduced vertical dimension seems to increase the risk for angular cheilitis (289). Denture stomatitis is another inflammatory condition that affects the mucosa under the removable partial or complete dentures (290, 291), affecting 15-70% of the denture wearers (292). Unstable dentures (293) and wearing dentures at night (293-296), and angular cheilitis are associated with denture stomatitis (290, 291, 297). Peltola et al. (2004) conducted a cross-sectional study with 260 long-term hospitalized
elderly patients (285). Of the total 260, 41% wore removal dentures, and one in four required either denture repair or replacement. About 37% had poor denture hygiene and it was significantly worse in men. About 25% of them had denture stomatitis, 28% had angular cheilitis (285).

The other factors seem to play a significant role in denture stomatitis include salivary pH, diet, and smoking (294, 295). Another important denture-related issue is traumatic ulcers. They are more commonly associated with ill-fitting dentures, and they affect 16% of the partial denture wearers and 25% of the complete denture wearers (298). The other denture-related issues include mucosal irritation from the sharp edges of the dentures, denture-related sore spots, and premature occlusal contacts (297-300). These can cause discomfort and discourage people from wearing dentures (298). Denture supporting tissue seems to be dependent on the strength and distribution of occlusal pressure (301). Therefore, regular denture monitoring of the dentures is essential for maintaining the denture fit for improving their masticatory efficiency and preventing mucosal lesions in both complete and partial denture wearers (290, 291, 298) and dental caries and periodontal diseases in partial denture wearers (288, 302).

2.2.2.10 Summary

Individuals who receive palliative or hospice care are those with life-limiting illnesses/conditions. Also, they may have comorbidities. Treatment of these conditions/illnesses is often associated with adverse effects, and oral complications are the most common ones. Pain, xerostomia, oral candida infections, loss of taste, and dysphagia are frequently observed treatment side effects in these individuals. These have significant clinical implications because they can cause pain and distress in patients, interfere and limit their nutritional intake, interfere in oral hygiene practices leading to plaque accumulation, tooth decay, periodontal disease, and
opportunistic infections, and negatively affect their speech, swallowing, and quality of life. Although palliative care/hospice patients are at significant risk for oral and systemic complications, as of now, very little has been reported concerning their prevalence and severity.

2.2.3 Impact of Oral Diseases and Their Symptoms

Oral health is very important for one’s overall wellbeing, and the mouth is seen as a window into the health of the body (303). Compromised oral health causes pain and discomfort and significantly affects one's wellbeing, by affecting their oral functions, systemic health, and quality of life (304-306). As mentioned earlier, terminally ill individuals frequently experience xerostomia, oral mucositis, oral ulceration, and fungal infections (27, 219). These conditions and their symptoms seem to affect the oral functions of these individuals in multiple ways. In addition to causing pain and discomfort in the mouth, they can interrupt one’s oral self-care practices leading to poor oral hygiene (305). Compromised oral hygiene allows plaque retention on the teeth or denture surfaces, and thus increases the risk for oral infections tooth decay and periodontal disease (27, 224). Although xerostomia does not cause pain directly, it affects oral lubrication, denture retention (128, 129, 307, 308), speech, mastication and swallowing; increases the risk for oral soft tissue trauma and fungal infections (307-309); and decreases antimicrobial activity (230, 231, 306). Tooth loss, loose teeth, loose dentures, and painful oral symptoms can cause significant difficulties eating (281, 283). Although oral symptoms such as xerostomia, oral mucositis, and sore mouth are common in all types of cancer patients, they are worse in head and neck cancer patients (310, 311) and terminally ill individuals (312). The oral problems in palliative care patients and their impact was illustrated by Wiseman (2006) and is presented in Figure 2.
Also, oral diseases/conditions and their symptoms can have a significant impact on the systemic health of an individual in multiple ways. In addition to causing pain and discomfort, they increase the risk of systemic infections (305). Oral ulcers serve as an entry point for the normal oral flora to enter the body and cause systemic complications (206) such as bacteremia (29), brain abscesses (30-32), endocarditis (29), and aspiration pneumonia (33-35) in immunocompromised individuals. In fact, aspiration pneumonia is a very frequent cause of death in frail older adults with compromised oral hygiene (126). Studies have reported that maintaining good oral hygiene can prevent cardiovascular disease (313), respiratory infections, and death from pneumonia in elderly individuals in hospitals and nursing homes (314, 315).

Furthermore, severe oral symptoms can interfere with the affected individuals’ caloric intake leading to unwanted weight loss. Unwanted weight loss may affect their treatment schedule, increase the need for parenteral pain medication and nutrition, prolong their illness, and negatively affect their treatment outcomes (214). Dry mouth, eating and swallowing difficulties (316) and tooth loss in older individuals has shown to be associated with malnutrition leading to weight loss (317) or obesity (318). It seems that those with compromised oral health tend to consume a soft and easily chewable high carbohydrate diet which can increase their blood sugar levels, and may also contain fat above the recommended levels increasing their risk of cardiovascular diseases and metabolic syndrome (127, 319).

In addition to oral and systemic effects, the oral diseases/conditions and their symptoms significantly impair the affected individual’s quality of life (119, 219). Compromised oral health and xerostomia affects ones’ nutritional intake (219, 232, 234, 320) and verbal communication (219), causes social disability (321), pain, distress (119, 219) and sleep disturbance (125); and negatively impairs the affected individuals’ quality of life (119, 219). Individuals who experience
eating or swallowing difficulties often alter their nutritional intake (322) and avoid certain foods (type and consistency), especially fresh fruits and vegetables (323), certain types of bread and “well-done” meat (324). This change can negatively affect the pleasure of eating and affect their quality of life (125). Also, saliva is essential for taste perception (325, 326), and taste perception can enhance the formation of saliva (327, 328). In fact, taste seems to be one of the important inputs for inducing salivation (329). Also, a lack of saliva can impair taste perception (328), which in turn can lead to a loss of appetite (330). Reduced salivary flow makes chewing and swallowing difficult and painful, affects speech and communication, and causes halitosis, leading to both frustration and embarrassment (219, 331). When tooth loss is extensive or complete, it restricts social interactions (125), detracts from physical appearance (332), inhibits intimacy (125) and lowers self-esteem (333). Swallowing difficulty more commonly affects elderly individuals which can be physically and social disabiling, leading to social isolation (334).

Rohr et al. (2010) qualitatively explored oral discomfort in 14 terminally ill patients registered at a palliative care service in a mid-size hospital on the east coast of Australia (219). The authors of this investigation did not specify what kind of palliative service the participants received. Xerostomia, mucosal ulceration, and thrush were some of the main concerns that they observed, although their severity varied from person to person. These symptoms affected the participants’ lives in many ways, such as their enjoyment of food, loss of appetite, weight loss, and difficulties in swallowing. As a result, the participants had to choose smaller meals and softer food. Also, they ate less frequently, their speech slurred, and they experienced a choking sensation (219). Additionally, the participants in this study were frustrated because their oral problems affected their communication and socialization. Some of the participants expressed embarrassment because of their speech difficulties, especially when stumbling over words (219).
In summary, compromised oral health has a significant impact on one’s oral function, systemic health, and quality of life. Oral symptoms can cause pain and distress, affect communication, nutrition intake, social wellbeing, and pose a serious risk for systemic complications. Oral diseases and their symptoms can interfere with their oral intake, interrupt their treatment schedule, prolong illness status, and increase the hospital stay.

2.3 Knowledge Gaps

Individuals with advanced-staged illnesses frequently suffer from severe adverse effects of the illness or its treatment. Although their oral symptoms vary widely based on their illness and the medications that they receive. The oral symptoms may increase patients’ physical and emotional burden, affect their nutritional intake and treatment compliance, cause systemic complications, and impair their quality of life. However, palliative care may not systematically apply mouth care, and also, the physicians and nurses may receive adequate mouthcare training (121). Although dentists can play a significant role in palliative care, they are usually not part of the palliative care teams. As a result, the responsibility of managing the oral symptoms of these individuals is placed on the palliative care physicians and nurses with no additional training in oral diseases and their consequences. Understanding the perceived needs of these patients may help the clinicians in providing better care to these individuals.

Currently, while some information is available for persons with terminal cancer and those at the end of life, very little is known about the oral health statuses of palliative care/hospice patients, and how their oral health is managed. When information is available, it concerns head and neck patients. Unlike other cancer patients or individuals with other life-limiting illnesses, head and neck cancer patients are routinely referred to dentists prior to their cancer treatment for
an oral health evaluation and to complete dental care, whether surgical or restorative. In addition, they receive preventive dental treatments.

A few studies have explored the oral health status of nursing home residents in their last year of life (59, 131). It is possible that some of them could have been receiving palliative/hospice care. One such study reported that some of these residents did not receive any dental treatment in their last year of life while the others received comprehensive dental treatment that was expensive and futile. It is not clear how treatment decisions were made for them and whether the given treatments benefited the patients, lessened their oral health-related challenges or improved their quality of life. Thus, it is essential to understand the patient's oral health related concerns, expectations, perceived needs, and the barriers that they may face in accessing dental care. Understanding these factors can help in planning holistic care that meets their values and expectations while lessening their oral health related burden and systemic complications due to compromised oral health.

2.4 Researcher’s Perspective

Reflexivity is the sensitivity to the ways in which I as a researcher, the research process, data collection, and my assumptions and experiences could influence the inquiry. I will be writing in the first person frequently in this thesis. My reasoning behind doing so is that I acknowledge the decisions that I have made during the entire research process. By writing in the first person, I am not trying to deceive my readers. Webb (1992) described “writing in the third person is, therefore, a form of deception in which the thinking of scientists does not appear, and they are obliterated as active agents in the construction of knowledge” (335). Also, I am positioning myself
in my study because, as a researcher, it is essential for me to realize that my presence cannot be removed. In this spirit, I will remain a part of it.

The oral health needs of terminally ill individuals with limited life expectancy remain understudied. My motivation for choosing to study these individuals comes from my past research work in the field of psychosocial oncology and cancer survivorship research. Coming with a background in dentistry and working with the cancer survivor population, what struck me was the oral symptoms that they experience. The majority of terminally ill individuals receive multiple medications, and these medications frequently cause severe oral symptoms. Severe oral symptoms not only cause pain and interfere with nutritional intake and routine oral hygiene practices, but they also lead to severe local and systemic complications, some of which are life threatening. In addition, these symptoms can affect a person’s quality of life and their physical and psychological wellbeing. Understanding their perceived oral health needs may help in designing and delivering a person-centred oral care to these individuals and may help in preventing and treating oral disease/conditions that cause pain, and thus decrease their suffering and prevent medical complications. However, as of now, very little is known about their oral health statuses and how oral care or treatment decisions are made for them. Also, very little emphasis has been placed on the oral health of these individuals. This initiated a curiosity in me and contributed to my wanting to learn more about the perceived oral care needs of individuals with advanced health conditions.
CHAPTER 3 – METHODOLOGY

3.1. Introduction

The purpose of this chapter is to discuss the research methodology used for the study. This chapter provides a detailed description of the study design and the procedures that were followed for answering the proposed research questions. This chapter also contains sections explaining the study rationale, study objectives, research design and methodologies, and research procedure, including data collection and data analyses. In addition, this chapter considers trustworthiness components, human subject considerations, and the timeline of the study.

3.2 Study Rationale

Good oral health is very important for preventing and managing systemic complications. Individuals with advance-stage illnesses frequently face illness or treatment-related adverse effects in the mouth. These adverse effects can increase their symptom burden, affect their caloric intake, increase their risk for systemic complications, and affect their quality of life. The importance of oral care in this population is often overlooked, and dental professionals are usually not included in palliative and hospice care teams. Also, there are no guidelines as to what kind of oral care should be provided to these individuals, when and where should it be provided, and who should be making the dental treatment decisions for these individuals.

Currently, very little is known about the oral health status of terminally ill adults. Specifically, the severity of dental diseases affecting them, how they seek oral care, how treatment decisions are made for them, and whether they have access to the needed dental care. The following questions about terminally ill adults who receive dental care should be considered: 1) does the
dental care meet their needs? 2) does it lessen their burden? 3) does it improve their quality of life? and finally, 4) does it improve their overall health?

Considering the knowledge gap in this area, the primary interest in this study was to understand the oral health related concerns and perceived oral care needs of individuals with advanced health conditions receiving palliative care. To further our knowledge in this topic, we conducted a study of individuals with advanced health conditions receiving palliative care to understand their oral health-related concerns, perceived oral care needs, and the barriers they face managing their oral care and seeking dental care services. Through this research, we hope to provide knowledge to the clinicians who provide care to these individuals with advanced-stage illness about the oral health-related challenges that this patient population group faces. Also, we hope to inform health care providers and decision makers who are responsible for this population about the importance of maintaining functional and symptom free oral health statuses in these individuals, and possibly about the need for incorporating systematic screening and preventive dental care services for those with advanced-stage illnesses.

3.3 Research Question

To gain insight into this topic, we employed a qualitative research approach to find answers to the following questions:

1) How do individuals with advanced stage, incurable health conditions perceive and value their oral health?

2) How do individuals with advanced, incurable health conditions maintain their oral health?
3.4 Study Objectives

1) To explore and better understand the oral health-related concerns and perceived oral care needs of palliative care patients.

2) To explore and better understand how palliative care patients maintain their oral health and their perceived barriers in accessing dental care services.

3.5 Study Method

The proposed research was exploratory and descriptive in nature, and I used a qualitative descriptive approach, attempting to learn from the participants’ narratives to understand their experiences (336). The descriptive qualitative research method is more naturalistic and it does not use the theoretical underpinnings or interpretive approaches that the other qualitative methodological frameworks employ and is the least theoretical among qualitative research approaches (336, 337). Epistemology, the theory of knowledge pertaining to its methods, validity, and scope, and it allows an investigation of a research question that distinguishes justified belief from opinion (338). The naturalistic inquiry is an approach used for understanding the social world in which the researcher observes, describes and interprets his/her observations of specific people in a societal and cultural context (339). Since the epistemological framework of our study was established within the paradigm of naturalistic inquiry (336, 337, 339, 340), our research team felt that a qualitative descriptive study was appropriate for our research. In this method, the narratives are accepted as the construction of naturalism, while the researcher remains close to the data (340). Sullivan-Bolyai et al. (2005) stated, “the qualitative descriptive method is not thick description (ethnography), theory development (grounded theory) or lived experience (phenomenology), interpretative meaning of an experience (hermeneutics), but, rather an accurate and relevant description of the experience depicted in easily understood language” (341).
The other reasons for choosing the qualitative descriptive method include its suitability to our research topic and the population of interest. Milne and Oberle (2005) used a qualitative descriptive methodological approach to describe the self-care strategies that individuals maintain at home and the factors that affect their decision-making processes (342). Although the content of their study was different from ours, the way the findings were reported, with a practical understanding of the topic, aligned with the intentions of our study. Based on the similarities between our study objectives and those of Miln and Oberle (2005), we decided that the qualitative descriptive approach was an appropriate methodology for this study (342).

This qualitative research study is a part of our larger mixed methods research project, which uses both quantitative and qualitative research methods to provide a better understanding of the research problems than either approach alone. Of the different types of mixed method research designs, we chose a variant of an “Embedded mixed method research design” (343), which is also known as “concurrent nested mixed method design” (Figure 3). This design allows both qualitative and quantitative studies to be conducted in one phase, the quantitative research methodology in tandem with a secondary qualitative data set to provide a supportive, secondary role (343). This design is intended to answer different research questions; therefore, the two data sets (quantitative and qualitative) will not converge but will be reported separately.

3.6 Study Setting

This mixed methods research project was conducted at the College of Dentistry and at the outpatient palliative care services of the University of Iowa Hospitals and Clinics in collaboration with the Division of Palliative Care at the University of Iowa Hospital and Clinics. Ethical approval has been obtained from the University of Iowa Institutional Review Board.
3.7 Study Participants

The study participants are seriously ill adults with limited life expectancy receiving palliative care at the University of Iowa Hospitals and Clinics.

3.8 Sample Selection

Quantitative (parent) study:

Since the parent study was a pilot study, the sample size was not estimated. However, our target was to obtain complete data from 40 participants to better understand their oral health statuses while receiving palliative care at the University of Iowa Hospitals and Clinics from October 2017 to August 2019.

Qualitative part:

Since this qualitative study was a part of the mixed method study, I selected the sample using the purposive sampling method (344), nested within the quantitative (parent) study. A purposive sample is a non-probability sample, also known as a judgmental, selective, or subjective sample. This sampling method was chosen to allow maximum variation in the sample. Thus, the participants were selected to ensure that the data was collected from participants with different backgrounds and different types of illnesses, allowing for more flexibility in capturing a wide range of perspectives and to gain more significant insights into the phenomenon from different angles. Since this is a qualitative study, no sample size estimation was required. Participants were recruited until the collected data reached saturation. Using the qualitative research expertise of the team, we estimated that we might need 8-12 participants.
3.9 Inclusion and Exclusion Criteria

The inclusion criteria for participation include: 1) participants must have an advanced, incurable health condition; 2) be receiving palliative care; 3) be able to undergo a 20-minute oral examination, a 20-minute structured interview, and a 30-minute long in-depth semi-structured interview; 4) be at least 18 years old; 5) be physically and cognitively able to participate in the study; and finally, 6) they must speak English.

Potentially eligible participants were excluded if they 1) have (had) cancer in the head and neck region 2) if they have health conditions requiring antibiotic prophylaxis prior to the oral examination.

3.10 Participant Recruitment

After obtaining the ethical approval, a graduate student identified the patients who were receiving care at the palliative care clinic through the EPIC electronic database for the University of Iowa Hospitals and Clinics. Once identified, the palliative care clinicians informed the patients about the study. If they were interested, the trained research assistants met with the patients at the outpatient palliative care clinic and explained the study to them. If they were interested in participating in the study, they were first screened using the “Participant’s Screening form” (Appendix A.1) to ensure that they met the inclusion criteria. If they met the requirements, they were recruited into the study by obtaining written informed consent (Appendix A.2). Once recruited into the study, they were assigned a unique participant identification number and I scheduled an appointment for data collection either at the Palliative Care Clinic, the College of Dentistry or by phone per the participants’ preferences. All participants were provided financial compensation.
3.11 Data Collection

Qualitative research allows researchers to delve into the attitudes, concerns, behaviors, and experiences of the study participants. The aim of this study allowed me to conduct one on one, in-depth, semi-structured interviews, to allow the participants to explain their perception, views, and concerns in detail in response to our research question (345). The interviews were conducted using an interview guide that was developed in consultation with the research team members with expertise in the subject as well as the research method (Appendix A.3). The interview guide contained several open-ended, key questions. There were five key questions and they include 1) What is good oral health? 2) Given your current situation, can you describe some of your oral health needs? and 3) Do you have a dentist to help with your dental care? 4) Is there something that I did not ask, but feel you would like to tell me? 5. Do you have any questions for me? The first three key questions had 3-5 probes to allow the interviewer and interviewee to diverge from the topic and to pursue an idea or response in more detail (346). We collected data by audiotaping the interviews and taking field notes. All interviews were audiotaped, and field notes were taken. Audiotaping provides a detailed account of the participant’s responses for transcribing them verbatim. It was essential for our study as audio recording reduces the potential bias and misinterpretations that could result from focusing on writing the notes during an interview and relying on the interviewer’s memory when transcribing and analyzing the data. Also, the audio tape was vital because it allowed us to go back if required, as Button and Lee explain: “The data is naturally occurring conversation as a feature of social life, and the use of tape-recordings and transcripts is a practical strategy for apprehending it, and making it available for extended analysis”(347).
3.11.1 Interviews

As an interviewer, I collected data through one-to-one, in-depth, semi-structured interviews using the interview guide, allowing and encouraging the participant to talk freely about their experiences. Each participant was interviewed at the palliative care clinic or the College of Dentistry, or by phone based on the participants’ preferences. The length and direction of each interview varied depending on the participants’ responses, and on average, the interviews lasted for approximately 20-40 minutes. After each interview, data from the audiotapes and field notes were partially transcribed to understand if I missed any information that we wanted to collect and to identify if any new information emerged. If any new information emerged that was relevant to the study questions, it was used in subsequent interviews. The interviews continued until the categories and themes reached saturation. Although the generated codes and categories became repetitious after eight interviews, I continued recruiting and interviewing until the categories and subcategories were saturated (348, 349). In addition, I collected the participants’ medical diagnoses and Palliative Performance Scale (PPS) scores from their medical records, and their oral health status and demographic information from the parent quantitative part of the study. I used the PPS scores for describing the participants’ status and thus providing the reader with some insights which could be applied in interpreting study findings. The PPS is a reliable and valid tool used for the identifying and tracking the care needs of palliative care patients, especially, how their needs change with the progression of their illnesses/conditions (350). The PPS has five domains and they include a) ambulation, b) activity and level of disease, 3) selfcare, 4) nutritional intake and 5) level of consciousness. The scores range from 100% to 0%, and a higher score indicates better functions.
3.11.2 The Content of the Qualitative Data Collected

The collected qualitative data included the perceptions of the individuals concerning their oral health. It included: what good oral health meant for them; whether oral health was important for them and why; how did oral health impacted their overall wellbeing; how were they performing oral selfcare; whether they were facing any challenges in preforming oral selfcare; what measures they have been taking for maintaining oral health; whether they had any oral health concerns; if yes, how did those concerns affect their wellbeing; what measures they took to address those concerns; whether they sought any care and if yes, from who; whether they had any oral health needs; if yes, what were they; how do they value good oral health; and lastly, and more importantly, whether they perceived any barriers in seeking dental care and what were they.

3.12 Data Analyses

The foundation of the data analysis was to describe the participants’ narrative accounts about the topic and to answer the research question. According to Parahoo (2014), data analysis should be conducted simultaneously and after completing the data collection (351). Qualitative content analysis was used for the subjective interpretation of the content of text data by systematically coding and identifying patterns (352). It is more than counting words; instead, it allows us to examine data for contextual meanings, themes, and patterns (340). Also, it provides the researchers with opportunities to better understand the social and professional contextual reality of the text (353). The qualitative content analysis process is divided into several systematic steps, and they include preparing the data, defining the unit of analysis, developing categories and a coding scheme, coding the text, and producing the report (354). I used a qualitative data analysis software, ATLAS.ti version 8, which allows to organize and sort the data and provides maximum benefits for systematically scoring and handling the data. Data were reviewed for completeness
through the data collection process. After each qualitative interview, the field notes were reviewed for completeness and clarity. I listened to the audio recordings immediately after each interview with the participants to make sure that the recording was clear. Data management and analyses followed as suggested by Zhang and Wildermuth (353).

3.12.1 Data Preparation

I transcribed the interviews verbatim, cross-checked, and compared the written transcripts with the audio-recorded interviews to ensure accuracy. I read and reread the transcripts to gain a complete understanding of the interview content, highlighting the keywords and phrases while taking notes.

3.12.2 Unit of Analyses

The transcribed interview was the first defined unit of analysis. I then condensed these the larger units into smaller ones for further analyses and summarized in its entirety.

3.12.3 Developing Categories and Coding Scheme

Codes were created inductively or deductively during the process (355). In the inductive coding, as more data became available, codes that I created earlier changed. The interpretations of units that appeared clear at the beginning became unclear during the process (355). Therefore, to increase the stability and reliability of the coding process, coding was performed repeatedly, starting on different pages of the text each time, as suggested by Downe-Wamboldt (1992) (356). The coded categories emerged based on the highlighted words and labels as we grouped them into categories and minor categories (Table 1) based on similarities and the participants’ own words as they appeared in the interview. Deductive coding initiated during the process from my own theoretical understanding (357).
3.12.4 Coding Text

I carried out initial testing of the coding scheme with a sample text, and then I rechecked and achieved coding consistency. Using the same process to code the entire text, I repeatedly assessed the coding consistency by going back and forth and confirming the process (354, 358).

3.12.5 Producing Report

I report the findings through the description of participant perceptions of their oral health concerns, perceived oral care needs and barriers in accessing dental service utilization in their own terms, using the categories and subcategories that emerged in the study relating them to the research question. I use a naturalistic organization of data from the participants’ own voices. To maximize the clarity, validity, and reliability of the emerging themes, categories, and subcategories, I continuously reviewed, expanded, merged, or modified the data as needed. The interviewing, data transcription, and data analyses process are presented in Figure 4.

3.13 Trustworthiness

To support the trustworthiness of this qualitative inquiry, it is necessary to illustrate the richness of the data and convey it to the reader by representing the congruence between the themes identified and the participants’ statements (359). Trustworthiness was established using the following criteria, credibility, confirmability, and transferability.

3.13.1 Credibility

It was our primary interest to represent the participants’ oral health-related concerns, perceived oral care needs, and barriers in utilizing dental care. Thus, I have described the extracts of the information and the stories that I heard from the participants as closely as possible to the
context and meaning attributed by the participants with a low inference (360). At the end of each interview, I checked my understanding of the participants’ views with them as a form of member checking. However, I was not able to contact the research participants at the end of the study to confirm the findings due to the nature of the participants’ illness statuses.

### 3.13.2 Confirmability

Confirmability is the degree to which the results of a study can be confirmed or validated by others. This was accomplished by adding a detailed audit trail on how the data were coded, the changes made to the codes, and when the changes were made. As suggested by Lincoln & Guba (1985), a research team member and I reviewed the audit trails, coding, and data independently to assure the categories and subcategories identified were accurate and complete (339). Any disagreements arose between us, we resolved them through discussion to guard against bias and enhance the robustness of our observations.

### 3.13.3 Transferability

Transferability allows others to find meaning in the research findings in a similar setting and context, meaning external validity and generalizability (72). However, it is not an absolute goal in qualitative descriptive research. Although the data collected using qualitative descriptive methods provide rich descriptions of the experiences (340) in question, it may not be transferable to other situations. Nevertheless, the findings of this study will provide valuable information to clinicians working with palliative care patients or in similar situations.

### 3.14 Human Subject Considerations

Throughout the study, I have maintained human subject protection. We obtained ethical approval through the Institutional Review Board (IRB) of the University of Iowa. Written
informed consent was obtained from all the participants prior to their participation in this study. I maintained the privacy and confidentiality of participants throughout the interview, analyses and while presenting the results. After providing consent, each participant was assigned a unique identification code and participants were identified only by that code. All researcher team members who participated in data analyses of this study referred to the participants only by their assigned codes. Later, I transferred these identification codes into pseudonyms. Also, I modified their age by ±4 years to guard their identity while presenting my study findings in a narrative manner. All data, field notes, and transcriptions were kept in password protected computers accessible only to the research members of the study.

3.15 Summary

This chapter summarizes the study design and the research method, and the data analyses used in this investigation in detail. The study used qualitative descriptive methods with in-depth, semi-structured interviews. Study participants were individuals with advanced-stage illnesses with limited life expectancy receiving palliative care. The participants were recruited at the palliative care clinic and were interviewed either in person in private consultation rooms or at the palliative care clinic or via telephone. The interview data and fieldnotes were transcribed and analysed for developing categories and subcategories.
CHAPTER 4: RESULTS

4.1 Introduction

The qualitative descriptive methodology was used to explore and describe the perceived oral health concerns and needs of palliative care patients and their perceived barriers in accessing oral health care. The purpose of this chapter is to report the study findings. Our study results yielded rich descriptive summaries of the perceived oral care needs and barriers faced by the palliative care patients who participated in this study and are described in a narrative manner.

4.2 Demographics and Description of the Sample

A total of 11 individuals with advanced-stage illness receiving palliative care treatment at the University of Iowa Hospitals and Clinics participated in the study. The participants consisted of eight women and three men whose ages ranged from 36 to 91 years, with a mean of 63 years. Ten were non-Hispanic White and one was African American. Nine participants stated that they had dental insurance, of them two specified that they were on Medicaid, and two did not have any dental insurance. Four participants stated that they routinely utilized dental services, five participants stated that they utilized dental services “when needed”, and two did not utilize even when needed.

Five participants had cancer, while three had cancer in addition to other chronic illnesses. Although all participants were familiar with the term “thrush” only two participants reported of experiencing it sometimes in the past while receiving chemotherapy. None reported mucosal ulceration, mouth sores or denture sores. Three participants reported taste changes due to their cancer treatments and one participant experienced swallowing difficulty. One participant reported
having discomfort in a tooth that was recently restored and another participant complained of loose teeth.

The general characteristics of the sample are presented in Table 2 and the participants’ general characteristics, medical diagnoses, dental visit pattern, brushing habits and their Palliative Performance Scale (PPS) scores are presented in detail using their pseudonyms and modified age (± 4 years) in Table 3. The palliative performance Scale (PPS) scores in our sample ranged from 50-90%, seven participants had 70% or above, two had 60% and two had 50%. According to the PPS scoring system, those who are 70% or above do not require assistance with selfcare; those with 60% require occasional assistance and those with 50% require considerable assistance.

4.3 Study Findings

With regard to addressing our study question, the analyses produced categories and subcategories. There were five major categories. They include: a) oral health and its importance, b) oral health maintenance, c) current oral health and perceived needs d) how existing problems are taken care of, and e) plans for dental service utilization. The categories and subcategories are presented in Table 4 and also described narratively using the participants’ quotes as follows.

4.3.1 Oral Health and its Importance

“Oral health and its importance” was an important category that emerged from the iterative process of content analyses. All eleven participants provided insight into what good oral health meant to them, although these perceptions varied from person to person. Their perceptions significantly reflected their illness status, past dental history, how they took care of their oral health in the past, what oral health-related challenges that they faced in the past and were facing, and how
those challenges affected their day to day lives. We identified two subcategories: a) the meaning of good oral health and b) the perceived importance of good oral health.

4.3.1.1 Meaning of Good Oral Health

For most of the participants, good oral health meant having their natural teeth, nice looking teeth, no pain, being able to eat what they like to eat, not having to think or worry about their food choices or money and able to socialize. Lucy, a long-term heart patient recently diagnosed with cancer and receiving chemotherapy, expressed:

“That’s (having good oral health) peace. It means no pain in your mouth, no loose teeth, have good taste, and able to eat what you enjoy eating and not think about surprises. I don’t need to think about the money (the treatment cost). It is important for staying pain-free, and I don’t want to have pain, and nobody likes pain, I guess.”

In addition to general wellbeing, the appearance was an essential element of good oral health for the majority of those interviewed. An 87-year-old participant affected by multiple cancers, Ann, proactively maintained good oral hygiene and had good oral health:

“Good oral health means (having good oral health), you have things working well in your mouth. If you have good oral health, you can eat well, speak, and you can socialize. If someone does not have good oral health means, he/she is not well. Maybe he has a condition that makes him suffer in his mouth for a long time. People hide sometimes (hide their faces). If I had poor oral health, I would suffer, visit a dentist many times probably”.

Interestingly, for a few participants, good oral health meant being their usual self—performing oral hygiene and taking care of their mouth regularly, maintaining freshness in the mouth, not having bad breath, and visiting dentist regularly. For 45-year-old Stella, who was suffering from metastatic breast cancer, good oral health meant:

“Keeping my teeth clean every day, able to brush and floss every day, able to see my dentist regularly.”
4.3.1.2 Perceived Importance of Oral Health

All participants, irrespective of their current oral health status and past dental experience, expressed that oral health was essential for them to maintain their general health, overall wellbeing, and social interactions. We came across two scenarios. One group of participants routinely utilized dental care while the other group sought dental care only when it was required. Nevertheless, both groups knew that compromised oral health could affect their general wellbeing. Lilly, a 90-year-old participant with cervical cancer, who utilized dental care regularly throughout her life, expressed:

“Oral health is very important for keeping your teeth clean to prevent bacteria from getting into them. Organisms have a chance to work in your mouth if you don't remove the food that collects. Cavities can develop if you don't keep your teeth clean, and they can cause pain and make it difficult to eat. If the teeth are bad and unattractive and repulsive looking, they may affect your social life. I think, also, my oral health can have some systemic effects.”

Another participant, a 40-year-old named Adam who disliked going to the dentist and only sought dental care when it was absolutely required, expressed:

“If I have good oral health, I’ll be able to chew food with my own teeth, not having pain, not having to think about my mouth all the time. If I have problems in my mouth, I think I will think about it all the time. It is very important. I sometimes get infection and pain in my mouth, and I get bothered a lot. It does not feel good when it hurts.”

When I asked about the five decayed teeth that we found in his mouth during the oral exam, a part of our quantitative research, he did not seem worried. He did not perceive it as a “required dental care need” because he had no symptoms in those teeth. Also, he said he was tired because of his life-limiting illness and expressed:
“I cannot expect much. I have this serious illness, and its treatment is making me very tired. So, I reserve my energy for that. Once I have passed that I may feel better in my mouth.”

4.3.2 Oral Health Maintenance

Oral health maintenance was another important category that emerged in the analyses. The participants mentioned how they performed oral hygiene practices and how they sought dental care. We identified three subcategories here, and they include a) self-care, b) assistance for self-care, and d) seeking dental care.

4.3.2.1 Self-care

The majority of the participants expressed that they performed oral hygiene regularly and took care of their mouths without anyone’s help. Oral hygiene measures included tooth brushing, brushing the gums (in edentulous patients), gargling with saline or mouthwashes, and flossing. All participants stated that they brushed their teeth or gums at least once a day, while two participants indicated that they brushed their teeth more than twice a day. Only three participants reported that they flossed their regularly, while three other participants reported that they only flossed when they felt the need. Also, two participants stated that they used interdental aids such as interdental brushes and toothpicks. A very health conscious participant, Ann expressed:

“I don't do that much to take care of my teeth. I just brush them two or three a day. Sometimes, I may brush more times if I feel like, not as a rule. I like to brush my teeth when I am not too lazy. I floss my teeth routinely, and also when the food is stuck. Especially when I feel there is some food between my teeth, it is not very pleasant for me, and I have to floss right away. I use that plastic floss introducer and floss wherever it passes. I may not be perfect in flossing.”

Some participants did not pay much attention to their oral health. Adam said:
“I brush once a day, and that's it. I have always been brushing once, and it has never changed. I use a mouth wash, 'Scope, Tom's of Maine.' I have always been using it. It is natural, is it organic, and I like it. I don't floss, I don't like, but I do floss if the food is stuck between my teeth.”

Bob, a 76-year-old, edentulous participant, described that he lost all his teeth due to periodontal disease 15 years ago. He despised halitosis and tried to prevent it by keeping his mouth clean and using mouthwash for a fresh feeling in his mouth. He explained:

“I use a soft brush for my gums, and I take good care of my mouth. I don't use paste or something like that (laughs). I don't have teeth, so I don't need toothpaste. I use mouthwashes. You know, I know how to take care of my mouth. I told you I don't like to have bad breath and I will do anything to stay away from it.”

4.3.2.2 Assistance for Self-care

None of the participants required assistance to perform oral hygiene at the time of the study. Although help was available for all, most of them wanted to take care of their mouth on their own. At least eight participants would not like to receive help for performing oral hygiene practices even when they felt very sick. Celine, a 71-year-old participant with ovarian cancer, said:

“I do not need assistance at the moment. As I told you, I feel very fatigued, but I brush my teeth and floss when required without anyone’s help. I would not be comfortable if someone does it for me. So, it feels right to do on my own.”

4.3.2.3 Seeking Dental Care

Of the total 11 participants, four utilized dental care regularly and had a dentist for a long time. Ann was one of them, and she explained:

“I see my dentists regularly. They are pretty good to me. I enjoyed going to the dentists. They take care of my teeth, and they cannot take care of my teeth if I do not go to them (laughs).”
Five participants stated they sought dental care only when required. Some of them disliked doing to dentists. Bob disliked going to dentists and doctors and admitted that he had no particular reasons for disliking them. He expressed:

“I never used to see a dentist regularly. The only time I used to see a dentist is if I have a tooth to be pulled out, something like that when I had teeth. I did not bother, I guess (laughs). I was the world's worse person to see a doctor. I hated the doctors. I did not like doctors, and that kinda stuff you know? Now, I have no choice.”

Mary, a 39-year-old participant with pulmonary hypertension, wore a partial denture that was loose and rocking. Although she felt that she might benefit if she got her dentures tightened, she also expressed that she could manage with the existing ones. She did not seem overly concerned and expressed:

“I go to the dentist only when I need. I don't have a regular dentist. I have always been this way. I am okay with that. Everyone is different, you know.”

4.3.3 Current Oral Health Concerns and Perceived Needs

Current oral health and perceived needs was another major category that arose from the iterative process of the analysis. All participants experienced some oral health-related concerns. We identified three subcategories: a) oral health perceptions, b) current oral health concerns, and c) perceived oral health needs.

4.3.3.1 Oral Health Perceptions

Most of the participants perceived that they had good oral health irrespective of their oral health statuses, non-painful symptoms, or the challenges that they were experiencing. For example, despite having five decayed teeth, Adam said:
“I have good oral health. I have no problem. I am able to chew food and I don't think about my mouth much.”

Christine, a 49-year-old participant with heart disease and morbid obesity, stated that she needs a partial denture to replace some of her missing teeth. Despite that, she was satisfied with her oral health and perceived it to be good. She expressed:

“My oral health is fine, and I have no problem. It is good. As good it can be, I can say. I am happy with it. I don't say it's perfect. I need some teeth to be replaced.”

Mary had no serious oral health-related concerns other than dry mouth and a rocking partial denture. Despite these, she was satisfied with her oral health. She expressed:

“Well (thinking), I won’t say I have good, I mean the best teeth, but I am okay with that.”

4.3.3.2 Current Oral Health Concerns

All participants experienced some issues in their mouth that bothered them. Some of those concerns were more serious than others. They all knew that most of the oral symptoms/challenges that they were experiencing were adverse effects of their illness/conditions and the treatments that they were receiving, and they would continue to experience those challenges during their treatments. Only one participant reported having some loose teeth and wanted to get them extracted, one participant had discomfort in her tooth that was restored by her dentist recently, and none reported broken or decayed teeth. We found four important subcategories: dry mouth, difficulty in eating, denture-related issues, and taste

4.3.3.2.1 Dry Mouth

Dry mouth was one of the common concerns for all but one participant. However, their degree of concern varied from person to person based on the chronicity of their illnesses/conditions. For those who experienced dry mouth for a long time, it became part of their
life and they adjusted to it and even learned to manage it. Although they were bothered by it, they were not seriously concerned about it. Bob suffered from heart disease and COPD for over fifteen years and had experienced dry mouth for a very long time. He said:

“I feel dry in my mouth, and it's because of the medication that I am taking. That's it. I don't know if that will disappear if I stop the medication. Well, That's my life now. I feel okay, no problem.”

Dry mouth was a significant concern for those who were in the acute stage of their illness, especially those who had a cancer diagnosis and were receiving chemotherapy. Celine, an ovarian cancer patient undergoing chemotherapy, expressed:

“Dryness is one of the main concern. I don’t remember ever experiencing it before. Sometimes I wonder my nose gets stuffed up and then I have to breathe from my mouth. I don't have a cold or something like that...”

Lucy, who had multiple illnesses and cancer, expressed:

“My mouth feels dry because of my cancer medications. Yes, it does wake me up. I don't know if it's just that my mouth is waking me up, or the water. I just don't know.”

4.3.3.2.2 Difficulty with Eating

All participants expressed that they were experiencing problems with eating irrespective of their illness status, and that they were pain with eating, loss of taste, difficulty in swallowing, loose teeth, loose dentures, food impaction, and digestion. Although one participant reported discomfort in her tooth that was recently restored, she said it did not cause pain while eating. Although some of the participants said that they could eat almost anything, they admitted that they had to make modifications to their eating habits and had limited food choices. Stella, a metastatic breast cancer patient, expressed:
“When I eat, depending on what I eat, it kinda hurts my tongue, and when I am done eating, it feels more sore than what it did prior to eating. So, I want to get through that. When it is (food) cleared up, I can feel better.”

Brian’s main oral health concern was dry mouth and difficulty swallowing, both of which began from the time he started his cancer treatment. He said it is because there is not enough saliva to lubricate his mouth. He explained:

“Major problem is eating, and I am not able to eat well. It is because I don’t have saliva and I don’t digest my food. You know, I don’t have much saliva, and so, I find it difficult to swallow. It makes my life a lot harder. Also, see, I don’t have teeth. It is difficult to eat well without teeth, and you know that. My body is not able to breakdown food. Sometimes, food gets stuck in my throat.”

4.3.3.2.3 Denture-related Issues

Bob and Elizabeth were complete denture wearers. Both were disgusted with food getting stuck under their dentures. Although Elizabeth had an implant supported lower denture and a conventional upper denture, she only wore the upper denture at the time of the interview. When asked about this, she said that she was not comfortable wearing the lower denture. She said:

“My dentures don’t fit very well. I have to put lots of glue if I have to use them. When I eat, food particles get under them, and I don’t like when that happens. If I use my denture glue, it’s difficult to remove them. So, when I go out to eat, I have to think about how am I going to deal with it. I don’t like to go to the restroom and struggle to remove my dentures, especially in front of others, you know. It’s hard, harder than you can imagine. If I don’t do it, I suffer until I come home and clean it. I can eat pretty much anything with my dentures.
4.3.3.2.4 Taste

At least four participants expressed concern with altered taste as an adverse effect of the treatments that they were receiving. Although it affected their eating habits, they accepted it. A participant expressed:

“My taste is very different. I don't like the sweets that I used to like. It tastes very different. It's too sweet. I don't think it affects my day to day life because it comes and goes.”

4.3.3.3 Perceived Oral Health Needs

Most of the participants expressed some kinds of oral health-related concerns and some felt they may feel better if they got them addressed. However, most of them did not perceive it as a priority. Lucy, a 62-year-old participant who was very afraid of dentists, stated that she has loose teeth and she wanted to get them extracted and have dentures made. She stated that her oral problems have been accumulated over time because of her dental fear of dentists and felt the need to seek dental care to get her oral concerns addressed. She said:

“The only treatment I need in my mouth is to remove some teeth and make dentures that can tolerate it. The teeth are not causing me any problems, but there are some teeth that are loose.

Another participant, Mary had an ill-fitting partial denture, and she described how she might feel better if she got it fixed. Despite that, getting her denture fixed was not her priority. She expressed:

“As such, I do not feel I have any dental needs... I have no pain, and I feel nothing. I think everything is okay.

When reminded about her ill-fitting denture, she said:

Ohh yeah, my denture is loose, and I need to get it fixed. I don't know if they will fix this or they have to make a new one. As of now, it’s not in my priority list.”
4.3.4 How the Existing Oral Problems Were Managed

Another major category that arose from the analyses was how the participants took care of their oral symptoms or issues that they were facing. Here we observed three subcategories: a) dry mouth management, b) contact person and information, and c) misconceptions.

4.3.4.1 Dry Mouth Management

As mentioned earlier, all except one participant experienced dry mouth. Most of them expressed that their responsible healthcare providers told them that they would get dry mouth as an adverse effect of the treatment. Those who were experiencing dry mouth tried to keep themselves well hydrated by sipping or drinking water during the day and night, as advised by their clinicians. Although dry mouth was very annoying, they had accepted it as a part of their treatment, and most of them learned to manage it. Stella, who was receiving chemotherapy for her metastatic breast cancer, was extremely bothered by dry mouth and expressed:

"Normally, I drink water. Also, I have this product (pulls out from her purse, Biotine). It helps, and water helps. Sometimes, I chew gum thinking it may help. I am not sure if it helps, though. Also, I do not know if there is something else that can help better."

Most of the participants sipped or drank water to manage dry mouth. Some participants tried pharmaceutical products that were prescribed for dry mouth. Some did not remember the names, but felt that they did not help reduce their symptoms. Adam expressed:

"I keep drinking water. Yeah, it helps, but momentarily; but then, I have to keep sipping water. I don't use any products for my dry mouth. I tried some; they don't work. I just sip water."

Although drinking water can help manage dry mouth, this was not an option for those with kidney disease. Kidney disease requires limited liquid intake, which can lead to dehydration and worsen
dry mouth and also affect dry mouth management. Elizabeth, who suffers from end-stage kidney
disease, explained:

“I have to keep drinking water. I don’t like to drink water much, but I drink. I use Biotine,
and that helps a lot. I use mouthwashes (Biotine). I am not supposed to drink water because
of my illness (kidney failure). It’s complicated.”

4.3.4.2 Contact Person

When asked who they would contact if they have a problem in their mouth, all participants
expressed that they would consult their medical team. However, if the problem was teeth or
denture-related, then they said they would ask dentists. They felt that most of the issues that they
were experiencing were adverse reactions to their treatments and felt comfortable talking to their
medical care team. Stella, who was on chemotherapy, consulted her oncology team when she had
a candida infection in her mouth. She believed it was related to the treatment that she was receiving
for her cancer and her compromised immunity because of her chemotherapy. Therefore, she felt it
was appropriate to consult her oncology team. She explained:

“Recently, I contacted my oncology office. With this thrush infection, I did not know if I
should be still. I mean, I am currently taking chemotherapy, and it’s a pill every day. I
didn’t know if still should be taking that medication. I thought it was best to contact them,
and then my oncologist could decide what to do with.”

Another participant with cancer, Celine, was concerned about her teeth getting discolored since
she started receiving chemotherapy for ovarian cancer. She expressed:

“If I have dental problems, I will ask the dentists. But, if there is anything treatment-related,
I will ask my oncologist. It’s difficult to make that decision.”

Although she stated that she would consult a dentist if she had a tooth-related problem, she did not
consult her dentist. She regretted not asking her dentist about it during her recent dental visit, which
was just two weeks before her participation in the study. Also, she said her dentist did not ask if she had any oral health-related concerns.

Most of the participants felt overwhelmed by their health condition and multiple medical appointments. If they had a problem that was not serious enough, they preferred not to consult anyone. Adam expressed:

“I don’t report to anyone. It’s (dry mouth) not so much as to seek help. I have many other problems, and I have to prioritize them.”

4.3.4.3 Information and Misconception

We observed some unmet information needs and misconceptions. Some explained if they received any information that could have helped them understand what to expect as they were undergoing treatments for their illnesses/conditions. Stella felt if she had received information about how to care for her mouth and what to expect that it would have helped her pay much closer attention to her oral health. She expressed:

“I don’t know what’s the spectrum is like. How oral health changes based on illnesses and their treatment? Like my cancer. I don’t know if cancer patients are prone to certain oral diseases or conditions or infections? It might be helpful if cancer patients know a little bit earlier on as to what to expect. Uhh. A little bit more information would be helpful. Especially about oral or dental health.”

Another participant, Lucy, felt that her teeth were chipping since she started her chemotherapy. Since she did not receive any information, she misunderstood and thought chemotherapy was breaking down her enamel. She expressed:

“My cancer caused a huge problem in my mouth. It has weakened my teeth. I don’t know what’s happening. My chemo is breaking my enamel down. My one tooth got so weak that it just broke it off. I guess it just got so weak.”

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In general, Lilly perceived that she had good oral health in general, except that she was bothered by one tooth which was causing her discomfort. Although it did not affect her eating, she did seek care for that tooth from her new dentist. However, she felt that her dentist did not provide her with enough information and was concerned. She expressed:

“You know, I have this problem with my tooth, and my dentist did not fix it, but she said she might have to pull it out. Maybe she understands it, but, she has not explained it to me well enough. I am concerned about it.

4.3.5 Dental Service Utilization

Dental service was another vital category that emerged in our analyses. It had two subcategories: barriers and plan for dental care

4.3.5.1 Barriers

Only four participants utilized dental care routinely. Of them, three stated that they felt no barriers in continuing to seek routine dental care. Lack of perceived oral care needs was one of the significant barriers for accessing dental care. The other barriers include their illness taking the priority, limited life expectancy, numerous medical appointments, fear of dentists, financial related (lack of insurance, publicly funded insurance), not having a dentist, dental anxiety, feeling discriminated against, not having a connection with the dentist, and physical challenges such as not able to sit through dental appointments, wheelchair access and transportation related issues. Lucy faced multiple barriers. She was afraid of dentists, overwhelmed with numerous appointments, and on top of that had transportation issues. Although she did not have a regular dentist, recently she went to a dentist and felt okay with seeking care. She explained:

“I am terrified of dentists, and that something is keeping me from going to the dentists. I had a bad rep(experience) with one. I don’t even like them coming near my face. I get
really spooked. (Laughs). Also, my health condition plays a big role, also. Some days are good, and some are not. Also, I have to go to the hospital quite often. So, I do not like to have additional appointments. Another thing is, I don't drive. So, someone else has to take me. If I drove, it could be different.”

One participant who had no regular dentist felt discriminated against by the dentist when he sought care the last time. He felt like he was being picked on because of his publicly funded dental insurance plan. He expressed:

“I felt discriminated. He does not like to have people like me, I mean those who are on Medicaid... He tried to dominate me, and I don't feel good there. He wanted to do what he wants, not what I want.”

Although Christine did not seek dental care regularly, she did have a dentist who stopped taking her because she was on Medicaid (publicly funded insurance). Her insurance status and limited life expectancies prevented her from seeking needed dental care. She explained:

“I don't have a dentist. I used to have one. Not anymore. So, I have no opportunity to discuss about my mouth. Actually, I don't have anything that urgent to discuss with a dentist, you know what I mean? I can live this way, for another year. Since they told me I have limited time.”

“If I was going to live longer, and I would have gone to any dentist who takes my insurance, I would have gone and got my teeth replaced. However, since I am not in that situation, I think and act differently, you know what I mean?”

4.3.5.2 Plan for Dental Care

Some participants perceived that they should seek dental care to get some of their concerns addressed. Their illness was a priority for the majority of them. Most of them expressed that their dentists understood their situation well. However, Stella was afraid that she might not be able to sit through her dental appointments. She explained:
“I used to go the dentists every 3-4 months when I was fine. Then when had an injury (back injury due to metastasis) last year, and the illness, I could not make it that often. Now that I started to feel a lot better, and more functional, I need to get back to my regular schedule, and I want to take care of my mouth as I used to.”

Lucy, who has been very afraid of the dentists, felt motivated to go and seek dental care after she participated in the study. She expressed:

“Although I am not too comfortable with that dentist, I feel, I am a step closer to going to a dentist.”
CHAPTER 5: DISCUSSION

5.1 Discussion

The purpose of this study was to describe the perceived oral health related concerns and perceived dental care needs of individuals with advanced health conditions with limited life expectancies receiving palliative care and the barriers they perceive in utilising dental care services. In this descriptive qualitative study, I interviewed 11 individuals with advanced health conditions receiving palliative care. The participants’ perceived oral health related concerns were dry mouth, eating difficulties, taste changes and denture-related issues. Their perceived dental care needs were getting loose teeth extracted, replacing lost teeth, getting a new denture or getting the old denture relined, and getting decayed teeth restored. Their perceived barriers were their illness taking the priority, countless medical appointments, limited life expectancy, financial issues (lack of insurance, publicly funded insurance), not having a dentist, disliking dentists, dental anxiety, feeling discriminated against, not having a connection with the dentist, and physical challenges such as not able to sit through the appointments, wheelchair access, and transportation related issues. Also, I observed a mismatch between their actual oral health statuses and perceived oral health statuses.

Most of the currently available literature that focuses on oral health status patients at the end of their life concerns the individuals living in long-term care facilities (59, 123, 285, 289). Although a significant proportion of them may require palliative care, it is not clear what proportion of these individuals receive it. Very little literature is available that specifically focuses on the oral health statuses of individuals receiving palliative care (121, 219). When available, it focuses on individuals with advanced-stage cancer (121, 361). As mentioned earlier, oral mucositis is one of the most common adverse effects of cancer treatments (201, 203, 204, 206, 208-210).
and it is more severe in those who receive bone marrow transplantation (210, 212-214, 362) and radiation in the head and neck region (211). Although eight participants in our study had cancer and none of them were experiencing oral mucositis at the time. This could be because we excluded the individuals with head and neck cancers and those who required antibiotic prophylaxis prior to their oral exam. Also, none of our study participants had hematologic malignancies and therefore, none were receiving bone marrow transplantation.

Moderate to severe oral pain is common in terminally ill individuals with AIDS, cancer, cardiovascular and respiratory diseases (60). Although eight of our study participants had cancer and a few had cardiovascular and respiratory diseases, none reported oral pain. However, all reported painful sensation which affected their eating, and they attributed this to dry mouth. Given that pain management plays a central role in palliative care (193), it is possible that most of the participants may have been receiving pain medications for issues which may have masked their oral pain.

Our study participants reported milder oral symptoms when compared with a similar study that was conducted in Australia by Rohr and associates (219). Rohr et al. (2010) did not report the inclusion and exclusion criteria for their study (219), and therefore we are unable to compare and contrast our study findings with theirs. It could be possible that they might have included head and neck cancer patients and those receiving bone marrow transplantations, or their study participants may have had any underlying diseases that increased their risk for oral symptoms, or they may have been undergoing different types of treatments, or they might have been in different phases of the treatment trajectory which much have caused significant impact on their oral health. Also, they did not specify what kind of palliative care services that their study participants might have been receiving (219). Some of their study participants did make the clinicians aware of their dry
mouth but did not receive any help (219). Our study was conducted at a university affiliated large hospital in the United States which has an established specialized palliative care program. Therefore, it is possible that our study participants may have been monitored closely for their symptoms by their clinicians. Also, four participants sought dental care regularly which may have significantly helped them in preventing oral health problems. Although oral candidiasis is expected in immunocompromised individuals affecting 8-94% of the terminally ill individuals% (236), only two of our study participants expressed that they experienced thrush sometime in the past. Although they felt very annoyed and agitated with the symptoms, they felt that they received adequate attention from their clinicians.

As mentioned above, dry mouth, eating difficulties, altered taste, and denture-related issues were significant concerns that we observed in this sample. All ten participants who were affected by dry mouth conveyed that they were bothered by it significantly, which is in line with the past research that was conducted with palliative care patients (219). Because of the dry mouth, most of our study participants had to wakeup in the night to drink water, carry a water bottle wherever they went, and at least two of them stated that it interfered with their social communication (talking). Despite that, they accepted it and felt there was not much that could be done because they had to continue the treatment of their illnesses/conditions. Dry mouth was a greater concern for those who were in the acute stages of their illnesses as observed in earlier research (219).

while those who were experiencing dry mouth for a very long time had accepted it and learned to live with it. Although most of them were just sipping/drinking water to manage dry mouth, some stated that they used Biotine or other mouthwashes that were prescribed for them. Most of them who used these mouthwashes felt that the mouthwashes were not helpful in reducing
dry mouth. However, one participant with end-stage kidney disease depended on it because she was required to limit her liquid intake and could not drink water frequently as the others.

Another major concern that we observed was difficulty eating due to dry mouth, swallowing difficulty, taste changes and denture related issues. Difficulty eating and dietary modifications are very common in older adults, especially those with advance-stage illnesses (232, 234). In our study, all participants reported difficulty eating and thus they had to make dietary modifications which left them with limited food choices. Most of them did not feel it affected their social life, except for an edentulous participant named Brian who reported difficulty eating and swallowing. Although there are many reasons for swallowing difficulty (266), he attributed it to the lack of saliva as an adverse effect of his cancer treatment. Although he made diet modifications and limited his food choice, he felt embarrassed, especially if he had to go out and eat with his friends. Only three participants reported taste changes and felt bothered by it. However, they accepted it as a temporary situation as an adverse effect to the chemotherapy that they were receiving for their cancer and they did not express a great concern.

Denture related issue was another serious problem that affected eating. Of the total 11 participants, three were denture wearers and another three expressed the need for new dentures. All three denture wearers reported that their dentures were loose and felt that they might benefit if they got them fixed. Past studies have reported that removable denture wearers are dissatisfied with their denture fit and comfort, and as a result, they may not wear them frequently (363). This was the case in our study as well. Although Mary wore her partial denture despite it being loose, both Bob and Elizabeth were not wearing their complete dentures regularly because of their ill fit. Although denture-related traumatic ulcers can affect up to 92% of those with ill-fitting dentures (291, 364), none of our study participants reported any traumatic ulcers or soreness due to their
dentures, and I confirmed this from their oral health statuses that we collected for the parent study. Another major denture-related concern was food getting trapped under the dentures. In general, food adheres to plastic surfaces easier than the mouth surfaces and denture wearers are very conscious about this (365). This may feel worse due to dry mouth and compromised salivary clearance. Elizabeth and Bob both disliked wearing dentures if they had to go out and eat because food getting trapped under their dentures made them extremely uncomfortable. Also, because of their loose dentures, they had to use a lot of denture adhesives to keep them in place. As a result, they were not able to remove their dentures easily and clean them, especially when they went out to eat.

All participants had some kind of oral health related concerns, some of them were treatable by dental care providers. However, eight participants explicitly mentioned that seeking dental care was not their priority because of their illness statuses. For example, Adam had five decayed teeth, three participants had loose dentures, and three participants expressed the need for dentures. Although some of these problems are treatable by dentists, utilizing dental care was not a priority for these participants. Although most of these individuals reported that they seek dental service when needed, they did not perceive it as “needed” care. This indicates that there was a mismatch between their oral health statuses and perceived oral care needs. Their oral care need perceptions would differ from the dental clinicians’ perceptions. It is possible that lack of painful symptoms, their illness status, numerous medical appointments, financial issues and other factors may have played a significant role in how the participant perceived the dental care needs. Past studies have reported that those who experience problems with esthetics, pain, cavities, and difficulty with chewing are more likely to perceive dental care needs and utilize dental care services (366-370). Lack of need perceptions seems to be a significant barrier in utilizing dental care (369, 371). Also,
self-perceived oral health needs are subjective and are individual perceptions, and thus they can vary from the normative needs (369, 372, 373) and so their dental care utilization pattern (374, 375). It was reported that those with normative needs are less likely to utilize dental services (369, 376). In addition, the extent of the oral impairments and their symptoms seems to play a significant role in whether they seek care or not (376). Also, perceived needs seem to be modified by various factors such as symptoms, social, cultural, financial and competing needs, and burdensome life situations (369, 373, 375). Lack of painful symptoms, financial issues and their health statuses may have modified the perceived needs in our sample.

We observed multiple barriers that the study participants perceived in accessing dental care services. Among them, their illness status and numerous medical appointments was a significant one. Individuals with advanced-stage illness/conditions have numerous medical appointments and often feel overwhelmed, and they will have to prioritize what is important to them given their health condition. This could affect their perceived needs and dental service utilization (377, 378). Adam, who reported utilizing dental care “when needed,” had five decayed teeth and felt overwhelmed with his health condition. He stated that he had to reserve his energy for his priorities, and dental care was not a part of it. Stella, another participant who was utilizing routine dental care all her life reported that her illness was a barrier in continuing to seek dental care. Even though oral health was very important for her, cancer treatment was her priority. Also, she was afraid that she might not be physically able to sit through her dental appointment because of her recent, cancer-related back injury.

The other barriers that we observed with for dental care services utilization were limited life expectancy, fear of dentists, financial issues, not having a dentist, dental anxiety, feeling discriminated against, not having a connection with the dentist, wheelchair access and
transportation related issues. Most of them experienced a combination of these factors. Two participants, Elizabeth and Celine, stated that they were given less than a year to live. This, together with other barriers, may have affected their priorities, perceived oral care needs and dental service utilization. Elizabeth did not have a dental insurance, was afraid of dentists, and felt that there are not many dentists who provide care for those in wheelchairs. Celine was on Medicaid and had a dentist in the past. However, her dentist refused to provide care for her because of her Medicaid status. Although Christine was free to seek care from other dentists, given her limited life expectancy, she did not feel comfortable to go and find a new dentist who might accept her dental insurance and importantly whom she may feel comfortable with. She felt she could manage for the remaining months of her life with her existing oral health status which she perceived to be good. Both Elizabeth and Christine might have perceived oral care needs differently if they were not facing significant barriers for seeking dental care. For example, both these participants may have acted differently and got new dentures made if they were not affected by limited life expectancy and also if they did not face financial barriers (Medicaid status).

Fear and dislike towards the dentists was another significant barrier to seeking dental care. At least four participants, Elizabeth, Bob, Adam, and Brian, disliked going to dentists. While Elizabeth was afraid of dentists, the other three said that they had no specific reasons for their dislike. However, Adam felt discriminated against by his dentist due to his Medicaid status. Having a good relationship with the dentist was very important for some participants. Lilly, a 90-year-old participant who sought dental care regularly, felt no connection with her new dentist. As a result, she felt anxious and was not comfortable seeking care for a tooth that she had discomfort with. Also, she felt that her dentist did not provide her with enough information. As a result, she felt that she could not trust her new dentist. The other barriers were transportation related and having to
depend on others. Both might have affected some participants significantly and altered their perceived needs as well as dental care utilization.

In addition to our research questions, we also explored other variables such as the participants’ perceptions of oral health, its importance, how were they trying to achieve it, and who they would contact if they are faced with oral health-related problems during their critical illness. Although these variables are not directly connected to our research question, the information we collected around these variables enhanced our understanding of the participants’ perceived needs. We found that oral health was very important to all participants to maintain their general health and their physical and social wellbeing. For most of them, oral health meant remaining pain-free and worry free, unconcerned about daily oral functions and money. This has been observed earlier (379). Interestingly, for three participants, good oral health meant being their usual self and doing the simple and routine things that they have been doing all their lives, like brushing their teeth, taking care of their mouth, and visiting dentists regularly. For some participants, this routine was interrupted because of their illnesses and illness-related challenges. Although all participants stated that they took efforts to maintain their oral health for the most part of their life, this was not reflected the oral health statuses of some of the participants. It is possible that some of those who did not pay much attention to their oral health during their earlier years might have learned the hard way as their oral health declined. For example, Bob, a 76-year-old participant who was completely edentulous for more than 15 years, explained that he takes good care of this mouth, brushes his gums with a brush, and uses mouthwash to prevent halitosis. Most likely, he would have retained his natural teeth if he had taken care of his mouth his entire life at the same level as he was taking care of it at the present time.
Dental diseases are preventable, but when left untreated, they can cause pain and suffering and lead to tooth loss (380). Most of the dental care needs that we observed in this study include loose teeth, decayed teeth, loose dentures, and requiring tooth replacements because of neglecting oral health for an extended period which could have been avoided if the participants maintained good oral hygiene and sought dental care regularly. Those four participants who had a dentist and visited dentists routinely perceived better oral health statuses and had fewer oral health concerns than those who did not utilize dental care regularly. This finding is in line with what has been observed earlier (381). Also, those who sought routine dental care perceived fewer barriers for seeking care when compared to those who sought care only when needed and those who did not seek care at all even when needed. The observed barriers include past negative experiences with dentists, disliking dentists, transportation related issues, feeling discriminated against, and financial related issues. In fact, these are some of the common barriers for seeking dental care in general (377, 382). Also, for some participants, their priorities had changed with their medical diagnosis. For example, for 45-year-old Stella who was taking good care of her mouth and utilizing dental care regularly until she was diagnosed with cancer expressed that her general health was a priority.

Although assistance was available to all of them for performing oral hygiene, none utilized it. They wanted to perform oral hygiene by themselves despite their life-limiting health statuses and despite feeling fatigued. They felt it was important to do so by themselves, and most of them expressed that they would not be comfortable with someone performing oral hygiene on them. Of the total eleven participants, two had 60% PPS scores, meaning they required occasional assistance with selfcare, and two participants had a score of 50%, meaning they required considerable assistance. Despite that, all participants were able to perform oral hygiene practices themselves.
and they felt it was important to do so. This conveys that autonomy was very important for them, which has been observed earlier (119, 383).

When asked who they would prefer to contact if they have oral symptoms, all participants expressed that they would reach their medical team. However, if the problem was tooth-related, they could ask a dentist. Adam, a 40-year-old participant with Melanoma, said he would try to manage on his own if he can. Since most of them felt that they were not in that situation, it is difficult to imagine and make that call. Celine, a 71-year-old participant, expressed that if she has a tooth-related problem, she would ask her dentist, and if the problem is not tooth-related, she would ask her oncology team. Although she had some questions about her tooth discoloration, which she thought was due to her chemotherapy, she neither asked her medical team nor her long-time dentist during her routine dental visit (two weeks prior to her interview with me). Another participant, 87-year-old Ann with multiple cancers, expressed that she would ask her dentist. However, her problem was completely tooth related, food getting stuck between her teeth which she said she had accepted it because her dentist told her it was age-related. Some participants experienced unmet informational needs. Stella, a 45-year-old participant with breast cancer, said that if she had received information about oral care she would have been able to pay closer attention to her oral health.

5.2 Strengths and Limitations of the Study

The qualitative research approach allowed me to explore the participants’ perceptions and their reasons for their perceptions that I may not have explored using a quantitative method. The rich data obtained in this research provided a deeper understanding of what the participants said in the proper context. Also, this research provided me with an opportunity to get underneath their superficial responses and rational thoughts, which might have influenced their oral care and oral
care seeking behaviors. Additionally, it allowed me to encourage the participant to express themselves with authenticity. Furthermore, the sampling methods that we chose provided us with an opportunity to learn from individuals with different types of illness and demographics and understand their perceptions within a short period.

The following limitations should be kept in mind while interpreting our study findings. It is important to note that this study reflects the perceptions of specific individuals taking receiving palliative care at the outpatient palliative care clinic at the University of Iowa Hospital and Clinics. Although I primarily aimed to recruit participants in both the inpatient and outpatient palliative care clinic, due to the participants’ illnesses statuses it was not feasible to recruit from the inpatient clinic. Therefore, the findings that we observed may not be applicable to the inpatient palliative care patients. Also, the recruitment was limited only to those who agreed to participate leading to a selection bias. It is possible that people who participate in the study may value oral health more than those who did not participate. Second, we used purposive sampling methods to include participants with different illness and backgrounds. Thus, those who participated in the study may not represent all palliative patients. To overcome that, we chose a purposive sampling method to recruit participants with different illnesses and demographic statuses and gathered their perceptions. However, including individuals with all kinds of illnesses was beyond the scope of this study. Third, there is a possibility that the participants may not have shared their reality with me. Considering that I am an interviewer who came from the College of Dentistry, they might have tried to exaggerate the way they see oral health or the value of oral health. They might have tried to impress me by talking about positive aspects even when they did not mean it or did not have good oral health now or in the past. Fourth, they may not have shared or interacted with me the way they think about oral health due to the cultural differences that they felt with me as I came
from a different ethnic background. Their interactions with me could have been moderated with for not wanting to be judged by me as not being one among them. To overcome this situation, I did not rely on only what they spoke, but what I saw, observed, and gathered the data within the limits of the study (384). Then, I matched their perception and value of health with their oral assessment data that we collected in our quantitative investigation and used that to explain what we observed and what the reality was. Fifth, qualitative research is sometimes criticized for the interpretive nature of analyses and lack of generalizability. Since qualitative research is iterative and interpretive, exact generalizability is not expected. Instead, the reliability of the research findings is measured by how well the methods of analyses are documented. For example, in this study, I have provided the evidence to support my interpretations using primary data in the form of participant quotes. Lastly, but more importantly, the educational level of the participants was high school or higher which may impact their value of oral health and oral health care, oral health literacy and self care pattern which may differ from general palliative care patients.

5.3 Implications for Practice

- Recognizing patients’ information needs and providing them with the needed information in a timely manner and in a way that the patients can understand may help them in paying closer attention to their oral health.

- Increasing oral health awareness among patients, raising oral health awareness and providing them with resources for managing oral health.

- Educating the healthcare team members about the importance of oral health, potential impact of oral disease and involving a dental care provider in palliative care teams.
• Exploring the associations between normative need, self-perceived oral health, dental care utilization may be helpful in addressing known gaps in dental health care utilization and reducing oral health disparities.

• Systematic collaboration with dental professionals may increase the detection of oral morbidity at an early stage, thereby improving symptom management.
CHAPTER 6: CONCLUSIONS

Oral health was important for individuals with advanced health conditions to maintain their general health and physical and social wellbeing. Oral symptoms were very common among them, especially dry mouth and eating difficulties. Eating difficulties included pain with eating, food impaction, and loose dentures. Despite these difficulties, only a few utilized dental care routinely. Dental care seeking behavior appeared to be interrupted depending on the illness status. Among those who expressed that they would seek dental care if required, did not plan on seeking care for some of the treatable conditions. They did not perceive it as a “need care” suggesting a serious mismatch with their perceive oral care needs and their oral health statuses. The other barriers that they faced include, their illness taking the priority, numerous medical appointments, limited life expectancy, not having dental insurance, financial issues, dental anxiety, dentists not understanding their problem, feeling discriminated against, dislike like towards the dentist, and seeing the problem as not a significant enough issue to seek care.

Despite their life-liming illnesses and assistance available, all participants were able to perform oral hygiene practices themselves and they felt it was important to do it on their own. Having said that, it is important to understand that most of the individuals who participated in this study were able to able to perform selfcare without any assistance. We observed some unmet informational needs concerning their oral health. Including oral health related information systematically in their care plan may help them manage their oral health better and may help them in pay closer attention to their oral health, seek dental care in a timely manner and reduce their risk for systemic complications.
Figure 1. Palliative Care Staffing

Source: CAPC.org (120)
Figure 2. Oral Problems in Palliative Care

Figure 3. Research Design

Concurrent embedded design (343)

Figure 4. Study Flowchart
## LIST OF TABLES

Table 1. The Code Groups and Categories

<table>
<thead>
<tr>
<th>Code groups</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to eat</td>
<td>Current oral health and perceived needs</td>
</tr>
<tr>
<td>Appetite</td>
<td></td>
</tr>
<tr>
<td>Current concerns</td>
<td></td>
</tr>
<tr>
<td>Dentures</td>
<td></td>
</tr>
<tr>
<td>Dry mouth</td>
<td></td>
</tr>
<tr>
<td>Taste</td>
<td></td>
</tr>
<tr>
<td>Dental care needs</td>
<td></td>
</tr>
<tr>
<td>Contact person</td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td></td>
</tr>
<tr>
<td>Misconceptions/Information</td>
<td>How existing problems are taken care of</td>
</tr>
<tr>
<td>Oncology team's skills</td>
<td></td>
</tr>
<tr>
<td>Dry mouth management</td>
<td></td>
</tr>
<tr>
<td>Appearance</td>
<td></td>
</tr>
<tr>
<td>Good oral health</td>
<td>Oral health and importance</td>
</tr>
<tr>
<td>Importance of good oral health</td>
<td></td>
</tr>
<tr>
<td>Poor oral health</td>
<td></td>
</tr>
<tr>
<td>Assistance for oral hygiene</td>
<td>Oral health maintenance</td>
</tr>
<tr>
<td>Oral hygiene practices</td>
<td></td>
</tr>
<tr>
<td>Past dental experience</td>
<td></td>
</tr>
<tr>
<td>Dental visits</td>
<td></td>
</tr>
<tr>
<td>Plan for dental care</td>
<td>Plans for dental service utilization</td>
</tr>
<tr>
<td>Access to dentists</td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td></td>
</tr>
<tr>
<td>Dentist relationship</td>
<td></td>
</tr>
<tr>
<td>Dentist's skills</td>
<td></td>
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## Table 2. The General Characteristics of the Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (mean, range)</td>
<td>63 (36-91)</td>
</tr>
<tr>
<td>Gender</td>
<td>n=11</td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>10</td>
</tr>
<tr>
<td>Black</td>
<td>1</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>2</td>
</tr>
<tr>
<td>Trade school</td>
<td>3</td>
</tr>
<tr>
<td>Some College</td>
<td>3</td>
</tr>
<tr>
<td>University</td>
<td>3</td>
</tr>
<tr>
<td>Dental insurance status</td>
<td></td>
</tr>
<tr>
<td>Has private dental insurance</td>
<td>7</td>
</tr>
<tr>
<td>Medicaid</td>
<td>2</td>
</tr>
<tr>
<td>No insurance</td>
<td>2</td>
</tr>
<tr>
<td>Dental visit</td>
<td></td>
</tr>
<tr>
<td>Regular</td>
<td>4</td>
</tr>
<tr>
<td>Only when needed</td>
<td>5</td>
</tr>
<tr>
<td>Avoids dental visits even when needed</td>
<td>2</td>
</tr>
<tr>
<td>Dentulous status</td>
<td></td>
</tr>
<tr>
<td>Partial denture wearers</td>
<td>1</td>
</tr>
<tr>
<td>Completely edentulous (do not have dentures)</td>
<td>1</td>
</tr>
<tr>
<td>Completely edentulous (have dentures)</td>
<td>2</td>
</tr>
<tr>
<td>Brushing habits</td>
<td></td>
</tr>
<tr>
<td>Brushing once a day</td>
<td>6</td>
</tr>
<tr>
<td>Brushing twice a day</td>
<td>3</td>
</tr>
<tr>
<td>Brushing more than twice a day</td>
<td>2</td>
</tr>
<tr>
<td>Using interdental aids (other than toothbrushes)</td>
<td></td>
</tr>
<tr>
<td>Floss</td>
<td>6</td>
</tr>
<tr>
<td>Interdental aids</td>
<td>2</td>
</tr>
<tr>
<td>Using mouth washes</td>
<td></td>
</tr>
<tr>
<td>For managing dry mouth</td>
<td>8</td>
</tr>
<tr>
<td>For managing dry mouth as well as for other reasons</td>
<td>5</td>
</tr>
<tr>
<td>Barriers in seeking care</td>
<td>8</td>
</tr>
</tbody>
</table>
Table 3. The Characteristics of the Participants by Their Pseudonyms

<table>
<thead>
<tr>
<th>Pseudonyms</th>
<th>Sex</th>
<th>Age</th>
<th>Race</th>
<th>Education</th>
<th>Diagnosis</th>
<th>PPS (%)</th>
<th>Brushing/day</th>
<th>Dental visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stella</td>
<td>F</td>
<td>45</td>
<td>White</td>
<td>University</td>
<td>Metastatic breast cancer</td>
<td>80</td>
<td>&gt; Twice</td>
<td>Regular</td>
</tr>
<tr>
<td>Mary</td>
<td>F</td>
<td>39</td>
<td>White</td>
<td>Highschool</td>
<td>Pulmonary hypertension, neoplasm of unknown origin</td>
<td>90</td>
<td>Once</td>
<td>Only when needed</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>F</td>
<td>69</td>
<td>White</td>
<td>Trade school</td>
<td>Chronic kidney disease</td>
<td>60</td>
<td>Once</td>
<td>No dental visits</td>
</tr>
<tr>
<td>Celine</td>
<td>F</td>
<td>71</td>
<td>AA</td>
<td>Trade school</td>
<td>Ovarian cancer</td>
<td>70</td>
<td>Twice</td>
<td>Regular</td>
</tr>
<tr>
<td>Christine</td>
<td>F</td>
<td>49</td>
<td>White</td>
<td>Some college</td>
<td>Heart failure, morbid obesity,</td>
<td>70</td>
<td>Once</td>
<td>Only when needed</td>
</tr>
<tr>
<td>Bob</td>
<td>M</td>
<td>76</td>
<td>White</td>
<td>Highschool</td>
<td>Heart disease, chronic obstructive pulmonary disease</td>
<td>70</td>
<td>Once</td>
<td>Only when needed</td>
</tr>
<tr>
<td>Lucy</td>
<td>F</td>
<td>62</td>
<td>White</td>
<td>Trade school</td>
<td>Pleural effusion, heart disease, and thyroid cancer</td>
<td>70</td>
<td>Twice</td>
<td>No dental visits</td>
</tr>
<tr>
<td>Adam</td>
<td>M</td>
<td>40</td>
<td>White</td>
<td>Some college</td>
<td>Melanoma</td>
<td>70</td>
<td>Once</td>
<td>Only when needed</td>
</tr>
<tr>
<td>Ann</td>
<td>F</td>
<td>87</td>
<td>White</td>
<td>University</td>
<td>Multiple cancers</td>
<td>50</td>
<td>&gt; Twice</td>
<td>Regular</td>
</tr>
<tr>
<td>Lilly</td>
<td>F</td>
<td>90</td>
<td>White</td>
<td>University</td>
<td>Cervical cancer</td>
<td>50</td>
<td>Twice</td>
<td>Regular</td>
</tr>
<tr>
<td>Brian</td>
<td>M</td>
<td>69</td>
<td>White</td>
<td>Some college</td>
<td>Esophageal cancer</td>
<td>60</td>
<td>Once</td>
<td>Only when needed</td>
</tr>
</tbody>
</table>

Age = real age ±4 years; AA - American African, PPS – Palliative Performance Scale (80-100% = full ambulation, 60-70% reduced ambulation, 50% = mainly sit or lie, 40% =mainly in bed, 10-30% = bound to bed and 0% death).
Table 4. The Categories and Subcategories of the Findings

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral health and its importance</td>
<td>Meaning of Good oral health</td>
</tr>
<tr>
<td></td>
<td>Perceived importance of good oral health</td>
</tr>
<tr>
<td>Oral health maintenance</td>
<td>Selfcare</td>
</tr>
<tr>
<td></td>
<td>Assistance for selfcare</td>
</tr>
<tr>
<td></td>
<td>Seeking dental care</td>
</tr>
<tr>
<td>Current oral health concerns and perceived oral care needs</td>
<td>oral health perceptions</td>
</tr>
<tr>
<td></td>
<td>Current oral health concerns (dry mouth, difficulty eating, denture related issues and taste)</td>
</tr>
<tr>
<td></td>
<td>Perceived oral health needs</td>
</tr>
<tr>
<td>How existing oral problems were taken care of</td>
<td>Dry mouth management</td>
</tr>
<tr>
<td></td>
<td>Contact person</td>
</tr>
<tr>
<td></td>
<td>Information and misconceptions</td>
</tr>
<tr>
<td>Plans for dental service utilization</td>
<td>Perceived barriers</td>
</tr>
<tr>
<td></td>
<td>Plan for current and future dental care</td>
</tr>
</tbody>
</table>
REFERENCES


93. Center to Advance Palliative Care. A Call to Action: Policy Initiatives to Support Palliative Care: America’s Care of Serious Illness 2015


212. Stiff P. Mucositis associated with stem cell transplantation: current status and innovative approaches to management.


APPENDICES

Appendix A.1: Participant’s Screening Form

Participant’s Screen Form

<table>
<thead>
<tr>
<th>Section I. Eligibility</th>
<th>Record #</th>
<th>First Name</th>
<th>Last Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient Name: __________________________________________</td>
<td></td>
<td>(Prefix)</td>
<td>(Last Name)</td>
</tr>
<tr>
<td>Record #_________</td>
<td></td>
<td>(First Name)</td>
<td>(Last Name)</td>
</tr>
<tr>
<td>2. For A-D mark ‘Yes’ or ‘No’ to indicate if the patient meets study eligibility criteria and .</td>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>A. Patient is 18 years of age or older</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Patient is fluent in English</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. Patient is able to participate in interview</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. Patient is not cognitively impaired.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If patient agrees to participate, complete Section II.

| Section II. Demographics                                      |
|-------------------------------------------------------------|----------|-----------|
| Patient Date of Admission to Hospice: _ _ _ / _ _ _ / _ _ _   |          |           |
| Month / Day / Year                                           |          |           |
| Admitting Diagnosis: (check all that apply)                  |          |           |
| □ Cancer                                                     |          |           |
| □ Dementia, Alzheimer’s Disease                              |          |           |
| □ Organ failure                                              |          |           |
| □ Other, specify:                                            |          |           |
| Other, specify:                                              |          |           |
| Patient Address: ___ __ __ __ __ __________________________ |          |           |
| (Street Address)                                            |          |           |
| (City)                                                      | (State)  | (Zip)     |
| Patient Phone: (_ _ _) _ _ _ -- _ _ _ _ work/cell/home       |          |           |
| (primary phone)                                             |          |           |
| (_ _ _) _ _ _ -- _ _ _ _ work/cell/home                     |          |           |
| (alternate phone)                                            |          |           |
| Can patient provide own consent:                            |          |           |
| □ No                                                        |          |           |
| □ Yes                                                       |          |           |

Completed by __________

Screening date __ __ ___
Appendix A.2: Informed Consent

INFORMED CONSENT DOCUMENT

Project Title: Oral health needs in older adults with advanced health conditions

Principal Investigator: Xi Chen

Research Team Contact: Dr. Xi Chen
Department of Preventive and Community Dentistry
College of Dentistry
University of Iowa
Phone: 319-335-7188
Email: xi-chen-6@uiowa.edu

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

If you have any questions about or do not understand something in this form, you should ask the research team for more information.

You should discuss your participation with anyone you choose such as family or friends.

Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We are inviting you to participate in this research study because you are receiving hospice or palliative care from University of Iowa Palliative Care Clinic or Holden Cancer Center. The purpose of this research study is to understand the self-perceived oral health needs of older adults with advanced health conditions and barriers for accessing the needed oral care.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 80 people will take part in this study conducted by investigators at the University of Iowa.

HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will last for about 45 minutes which can be completed in one visit or multiple visits per the patient preference. It will take an additional 30 minutes if you agree to take part in the optional audiotaped interview.

There is an optional retest of the same questionnaire done immediately following the completion of the first questionnaire or two weeks follow-up (this two week follow-up can be done in person or by telephone). Completing this optional retest allows us to access the reliability and validity of...
our questionnaire and study personnel. This retest should only take an additional 10-15 minutes. You will be compensated with a $10 Target gift card or $10 check that will be mailed to you, in addition to the compensation for completing the initial study activities.

**WHAT WILL HAPPEN DURING THIS STUDY?**

If you are the subject receiving hospice or palliative care, a member of the research team will collect information about your medical history and medications from your medical record for use in research analysis. She will then interview you about your oral and overall health, and your care needs. Specifically, interview questions will ask about your access to and use of professional oral care, changes in oral health over the past year and current oral health status, and self-perceived value of oral health and oral care. We will also ask about your age, race, ethnicity, and educational background. Following the interview, a brief oral exam will also be given to understand your current oral health status. This exam will last about 10-15 minutes and will be given at the University of Iowa Hospital or College of Dentistry.

The interview will take about 20 minutes, and can be completed in-person at the place of your choosing. You are free to skip any questions that he/she would prefer not to answer.

If you agree to participate in an additional audiotaped Qualitative interview (optional), this can be completed in-person or over the telephone (whichever is more convenient). You are free to skip any questions that he/she would prefer not to answer. This interview will take approximately 30 minutes.

If you agree to participate in the optional retest, two different study personnel will ask you the interview questions again. This will be done either immediately following the initial study procedures or two-weeks later. Participating in the interview questions two weeks later can be done either in person or over the telephone. These questions should only take an additional 10-15 minutes.

**Photographs/Audiotapes/Optional additional interviews**

Currently, little is known regarding the pattern of oral disease among older adults with advanced health conditions. One aspect of this study involves making photographs of your oral health problems. Only the principal investigator of this study has access to these photos. After the study is completed, these photos will not be destroyed and will be used to better understand and develop measures, classifications and/or intervention for the oral disease of this vulnerable population. Another aspect we aim to explore and better understand are the caregivers’ perceptions and the patients perceived oral health needs of older adults with advanced health conditions and the barriers for accessing the needed oral care.

Being photographed is optional, you would still be eligible for the study if you refused that aspect of the study.

[ ] Yes   [ ] No   I give you permission to make photographs of me during this study.
Participating in the Qualitative Audiotaped interview is optional, you would still be eligible for the study if you refused that aspect of the study.

[ ] Yes  [ ] No  I give you permission to make audiotapes of me during this study.

Participating in the optional retest interview is optional, you would still be eligible for the study if you refused that aspect of the study.

[ ] Yes  [ ] No  I agree to participate in the optional retest interviews.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

The study involves minimal risk for the participants. Although it is unlikely, given your (the person for whom you represent and provide care) compromised systemic health, it is possible that the interview itself could be a stress for you. The oral examination is non-invasive. During the examination of your gums, you may feel minor discomfort.

If you are the subject receiving hospice or palliative care, there is a risk of loss of confidentiality of data due to the use of data from your dental record in research. Measures in place to protect confidentiality are indicated in the ‘What About Confidentiality’ section later in this document.

WHAT ARE THE BENEFITS OF THIS STUDY?

You will not benefit from being in this study.

However, we hope that, in the future, other people might benefit from this study because the information gathered from this study may help physicians and dentists better address the oral health needs in individuals with advanced health conditions.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study

WILL I BE PAID FOR PARTICIPATING?

You will be compensated based on the components you have completed in the study. If you complete the initial survey you will receive a check for $25. If you complete the oral exam you will receive a check for $25. If you are the patient participating in the Audiotaped Qualitative interview, you will receive an additional $10. If you complete the optional retest interviews you will receive $10 in Target gift cards or an additional $10 check mailed to you in addition to the study compensation. In addition to the above compensation, you will receive parking pass(es) to cover the time necessary to complete the study activities.

WHO IS FUNDING THIS STUDY?
The National Institute of Health (NIH) and the Delta Dental of Iowa Foundation are funding this research study. This means that the University of Iowa is receiving payments from NIH and the Delta Dental of Iowa Foundation to support the activities that are required to conduct the study. No one on the research team will receive a direct payment or increase in salary from NIH and the Delta Dental of Iowa Foundation for conducting this study.

WHAT ABOUT CONFIDENTIALITY?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

federal government regulatory agencies,

auditing departments of the University of Iowa, and

the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, we will assign a study ID for you after enrollment. This study ID will be used on all study documents. You name and contact information will be kept in a locked cabinet in a locked office until the end of the study. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

The University of Iowa Hospitals and Clinics generally requires that we document your participation in research occurring in a University of Iowa Health Care facility. This documentation will be in either your medical record or a database maintained on behalf of the institution reflecting that you are participating in this study. The information included will provide contact information for the research team as well as information about risks associated with this study. We will keep this Informed Consent Document in our research files; it will not be placed in your medical record chart.

WILL MY HEALTH INFORMATION BE USED DURING THIS STUDY?

The Federal Health Insurance Portability and Accountability Act (HIPAA) requires your health care provider to obtain your permission for the research team to access or create “protected health information” about you for purposes of this research study. Protected health information is information that personally identifies you and relates to your past, present, or future physical or mental health condition or care. We will access or create health information about you, as described in this document, for purposes of this research study. Once your health care provider has disclosed your protected health information to us, it may no longer be protected by the Federal HIPAA privacy regulations, but we will continue to protect your confidentiality as described under “Confidentiality.”
We may share your health information related to this study with other parties including federal government regulatory agencies, the University of Iowa Institutional Review Boards and support staff, and the sponsors of this study. You cannot participate in this study unless you permit us to use your protected health information. If you choose not to allow us to use your protected health information, we will discuss any non-research alternatives available to you. Your decision will not affect your right to medical care that is not research-related. Your signature on this Consent Document authorizes your health care provider to give us permission to use or create health information about you.

Although you may not be allowed to see study information until after this study is over, you may be given access to your health care records by contacting your health care provider. Your permission for us to access or create protected health information about you for purposes of this study has no expiration date. You may withdraw your permission for us to use your health information for this research study by sending a written notice to Dr. Xi Chen at the Department of Preventive and Community Dentistry, College of Dentistry, University of Iowa, Iowa City, IA 52242. However, we may still use your health information that was collected before withdrawing your permission. Also, if we have sent your health information to a third party, such as the study sponsor, or we have removed your identifying information, it may not be possible to prevent its future use. You will receive a copy of this signed document.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won’t be penalized or lose any benefits for which you otherwise qualify.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, or if you experience a research-related injury, please contact Dr. Xi Chen at 319-335-7188.

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or e-mail irb@uiowa.edu. General information about being a research subject can be found by clicking “Info for Public” on the Human Subjects Office web site, http://hso.research.uiowa.edu/. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this research study has been explained.
to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name (printed):

________________________________________________________________________

Do not sign this form if today’s date is on or after EXPIRATION DATE: 06/02/20.

________________________________________________________________________

(Signature of Subject) (Date)

Statement of Person Who Obtained Consent

I have discussed the above points with the subject or, where appropriate, with the subject’s legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

________________________________________________________________________

(Signature of Person Who Obtained Consent) (Date)
Appendix A.3: Interview Guide

Interview guide for research participants

A. Perceptions of oral health and its impact
1. What is good oral health?
   Probes
   a. How would you describe your current oral health?
   b. Does your oral health effect how you live your life?
   c. What works the best for you to help with your oral health?

B. Perceived needs of oral health and it value
2. Given your current situation, can you describe some of your oral health needs?
   Probes
   a. Do you how to get these needs addressed and who to see? (are you seeking help, if yes, can
      you describe?)
   b. Please describe how you take care of your teeth?
   c. Do you require assistance in managing your care of your teeth? (regular basis or time to
      time)? If yes, how are they helping you in meeting your needs? What challenges do you
      face while taking assistance?

C. Perceptions of oral care
3. Do you have a dentist to help with your dental care?
   Probes
   a. Do you get help from dentists and or hygienist? If yes, can you tell me about your last visit
      to the dentist?
   b. If you were getting help from a dentist, were there any situations you felt the dentists did
      not understand your concerns? Could you describe?
   c. Has there been any changes in how often you see a dentist? If yes, how and why?
   d. Are there any problems that prevent you or discourages you from seeing a dentist? If yes,
      could you describe some of them?
      Can you tell me about something that would help with seeing a dentist on a more regularly
      basis?

4. Is there something that I did not ask, but feel you would like to tell me?
5. Do you have any questions for me?