

Oral Health of the Palliative and Hospice Patient



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The World Health Organization defines palliative medicine as specialized medical care for people living with a serious illness. It focuses on providing comfort and quality of life through the comprehensive assessment and treatment of physical, psychosocial, and spiritual needs [1]. Oral healthcare represents an essential aspect in the management of patients with serious and advanced life-threatening conditions. As a result, oral healthcare professionals become indispensable members of palliative care and hospice interprofessional teams [2]. The purpose of this chapter is to review the concepts of palliative care and hospice in the context of dental practice. We will review the definitions of palliative care and hospice, focus on specific oral healthcare issues arising during the care of patients with palliative care and hospice needs, review key ethical concepts at the end of life, and discuss the role of oral healthcare professionals as members of the palliative care team.

Research shows that older adults with serious illness and those with life-limiting conditions at the end of life have a high prevalence of oral problems that results from the direct effects of the underlying disorders and the adverse effects of the recommended therapies for these conditions [3, 4]. Oral diseases including mucositis, xerostomia, oral candidiasis, and oral pain, can have significant local and

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systemic consequences and substantially compromise the quality of life of individuals with serious illness. The early identification and treatment of oral conditions among older adults with palliative care and hospice needs could minimize pain and suffering [3]. However, there are important barriers to overcome when managing these patients. Evidence reveals that about 40% of palliative patients at one point during their illness may lose the ability to communicate their symptoms [5]. This may contribute to the underreporting and underestimation of oral conditions, which may result in the failure of healthcare professionals to properly address them [6]. Regular assessments may help identify oral conditions and facilitate the implementation of appropriate and timely interventions. As we will review during this chapter, caregivers play a critical role during clinical encounters when patients with palliative care and hospice needs are unable to communicate.

1 The Concepts of Palliative Care and Hospice

Palliative care and hospice are part of a continuum of healthcare for patients with serious illnesses. Palliative care can be provided at any time during the trajectory of any serious illness, while hospice care is offered for patients at the end of life. In the next sections, we address each of these concepts, highlighting the main commonalities and differences between both concepts (Fig. 1).

1.1 Palliative Care

Palliative care focuses on anticipating, preventing, diagnosing, and treating symptoms experienced by patients with serious illnesses. Moreover, palliative care professionals play an essential role in assisting patients and their families in making important healthcare decisions. Palliative care becomes a resource for anyone living with a serious illness, and it is appropriate at any stage of the illness. Palliative care can be provided along with the delivery of curative treatments [1, 3]. A centerpiece

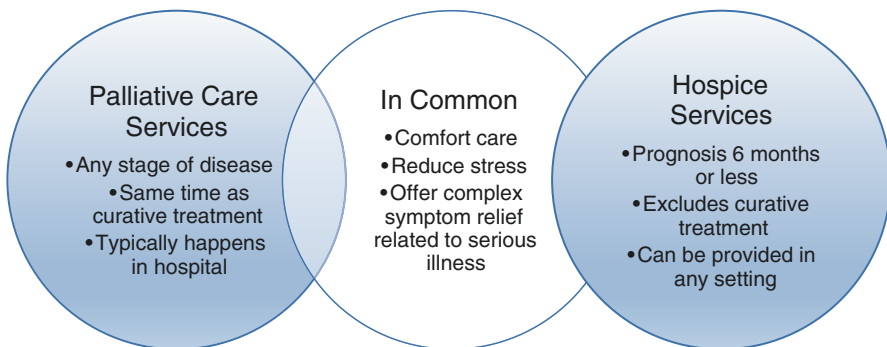


Fig. 1 Differences and similarities between palliative care and hospice

of the palliative care approach is the interprofessional team that provides comfort care while maintaining optimal function and well-being [7]. The team often consists of palliative care physicians, nurses, dietitians, social workers, and chaplains.

The delivery of palliative care early in the course of a life-limiting illness can improve the quality of life for patients; decrease overall healthcare utilization, including hospitalization [8]; shorten hospital stays; and reduce the need for non-beneficial therapies [9]. The palliative care approach does not aim to hasten or postpone death. Research shows that palliative care increases hospice care use and improves patients' quality of life and even survival [10]. In terms of healthcare utilization, palliative care interventions can significantly reduce total healthcare costs in patients with advanced cancers [8, 11]. Each year, an estimated 40 million people need palliative care. Unfortunately, despite the potential benefits of palliative care approaches for patients with serious illness, only about 14% of people, who need palliative care worldwide, currently receive it [1].

Worldwide, efforts are underway to expand palliative care services for patients in need. The 2014 World Health Assembly passed a resolution appealing to member countries to incorporate palliative care services into their respective healthcare systems [12]. Furthermore, two more important developments at the global policy level are worth mentioning. First, in 2000, palliative care was included in the United Nations' International Covenant on Economic, Social, and Cultural Rights, which states: "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons... to preventive, curative, and palliative health services." Second, essential medicines for palliative care were included into the 18th World Health Organization (WHO) essential medicines list in 2013 [13].

1.2 *Hospice*

As curative interventions no longer achieve the patient's care goals, patients may begin the transition to hospice care. Hospice care is defined as comfort care for patients facing a terminal illness [14]. Patients qualify for hospice care when their physicians estimate that the patient's prognosis for survival is 6 months or less if the disease runs its course. As with palliative care, hospice provides comprehensive comfort care as well as family support. Unlike palliative care, hospice no longer focuses on cure. Increasingly, people with serious illnesses that no longer respond to curative interventions are choosing hospice care as an alternative at the end of life. Hospice can be provided in any setting—home, nursing home, assisted living facility, or inpatient hospital. In the USA, hospice services are covered by government insurance such as Medicare or Medicaid, as well as most private healthcare insurance. Medicare and many private insurance plans cover the cost of palliative care. This coverage is different from the hospice care benefit [14]. In other high-income countries such as Australia, palliative and hospice services are funded by Medicare [15], whereas in Canada, palliative care is provided free of charge to eligible patients [16]. An example of a middle-income country, Colombia, has a palliative care law requiring that palliative care be offered to all patients with cancer [17].

Table 1 Karnofsky Performance Scale Index [22]

Able to carry on normal activity and to work; no special care needed	<p>[100] Normal no complains; no evidence of disease</p> <p>[90] Able to carry on normal activity; minor signs or symptoms of disease</p> <p>[80] Normal activity with effort; some signs or symptoms of disease</p>
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed	<p>[70] Cares for self; unable to carry a normal activity or to do active work</p> <p>[60] Requires occasional assistance but is able to care most of his personal needs</p> <p>[50] Requires considerable assistance and frequent medical care</p>
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	<p>[40] Disabled; requires special care and assistance</p> <p>[30] Severely disabled; hospital admission is indicated although death not imminent</p> <p>[20] Very sick; hospital admission necessary; active supportive treatment necessary</p> <p>[10] Moribund; fatal processes progressing rapidly</p> <p>[0] Dead</p>

Table 2 Palliative Performance Scale (PPS)

%	Ambulation	Activity level evidence of disease	Self-care	Intake	Level of consciousness
100	Full	Normal, no disease	Full	Normal	Full
90	Full	Normal, some disease		Normal	
80	Full	Normal with effort, some disease		Normal or reduced	
70	Reduced	Can't do normal job or work with effort, some disease		Normal or reduced	
60	Reduced	Can't do hobbies or housework significant disease	Occasional assistance needed	Normal or reduced	Full or confusion
50	Mainly sit/lie	Can't do any work, extensive disease	Considerable assistance needed	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full or drowsy or confusion
30	Bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full or drowsy or confusion
20		Unable to do any work, extensive disease		Minimal	
10		Unable to do any work, extensive disease		Mouth care only	
0	Death	–	–	–	–

In the USA, hospice eligibility requires that a physician certifies the patient has less than 6 months to live if the disease follows its usual course [18–20]. Accurate prognostic information is important for patients, families, and physicians, i.e., it can help physicians decide whether to initiate or continue anticancer therapies [21],

facilitate transitions to hospice care, enable appropriate advance care planning, and ensure end-of-life shared decision-making. Clinicians may use performance status measures defined as global assessments of the patient's level of function. The Eastern Cooperative Oncology Group (ECOG) scale and the Karnofsky performance status (KPS) [22, 23] are two widely used methods to assess the functional status of patients with serious illnesses [24]. The Palliative Performance Scale (PPS) (Table 2) [25] is another tool to assess functional performance. It also helps determine progression toward the end of life. PPS ratings directly correlates with short-term prognosis for terminally ill patients with or without cancer. The ECOG is a scale extensively used in oncology settings to assess disease progression, assess the disease impact on activities of daily living, and determine appropriate treatments and prognosis. It describes the patient's level of functioning in terms of their ability to care for themselves, activities of daily living, and physical function. Researchers worldwide use the ECOG performance status when planning trials to study new treatment strategies. The ECOG assists physicians in monitoring the patient's level of functioning during treatment and determine disease progression. Like the ECOG, KPS (Table 1) classifies a patient according to their levels of functional impairment, compares the effectiveness of therapies, and assesses patient prognosis. The lower the Karnofsky score, the worse the survival for most serious illnesses [26]. It is generally accepted that a KPS or PPS score of 50 or less indicate that the patient may have a prognosis of 6 months or less for survival [25].

2 The Role of the Dental Care Professional in Palliative Care and Hospice

The World Congress of 2015 adopted the Tokyo Declaration on Dental Care and Oral Health for Healthy Longevity, with the main goal of collecting scientific evidence on the contribution of oral healthcare and formulate policies based on such evidence [27]. Oral health is a key indicator of overall health, well-being, and quality of life. The Global Burden of Disease Study 2017 estimated that oral diseases affect 3.5 billion people worldwide [28]. Unfortunately, there is insufficient data to assess the extent of oral health problems in patients with severe and life-limiting illness. This is likely because of an underestimation of oral conditions in many patients with serious illness receiving palliative care or hospice services.

Although not often considered standing members of core palliative care or hospice teams, dentists and other healthcare professionals play important roles in the care of these patients [3]. Dental professionals provide needed expertise to assess and manage the oral healthcare needs of individuals with serious and life-limiting illness, improving symptom management and promoting oral self-care in close collaboration with members of the core interprofessional team. Palliative oral care focuses on strategies for maintaining patients' quality of life and comfort. In palliative care, oral healthcare goals include adequate pain control, avoidance of infection, and prevention of and prompt removal of dental plaque, calculus, or food debris. The interprofessional team works in close collaboration with dental

healthcare professionals, patients, and families to prevent and treat problems as they arise. The basic principle of oral palliative care is focused primarily on the principle that good oral hygiene is critical for oral integrity. Dentists may mitigate oral complications by performing regular oral prophylaxis and providing necessary preventive, corrective, and restorative dental treatments. These interventions may serve to alleviate oral symptoms, reduce their risk for mouth sores, denture sores, periodontal disease, and oral infections. Early and accurate clinical diagnosis of oral conditions in palliative patients must be instituted to minimize pain and suffering.

Although most palliative care patients may have compromised oral health, they seldom receive adequate and timely oral care services [29]. The reasons for these deficiencies are various [30]. Traditionally healthcare providers in palliative care have focused on general healthcare often overlooking oral needs. Other contributory factors are lack of dental insurance [31], high dental treatment costs, not understanding the importance of oral health [32], lack of access to dental care services, and lack of specialized dental training in palliative care and hospice [3]. Another common problem is that dental care professionals are not often included in core palliative care teams [33, 34]. Solutions to these problems may require a repertoire of strategies. Proposed solutions include promoting bedside oral healthcare for older adults with serious illness and symptom management through an enhanced collaboration between interprofessional team members, regular mouth care, and early identification of dental problems to minimize pain and complications. Finally, this interprofessional collaboration could also help dentists understand their patients' prognoses, better address when and how to implement palliative treatment, and how to minimize futile and potentially harmful dental treatments with the goal of improving quality of care [35].

3 The Oral Assessment of the Older Adult with Palliative Care and Hospice Needs

An adequate assessment is the first step to establish the patients' baseline oral health status. The assessment may determine the existence of any oral conditions requiring additional evaluation and treatment by a dental health professional. In institutionalized patients, examination of the mouth should be done daily for early detection and treatment of oral problems [36]. Multiple oral health assessment instruments have been developed. A meta-analysis compared several of these instruments and concluded that three instruments – the Brief Oral Health Status Examination Tool (BOHSE), the Oral Health Assessment Tool (OHAT), and the Dental Health Registration (DHR) – are valid and reliable assessment tools to assess the oral health of nursing home residents [36]. For community dwelling patients, if they are unable to perform self-care, much of their oral care is provided

by family members or home health aides who provide care at home. We were not able to find research describing training or screening tools recommended for the assessment of oral health in palliative care patients in community settings. Therefore, it would be advisable to adapt some of the previously described instruments for use in community-dwelling settings.

Trained nursing personnel can use the BOHSE and the OHAT to assess the oral health of nursing home residents. Both tools serve as screening instruments that would trigger appropriate and timely referrals to dentists for additional evaluation and treatment. The DHR evaluates plaque formation as a measure of dental hygiene without the need of special equipment, which may not be widely available in long-term care facilities. The BOHSE consists of 10 items that reflect the status of oral health and function, including lips, tongue, tissue inside the cheek, floor and roof of mouth, gums, saliva, condition of natural teeth, condition of artificial teeth, pairs of teeth in chewing position, and oral cleanliness. The final score is the sum of the scores from the 10 categories and can range from 0 (very healthy) to 20 (very unhealthy) [37]. The OHAT is a modified version of the BOHSE consisting of eight areas: lips, tongue, gums/tissues, saliva, natural teeth, dentures, oral cleanliness, and dental pain. The final score can range from 0 (very healthy) to 16 (very unhealthy) and is obtained from the sum of the scores of the abovementioned eight areas, which are rated on a 0–2 scale: 0, healthy; 1, oral changes; and 2, unhealthy [38]. The DHR is a quick and easy to use assessment tool that nursing personnel can implement with dentate patients. It registers the presence or absence of plaque on teeth and can serve to monitor changes over time. The scale is scored from 1 to 4: 0, continue as usual; 1, check for deterioration and pay attention to difficult areas; and 2–4, dental hygiene needs to improve [39]. These tools have been validated in cognitively intact and cognitively impaired nursing home residents. However, there are no studies that have specifically validated these instruments in patients receiving palliative care or hospice. There is a need for more research that validates the use of these instruments in patients with palliative care and hospice needs in noninstitutional settings.

4 Risk Factors of Poor Oral Health

4.1 Poor Oral Hygiene

Poor oral hygiene is associated with physical, psychological, and social consequences for patients with palliative care needs. Unfortunately, poor oral hygiene is common in this population [40–43]. Healthcare professionals should regularly encourage their patients to participate in daily oral self-care activities. When unable, because of cognitive or functional impairment, caregivers should assist patients

with these tasks. Risk factors for poor oral hygiene include patient and caregivers' educational level and lack of awareness of the importance of routine oral care to prevent complications [29]. Many patients may not have the means or ability to visit a dentist or dental hygienist in a timely manner due to limited transportation, lack of dental insurance, and/or economic constraints. For a more in-depth discussion on the topic of health disparities, please refer to chapter "[Health Disparities in Oral Health](#)".

4.2 Polypharmacy

Drugs are by far the most common cause of xerostomia, dysgeusia, and stomatitis [44]. Many medications can cause dry mouth including among the most frequent offending medications those with anticholinergic activity, including many antiemetics, antihistamines, antipsychotics, tricyclic antidepressants, antispasmodics, and bronchodilators. Other frequent culprits include several types of antihypertensives, diuretics, benzodiazepines, and opioids [44, 45]. Dysgeusia, the altered perception of taste, is associated with several medications use to treat serious illness, including antineoplastics (bleomycin, carboplatin, cisplatin, cyclophosphamide, doxorubicin, 5-fluorouracil, gemcitabine, levamisole, and methotrexate), psychotropics, opioids, antimicrobials, and antihypertensives [46]. A thorough medication review may identify responsible medications. If possible, deprescribing the suspected medications should be attempted as the initial approach to improve symptoms. For a more in-depth discussion on the topic of xerostomia, please refer to chapter "[Xerostomia and Hyposalivation](#)".

4.3 Functional Impairment and Frailty

Evidence suggests that functional impairment and frailty are associated with worse dental health [47]. In many patients with serious or terminally illness, traditional oral hygiene practices may not be feasible due to declining health and poor physical function [48, 49]. Many palliative patients are disabled, weak, cognitively impaired, and often institutionalized. Unfortunately, oral health procedures are frequently given low priority when compared to other care tasks performed by nursing staff and caregivers [50]. This can stem from inadequate training, limited time availability due to other competing needs, or the unpleasantness of the task [51]. Patients who need help with oral hygiene have twice as many cases of dental caries or retained roots than those who are independent [5]. Individualized oral hygiene care plans that incorporate caregivers, caregiver training programs, shorter intervals between dental evaluations, the use of fluoride, and management of xerostomia constitute adequate interventions [5].

4.4 Cognitive Impairment

Compared with patients with intact cognition, individuals with cognitive impairment have poorer oral hygiene, more gingivitis, more decayed root surfaces, a higher plaque index, higher number of decayed coronal surfaces, higher number of filled root surfaces, and more missing teeth [5, 52]. In community-dwelling patients with cognitive impairment, the risk of dental caries increases due to diminished oral hygiene, insufficient caregiver support, and lack of regular dental care [5]. Patients with severe cognitive impairment often require the assistance of a caregiver to perform oral care. These patients may also become uncooperative and even resist care with oral hygiene routines [53]. Strategies to improve patients' cooperation include allowing patients to determine the location of the examination, explaining the steps of the procedure, allowing rest periods during the examination, and including caregivers that the patient knows and trusts [37]. For a more in-depth discussion on the topic of dementia, please refer to chapter "[The 3 Ds: Dementia, Delirium and Depression in Oral Health](#)".

5 Common Oral Health Conditions in Palliative and Hospice

5.1 Swallowing Disorders and Aspiration

Dysphagia or difficulty swallowing is often present in patients with advanced physical and mental illness. Dysphagia frequently leads to aspiration, which can result in aspiration pneumonitis, pneumonia, and even death. Additionally, it can lead to dehydration, malnutrition, caregiver burden, and poor quality of life [54]. In many palliative patients with dysphagia, a joint decision between the palliative medicine team and patients or surrogates may be to allow patients to continue eating despite their risk of aspiration. In these cases, the goal is to provide pleasure, socialization, and nutrition. Different approaches are used to manage swallowing impairment and may include diet modifications, such as thickening liquids and pureeing solids, keeping an upright head position during meals, and exercise programs targeted to strengthening muscles involved in swallowing such as functional dysphagia therapy [55]. For a more in-depth discussion on the topic of swallowing disorders, please refer to chapter "[Swallowing, Dysphagia, and Aspiration Pneumonia](#)".

5.2 Cancer Treatment and Oral Mucositis/Stomatitis

Mucositis is the inflammation of the mucous membranes lining the digestive tract. It is caused by the loss of epithelial cells and release of proinflammatory substances frequently associated with radiotherapy of the head and neck, with or without

chemotherapy [56]. Stomatitis is the inflammation of the mucous lining of the mouth structures [57]. Clinical manifestations can vary from erythema to necrosis or deep ulceration of the mucosa [58]. Mucositis causes severe discomfort and pain which can be debilitating and lead to intolerance of normal diets, sometimes to the point where patients may need gastrostomy tubes to provide supplemental nutrition and hydration [56]. It is important that patients with planned radiation therapy to the head and neck undergo a comprehensive, baseline oral/dental exam including radiographs. Providers should educate patients on maintaining good oral hygiene and avoiding caustic and drying agents that could further exacerbate their symptoms [59]. Most treatments for mucositis are limited to palliation and treatment of pain (see Orofacial Pain section). Providers should have a low threshold to obtain cultures for suspected infections, including fungal and viral, as they may not present typically, go unrecognized, and lead to bacterial superinfections.

5.3 Problems with Saliva

Xerostomia or dry mouth is quite common in palliative and hospice patients with some studies reporting a prevalence as high as 70%. It can be objective or subjective, depending on the presence of signs of dry mouth such as frothing, stringing of saliva or glazing of the oral mucosa [45, 60, 61]. There are several causes of xerostomia, including drug induced, irradiation, salivary gland diseases, infections, and dehydration [44, 45]. Xerostomia can cause discomfort and pain, difficulty eating and swallowing, problems with dentures, altered taste of food, difficulty speaking, increased risk of infections and dental caries, halitosis, nutritional impairment, and decreased quality of life [45, 60]. The main pillars of the treatment of xerostomia are treating the underlying causes, symptomatic treatments, and treatment of associated complications [62]. Any causal agents should be eliminated, if possible. Other treatment modalities consist of saliva substitutes, stimulation of residual gland function with sugar-free candy or chewing gum, and cholinergic agonists (pilocarpine and cevimeline). Staff should educate and encourage patients to maintain good oral hygiene, including the use of alcohol-free antimicrobial mouthwashes [45]. For a more in-depth discussion on the topic of xerostomia, please refer to chapter “[Xerostomia and Hyposalivation](#)”.

Sialorrhea or excess salivation is usually caused by overproduction or excessive secretion of saliva [63, 64]. Sialorrhea usually represents a side effect of medications, vitamin deficiencies, gastroesophageal reflux, or poor oral clearance of saliva secondary to dysphagia. The most common causes of dysphagia associated with sialorrhea are underlying neurologic and neuromuscular diseases such as Parkinson’s disease, and amyotrophic lateral sclerosis (ALS), and malignancies such as head a neck cancers. The excess saliva can then spill over the bottom lip leading to drooling, which in turn can cause rashes, skin irritation and breakdown, and poor quality of life. Sialorrhea can also result in aspiration, choking, poor oxygenation, and the onset of pneumonias [65]. Management of sialorrhea can be

non-pharmacologic or pharmacologic. Non-pharmacologic modalities include orthodontic procedures, functional dysphagia therapy, use of cough assistance devices, and suction devices [63, 64]. Pharmacologic agents may include glycopyrrolate, scopolamine, atropine, and benztropine. These medications are anticholinergic and an expected adverse effect is xerostomia. Botulinum toxin injections into the salivary glands have also demonstrated positive effects [65].

5.4 *Dysgeusia*

Dysgeusia or distortion of the sense of taste is frequently seen in palliative patients [49, 66–68]. Dysgeusia can lead to the loss of eating pleasure, anorexia, nutritional deficiencies, and decreased quality of life [69]. Most affected are patients with head and neck cancers treated with chemotherapy and radiation. Dysgeusia can also be caused by infections, zinc deficiency, hypothyroidism, Cushing’s syndrome, liver disease, sequelae from ENT operations, and some medications like psychotropics, opioids, and antihypertensives (Table 4). In cases of chemotherapy and radiation to the head and neck, taste disturbances are caused by damage to the taste buds or salivary dysfunction. Other causes may include an underlying infection which may require antimicrobial therapy. Providers should routinely ask about these symptoms as patients may not volunteer the information. Management of taste disturbances includes treatment of the underlying cause, dietary therapies focusing on foods that have pleasurable tastes and are culturally appropriate, avoiding unpalatable foods, and providing food enhancers. Zinc therapy is also recommended as its deficiency has been associated with dysgeusia [46].

5.5 *Orofacial Pain*

Causes of orofacial pain are various (Table 3). Orofacial pain is often encountered in palliative patients with a reported prevalence ranging from 4% to 67% (Table 3). Like in any other patient, individuals with serious and terminal illness may also complain of pain originating from common dental conditions, including dental caries, abscesses, pulpal pain, and periodontal disease. Lesions of the oral mucosa may also include aphthous stomatitis, herpes simplex, candidiasis, blistering conditions, traumatic lesions, and radiation- or chemotherapy-induced mucositis [70]. Pain is usually located around the tooth or lesion. This type of pain can lead to anorexia as chewing and temperature changes usually increase pain. Periodontal and pulpal pain disorders are managed by dental practitioners. Musculoskeletal pain disorders such as temporomandibular disorders (TMD) are usually secondary to pain of the muscles of mastication, the temporomandibular joints (TMJ), and/or associated ligaments and tendons. Pain is usually felt in the preauricular areas and can lead to restricted mouth opening and pain with eating or talking. Management usually includes

Table 3 Causes of oral pain

System	Sources of pain
Dentoalveolar/oral mucosal	Dental Periodontal Pulpal Salivary gland disease Oral mucosal disease Maxillary sinusitis Cancer
Musculoskeletal	Temporomandibular disorders
Neurovascular	<i>Primary headache</i> Migraine Tension-type headache Temporal arteritis Trigeminal autonomic cephalalgias <i>Neuropathic pain</i> Trigeminal neuralgia/trigeminal neuropathic pain Glossopharyngeal neuralgia Postherpetic neuralgia Burning mouth <i>Other</i> Central stroke pain Chronic idiopathic facial pain Atypical odontalgia

Modified from: Orofacial Pain (Book) Zakrzewska, Joanna [70]

Table 4 Prevalence of oral health problems in different studies

Study	Population type/size	Oral pain (%)	Xerostomia (%)	Dysgeusia (%)
Oneschuk et al. 2000 [43]	Patients with advanced cancer (n = 99)	16	88	
Davies et al., 2001 [62]	Inpatient or outpatient palliative advanced cancer patients (n = 120)	–	78	–
Alt-Epping et al. 2012 [66]	Palliative care inpatients (n = 101)	4	83	68
Wilberg et al. 2012 [67]	Palliative care cancer inpatients (n = 99)	67	78	68
Van Lancker et al. 2016 [68]	Older patients receiving palliative cancer care (n = 400)	17.3	77	35
Özalp et al. 2017 [99]	Palliative care clinic (n = 170)	–	87.6	–
Magnani et al. 2019 [49]	Hospice patients (n = 75)	14.7	74.9	49.3

exercise programs, pain medications, and intraoral splint therapy. It is important to include a psychosocial evaluation of these patients, since depression and anxiety can be associated to TMD. Cognitive behavioral strategies can lead to better outcomes in patients with TMD and depression or anxiety [70]. Neuropathic pain is felt in structures that follow a nerve distribution but may not show any clinical evidence of

pathology. The pain is usually described as tingling, burning, pins and needles, and electrical and may be associated with anesthesia, paresthesia, dysesthesia, hyperesthesia, or hypoesthesia. Trigeminal neuralgia, postherpetic neuralgia, and burning mouth syndrome are examples of this type of pain. Neurovascular pain includes migraines, temporal arteritis, and tension headaches. Neuropathic and neurovascular pain disorders are managed medically with therapies directed to the underlying pathophysiology [70]. In patients with cancer receiving palliative care, pain can be the consequence of a primary, systemic, or metastatic cancer affecting peripheral and/or central nervous systems [71]. Three of the most common pain presentations of patients with intracranial tumors who come to the dental office are symptoms of TMD, trigeminal neuralgia, and persistent idiopathic facial pain [72]. Pain can be secondary to metastatic lesions to the mandible, the TMJ, and other areas of the head and face. In systemic cancers like lymphoma, leukemia, and myeloma, pain can result from tumor infiltration of bone, gingiva, and tissues proximal to teeth [72].

Pharmacologic management of orofacial pain includes the use of NSAIDs. However, dentists should be aware of the significant risks associated with the use of these medications in older adults. When used chronically, NSAIDs can cause hypertension, worsening of kidney function, and gastric irritation. Topical analgesics can be used in different forms: injections of lidocaine for trigeminal neuralgia or lidocaine patches for neuropathic pain [70]. Liquid anesthetic administered intra-orally may be beneficial in oral mucosal lesions. Corticosteroids can be applied topically or injected directly into the TMJ. However, these medications should be reserved for cases of acute trauma, severe limitations of mouth opening, or as a brief therapeutic trial [70]. Antidepressants, including tricyclic, selective serotonin reuptake inhibitors (SSRI), and serotonin noradrenaline reuptake inhibitors (SNRI), are an important part of the management of neuropathic pain. Opioids should be reserved for patients with malignant pain and those with nonmalignant pain for whom more conservative measures have failed or who are at high risks of adverse effects from the use of other medications, including NSAIDs.

5.6 Oral Infections

The oral cavity is colonized by a stable microbiota (“microbial homeostasis”). Biofilm is a layer of microorganisms that covers the teeth, the gingival crevice, and the dorsum of the tongue. Multiple mechanisms help to maintain the normal commensal flora and prevent infections. The *oral mucosa* serves as a physical barrier to invading organisms, and in many areas, a biofilm cannot establish due to the rapid turnover of the surface cells. Oral infections occur in patients with damage to the oral mucosa. *Commensal flora* prevents the colonization of pathogenic organisms by competing for space and nutrients. Commensal organisms can be affected by the use of antibiotics, salivary dysfunction, and a high carbohydrate diet, which leads to a decrease in the pH of the oral cavity favoring the growth of pathogenic microorganisms that cause dental caries. *Saliva* has many different actions and salivary gland dysfunction can lead to an increased prevalence of oral and systemic

infections. The *immune system* in the mouth includes innate immunity, consisting of phagocytes and complement, and acquired immunity consisting of humoral (immunoglobulins including secretory IgA, and serum IgG, IgM, and IgA) and cellular immunity that includes T cells. The components of the immune system reach the mouth through the gingival crevicular fluid, which is a serum transudate that passes into the gingival crevice from the systemic circulation. Immunodeficiency causes changes of the oral microflora that may lead to an increased prevalence of oral infections [36]. Infections affecting the mouth can be bacterial, viral, and fungal.

5.7 Halitosis

Halitosis is defined as offensive odors emanating from the mouth, nose, sinuses, or pharynx. Pathologic halitosis can be a symptom of regional pathology such as periodontal disease or systemic pathologies such as esophagitis, pyloric stenosis, uremia, diabetes ketosis, or neoplasms. Xerostomia (discussed above) can also contribute to halitosis [73]. Halitosis can have psychological and social effects in patients with serious and terminal illness [46].

6 Oral Health at the End of Life: Dying with Dignity

The Institute of Medicine defines a good death “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general, in accord with patients’ and families’ wishes and reasonably consistent with clinical, cultural, and ethical standards” [74]. Oral healthcare professionals have a responsibility to address oral symptoms at the end of life with the goal of improving or maintaining patients’ comfort and quality of life.

Hospice patients have a high prevalence of oral problems associated with their serious and terminal illnesses [3, 4, 75]. Evidence shows that 40% of palliative patients suffer from oral conditions for a prolonged period. The loss of the patients’ ability to communicate their oral health needs may further contribute to the underreporting of oral conditions among terminally ill patients. The early identification and treatment of these oral conditions by dentists will minimize patients’ pain and suffering. Table 5 shows an example of strategies aimed at maintaining and treating oral health for patients at the end of life.

7 Ethical Considerations at the End of Life

Clinicians play a pivotal role both in defining and executing the medical care plan and in providing continuity of care as goals evolve and change over time [76]. Practitioners often initiate discussions about life-sustaining treatments, educate

Table 5 The Scottish palliative care guidelines for the management of oral care of patients nearing the end of life [100]

Include mouth care in the patient's care plan
Encourage family members to participate in mouth care activities with guidance and support from the team
If possible, change or stop medications that are causing dry mouth
Conduct mouth care as often as necessary to maintain a clean mouth
In patients who are conscious, the mouth can be moistened every 30 minutes with water from a water spray or dropper or ice chips can be placed in the mouth
In unconscious patients, moisten the mouth frequently, when possible, with water from a water spray, dropper, or sponge stick or ice chips placed in the mouth
Water-soluble lubricant should be applied to prevent cracking of the lips
Use a room humidifier or air-conditioning when the weather is dry and hot
Ensure help is offered to clean teeth or dentures
Manage oral pain symptomatically, using analgesics via a suitable route
Most importantly, stop treatment of the underlying cause of oral pain when the burden of treatment outweighs the benefits

patients and families, help families deliberate care options, and make recommendations about treatment plans. As part of this role, the hospice team is responsible for guaranteeing that the patient's wishes are documented and supported by the appropriate medical orders [76, 77]. Oral health professionals may contribute to this conversation by sharing their expert opinion on best practices for adequate oral health maintenance and treatment. The focus of the following sections is on ethical issues at the end of life. For a more in-depth discussion on the topic of ethics, please refer to the chapter "[Ethical Considerations](#)".

7.1 *Withholding and Withdrawal of Life Support*

The withholding and withdrawal of life-sustaining therapies are considered by most experts ethical, moral, and medically appropriate decisions when the treatment no longer fulfills the patient's goals. Although withdrawal and withholding of life support are considered ethically equivalent, the reality is that most clinicians and patients may not feel so. The experience of withholding as compared to withdrawal therapy has been examined in two large questionnaire-based surveys, one from North America and the other from Europe [78, 79]. In the North American study, 61% of physicians reported being more distressed at the prospect of the withdrawal of therapy than they were about withholding treatments. Similarly, a European survey [78], showed that physicians were more willing to withhold treatment than they were about the withdrawal of the same therapies. Healthcare professionals are under no obligation to offer ineffective treatments, i.e., treatments that no longer offer benefits to the patient. Acceptable clinical practices on withdrawal or withholding of treatments depend on an understanding of medical, ethical, cultural, and religious issues. There is a need to individualize goals of care discussions

considering the preferences, beliefs, values, and cultural background of both the patient and their families [76]. A strong consensus is that the withdrawal or withholding of life supporting treatments is seen as a decision that allows the disease to run its natural course, rather than a decision to hasten death.

7.2 *Shared Decision-Making (SDM)*

Shared decision-making is a structured method that incorporates clinical evidence as well as patient values and preferences into medical decision-making. Clinicians should periodically revisit treatment preferences as goals evolve and change over time in patients with serious and life-limiting illnesses. Shared decision-making is supported by evidence from 86 randomized trials showing that participation in SDM fosters patients and family's knowledge of their conditions, increases patients' confidence in their decisions, makes patients more active participants in their care, and, in many situations, leads patients to select more conservative treatment options [80]. Achieving shared decision-making depends on building a good relationship between clinicians and patients so that information is shared, and patients are supported in the deliberation and expression of their preferences and views. To accomplish these tasks, there is a proposed model based on choice, option, and decision talk. The model has three steps: (a) introducing choice; (b) describing options, often by integrating the use of patient decision support; and (c) helping patients explore preferences and make decisions. This model rests on supporting a process of deliberation and understanding that clinicians must respect the patients' preferences [80, 81].

7.3 *Informed Consent*

Informed consent has become the mainstay for protecting patients' legal rights and guiding the ethical practice of medicine [82]. The higher standard of informed consent further protects patients' rights to autonomy, self-determination, and inviolability. The ethical principle of informed consent seeks to respect patient autonomy by ensuring that treatments are directed toward the ends desired by the patient. Informed consent involves providing patients with accurate and adequate information about the risks, benefits, and alternatives of a treatment in a manner that is free from coercion. Unfortunately, research evidence shows that patients remember little of the information disclosed during the informed consent process [83–86] and that their level of comprehension is often overestimated [87, 88]. Comprehension is related to factors such as patient age, education, intelligence [86], cognitive function, locus of control, and anxiety [82, 83, 89]. These problems are exacerbated in older adults at the end of life when the prevalence of terminal delirium is high, impairing the patient's ability to actively participate in the decision-making process. In this

context, clinicians will need to engage surrogate decision-makers including family members and loved ones.

7.4 *Decision-Making Capacity*

As we have seen in the previous section, active participation in the medical decision-making process requires that patients retain the ability to understand the benefits and risks of, and the alternatives to, a proposed treatment or intervention (including the option of no treatment). Patients have medical decision-making capacity if they can demonstrate an understanding of the situation, appreciation of the consequences of their decision, reasoning in their thought process for the decision, and the ability to communicate their wishes. Physicians will often be called to determine the patient capacity to give consent for treatment. During the process, the physician making these determinations will consider four elements: Patients must be able to (1) demonstrate understanding of the benefits and risks of, and the alternatives to, a proposed treatment or intervention (including no treatment); (2) demonstrate appreciation of those benefits, risks, and alternatives; (3) show reasoning, or the ability to compare benefits and risks in making a decision; and (4) communicate their choice [90, 91]. If the patient is unable to meet the capacity criteria, the healthcare team will have to rely on appointed or designated surrogate decision-makers.

7.5 *Advance Care Planning (ACP) and Advance Directives (AD)*

Advance care planning is the communication process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care [92]. The objective of ACP is to ensure that patients make treatment decisions in anticipation of the onset of serious illness so that clinicians can provide care that is consistent with such goals [93]. Advance directives, on the other hand, are documentation of the patients' goals and values reflecting the results of advance care planning discussions [94–97]. ACP may or may not include completion of an advance directive (AD). Advance directives may state how treatment decisions should be made on their behalf in the event they lose the capacity to make such decisions in the future. There are various kinds of ADs, but the most recognized in the United States are the Living Will (LW) and the Durable Power of Attorney for Health Care (DPAHC). LWs document patient preferences for life-sustaining treatments and resuscitation. DPAHCs (also known as "Health Care Proxy Designations") document their choice of a surrogate decision-maker. It is a signed legal document authorizing another person to make medical decisions on the patient's behalf in the event the patient loses decisional capacity [98]. Most recently, the Physician Orders for Life-Sustaining Treatment (POLST)

have become a valuable addition to the arsenal of available advance directives [89]. A key advantage of POLST advance directives is that these documents serve as a set of actionable and transferable medical orders that direct medical care consistent with patients' goals of care at the end of life. Dental professionals will need to be aware of their patients' preferences as they may be caring for patients with serious and life-limiting illness who may have lost their ability to participate in shared decision-making.

8 Conclusions

Oral health professionals have an opportunity to make significant contributions to palliative care by addressing oral symptoms of patients with serious and terminal illness and thereby contribute to improving and maintaining their comfort and quality of life. Palliative dentistry is necessary in the management of patients with advanced life-threatening diseases or conditions. Dentists and other oral health care professionals may be able to alleviate some of the common oral problems faced by these individuals. Oral health care professionals may offer these patients preventive, corrective, and restorative dental treatments. Educating healthcare team members on the important role of dental care providers in palliative care teams is essential for achieving patients' comfort and well-being. Advance care planning and completion of advance directives may serve to foster a process of shared decision-making that aims to preserve patients' autonomy.

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