Oral Health in Adult Patients Receiving Palliative Care: A Mixed Method Study

Xi Chen, DDS, PhD¹, Violet D’Souza, BDS, MPH, PhD², Timothy A Thomsen, MD³, Stephanie Gilbertson-White, PhD, APRN-BC⁴, Jirakate Madiloggovit, BDS, PhD⁵, Chandler Pendleton, MS⁵, Arshi Munjal, BS⁵, and Xie Xianjin, PhD⁵

Abstract

Background: Oral disease is highly prevalent in persons receiving palliative care (PRPC). Yet, little is known about how PRPC perceive their oral health status and related treatment needs. Methods: This mixed-method study included 49 English-speaking PRPC (age ≥18) recruited from the University of Iowa Palliative Care Clinic. Participants first completed a structured review of oral symptoms, followed by an oral exam. A nested sample of 11 participants also completed a semi-structured, in-depth interview querying their perceived oral health concerns and related treatment needs. Quantitative and qualitative data was analyzed and integrated for interpretation. Results: Participants averaged 58.4 years. Nearly 70% had terminal cancer and 25% had advanced organ failure. Eighty-six percent of participants reported at least one oral symptom, including dry mouth (83.7%), a pain-related symptom (40.8%), or oral function difficulties (51.0%). Among the 31 dentate participants, 52% had untreated decayed/broken teeth and 33.3% had oral soft tissue lesions. Ill-fitting dentures and denture sores were common among denture users. About 40% of participants reported compromised health and/or quality of life due to oral conditions; however, the perceived impacts were modest. With the exception of painful conditions, oral treatment was not a priority for most of the participants. Conclusion: Oral disease was highly prevalent in PRPC, yet its overall impact was modest. In the absence of painful symptoms, most participants reported limited desire to seek treatment for oral health conditions. However, given the serious impacts of untreated oral diseases, oral healthcare decision should not be based solely on self-reported symptoms or distress.

Keywords
oral health, dental caries, xerostomia, palliative care, end of life, mixed method

Introduction

Six million Americans are in need of palliative care (PC) every year,¹ a large proportion of whom suffer from xerostomia (dry mouth, 94%),² fungal infections (94%),³ oral pain (67%),⁴ or other oral diseases yet receive no dental care prior to death.⁵,⁷ This has the potential to compromise the quality of life (QOL) of these vulnerable individuals.²,⁸,⁹

Unlike hospice care, PC can be provided to persons with any diagnosis or stage of serious illness (and in combination with life-prolonging treatment) in order to improve the QOL of persons receiving palliative care (PRPC) and their families.¹⁰ Depending on the underlying illness, PRPC can survive up to several years,¹¹ much longer than the average 76-day survival for hospice patients.¹² During treatment, PRPC usually experience substantial physical, psychological, and spiritual distress.¹³,¹⁴ Highly prevalent depression, anxiety, desire for death, and other emotional distress can lead to loss of interest in activities of daily living, including oral self-care.¹⁴ These issues, together with terminal functional impairment, polypharmacy, lack of access to dental care, perceptions that mouth care is unimportant/unpleasant, and inadequate caregiver support/training, can increase the risk of oral disease in seriously-ill persons.⁵,⁷,¹⁵-¹⁹

Although limited, existing evidence suggests that oral health is poor in PRPC. A majority (50-76%) of persons at the end of life lose the ability to independently provide oral self-care.¹⁵,²⁰

¹ Department of Preventive and Community Dentistry, College of Dentistry, University of Iowa, Iowa City, IA, USA
² Faculty of Dentistry, University of Toronto, Toronto, Canada
³ Roy J. and Lucille A. Carver College of Medicine, University of Iowa, Iowa City, IA, USA
⁴ College of Nursing, University of Iowa, Iowa City, IA, USA
⁵ College of Dentistry, University of Iowa, Iowa City, IA, USA

Corresponding Author:
Xi Chen, DDS, PhD, Department of Preventive and Community Dentistry, College of Dentistry, University of Iowa, Iowa City, IA 52242, USA. Email: xi-chen-6@uiowa.edu
Consequently, oral hygiene is usually poor in these individuals, increasing the risk of caries and periodontal infection. A study of 126 palliative cancer patients found that over half had untreated dental caries. In another study, nearly 40% of the remaining teeth of older adults in the last year of life were carious. Tooth loss is commonly seen in persons at the end of life, and 34-36% of seriously-ill nursing home residents lose all natural teeth. Xerostomia (78-94%), oral pain or discomfort (67%), taste disturbance (71%), and dysphagia (61%) are highly prevalent in persons with limited life expectancy, as are oral soft tissue pathologies such as candidiasis (27-94%), tongue inflammation (46-67%), erythema (50%), or ulceration (20%), especially in those with terminal cancer. These conditions, if untreated, can limit food choices, interfere with social interactions and, therefore, compromise QOL. For many, they can also limit the ability to tolerate chemotherapy or radiotherapy, accelerate cognitive decline, and cause life-threatening septicemia, aspiration pneumonia, deep neck space infection, and even death.

However, while the high prevalence of oral conditions in seriously-ill persons is known, important questions remain. In particular, it is unclear how concerned seriously-ill persons are about their oral health, how much oral disease affects their QOL, and whether they have a perceived need for treatment. Answers to these questions are critical for dental, medical, and nursing professionals wanting to maximize end of life QOL, and instrumental to integrating oral health care into the overall PC plan. Dental professionals can also utilize such information to develop individualized oral health interventions for PRPC. We therefore conducted a preliminary study using a mixed-method approach to describe the oral health status of PRPC and understand patient perceptions of its severity, distress, and need for treatment.

**Materials and Methods**

This pilot study utilized a concurrent, embedded mixed-method design. It included a cross-sectional quantitative study and a descriptive qualitative study conducted concurrently. This study was conducted at the University of Iowa (UI) Palliative Care Clinic and the UI College of Dentistry between 7/1/2017 and 9/30/2019. The study protocol was approved by the UI Institutional Review Board.

**Study Setting and Participants**

A convenience sample (N=49) was recruited from the UI Palliative Care Clinic, a regional center offering tertiary-level PC for seriously-ill persons in Iowa and surrounding states. The UI palliative care team consists of physicians, nurse practitioners, supportive care nurses, pharmacists, clinical psychologists, music therapists, chaplains, social workers and volunteers. It provided 1,013 outpatient and 5,334 inpatient consults in the fiscal year 2019. Among the 3,480 patients who received palliative care at the UIPC clinic in fiscal years 2018-2019, 86.6% were Caucasian, 4.2% were African American, 2.1% were Hispanic, 1.2% were Asian, 0.2% were Native American and 0.1% were Native Hawaiian/Pacific Islanders. Men accounted for 52.2%, and women accounted for 47.8%.

Eligible participants were outpatients who: 1) had an advanced, incurable health condition; 2) received palliative care; 3) were physically and cognitively able to participate; 4) were at least 18 years old; and 5) spoke English. Those with: 1) head or neck cancers; 2) conditions requiring antibiotic prophylaxis prior to oral exam per the guideline of the American Dental Association; or 3) cognitive impairment as identified by the protocol recommended by the UI Institutional Review Board, were excluded.

**Data Collection**

1. **Quantitative interview and oral exam**
   **Structured interview:** After written informed consent, an oral symptom review was conducted using the modified Memorial Symptom Assessment Scale, which assesses oral symptoms in four dimensions (frequency, intensity, distress, and perceived need for treatment) on a five-point Likert scale. Socio-demographics, dental insurance, self-perceived oral health decline, and related impacts on overall health and QOL were queried using a structured questionnaire. Participants’ primary diagnosis and their Palliative Performance Scale (PPS) scores were collected from medical records.

   **Oral exam:** Only 40 participants completed an oral exam. The rest of the participants consented for but missed oral exams due to death, time conflicts, or other reasons. Depending on participants’ preferences and availability, oral exams were conducted at the UI palliative care clinic, College of Dentistry, or the Infusion Clinic using a protocol designed for assessing the oral health status of persons with special needs in non-dental environments (e.g., nursing homes and medical clinics). The exam included assessments of xerostomia, oral hygiene, periodontal health, denture hygiene and fit (denture patients only), oral soft tissue, number of missing teeth, and dental caries. Xerostomia assessment used a 100-point scale and an objective mirror sliding test. Besides gingival index, presence of periodontal abscess was included in the periodontal assessment. Dental caries were detected using visual and tactile methods.

2. **Qualitative Interview**

   The qualitative study participants were a nested sample, selected from those who took part in the quantitative study, using purposive sampling approach. Given that our aim was to better understand how PRPC perceive their oral health, the purposive sampling method allowed us to be as inclusive as possible, including individuals with different illnesses and socio-demographic backgrounds in exploring their perceptions of oral health status and oral health needs. Semi-structured, qualitative interviews were conducted concurrently with the oral symptom reviews and oral exams at the UI Palliative Care Clinic, College of Dentistry, or by phone, based on participant feedback.
preference. A predesigned interview guide queried participants regarding their oral health concerns, how those concerns affected their well-being, what measures they took to address those concerns, whether they sought care, who they sought care from, whether they had treatment needs, and what those needs were. Any new information that emerged from the interviews was added to subsequent interviews. Though the generated codes and categories became repetitious after the first eight interviews, recruitment and data collection continued until the categories and subcategories were saturated.38,39 Eleven participants completed the qualitative interview.

**Staff training and quality control.** Research assistants were trained in data collection conducting supervised, simulated interviews until mastery was reached. The two geriatric dentists involved in oral examinations were calibrated prior to data collection. Oral examiners were blinded to the results of the structured and in oral examinations were calibrated prior to data collection. Any new information that emerged from the interviews was added to subsequent interviews. Though the generated codes and categories became repetitious after the first eight interviews, recruitment and data collection continued until the categories and subcategories were saturated.38,39 Eleven participants completed the qualitative interview.

**Data Analysis**

**Quantitative analysis.** Descriptive analyses were conducted on the data collected from oral symptom reviews and oral exams. Self-reported oral symptoms were classified into four groups: xerostomia, oral pain, infection, and functional impairment. Means and standard deviations were calculated for continuous variables. Frequencies and percentages were calculated for categorical variables. Since this paper aimed to describe PRPC’s oral health profile, multivariate analysis was not conducted. All analyses were conducted using R 3.6.2.

**Qualitative analysis.** Content analysis was used for analyzing the qualitative data40 and was done concurrently as data were collected. All interviews were transcribed verbatim, with transcripts compared to audiotapes and field notes to ensure accuracy. New information that emerged from the interviews was queried in the subsequent interviews. The transcribed interviews were broken down into smaller units of text for further analyses and summary. Two research assistants reviewed the transcripts and coded the data inductively or deductively.41 As more data became available, codes were reviewed, changed, and grouped into subcategories and categories using descriptive labels. Coding and labeling disagreements were resolved through team discussion to guard against bias and enhance robustness of observations. The ATLAS.ti version 8 was used for qualitative data analysis.

**Results**

**Characteristics of the Study Participants**

Of the 49 PRPC who completed the structured interview, 40 completed the oral evaluation and 11 completed the qualitative interview. The majority were white (95.92%) and female (57.14%), and the mean age was 58.39 years (Table 1). Almost all had a high school degree or higher education. Two-thirds (67%) had dental insurance. Nearly 70% had terminal cancer, while 25% had advanced organ failure (e.g., cardiomyopathy) and another 17.50% had neurological or other health conditions.

**Quantitative analysis.** Descriptive analyses were conducted on the data collected from oral symptom reviews and oral exams. Self-reported oral symptoms were classified into four groups: xerostomia, oral pain, infection, and functional impairment. Means and standard deviations were calculated for continuous variables. Frequencies and percentages were calculated for categorical variables. Since this paper aimed to describe PRPC’s oral health profile, multivariate analysis was not conducted. All analyses were conducted using R 3.6.2.

**Qualitative analysis.** Content analysis was used for analyzing the qualitative data40 and was done concurrently as data were collected. All interviews were transcribed verbatim, with transcripts compared to audiotapes and field notes to ensure accuracy. New information that emerged from the interviews was queried in the subsequent interviews. The transcribed interviews were broken down into smaller units of text for further analyses and summary. Two research assistants reviewed the transcripts and coded the data inductively or deductively.41 As more data became available, codes were reviewed, changed, and grouped into subcategories and categories using descriptive labels. Coding and labeling disagreements were resolved through team discussion to guard against bias and enhance robustness of observations. The ATLAS.ti version 8 was used for qualitative data analysis.

**Table 1. Characteristics of Study Participants.**

| Characteristics                      | Sample size | Value                     |
|--------------------------------------|-------------|----------------------------|
| Age (mean, SD, range)                | 49          | 58.39, 14.59, 32-93        |
| Female gender (%)                    | 49          | 57.14                      |
| Racea                                | 49          |                            |
| White (%)                            | 49          | 95.92                      |
| Black (%)                            | 49          | 4.08                       |
| Other (%)                            | 49          | 2.04                       |
| Education                            | 49          |                            |
| Some high school (%)                 | 49          | 2.04                       |
| High school degree (%)               | 49          | 24.49                      |
| Some college or associate degree (%) | 49          | 44.90                      |
| Bachelor’s degree/graduate Degree (%)| 49          | 28.57                      |
| Primary diagnosis for palliative careb| 40          |                            |
| Cancer (%)                           | 40          | 67.50                      |
| Organ failure (%)                    | 40          | 25.00                      |
| Other (%)                            | 40          | 17.50                      |
| Dental insurance                     | 48          |                            |
| No (%)                               | 48          | 25.00                      |
| Yes (%)                              | 48          | 66.67                      |
| Don’t know (%)                       | 48          | 8.33                       |

*Total don’t equal to 100% because one participant marked both White and American Indian or Alaska Native.

**Table 2.** All participants brushed their teeth at least once daily and some brushed more than twice daily. Four maintained regular dental visits during PC, five visited dentists only when needed, and two had no PC dental visits at all.

**Self-perceived Oral Health**

1. Oral health perception
   One-fourth of participants reported an overall oral health decline in the past year, and 44.90% felt their dry mouth had worsened in the past year (Figure 1). Declines were reported in the ability to chew food (25%), taste (22.45%) and swallow (20.41%). Facial and mouth appearance had declined for 18.37%.

   During the symptom review, 42 (85.71%) participants reported at least one oral symptom, including xerostomia, pain and impaired oral function (Table 3). Most of these conditions were surfaced in the qualitative study as well. Although all 11 participants of the qualitative interview reported some oral health issues, most of them reported good oral health irrespective of their oral health conditions or functional difficulties. A 39-year-old participant (ID=8) with five decayed teeth stated:
2. Xerostomia

Xerostomia was the most prevalent oral health symptom reported, with 83.67% experiencing dry mouth in the past week and 55.10% suffering frequently or almost constantly. This condition was also frequently reported during the qualitative interview. 10 of the 11 participants reported dry mouth; concern about it was greatest for participants receiving chemotherapy. One participant (ID=1) reported:

“It [my mouth] gets really dry and I get frustrated. So, I try not to talk much. It [xerostomia] affects my eating too. There is no saliva to help move my food into the throat. It gets harder. I cannot swallow well.”

However, participants who suffered dry mouth for a long time were less concerned, as it has become a part of their life. A 76-year-old, edentulous participant (ID=6) explained:

“I feel dry in my mouth, and it’s because of the medication that I am taking. That’s it... Well, that’s my life now. I feel okay, no problem.”

3. Oral function impairment

Xerostomia can affect eating, taste and other oral function. As a result, 25 participants (51.02%) reported difficulty performing oral function, including difficulty tasting (31.25%), difficulty chewing food (26.53%), and swallowing problems (25%), during the symptom review. These issues were also confirmed in the qualitative interview in which all participants
experienced eating problems. Some participants said they could eat almost anything, but many admitted to eating habit modifications and limited food choices. One participant (ID = 11) explained how xerostomia affected her eating:

“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.”

4. Oral pain

During the symptom review, 20 participants (40.82%) reported at least one pain-related symptom, including oral pain (26.53%) and mouth soreness (24.49%). Oral pain could also be a result of xerostomia. A participant (ID = 1) receiving chemotherapy for metastatic breast cancer said:

“When I eat, depending on what I eat, it kind of 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 [food] is cleared up, I can feel better.”

5. Tooth and denture related issues

One-third of dentate participants complained of dental related problems (Table 3). Except suspected cavity (17.50%), swollen face, toothache, and other dental-related
symptoms were reported infrequently. Among denture users, 42.85% reported that in the past week their dentures were too loose to function most of the time. Thirty-six percent reported denture sores, and 14.29% suffered this problem almost constantly. Among the 11 participants of the in-depth interviews, three wore dentures and all of them reported their dentures were loose and dysfunctional. In fact, two of the three stopped wearing their dentures.

6. Oral health related distress and treatment needs

The perceived severity, distress, and treatment needs for the majority of reported symptoms were modest (mean ratings 2-3 on a 5-point scale, Table 3). Fungal infection and mouth pain affecting toothbrushing received higher ratings for perceived distress (Mean=4.00 for both conditions) and treatment needs (Mean=5.00 for both conditions), but were reported rarely. Individuals suffering toothache also perceived an urgent treatment need (Mean=5.00).

Perceived dental care needs were reported during the qualitative interview, which included having loose teeth extracted, replacing lost teeth, getting a new denture or getting the old denture relined, and having decayed teeth restored. Participants felt they would feel better if their oral health concerns were addressed. However, oral healthcare was not generally a priority because they did not experience pain. A 39-year-old participant (ID=2) with pulmonary hypertension wore an ill-fitting partial denture described how she might feel better if her denture was fixed. Despite this, getting her denture fixed was not a 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.”

7. Impacts of oral conditions

Of the 36.74% of participants reporting that oral conditions affected their health, it affected them quite a bit/very much (12.24%), somewhat (14.29%), and a little (10.20%) (Figure 2). Additionally, 40.82% reported that their oral conditions compromised their QOL either quite a bit/very much (16.32%), somewhat (12.24%), or a little (12.24%). Although we did not specifically explore how poor oral health affects QOL, participants of the qualitative interview reported that oral disease could cause embarrassment and affect their social life. One participant (ID=11) explained:

“I am a little more shy now. I don’t feel normal now. I have lost my confidence. I am embarrassed. I can eat majority of the things, but not everything. I have dry mouth, no taste and no appetite too. But, I am sure, it will pass. I don’t go to restaurants and because I cannot eat like I used to.”

Clinical Exams Findings

Among 40 participants who completed the oral exam, 25.47% had visible food particles in one or more areas (Table 4). Moderate dryness was reported (mean=43.61, SD=31.70), and some friction was registered when the back of a mouth mirror was drawn along the right and left buccal mucosa in nearly 70% of participants (mean=1.84, SD=0.65).

Nearly one-third (32.50%) of participants presented at least one oral soft tissue pathology, with white lesions (e.g., candidiasis and lichen planus) being most common (12.82%).

Nearly one-fourth (22.50%) of participants had no natural teeth. Among dentate participants, the mean plaque index score was 0.91 (SD=0.45), implying that soft deposits covered
Nearly one-third (32.50%) of participants wore a dental prosthesis. Among them, 45.45% had food particles on at least one denture area. The mean denture index score was 0.82 (SD=0.53). Broken dentures, ill-fitting dentures or denture sores were found in 16.67%, 50.00% and 10.00% of participants, respectively.

**Discussion**

To our knowledge, the present study was the first study aiming to describe the oral health problems of PRPC using both self-reported data and clinical exam data. A very large proportion (85.71%) of PRPC suffered from various oral conditions, especially xerostomia, oral functional difficulties, dental caries or other oral conditions. About 40% of participants reported that their systemic health and QOL were affected by oral diseases/conditions. Despite this, participants reported good oral health and the perceived severity and impacts of oral conditions tended to be modest. Except for a few painful conditions, treating these conditions was not a priority for most participants even if they appreciated the benefits of dental care.

However, these findings do not undermine the need to maintain good oral health in PRPC because some modest ratings could result from gradual adaptation and acceptance of the condition. In qualitative interviews, xerostomia significantly bothered participants and interfered with their social communication and oral functions; yet patients had come to accept it as a consequence of their illnesses and/or related treatment. Then too, the impact of poor oral health can go beyond self-perceived distress. Reduced salivary gland output can compromise the self-cleaning, buffering, and antimicrobial effects of saliva accelerating the progression of dental caries. Caries can cause pain and odontogenic infections, leading to life-threatening complications such as septicaemia and deep neck space infection, especially in immunocompromised patients. Poor oral hygiene can also substantially increase the risk of aspiration pneumonia, a leading cause of death among medically compromised persons. Given the serious impacts of untreated oral conditions, the decision to pursue oral health care should not be based only on self-reported symptoms or distress.

Several factors may help explain the apparent discrepancy between high oral health condition rates and low perceived need for treatment. First, participants might have lacked a full appreciation of the impact of oral disease on their QOL before they ever entered the terminal stage of their lives. As such, their low treatment desire may reflect their low baseline concern regarding oral health and care. Second, because the distress of many oral conditions were modest and chronic (e.g.,

---

Table 4. Outcomes of Clinical Exams.

| Oral health measures                  | Sample size | Results          |
|---------------------------------------|-------------|------------------|
| Oral health measures                  |             |                  |
| **Measures applicable to all participants** |             |                  |
| Oral cleanliness                       |             |                  |
| No food particles in mouth (%)         | 34          | 70.59            |
| Food particles in 1-2 areas of mouth (%) |             | 17.65            |
| Food particles in most areas of mouth (%) |             | 8.82             |
| Unable to assess (%)                   |             | 2.94             |
| Xerostomia                            |             |                  |
| Self-rating of mouth dryness (Mean, SD, range) | 36          | 43.61 (31.70) (0, 100) |
| Mirror test (Mean, SD, range)          | 38          | 1.84 (0.65) (0, 3) |
| % of participants with ≥ 1 soft tissue lesion a | 36-39       | 32.50            |
| % of participants with no teeth         | 40          | 22.5             |
| % of participants wearing a dental prosthesis | 40         | 32.50            |
| **Measures applicable to dentate participants only** |     |                  |
| Plaque Index (mean, SD, range)         | 26          | 0.91 (0.45) (0.17-1.75) |
| 0 (%)                                  |             | 0.0              |
| >0 - 1 (%)                             |             | 69.23            |
| > 1 (%)                                |             | 30.77            |
| Gingival Index (mean, SD, range)       | 30          | 1.11 (0.41) (0.50-2.25) |
| 0 (%)                                  |             | 0.0              |
| >0 - 1 (%)                             |             | 56.67            |
| > 1 (%)                                |             | 43.33            |
| Periodontal abscess (%)                | 29          | 3.45             |
| Number of missing teeth (Mean, SD, range) | 31          | 4.97 (5.94) (0-22) |
| Number of teeth with class III mobility (Mean, SD, range) | 31        | 0.65 (3.06) (0-17) |
| Number of decayed/broken teeth (Mean, SD, range) | 31 | 1.26 (1.95) (0-9) |
| % of participants with at least one decayed/broken tooth | 31 | 51.61 |
| **Measures applicable to denture users only** |         |                  |
| Denture cleanliness                    |             |                  |
| No food particles on dentures (%)      | 11          | 45.45            |
| Food particles in 1-2 areas of dentures (%) |             | 27.27            |
| Food particles in most areas of dentures (%) |         | 18.18            |
| Unable to assess (%)                   |             | 9.09             |
| Denture Index (Mean, SD, range)        | 11          | 0.82 (0.53) (0-1.71) |
| Denture with a broken area (%)         | 12          | 16.67            |
| Ill-fitting denture (%)                | 12          | 50.00            |
| Denture Sore (%)                       | 10          | 10.00            |

aSample size varied because some participants did not complete the oral exam due to limited time available, exhaustion or terminal illness.
bThis assessment consisted of 10 disease categories. Participants who completed different disease categories varied due to limited time available or inability to tolerate the lengthy interview and exam.
cThe third molars were not included in the assessment.
chewing difficulty, xerostomia), PRPC might have learned to tolerate these discomforts, accepting them as a part of their “new life” with a terminal illness. In comparison with other more distressing symptoms (e.g., death anxiety, pain and dyspnea), and in the absence of adequate resources and social support, oral symptoms may be considered low priority. Third, psychiatric disorders (e.g., anxiety and depression) and existential distress (e.g., an overwhelming sense of hopelessness, spiritual angst, loss of sense of dignity, or a growing desire for death) are highly prevalent in PRPC and may shatter one’s lifetime assumptions about meaning, value, and health beliefs overall, lowering their treatment desires. Fourth, participants expressed feeling overwhelmed by numerous medical appointments in qualitative interviews, and adding a dental visit could be emotionally challenging due to perceptions of being a burden to others or feelings of guilt for caregiver hardship, financial hardship) were reported as barriers to oral health care. 5 Consistent with the Andersen Model, enabling factors (e.g., dental fear, lack of transportation, and financial hardship) were reported as barriers to oral health care during qualitative interviews, and these may also contribute to participants’ decisions not to seek treatment for the oral conditions they suffer.

Given the impact of poor oral health on the systemic health and QOL of PRPC, our preliminary findings on a convenience sample call for more and larger studies to better understand PRPC perception for dental treatment in order to develop individualized interventions to improve their QOL. When indicated, psychotherapy to help PRPC sustain a sense of meaning, value, and purpose can be provided to ease existential distress. For those with perceptions that oral health is unimportant or that not much can be done for their oral health problems, educational programs can be developed to improve their awareness of the systemic and psychosocial impacts of oral conditions and the benefits of end-of-life oral health care. An interdisciplinary collaborative practice that includes a dental team can also be established. In this way, PRPC with oral health needs can be easily identified and referred in a timely manner. Dental consults can be provided in conjunction with PC consults, reducing the number of appointments and easing the burden of PRPC who lack transportation and caregiver support, or feel guilt for being a burden. With the support of their dental colleagues, many oral health problems (e.g., xerostomia, oral candidiasis, mouth pain and infection) could also be managed by PC providers in the clinic or at the bedside. This team approach is particularly helpful for home-bound PRPC and bedridden hospice patients. By teaming dental hygienists with hospice or home health nurses, oral hygiene and other preventive interventions (e.g., fluoride varnish and silver diamine fluoride) could be effectively provided for these individuals who otherwise have no access to needed dental care.

Study limitations include the small sample size, which limited our ability to explore correlations between self-perceived oral health, perceived treatment needs, and normative needs while controlling other covariates. The lack of healthy controls also prevented us from knowing the potential differences in perceived oral health and treatment needs between PRPC and their healthy counterparts. Due to the lack of a validated instrument, we were not able to evaluate the impact of oral diseases on PRPC’s QOL. How comorbidities and psychological distress affected PRPC’s perception of oral health and treatment needs also remains unknown, which is another major limitation of this study. PRPC who chose to participate in this study could be those who valued oral health or those who wanted to use study compensation to ease financial hardship (at least two people participated for this reason), raising concerns over selection bias. The fact that nearly all participants were white and completed a high school degree or higher education also suggests selection bias. Caution should therefore be used in applying these findings to other populations.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research: This study was supported by the Delta Dental of Iowa Foundation. The authors also thank the University of Iowa Palliative Care Team, the University of Iowa Hospitals and Clinics and the University of Iowa College of Dentistry Clinical Research Center for their support on this study.

ORCID iD

Xi Chen https://orcid.org/0000-0002-2821-0726
Jirakate Madiloggovit https://orcid.org/0000-0002-6890-5653

References

1. The Center to Advance Palliative Care and the National Palliative Care Research Center. America’s care of serious illness: 2019 state-by-state report card on access to palliative care in our nation’s hospitals. https://reportcard.capc.org/. Accessed March 24, 2021.
2. Fischer DJ, Epstein JB, Yao Y, Wilkie DJ. Oral health conditions affect functional and social activities of terminally ill cancer patients. Support Care Cancer. 2014;22(3):803-810.
3. Chausha G, Bercovici M, Dori S, et al. Salivary flow and its relation with oral symptoms in terminally ill patients. Cancer. 2000;88(5):984-987.
4. Wilberg P, Hjermstad MJ, Ottesen S, Herlofson BB. Oral health is an important issue in end-of-life cancer care. Support Care Cancer. 2012;20(12):3115-3122.
5. Rohr Y, Adams J, Young L. Oral discomfort in palliative care: results of an exploratory study of the experiences of terminally ill patients. Int J Palliat Nurs. 2010;16(9):439-444.
43. Dawes C, Pedersen AM, Villa A, et al. The functions of human saliva: A review sponsored by the World Workshop on Oral Medicine VI. Arch Oral Biol. 2015;60(6):863-874.

44. JL S. Existential psychotherapy in palliative care. In: Chochinov H, Breitbart W, ed. Handbook of Psychiatry in Palliative Medicine. Oxford University Press; 2000:197-214.

45. D’Souza V. Perceived oral Care Needs of Terminally ill Adults – a Qualitativeinves-tigation Iowa Research Online. Preventive and Community Dentistry University of Iowa; 2019.

46. Kissane DW. Demoralisation: its impact on informed consent and medical care. Med J Aust. 2001;175(10):537-539.

47. Hanson C. Mouth care – how important is it? J Commu Nurs. 2004;18(8):4-9.

48. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? J Health Soc Behav. 1995;36(1):1-10.

49. Chen X, Kistler CE. Oral health care for older adults with serious illness: when and how? J Am Geriatr Soc. 2015;63(2):375-378.