

Caregivers' perspectives on oral health problems of end-of-life cancer patients

Miriam O. Ezenwa, Dena J. Fischer, Joel Epstein, Julie Johnson, Yingwei Yao & Diana J. Wilkie

Supportive Care in Cancer

ISSN 0941-4355

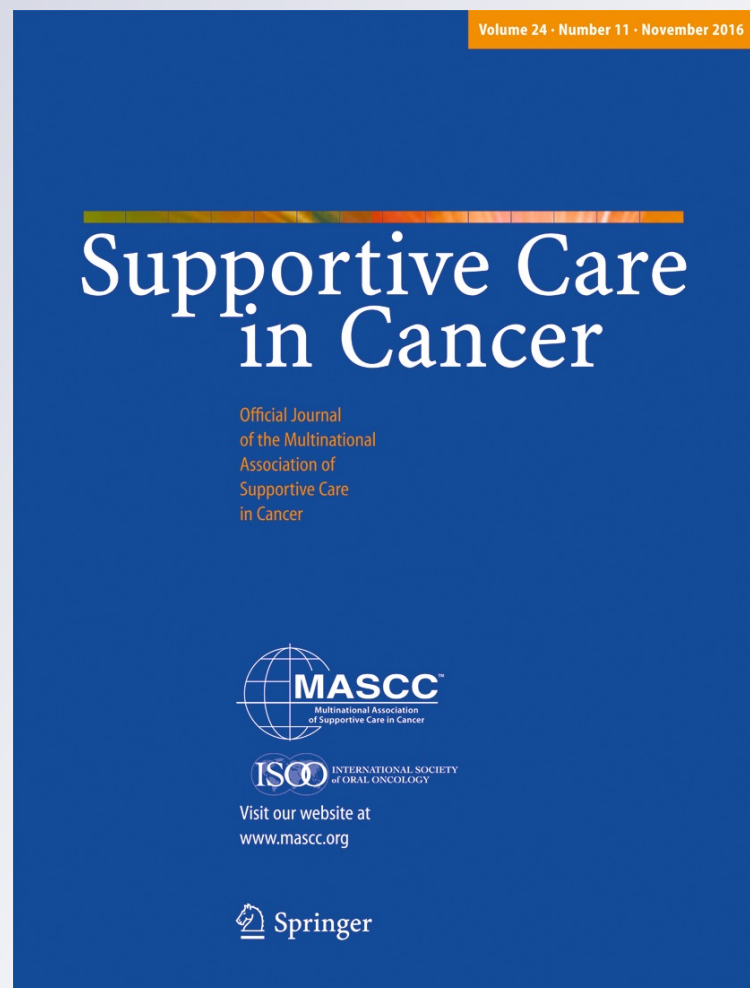
Volume 24

Number 11

Support Care Cancer (2016)

24:4769-4777

DOI 10.1007/s00520-016-3328-6



Your article is protected by copyright and all rights are held exclusively by Springer-Verlag Berlin Heidelberg. This e-offprint is for personal use only and shall not be self-archived in electronic repositories. If you wish to self-archive your article, please use the accepted manuscript version for posting on your own website. You may further deposit the accepted manuscript version in any repository, provided it is only made publicly available 12 months after official publication or later and provided acknowledgement is given to the original source of publication and a link is inserted to the published article on Springer's website. The link must be accompanied by the following text: "The final publication is available at link.springer.com".



Caregivers' perspectives on oral health problems of end-of-life cancer patients

Miriam O. Ezenwa^{1,2} · Dena J. Fischer³ · Joel Epstein^{4,5} · Julie Johnson¹ · Yingwei Yao^{1,2} · Diana J. Wilkie^{1,2}

Received: 22 October 2015 / Accepted: 22 June 2016 / Published online: 29 June 2016
© Springer-Verlag Berlin Heidelberg 2016

Abstract

Purpose The purpose of this study was to determine caregivers' perspectives on oral health problems in cancer patients at the end of life and explore factors that contribute to those perspectives.

Methods A cross-sectional, observational clinical study design was used. We recruited dyads of lay caregivers and patients with advanced cancer who were receiving hospice or palliative care in their homes. Caregivers [$N = 104$, mean age = 55.4 ± 15.0 years (18–100); $n = 50$ (48 %) African-American; and $n = 80$ (77 %) female] completed the proxy version of the Oral Problems Scale to provide their perspectives regarding their care recipients' xerostomia, orofacial pain, and taste change in the past week.

Results More than half of the caregivers reported that care recipients' oral hygiene was a very important responsibility for caregivers, and over 80 % reported that it was very important to evaluate their care recipients' oral problems. However, caregivers reported that they asked their care recipients about oral problems infrequently. There were statistically significant

correlations between caregivers' and care recipients' ratings on xerostomia, orofacial pain, taste change, and functional/social impact. Caregivers' age and well-being predicted their awareness of care recipients' oral health problems.

Conclusions Future research efforts should focus on understanding the challenges that prevented caregivers from translating their awareness of the importance of care recipients' oral health to frequent evaluation and provision of oral care.

Keywords Xerostomia · Orofacial pain · Hospice · Palliative care · End of life

Introduction

In 2013, hospice services were delivered to more than 1.5 million US patients, many of whom died that year while under hospice care [1]. Hospice and palliative care may be delivered in the home with a family member or close friend serving as the lay primary caregiver. Unrelieved symptoms typically increase as the end-of-life approaches [2]; hence, the focus of hospice and palliative care is to manage symptoms and maximize quality of life during the end-of-life transition.

Oral health plays an important role in symptom management for patients at the end of life, as the oral cavity is a common site for oral problems such as dry mouth, mouth sores, and fungal infections [3, 4]. The prevalence of these oral problems reported in one study was salivary hypofunction (98 %), mucosal erythema (50 %), fungal infection (36 %), and ulceration (20 %) [3]. Others reported dry mouth (40.4 %), mucositis (22.3 %), dysphagia (15.4 %), and dysphagia for liquid (52.4 %) in patients with advanced cancer [5]. These findings are concerning due to the implications of oral problems for reduced nutrition and liquid intake, poor quality of life, and increased mortality. Although lay

✉ Diana J. Wilkie
diwilkie@ufl.edu

¹ Department of Biobehavioral Health Science, College of Nursing, University of Illinois at Chicago, Chicago, IL 60612, USA

² Department of Biobehavioral Nursing Science, College of Nursing, University of Florida, 1225 Center Drive, Room 2203, Gainesville, FL 32610, USA

³ Department of Oral Medicine and Diagnostic Sciences, College of Dentistry, University of Illinois at Chicago, Chicago, IL 60612, USA

⁴ Samuel Oschin Comprehensive Cancer Institute, Cedars-Sinai Medical Center, Los Angeles, CA, USA

⁵ Division of Otolaryngology and Head and Neck Surgery, City of Hope, 1500 East Duarte Road, Duarte, CA 91010, USA

caregivers play an essential role in providing care and symptom management for their care recipients at the end of life, minimal literature exists regarding the caregivers' understanding of their care recipients' oral health problems and whether caregivers' socio-demographic characteristics contribute to their awareness and understanding of the care recipients' oral health problems. To address this gap, the purpose of this study was to determine caregivers' perspectives on oral health problems in cancer patients at the end of life and to explore factors that contribute to those perspectives.

Oral health has been recognized by the World Health Organization (WHO) as a significant health issue [6]. The WHO has encouraged standardized reporting of oral health problems worldwide [6]. Some of the fundamental tenets of WHO's guidelines were operationalized by a multinational task force determined to improve cancer and cancer therapy-related oral health problems by recommending a protocol focused on preventing infections, controlling pain, managing oral treatment-related complications, and maintaining oral function in patients with cancer to improve quality of life [7]. A team suitable to provide such comprehensive care to patients at the end of life must be inclusive of multidisciplinary health professionals [8]. Lay caregivers must be an integral part of this team not only because of an increasing number of patients receiving hospice care and end-of-life care at home but also because lay caregivers play dual roles of carers and advocates for their loved ones.

As the care recipient's condition deteriorates, nurses and other health care professionals often rely upon the caregiver to provide information about the care recipient's symptom status. A few studies have examined the concordance of symptoms between terminally ill patients and their caregivers. In one study of 264 care recipients with advanced cancer in hospice home care and their caregivers, symptom intensity and severity of pain, dyspnea, and constipation were assessed. Results showed weak-to-moderate correlations between care recipients' and caregivers' ratings for all symptoms and indicated that caregivers overestimated care recipient's symptom intensity. The authors concluded that data about symptom intensity collected from caregivers are not accurate much of the time [9]. Another study of 988 terminally ill patients and 893 self-designated caregivers found that 52 % of care recipients agreed with their caregivers about their level of pain. When they disagreed, 31 % of caregivers reported higher levels of pain than did care recipients and 17 % of caregivers reported lower levels than the care recipients. The authors suggested that the presence of nonconcordance may be a feature of the overall experience at the end of life and that caregivers may need education to improve their recognition of care recipients' needs [10].

There is a paucity of literature that addresses care recipient and caregiver concordance of oral health problems or symptoms. To address this gap, the aims of this exploratory study

were to (a) describe caregivers' awareness of oral health problems, (b) compare the caregivers' reports of oral problems with those of the care recipients, and (c) explore the influence of caregivers' socio-demographic characteristics on their awareness of care recipients' oral health problems. We hypothesized that (a) caregivers would be aware of oral health problems and (b) the caregivers' Oral Problems Scale scores would be greater than the care recipients' scores. Further, as an exploratory aim, we evaluated caregivers' socio-demographic characteristics that may contribute to their awareness of care recipient oral health problems.

Methods

Study design

The design was a cross-sectional, comparative clinical inquiry with hypothesis generating analyses. It was approved by the Institutional Review Board at the University of Illinois at Chicago. Prior to data collection, we obtained signed written informed consents from each subject after they had a chance to ask questions about the study.

Subjects

Dyads of advanced cancer patients who were at their end of life and their caregivers were recruited from two hospice and palliative care programs to participate in this study. One program serves predominantly minority patients, and the other serves predominantly Caucasian patients. For purposes of this study, the caregiver was defined as the person identified by the care recipient upon entry into hospice or palliative care as the family member, friend, or paid caregiver who provided the majority of direct care. Care recipients were eligible for the study if they (1) were admitted to and receiving home care level of hospice or palliative care service; (2) had a diagnosis of advanced cancer; (3) were able to communicate in English; (4) were ≥ 18 years; (5) had a caregiver, identified by the care recipient, who was able to communicate in English; (6) had a caregiver who was ≥ 18 years; (7) had a caregiver who cared for the patient no fewer than 5 days/week or 6 h/day; and (8) had a life expectancy of at least 1 week at the time of study enrollment, as suggested by a Palliative Performance Scale (PPS) [11] score of ≥ 30 . The PPS, a modified Karnofsky Performance Scale, a tool for measurement of physical status in palliative care, has predictive validity for median survival of 6 days at a score ≥ 30 [12], which excluded subjects with rapidly declining health status. Care recipients were excluded if they (1) had cognitive or physical impairments that made it impossible to communicate or complete study instruments or (2) had a caregiver who had cognitive or physical impairments that made it impossible for the caregiver to communicate or

complete study instruments. The most frequent cancer diagnosis for care recipients was lung cancer ($n = 27$, 26 %). Other primary cancer diagnoses for care recipients are reported in Table 1.

Table 1 Socio-demographic characteristics of caregivers and care recipients

Socio-demographics	Caregivers ($N = 104$) Frequency (%)	Patients ($N = 104$) Frequency (%)
Age group		
29–49	30 (29)	16 (15)
50–64	48 (46)	30 (29)
65–74	14 (13)	24 (23)
75–84	9 (9)	17 (16)
85–112	2 (2)	16 (15)
Unknown	1 (1)	1 (1)
Gender		
Female	80 (77)	61 (59)
Male	24 (23)	42 (40)
Unknown	0 (0)	1 (1)
Race/ethnicity		
African-American	50 (48)	47 (45)
Caucasian	40 (38)	45 (43)
Hispanic	6 (6)	5 (5)
Asian/Pacific Islander	3 (3)	2 (2)
Native American	0 (0)	1 (1)
Other	3 (3)	2 (2)
Unknown	2 (2)	2 (2)
Education		
Grades 1–11	13 (13)	18 (17)
High school/GED	25 (24)	32 (31)
Some college	43 (41)	31 (30)
Bachelor's degree	13 (13)	9 (9)
Advanced degree	10 (10)	14 (13)
Marital status		
Married	56 (54)	38 (37)
Live with partner	12 (12)	5 (5)
Widowed	5 (5)	32 (31)
Divorced or separated	16 (15)	11 (11)
Never married	15 (14)	17 (16)
Unknown	0 (0)	1 (1)
Household income		
0–14,999	16 (15)	38 (37)
15,000–24,999	14 (13)	11 (11)
25,000–34,999	14 (13)	7 (7)
35,000–49,000	13 (13)	11 (11)
50,000 and above	21 (20)	15 (14)
Not reported	26 (25)	22 (21)
Cancer		
Lung		27 (26)
Colorectal		15 (14)
GU		12 (12)
Prostate		9 (9)
Pancreas		7 (7)
Breast		6 (6)
Lymphomas		4 (4)
Liver		3 (3)
Head and neck		3 (3)
GI		3 (3)
Brain		2 (2)
Other		7 (7)
Unknown		6 (6)

Of the dyads approached, 104 patient-caregiver dyads consented. The main reasons for declining participation were lack of interest and too much going on at this time of life. The *caregivers'* mean age was 55.4 ± 15.0 years, 50 (48 %) were African-American, and 80 (77 %) were female. The *care recipients'* mean age was 66.4 ± 16.5 years, 47 (45 %) were African-American, and 61 (59 %) were female. The more complete demographic information can be found in Table 1.

Study procedures

The principal investigator (DJF) trained a research specialist on all study-related procedures. The research specialist obtained referrals for potential subjects from the hospice and palliative care staff and contacted these potential subjects to ascertain interest in study participation and screen for inclusion and exclusion criteria. During a single home visit, eligible subjects underwent written consent procedures for the caregiver first and then for the care recipient. Informed consent procedures for the care recipients included consent to allow for medical chart data abstraction. Care recipients and caregivers completed study questionnaires separately without the knowledge of each other's responses. Demographic data for both the care recipient and caregiver were obtained via demographic questionnaires. When possible, the caregiver provided the care recipient's demographic information to prevent taxing the care recipient during data collection. If the patient or caregiver was not able to complete the questionnaire materials independently, the research specialist interviewed the care recipient and/or primary caregiver to complete the data instrument(s). Care recipients then completed the Oral Problems Scale. Separately, caregivers completed the proxy version of the Oral Problems Scale.

Study measures

Demographic questions Data were collected to describe the population sample. Age, gender, education level, marital status, race, ethnicity, and family income were collected from both care recipients and caregivers.

Oral Problems Scale We ascertained self-reported dry mouth (xerostomia), oral pain, taste change, and functional and social impact of oral problems within the previous 7 days through the Oral Problems Scale, which is composed of (a) 16 questions using a 0–4 Likert-type response format, where 0 = *never* and 4 = *always*, and (b) 4 questions using an 11-point scale from 0 to 10. The conceptual dimensions for question stems remained as have been utilized previously and described in the following section. The question stems were modified after cognitive testing with advanced cancer patients at their end of life. The response options were modified to the above mentioned Likert-type format.

1. The frequency of subjective dry mouth (xerostomia) was assessed using three items modified from prior studies of xerostomia related to output of saliva [13–15]. The severity of xerostomia was assessed with a single 11-point item adapted from the Brief Pain Inventory (BPI), where the subjects selected a number from 0 to 10, where 0 = *no dry mouth* and 10 = *dry mouth as much as you can imagine*. Cronbach's alpha (internal consistency) for the xerostomia subscale of the OPS was found to be 0.86 in care recipients [3] and 0.83 in caregivers.
2. The frequency of orofacial pain was assessed with four items, modified from the physical pain subscale of the Oral Health Impact Profile (OHIP) [16] and the mouth and face pain subscale of the Oral Symptom and Function Scale developed for patients following treatment for head and neck cancer [17]. The severity of orofacial pain was assessed with one item adapted from the BPI. The subject chose a number from 0 to 10, where 0 = *no pain* and 10 = *pain as bad as you can imagine*. This orofacial pain subscale showed a good reliability alpha of 0.84 in this sample of care recipients [3] and 0.83 in caregivers.
3. Taste change was evaluated using one item from the mouth function subscale of the Oral Symptom and Function Scale [17].
4. The frequency of functional impact of xerostomia and oral pain was rated using four items from the mouth function subscale of the Oral Symptom and Function Scale [17]. The severity of functional impact of xerostomia and oral pain was assessed with two items modified from the BPI. Subjects indicated how much xerostomia or pain impacts their daily activities, with 0 = *no interference* and 10 = *completely interferes*. These functional impact items were originally developed to assess pain in cancer patients and are widely used in both clinical and research settings [18]. In this sample, we found the internal consistency of functional impact scale to be 0.80 for care recipients [3] and 0.81 for caregivers.

Social impact of xerostomia was measured using two items adapted from the psychological discomfort subscale of the OHIP to assess psychological discomfort [16] and two items modified from the handicap subscale of the OHIP to assess social and global impact [16]. In this study, these items demonstrated good internal consistency alpha values 0.81 for care recipients [3] and 0.80 for caregivers.

Caregivers' attitude Developed for this study, we measured caregivers' attitude toward care recipient's oral health using two items. The first asked caregivers "How important is oral hygiene as part of your personal hygiene responsibilities for your care recipient?" The second question was "How important do you think it is to evaluate oral problems (dry mouth,

oral pain, mouth sores) of your care recipient?" Response options ranged from "very important" to "somewhat important."

Data analyses

Data were entered into an Excel database using double data entry and imported into R for data analysis. Descriptive statistics including mean, standard deviation, frequency, percentage, and correlation were computed for demographic and Oral Problems Scale ratings of both caregivers and care recipients. Student's *t* tests and linear regressions were used for statistical inference. Statistical significance was set at a two-sided type I error of 0.05.

Results

General description of caregivers' characteristics

Most of the caregivers reported being family members ($n = 82$, 79 %) of the care recipients. A small proportion of caregivers were paid caregivers ($n = 11$, 11 %) or friends ($n = 8$, 8 %) of the care recipients. Forty-eight percent ($n = 50$) of caregivers were not formally trained. These were individuals who became caregivers, likely because their family members or friends became sick. In Table 2, we present the more detailed general characteristics of the caregivers.

Primary caregivers' attitudes toward oral care of care recipients

In Table 3, we present the caregivers' attitudes toward the care recipients' oral care. More than half ($n = 56$, 54 %) of the caregivers reported that care recipients' oral hygiene was a very important responsibility for the caregiver, and even more ($n = 83$, 81 %) reported that it was very important to evaluate their care recipients' oral problems. However, caregivers asked their recipients about oral problems infrequently. For example, 30 % ($n = 31$) of caregivers evaluated care recipients' oral health problems only when needed. Thirteen percent of caregivers ($n = 13$) reported that they never asked their care recipients about their oral health problems.

Comparison of the caregivers' Oral Problems Scale scores with those of the care recipients

There were statistically significant correlations between caregivers' and care recipients' ratings on the Oral Problems Scale for all five areas assessed: xerostomia, orofacial pain, taste change, functional impact, and social impact (Table 4). We compared the ratings for each item of the Oral Problems Scale given by caregiver and care recipient dyads (Table 5).

Table 2 Caregivers' well-being, experience, training, and relationship to care recipient (N = 104)

Variable (mean ± SD, median for continuous variables)	Response option	Frequency (%)
Caregivers' well-being Existing health problem	Yes	40 (38)
	No	62 (60)
	Unknown	2 (2)
Health problems interfere with daily life	Yes	14 (13)
	No	88 (85)
	Unknown	2 (2)
Caregivers' experience, training, and relationship to recipient Total caregiving experience [mean ± SD, median (years) = 7.7 ± 11.9, 2.8]	Inexperienced (≤1 year)	33 (32)
	Experienced (1–5 years)	24 (23)
	Very experienced (>5 years)	39 (38)
	Not reported	8 (8)
Caregiving time for the current patient [mean ± SD, median (years) = 3.1 ± 8.7, 1.0]	Short (≤3 months)	30 (29)
	Medium (3–12 months)	24 (23)
	Long (>1 year)	38 (37)
	Not reported	12 (12)
Formal caregiving training [mean ± SD, median (years) = 1.6 ± 4.3, 0]	Not trained	50 (48)
	Minimal training (1 week to 3 months)	11 (11)
	Trained (≥4 months)	23 (22)
	Not reported	20 (19)
Relationship to care recipient	Family	82 (79)
	Friend	8 (8)
	Paid caregiver	11 (11)
	Unknown	3 (3)

For the xerostomia items (e.g., thirst, dry lips, and dry mouth), caregivers assigned ratings lower than self-ratings of care recipients. We found that there was high agreement for

orofacial pain items, ranging from 47 % (frequency of intraoral pain) to 71 % (frequency of mouth sores). Also for social impact items, percent agreement ranged from 41 %

Table 3 Caregivers' attitude toward recipient oral care and assessment frequency

Question	Answer	n (%)
Caregivers' responsibility to recipients' oral hygiene (missing = 1)	Very important	56 (54)
	Somewhat important	4 (4)
	Important	31 (30)
	Somewhat unimportant	8 (8)
	Very unimportant	4 (4)
Evaluation of recipients' oral problems (missing = 1)	Very important	83 (81)
	Somewhat important	6 (6)
	Important	14 (14)
	Somewhat unimportant	0 (0)
	Very unimportant	0 (0)
Frequency of asking recipient about oral problems	A few times per day	21 (20)
	Once per day	20 (19)
	A few times per week	6 (6)
	Once per week	6 (6)
	A few times per month	6 (6)
	Once per month	1 (1)
	When needed	31 (30)
Never	13 (13)	

Table 4 Correlations between caregivers' and care recipients' Oral Problems Scale ratings

Subscale	Components of scale (0–4 unless indicated otherwise)	Mean \pm SD		Correlation*
		Recipients' self-rating	Caregivers' rating	
Xerostomia	Frequency of thirst	2.4 \pm 1.1	2.3 \pm 1.1	0.46
	Frequency of dry lips	2.5 \pm 1.2	2.0 \pm 1.2	0.33
	Frequency of dry mouth	2.4 \pm 1.2	2.2 \pm 1.2	0.40
	Average severity of dryness (0–10)	5.0 \pm 3.1	4.6 \pm 3.0	0.50
Orofacial pain	Frequency of facial pain	0.5 \pm 1.1	0.6 \pm 1.0	0.42
	Frequency of intraoral pain	1.1 \pm 1.3	1.0 \pm 1.2	0.50
	Frequency of mouth sores	0.7 \pm 1.2	0.7 \pm 1.1	0.62
	Frequency of sharp or shooting facial/intraoral pain	0.4 \pm 0.9	0.5 \pm 0.9	0.30
	Average pain severity (0–10)	2.0 \pm 2.6	2.3 \pm 2.5	0.47
Taste change	Frequency of taste change when not eating	1.8 \pm 1.4	1.7 \pm 1.4	0.40
Functional impact	Frequency of swallowing difficulty	1.3 \pm 1.2	1.3 \pm 1.3	0.53
	Frequency of speaking difficulty	1.2 \pm 1.2	1.2 \pm 1.2	0.41
	Frequency of eating difficulty	1.2 \pm 1.4	1.5 \pm 1.4	0.47
	Frequency of food restriction	1.1 \pm 1.3	1.2 \pm 1.3	0.42
	From dryness (0–10)	3.1 \pm 3.1	2.5 \pm 3.0	0.31
	From pain (0–10)	1.9 \pm 2.8	1.9 \pm 2.6	0.47
Social impact	Worried frequency	1.1 \pm 1.3	1.3 \pm 1.3	0.49
	Bothered frequency	1.0 \pm 1.2	1.2 \pm 1.3	0.41
	Frequency of not wanting people around you	0.4 \pm 0.9	0.6 \pm 1.1	0.53
	Life less satisfying frequency	0.7 \pm 1.2	0.8 \pm 1.2	0.42

*All correlations are highly significant ($p < .01$). Responses: 0 to 4 with 0 = *never*, and 4 = *always*

(bothered frequency) to 64 % (frequency of not wanting people around you). When there was disagreement, caregivers rated the social impact higher than care recipients.

We also compared caregivers' and recipients' ratings for five subscales of the Oral Problems Scale (Table 5). We found significant difference in mean caregivers' and care recipients' ratings on the xerostomia subscale ($p < .01$) and social impact subscale ($p = .02$), with caregivers underestimating xerostomia and overestimating social impact, reinforcing the findings shown in Table 5.

Predictors of caregivers' awareness of care recipients' oral health problems

We examined caregivers' age, gender, race, education, and well-being as possible contributors to their awareness of care recipients' oral health complaints or functional/social impact (Table 6). We considered the caregivers' rating to be accurate if it was within 1 of the corresponding care recipients' rating for a 5-point item and within 2 of the care recipients' rating for an 11-point item. We found that age was associated with caregivers' awareness of care recipients' oral health problem ($p = .02$). Caregivers 18–64 years old were likely to be aware

of care recipients' oral health problems with 79 % accuracy, compared to caregivers 65+ years old who reported care recipients' oral health problem with 71 % accuracy. Caregivers' well-being was also a statistically significant predictor of their awareness of care recipients' oral health problems ($p = .03$). Caregivers who reported significant health problems were less aware of care recipients' oral health issues than caregivers with no significant health problems. Caregivers' gender, race, and education were not significant predictors of their awareness of care recipients' oral health problems.

Discussion

In this exploratory study with hypothesis-generating analyses, we found that approximately half of the caregivers in this study reported that oral care of the recipient was very important, and most reported that it was very important to evaluate the care recipients' oral health. Despite this awareness, a majority of caregivers reported evaluating oral status of their care recipients infrequently, and over 10 % of caregivers stated that they never assessed the care recipients' oral health. Relative to care recipients' self-ratings, caregivers in our study rated

Table 5 Comparison of caregivers' and care recipients' ratings on Oral Problems Scale items ($N = 104$)

Scale	Item	CG > CR (%)	CG = CR (%)	CG < CR (%)	p value ^a
Xerostomia	Thirst frequency	31	35	34	.63
	Dry lips frequency	20	32	49	<.01
	Dry mouth frequency	26	32	42	.06
	Average severity of dryness (0–10)	29	29	42	.13
Orofacial pain	Facial pain frequency	23	62	15	.25
	Intraoral pain frequency	24	47	29	.43
	Frequency of mouth sores	16	71	13	.63
	Sharp or shooting facial/intraoral pain frequency	21	66	13	.13
Taste change	Average pain severity (0–10)	33	40	27	.41
	Frequency of taste change	30	37	33	.67
Functional impact	Frequency of swallowing difficulty	27	47	26	.83
	Frequency of speaking difficulty	25	47	28	.67
	Frequency of eating difficulty	37	39	24	.11
	Frequency of food restriction	32	45	23	.27
	From dryness (0–10)	29	34	36	.38
	From pain (0–10)	32	40	28	.62
Social impact	Worried frequency	31	48	20	.13
	Bothered frequency	36	41	23	.09
	Frequency of not wanting people around you	26	64	10	.01
	Life less satisfying frequency	22	58	20	.67

Caregivers' and care recipients' ratings on Oral Problem Subscales ($N = 104$)

Subscale	Mean \pm SD		p value
	Care recipient	Caregiver	
Xerostomia	5.8 \pm 2.5	5.1 \pm 2.4	<.01
Orofacial pain	1.8 \pm 2.1	1.9 \pm 2.0	.57
Taste change	4.4 \pm 3.6	4.3 \pm 3.5	.74
Function impact	2.8 \pm 2.2	2.9 \pm 2.2	.80
Social impact	2.0 \pm 2.2	2.5 \pm 2.5	.02

CG caregiver, CR care recipient

^a The p value was obtained by regression of the sign of CG-CR against a constant. It indicated whether there is significant underestimation or overestimation in caregivers' ratings

xerostomia lower and social impact of oral problems higher. Caregivers' age and well-being were the only socio-demographic characteristics that significantly predicted caregivers' awareness of care recipients' oral health problems.

Caregivers' and care recipients' ratings on the Oral Problems Scale had highly significant correlations. This finding is pertinent because the agreement between caregiver and care recipient regarding the presence and severity of care recipients' oral health problem is a first step that will likely translate into better oral care for the care recipients.

We, like others [9, 10], found that, in some instances, there was systemic bias between caregivers' and care recipients' ratings. It would be unreasonable to expect complete care recipient-caregiver concordance on the Oral Problems Scale because of the subjective nature of the reports. Nonetheless, significant misalignment of care recipient self-assessment and

caregiver assessment in xerostomia and social impact of oral problems suggests that further research is needed to understand the cause and implication of such reporting differences.

Caregivers' awareness of care recipients' oral care needs and their understanding about the importance of evaluating care recipients' oral health problems did not translate into behavior such as more frequent assessment and evaluation of care recipients' oral care needs. It is possible this gap exists because caregivers must prioritize the multiple care responsibilities they have toward the care recipients, which may include managing cancer pain and bothersome physical symptoms. Consequently, oral health problem may receive a lower priority. Nonetheless, this gap between awareness and behavior is critical to address because most caregivers are family members and friends upon whom the health care providers heavily rely to assist care recipients with their oral care needs

Table 6 Socio-demographic predictors of caregivers' awareness about care recipients' oral health problem ($N = 104$)

Predictor	Accuracy (%)	<i>p</i> value
Gender		
Male	78.5	.56
Female	76.3	
Age		
18–64	78.8	.03
65+	70.6	
Education		
GED or below	77.7	.68
Some college +	76.3	
Significant health problem		
Yes	68.3	.03
No	78.2	
Caregiving training		
No	77.1	.82
Yes	76.3	
Caregiving experience		
0–1 year	79.5	.31
1–5 years	72.6	
>5 years	76.9	
Frequency of asking about oral problems (CG reported)		
Daily	76.7	.99
Weekly	77.7	
Monthly	77.7	
As needed	75.8	
Never	78.3	
Caregivers' race		
White	75.7	.40
Black	76.2	
Other	83.0	
Care recipients' race		
White	76.9	.62
Black	75.6	
Other	81.1	

at the end of life. Because the oral cavity is a frequent site for oral problems such as dry mouth, mouth sores, and fungal infections [3], if caregivers fail to properly evaluate care recipients' oral problems, then the care recipients may have worsened symptom management and quality of life at the end-of-life transition. Future studies that target caregivers will be instrumental in better understanding the barriers and challenges that deter caregivers from regularly evaluating care recipients' oral health problems at the end of life. Findings will provide evidence for developing interventions to assist caregivers in giving better oral care to care recipients.

Our finding that younger caregiver age significantly predicted awareness about care recipients' oral problems and treatments may be explained by caregivers older than 65 years not having the energy to provide proper oral care for care

recipients at the end of life. Additional assistance from other family members or paid caregivers might be needed [3].

Caregivers' well-being was also a significant predictor of caregivers' awareness of care recipients' oral problems. It is possible that caregivers with significant health problems were less aware of care recipients' oral problems than caregivers' counterparts because they are preoccupied with managing their own health issues. Evidence from our sample indicates that 38 % of the caregivers reported significant health issues. Another group of researchers found that caregivers themselves had significant health problems and comorbidities, including cardiovascular (61 %), endocrine or metabolic (35 %), and musculoskeletal (33 %), while caring for cancer patients [19]. Further, this group of caregivers perhaps struggle with their own mortality or recognize their own issues of disability and lack of energy to tend to oral health issues, which may seem less important or threatening. Efforts that focus on increasing oral care awareness for all caregivers and providing respite care to support caregiving roles should be considered. Though we found that caregivers' age and well-being were predictors of their awareness of care recipients' oral problem, one needs to interpret this result with caution. The percentage differences were small and may not be replicated in another study.

There are some limitations to the study. Only 51 % of the caregivers explicitly stated that they evaluated care recipients' oral problems at least weekly, though a higher percentage claimed that evaluating care recipients' oral problems was important. Sorting out the reason for this gap is important but was beyond the scope of the current study. Our finding that caregivers 18–64 years old were more likely to have awareness of care recipients' oral health problems than caregivers 65+ years old should be interpreted with caution because this association may be confounded by unknown factors not measured or controlled for in this study.

Conclusion

Caregivers were likely to be relatives and friends and were aware of the care recipients' oral health problems. A substantial portion of caregivers did not evaluate oral status of care recipients. Caregivers in our study underrated xerostomia and over-rated social impact of oral problems compared to recipients' self-ratings. Given that older caregivers and those with significant health problems were less aware of care recipients' oral health problems, health care providers should consider these two factors as they provide discharge instructions to these caregiver groups caring for cancer patients at the end of life. Future efforts and qualitative studies should focus on understanding the challenges that prevent caregivers from translating their stated understanding of importance of care recipients' oral health problems to behavior to help care recipients meet their oral care needs at end of life.

Acknowledgments This publication was made possible by Grant P30NR010680 from the National Institutes of Health, National Institute of Nursing Research. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Institute of Nursing Research. The final peer-reviewed manuscript is subject to the National Institutes of Health Public Access Policy. The authors thank Jan Durham from Horizon Hospice & Palliative Care and Hope Engeseth and Julie Vecchio from the University of Illinois at Chicago for the subject referral and data collection.

Compliance with ethical standards

Conflict of interest Dr. Wilkie received a grant from Pfizer for a study not connected to the current manuscript and is also the Chairman and Founder of eNURSING LLC.

References

- National Hospice and Palliative Care Organization (2014) Facts and figures—hospice care in America. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf
- Weitzner MA, Moody LN, McMillan SC (1997) Symptom management issues in hospice care. *Am J Hosp Palliat Care* 14(4):190–195
- Fischer DJ, Epstein JB, Yao Y, Wilkie DJ (2014) Oral health conditions affect functional and social activities of terminally ill cancer patients. *Support Care Cancer* 22:803–810
- Wilberg P, Hjermstad MJ, Ottesen S, Herlofson BB (2012) Oral health is an important issue in end-of-life cancer care. *Support Care Cancer* 20:3115–3122
- Mercadante S et al. (2015) Prevalence of oral mucositis, dry mouth, and dysphagia in advanced cancer patients. *Support Care Cancer* 23(11):3249–3255
- World Health Organization (2013). Oral health surveys: basic methods, 5th edn. Retrieved from <http://www.icd.org/content/publications/WHO-Oral-Health-Surveys-Basic-Methods-5th-Edition-2013.pdf>
- Elad S et al. (2015) Basic oral care for hematology-oncology patients and hematopoietic stem cell transplantation recipients: a position paper from the joint task force of the Multinational Association of Supportive Care in Cancer/International Society of Oral Oncology (MASCC/ISOO) and the European Society for Blood and Marrow Transplantation (EBMT). *Support Care Cancer* 23(1):223–236
- Epstein JB et al. (2012) Oral complications of cancer and cancer therapy: from cancer treatment to survivorship. *CA Cancer J Clin* 62(6):400–422
- McMillan SC, Moody LE (2003) Hospice patient and caregiver congruence in reporting patients' symptom intensity. *Cancer Nurs* 26:113–118
- Hauser JM, Chang CH, Alpert H, Baldwin D, Emanuel EJ, Emanuel L (2006) Who's caring for whom? Differing perspectives between seriously ill patients and their family caregivers. *Am J Hosp Palliat Care* 23:105–112
- Anderson F, Downing GM, Hill J, Casorso L, Lerch N (1996) Palliative Performance Scale (PPS): a new tool. *J Palliat Care* 12: 5–11
- Virik K, Glare P (2002) Validation of the palliative performance scale for inpatients admitted to a palliative care unit in Sydney, Australia. *J Pain Symptom Manag* 23:455–457
- Fox PC, Busch KA, Baum BJ (1987) Subjective reports of xerostomia and objective measures of salivary gland performance. *J Am Dent Assoc* 115:581–584
- Narhi TO (1994) Prevalence of subjective feelings of dry mouth in the elderly. *J Dent Res* 73:20–25
- Ship JA, Fischer DJ (1997) The relationship between dehydration and parotid salivary gland function in young and older healthy adults. *J Gerontol A Biol Sci Med Sci* 52:M310–M319
- Slade GD, Spencer AJ (1994) Development and evaluation of the Oral Health Impact Profile. *Community Dent Health* 11:3–11
- Epstein JB, Emerton S, Kolbinson DA, Le ND, Phillips N, Stevenson-Moore P, Osoba D (1999) Quality of life and oral function following radiotherapy for head and neck cancer. *Head Neck* 21:1–11
- Cleeland CS, Ryan KM (1994) Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med Singap* 23:129–138
- Grant M, Sun V, Fujinami R, Sidhu R, Otis-Green S, Juarez G, Klein L, Ferrell B (2013) Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncol Nurs Forum* 40:337–346