Oral care experiences of palliative care patients, their relatives/carers and healthcare professionals: a qualitative systematic review

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Abstract

Objective: To explore the oral care experiences of palliative care patients and of those who support or deliver oral care to these patients: nurses, doctors, dentists, their relatives and carers.

Data Sources: Electronic search of the databases included: Embase, MEDLINE, DOSS, AMED and PsycINFO.

Data selection: Six articles were included in the final synthesis.

Data extraction: Thematic analysis was applied by two researchers.

Data synthesis: Three themes were identified: 'performing oral care', 'effects on oral health' and 'challenges in palliative care'.

Conclusions: Despite similarities of oral care experiences, this review identified some differences, crucially in terms of the wider impact of oral symptoms, namely social interactions with others and challenges to oral care. This confirms the need to investigate these topics further in relation to different stakeholders, such as nurses; and to have consistent guidance to facilitate the provision of effective oral care to palliative care patients.

Keywords: Palliative care, patients, healthcare professionals, nurses, oral care, oral health.

Introduction

There is a projected growth in demand for palliative care in England and Wales between 25% and 40% by 2040 (Etkind et al., 2017). Similar estimates are expected for other high-income countries. The drive for more palliative care is due to a rise in deaths from chronic illnesses and people living longer. However, it is unclear how healthcare professionals (HCPs), namely nurses, and services are to meet this rise in demand (Etkind et al., 2017).

Oral symptoms, such as xerostomia, mucositis and candidiasis are amongst the most common symptoms palliative care patients experience (Kinley and Brennan, 2004, Kvalheim et al., 2016, Milligan et al., 2001, NICE, 2018). Oral symptoms can precipitate further life-threatening complications such as anorexia, malnutrition, cachexia and aspiration pneumonia (Lee et al., 2001, Wiseman, 2000). Indeed, the number of decayed teeth, frequency of brushing and dependency on others for oral care are considered to be significantly associated with aspiration pneumonia (Langmore et al., 1998, Langmore et al., 2002).

Research on the oral care of palliative care patients appears to be scarce (Kvalheim et al., 2016, Bernardes Delgado et al., 2018, Fitzgerald and Gallagher, 2018). To our knowledge, a systematic literature review on the oral care experiences of palliative care patients, their relatives and HCPs has not yet been conducted. Therefore, the aim of this systematic review was to explore the oral care experiences of palliative care patients and of those who support or deliver oral care to these individuals: nurses, doctors, dentists, their relatives and carers.

Methods

This qualitative systematic review is reported adhering to the ENTREQ (Tong et al., 2012) statement for reporting of synthesis of qualitative studies and the review protocol was registered with PROSPERO (registration number CRD42017071929).

Inclusion criteria

The WHO (2004) definition for palliative care was used to define the population of interest. Palliative care includes terminally-ill patients and those receiving end-of-life care (WHO, 2004). Therefore, studies recruiting adult 'terminally-ill patients' and patients receiving 'end-of-life care' were included.

No limits were applied regarding date of publication, setting and location. Studies exploring oral care of palliative care patients using qualitative methodology such as focus groups, interviews and open-ended questionnaires were included. Articles were included if the main topic was oral care and there was some description of the phenomenon of interest. Papers that did not use qualitative methodology or only described oral symptoms were excluded. Predefined eligibility criteria are described in Table 1.

Table 1: Inclusion and exclusion criteria					
	Inclusion criteria	Exclusion criteria			
S: Sample	Adult palliative care patients.	Under 18 years of age patients.			
PI: Phenomenon of interest	Oral care*, such as tooth brushing and moistening oral cavity (self-care or provided by relatives, carers, nurses, and dental professionals); Professional oral care (dental professionals).	Papers in which the main topic is not oral care and/or oral health			
D : Design	-	No exclusions regarding types of qualitative data collection or analysis			
E: Evaluation	Experiences of oral care	Papers only describing oral symptoms; Papers that do not mention some form of oral care/mouth care experience.			
R: Research type	Primary, empirical, quantitative studies with open-ended questionnaires; Qualitative studies; Mixed-methods studies	Quantitative studies, including closed-ending questionnaires and cross-sectional methods; Non-empirical work, such as editorials and opinion papers; Narrative reviews.			
Other	Own residence, care-home, nursing-home, hospital or hospice. Papers written in English.	No exclusions regarding setting. Non-English language papers.			

Oral care* measures for palliative care patients include, but are not limited to:

- Oral hygiene, such as tooth brushing, cleansing of dentures, rinsing the mouth, removing coatings, debris and plaque from oral mucosa and lips (NHS Scotland, 2014);

Keeping the mouth and lips moist and intact (NHS Scotland, 2014);

- Management of painful mucositis (Milligan et al., 2001);
- Management of xerostomia, fungal infections and oral pain (Milligan et al., 2001).

Data sources and search strategy

A systematic literature search was undertaken by an information specialist using the databases Embase (Ovid), MEDLINE (Ovid), DOSS (EBSCOhost), CINAHL (EBSCOhost), AMED (EBSCOhost) and PsycINFO (HDAS). The searches were initially completed on 31st August 2017 and updated on 22nd January 2021. Full details of the search strategy used in Embase is available in Appendix 1. The strategy was translated across the other databases changing the operator syntax and subject headings as appropriate.

The database searches generated a total of 4247 records which were imported into Endnote X9. One additional record was generated through citation searching. De-duplication produced a total of 2446 records. These were uploaded to Rayyan QCRI, asystematic review free internet application (Ouzzani et al., 2016), and titles and abstracts were examined independently by two reviewers (XXX and XX) against pre-defined eligibility criteria. 67 articles were deemed relevant and were read in full text independently by the two reviewers. Disagreement in one article was solved by discussion with a third reviewer (XX). Six articles were included in the final synthesis (Figure 1).

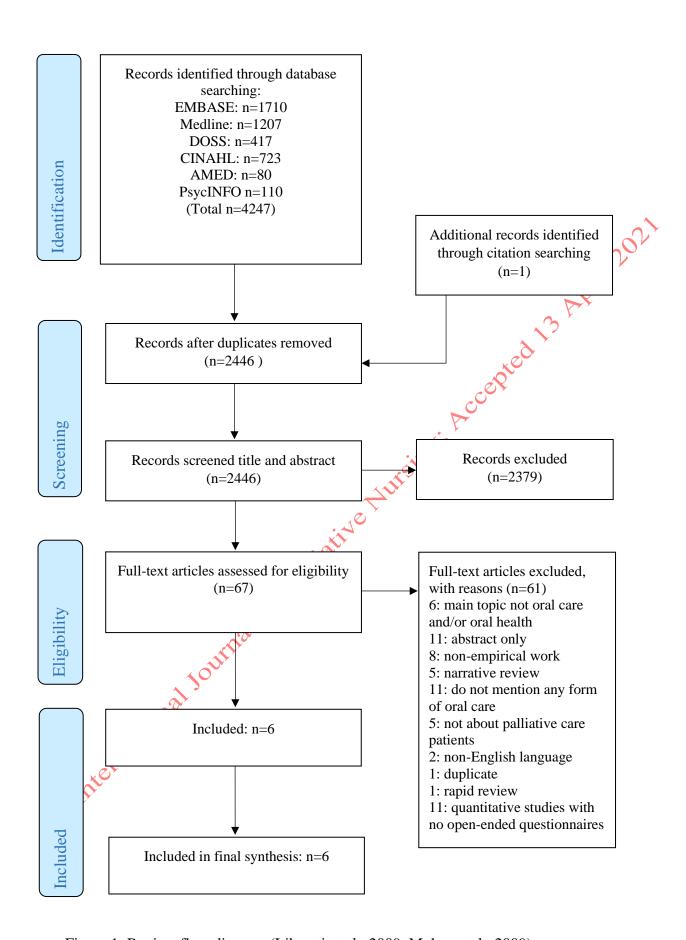


Figure 1: Review flow diagram (Liberati et al., 2009, Moher et al., 2009)

Data synthesis

Thematic analysis was applied by two reviewers to identify patients', carers/relatives' and HCPs' perspectives regarding oral care of palliative care patients. This method allows identification of themes and patterns across the dataset. It also allows the researcher to analyse the data according to the three different perspectives and then compare and contrast the themes generated from patients, relatives/carers and HCPs, such as nurses.

The six papers included were uploaded into a qualitative analysis software: NVivo12 (Bazeley and Jackson, 2013). Thematic analysis (Braun and Clarke, 2006) was applied by two researchers (XXX and XX). First, the six papers were read and re-read with a focus on relevant sections. Next, the relevant sections were extracted and initial codes were generated. Step three included the synthesis of the initial codes in sub-themes and themes. Step four involved the refinement of the themes. The fifth step included the review of the entire dataset and sought to identify the essence of each theme. Final refinement of the themes took place during discussion between the reviewers and step six included the final writing as reported in this paper.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) Qualitative checklist (CASP., 2018) (Table 2) was employed independently by two researchers to assess the quality of the included studies. An open dialogue was maintained between the two researchers and disagreements were resolved through discussion.

Table 2: Assessment of methodological quality										
CASP Qualitative checklist	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Bernardes Delgado et al. (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	СТ
Croyere et al. (2012)	Y	Y	CT	CT	CT	N	Y	CT	Y	Y
Kong et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT
Milligan et al. (2001)	Y	CT	CT	CT	CT	N	Y	N	Y	CT
Rohr et al. (2010)	Y	Y	Y	Y	Y	N	Y	CT	Y	Y
Venkatasalu et al. (2020)	Y	Y	Y	Y	Y	N	Y	CT	Y	СТ

Q1-Q6: Are the results valid?

- Q1: Was there a clear statement of the aims of the research?
- **Q2:** Is a qualitative methodology appropriate?
- Q3: Was the research design appropriate to address the aims of the research?
- **Q4:** Was the recruitment strategy appropriate to the aims of the research?
- **Q5:** Was the data collected in a way that addressed the research issue?
- **Q6:** Has the relationship between researcher and participants been adequately considered?

Q7-Q9: What are the results?

- Q7: Have ethical issues been taken into consideration?
- **Q8:** Was data analysis sufficiently rigorous?
- **Q9:** Is there a clear statement of findings?

Q10: Will the results help locally? How valuable is the research?

Y: yes; N: no; CT: can't tell

Results

Six papers were included in the synthesis (Figure 1). The characteristics of the included studies are summarised in Table 3.

Table 3: Characteristics of included studies					
Included studies	Methodology	Phenomenon of interest	Participants and sample	Setting	Key findings
Bernardes Delgado et al. (2018)	Qualitative study: Thematic analysis.	Oral care experiences of palliative care patients, from the perspective of their relatives and/or carers.	Relatives of palliative care patients. Not possible to ascertain diagnosis of all palliative care patients. It included patients with Alzheimer's and cancer. 8 authors of bogs and 8 contributors to discussion forums 13 females, 2 males and 1 not possible to identify gender	USA, UK and Canada (blogs and discussion forums).	Oral care was not the main topic in any of the blogs and most of the discussion forums. Oral care tends to be over-looked until the person's quality of life becomes noticeably compromised by the oral symptomatology.
Croyere et al. (2012)	Mixed-methods: Focus groups and questionnaire. Analysis according to the theory of self- efficacy.	The social representation that nurses and healthcare assistants share regarding oral care for patients in a non-specialist palliative care setting.	Nurses and healthcare assistants providing non-specialist palliative care. 84 completed questionnaires (84 nurses and healthcare assistants) 38 participated in focus group (12 nurses and 26 healthcare assistants) Palliative care patients with diagnosis of respiratory problems and neuro-oncology pathologies.	France Five surgical and rehabilitation hospital units.	Staff reported confusion regarding the choice of products and resources. Oral care for palliative care patients was part of their role.
Kong et al. (2020)	Qualitative study: Focus groups. Thematic analysis	The perceptions of nurses working in Australian palliative care settings towards patients' oral health and provision of oral care.	8 Community palliative care nurses 10 Inpatient palliative care nurses	Australia Same Australian Local Health District: Community Health Centres and Specialist Inpatient Palliative Care Units.	Participants believed oral health is important for people receiving palliative care. They also recognised the need for a model of care that would help integrate oral care into nurses' existing practices. The participants argued for formal oral health guidelines, alongside oral health training to provide better oral care.
Milligan et al. (2001)	Mixed methods: Survey, visual assessment, interviews and	To monitor prevalence of oral problems among patients admitted to hospices and assess changes	Managers and patients with advanced cancer 23 patients took part in the interviews.	UK. Hospices and hospice units.	Oral care based on the protocol, if delivered consistently, resulted in improvements in oral cleanliness and patients' perceptions of oral comfort.

	microbiological assessment. Analysis not stated.	in oral health with implementation of oral care according to a protocol.					
Rohr et al. (2010)	Qualitative study: Semi-structured interviews.	Experiences of terminally- ill patients regarding oral discomfort.	Terminally-ill patients 14 patients. not possible to ascertain diagnosis of palliative care patients.	Australia. Palliative care service (hospital).	All participants described a range of oral problems that impacted on their quality of life. There was either a casual approach or an absence of oral assessments.		
Venkatasalu et al. (2020)	Qualitative study: Focus groups. Thematic analysis	Perceptions of nurses, doctors and dentists regarding palliative care patients' oral problems and their oral care.	7 Palliative care nurses 4 Palliative care doctors 4 Oncology nurses 4 Oncologists 6 Dentists	Brunei 3 hospital settings providing specialist and general palliative care services.	Participants were aware of the importance of oral care in ensuring good quality of life. However, they did not prioritise oral care. Oral care was often opportunistic. Compliance amongst patients affected their oral care. The barriers faced by HCPs in providing oral care were mainly lack of staff and absence of clear guidance for the oral assessment of palliative care patients.		
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Review findings

Thematic analysis identified three themes regarding the oral care experiences of palliative care patients, relatives/carers and HCPs: 'performing oral care', 'effects on oral health' and ch study in the st 'challenges in palliative care'. The contribution of each participant group to the themes and subthemes identified is depicted in Table 4. In addition, the contribution of each study to

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Table 4: Contribution of participants and authors to themes and sub-themes						
Themes	Sub-themes	Co	Authors' comments			
		Palliative care patients	Relatives/carers	HCPs		
Performing oral care	Oral hygiene	X	X		X	
	Promoting comfort	X	X	X	X	
	Timing of oral care	X		X	X	
Effects on oral health	Oral symptoms	X	X So		X	
	Wider impact of oral symptoms	X		X	X	
	Improving oral symptomology	x			X	
Challenges in palliative care	Wider impact of oral care	X	X	X	X	
•	Barriers to oral care	X	X	X	X	
	Overcoming challenges in oral care			X	X	



Table 5: Contribution of studies to themes and sub-themes **THEMES** SUB-**CONTRIBUTION OF STUDIES** CONTRIBUTION OF STUDIES **THEMES** Study participants Authors' comments 'swabbing my father's mouth with a little sponge dipped in solution' P1, p3 **Performing** Oral hygiene 'The predominance of hygiene and comfort over the other themes in the results was explored with the help of the focus 'You know when your mouth is clean.' P4, p424 oral care groups. One explanation given was that hygiene is seen as a 'I have my own teeth... I clean my teeth a lot more than what Lused to.' P5, principal nursing role and that for health-care assistants tooth brushing is seen as part of routine daily care and therefore it is their job to assist with it. According to the focus 'At home... I was washing my teeth a lot. [In here] oh, well when they come to group the idea of freshness was associated with hygiene, wash you, the first thing I do is clean my teeth... And then the same at night, probably owing to the participants' personal use of when they come to put the lights out and turn me over. I, I make sure I've toothpaste and tooth brushing. 'P2, p437, 438 cleaned my teeth. Yes [I do that in my bed]. Like I manage the toothbrush. P5, p442 'The present study identified a concern for both cleanliness and comfort' P2, p439 'There was consensus among nurses for the need of oral hygiene among people receiving palliative care. Both community nurses and inpatient nurses recognised that oral health was "really, really important" (CN1). Inpatient nurses observed that "good mouth care" (IN1) was imperative to maintain a person's comfort.' P3, P501 'Care based on this protocol, when consistently delivered, resulted in measurable improvements in oral cleanliness and patients' perceptions of oral comfort. This is despite the fact that the care provided is neither complicated nor expensive. P4, p425 'All I could do was put some lip balm on his lips and pray that it would offer 'All participants described an oral care procedure, albeit **Promoting** him some relief to the dryness of his lips and he would forget about his dry without much detail. These were mainly a technical act to comfort mouth' P1, p3 address oral symptoms and provide comfort. When oral care was not provided this was in order to avoid causing stress to 'I used Difflam anaesthetic mouthwash to numb the ulcers for long enough to their loved one and was usually because they had been eat. It has to be taken 20 minutes before a meal. 'P1, p3 advised not to so. It appears that generally oral care was

		'if the mouth is clean the patient is comfortable and therefore presentable for his or her family. Other prerequisites for comfort are the absence of a dry mouth and the absence of pain associated with mouth lesions.' P2, p438 'Also, the end of life, it's very important because if someone else can't - if they can't do it themselves, we need to do it for them to keep them as comfortable as possible' P3, p501 'My mouth feels better in every way' P4, p424	provided in reaction to signs and symptoms rather than to pro-actively improve quality of life.' P1, p4 'The present study identified a concern for both cleanliness and comfort' P2, p439 'Care based on this protocol, when consistently delivered, resulted in measurable improvements in oral cleanliness and patients' perceptions of oral comfort. This is despite the fact that the care provided is neither complicated nor expensive.' P4, p425
	Timing of oral care	'At home I was washing my teeth a lot. [In here] oh, well when they come to wash you, the first thing I do is clean my teeth And then the same at night, when they come to put the lights out and turn me over. I, I make sure I've cleaned my teeth. Yes [I do that in my bed]. Like, I manage the toothbrush.' P5, p442 'A lot of time, it's opportunistic, we are only alerted regarding the issue if family is concerned about any mouth ulcer, difficulties swallowing, or poor oral intake.' P6, P1333	'the health-care assistants considered that oral health care should take place systematically during each general hygiene care, rather than following meals or at a time of patient choicethe nurses considered that oral care should be performed when they think it is necessaryit seems that proper oral health should indeed not be automatic but rather a question of thoughtful organisation' P2, p439
Effects on oral health	Oral symptoms	'swabbing my father's mouth with a little sponge dipped in solution would help with dryness' P1, p3 'They had provided sponges that we could use to moisten her lips and tongue'	'it is not surprising that most participants described oral symptoms such as dry mouth, dry lips and difficulty in swallowing. Oral diseases which can be symptomless and less easy to identify were not reported.' P1, p4
		P1, p3 'want to moisten their mouth, you can feed them tiny ice chips' P1, p3	'Patients on admission consistently reported that their mouths were dry or painful' P4, p425
		'My brother noticed a few hours before he died that his mouth was dry and he held a cotton wool swab dipped in water to his mouth' P1, p3 'his mouth is totally dry and obviously very unpleasant' P1, p3 'The soreness has gone.' P4, p424	'One man who was thought by previous carers to be withdrawn proved, on questioning, to be avoiding conversation simply because he found speaking too painful.' P4, p425
		'I can taste better.' P4, p424 'My mouth feels better in every way' P4, p424 'My mouth feels as though I have burnt it.' P4, p425	'Dry mouth extending from the lips to the throat was common among the oral problems described by patients. The degree of severity of dry mouth ranged from 'manageable' to 'out of control'' P5, p440
	,	'Over the years I've had [dry mouth] nothing like the severity of this [laughs] I get a little bit of dry mouth, but absolutely nothing like this. This is just, um, full out of control [laughs]' P5, p440	'Other oral problems experienced included mucosal ulceration, thrush and loose and ill-fitting dentures' P5, p440 'The impact of the effects of oral discomfort encompassed many aspects of the lives of the participants including loss of

'Ah very bad dryness... since I've been sick... all I want is an undry mouth P5, p440

'Dryness it's still about the same. Right down to my lips. They break out, but they're dry. But there's no moisture in my mouth at all' P5, p440

'I have to wake up ten times a night to have a sip of water' P5, p440

'But I had a lot of problems with ulcers, inside my mouth... and a lot of thrush right on top of the tongue, and the whole mouth was... very sore... approaching 3 months now, although it's been under control now for the last month' P5, p440

'When the thrush was happening... I got the very unpleasant taste in my mouth... Well I'm not eating very well anyway'" P5, p440

'It is very harsh and dry. Very dry, the mouth. Very dry. All right. And I have no appetite.' P5, p441

'I slur everything... It makes you feel a bit stupid because you're slurring away there...I know my mouth's sticking together, that's why. And my tongue's stuck to my plates.' P5, p441

'I have problems because I can't talk and I get sort of like, choking me. Some days, it's not too bad, I can talk a bit.' P5, p441

'I had this big white fungus growing and all these ulcers... Ahh, it was just a continual battle to try and keep my mouth from getting that sore that I couldn't eat.' P5, p441

enjoyment of food, loss of appetite, loss of weight and swallowing difficulties. Such consequences led to patients' making adjustments to their eating habits such as eating smaller meals, opting for softer foods and eating less frequently. At times oral dryness also meant speech was difficult, with participants describing choking sensation or slurring of speech.' P5, p440

'Participant reports of physical problems of mucosal ulceration and infection, and especially recurrent and persistent oral dryness...' P5, p443

Wider impact of oral symptoms

'...had those issues, and having a dry mouth is affecting how they talk and communicate with their family. It might be - have an odour. So feeling more self-conscious and things like that... it's very socially isolating.' P3, p501

'serious problems like aspiration pneumonia and stuff... because it just starts - if you don't treat the oral problem, it just -then they don't eat, and then they're weak, and then they get sick' P3, p501

'You have no taste... And that's what makes me so cross, because taste to me is a low... what's the use of bloody having it? Let's face it, if I can't, if I can't taste food I won't eat.' P5, p441, 442

My mouth is very dry, sometimes my mouth gets stuck, I've got a job to speak clearly, I sip water to be able to say anything... seems to have gone on forever... a bit short tempered... with trying to repeat yourself [Interviewer: "so you find it a bit frustrating?"] yeh, because it's there all the time.' P5, p442

'As well as dealing with physical discomfort, most participants described their 'frustration' at dealing with oral problems and associated effects.' P5, p441

'The most common social discomfort for participants stemmed from difficulties in communication. Speech difficulties led participants to feel embarrassed when stumbling over words.' P5, p442

'Another experience common to many interviewees was the social impact of being unable to enjoy and share meals with friends and family. Painful mouths and/or the necessity for mashed foods limited social outings and participation at special occasions, such as Christmas dinner.' P5, p442

		'I had one [ulcer] on my tongue and one inside my mouth there you know you'd mash it [food] up, but it was very annoying, to try to eat you know.' P5, p442 'Well I think it's the same thing, my wife can't understand me half the time but eh it's irritating when I've got to try repeating yourself because I can't get the words out, yeh yeh.' P5, p442 'And also, I can be conscious about a smell coming out of my mouth I clean it, I clean it of course well I don't know if there's a smell. I can't smell myself.' P5, p442	' the current analysis reveals that oral health difficulties more generally significantly hinders patients' daily living and quality of life. 'P5, p443 'The range of oral problems endured by participants affected social and emotional aspects of living.' P5, p443
	Improving oral symptomology	'All those mouthwashes really make a difference.' P4, p424 'Your mouthwashes worked last time.' P4 p425 'One of your orange mouthwashes will help.' P4, p425 'My mouth is very, very dry, sometimes my mouth gets stuck, I've a job to speak clearly, I sip some water to be able to say anything my voice will come louder' P5, p442 ' to have a conversation with somebody, I only needed 2-3 minutes and my mouth was like a piece of parchment. It just would turn to parchment, and that's why that is the greatest thing that was ever invented (bottle of water) just wet my mouth and continue for another couple of minutes and that's how I got through, through each day.' P5, p442 ' my mouth will stick to my teeth, and I can't open it till I have a, a drink and, and oh [in frustration] Artificial saliva, yes. [It helps] only for a little while. Not for very long oh I'd say only around about ten minutes, and then I have to have a drink of water. The water seems to be best.' P5, p443 'Nothing helps. I tried honey, and a cup of tea, and chamomile tea. It doesn't help. I tried all kind of lollies. It doesn't help' P5, p443	'Several comments from patients who had already experienced mouth care at Accord revealed that they remembered the beneficial effects' P4, p425 (citations from patients mentioning mouthwashes follow this statement by the authors) 'In response to dry mouth, all participants reported increasing their daily fluid intake, with a particular preference for water, needing to be readily available for quick consumption.' P5, p442 'Mouthwash was used by participants for remedial effect for dry mouth, ulcers and thrush, although its effect was limited when problems were severe and long lasting. The antifungal treatment was effective when introduced early but was more commonly used for much longer periods of time. A number of interviewees had tried saliva, with varying degrees of success' P5, p442, 443 'Sugar-free gum, lollies, herbal teas and honey were remedies tried by some respondents with little or no success.' P5, p443
Challenges in palliative care	Wider impact of oral care	'As I removed the sponge every other person in the room reacted with revulsion' P1, p4 we were anxious to keep him as comfortable as possible so continued to offer the swab dipped in water. The problem is that I can't stop worrying about the fact that we might have caused him to choke.' P1, p4 'Like you, I found it so hard to be unable to do anything for her at all, because I was told not to even swab her mouth to moisten it' P1, p4	'The emotions described by the participants varied from anger, guilt, worry, and trauma to a more neutral approach. When oral care was described as a technical act, participants did not report any positive or negative emotions. Some form of oral care was expected to happen and therefore this did not initiate an emotional response from participants. However, when there was an emotional response to oral care, this was a negative one. One participant described the incompetence of staff providing oral care and this led to

'participants, who reported that it violates the personal space of both parties and generates feelings of disgust about bad breath. The nursing staff also felt that these unpleasant feelings were reciprocated by the patients. The participants reported that they would not like to receive oral care but they would also not like not to receive it. They felt there is little reward in carrying out mouth care as it needs to be repeated frequently.' P2, p438, 439

'It's [staff assistance with oral care] humiliating... I'm so, I like to be independent... I'm a very independent person...' P5, p442

anger and stress. The fact that staff did not seem to know what to do was thought to have caused discomfort, pain and harm to the patient. This inevitably led to the relative feeling the emotions described above. Furthermore, when one of the participants swabbed her grandmother's mouth, other family members turned away or walked away expressing disgust, proving oral care is not seen as being easy or pleasant to perform for others.' P1, p4

Finally some participants felt guilt specifically in relation to oral care. There was guilt because they perceived that the oral care they provided was not correct and was potentially harmful. There was guilt for not being able to provide oral care or being told not to do so.' P1, p4

'There was an initial expectation that the participants would report resistance to carrying out oral care, but instead the focus group showed that they considered it as much a part of their job as any other aspect of patient care. They did not consider oral care to be more unpleasant than some other aspects of their job, such as dealing with vomiting, faecal secretion, and expectoration. Questioning the possible unpleasantness felt by caregivers in their daily job may devalue all of the care carried out in close proximity to patients' bodies.' P2, p439

'psychosocial functions of the mouth and positive self-image are also absent from the consideration of caregivers' P2, p439

Barriers to oral care

'The little sponge should be squeezed and most of the solution or water drained out of it, then the person who is unable to swallow (my father)... will not aspirate liquid which could kill him. I turned my back... I saw another one pull the sponge from my father's mouth, dip it in the solution and reinsert it. My father began choking...' P1, p3

'sponge in a blue liquid, and heading towards my father's open mouth... I told her to get away from my father and the nurse supervisor came in and quickly removed the evidence' P1, p4

'There was confusion over the choice of products and resources. This confusion was related to different recommendations given by the mobile palliative care teams, to the variety of medical prescriptions, and to changes in the guidelines, which led to participants not knowing whether they were current or pertinent. Other points of confusion were due to organisational and

'The objectives of oral care and its adaption to individual patients needs are rarely referred to.' P2, p439

'psychosocial functions of the mouth and positive self-image are also absent from the consideration of caregivers' P2, p439

'While most participants administered their own oral care, tiredness and fatigue made the oral care regimen 'more tedious'' P5, p442

'Solutions did not seem to be readily available for those with ill-fitting or problematic dentures: only two participants mentioned involvement with their dentist in relation to their oral problems, whilst another participant, despite repeated logistical factors, such as availability of resources and products constantly changing, for various reasons. The cost of different products could be an issue, as could changing recommendations and the need to test new resources like soft toothbrushes. The participants reported that they ultimately provide the oral care they think is appropriate with the resources they are comfortable with.' P2, p438

'in the focus groups, participants who indicated that patients sometimes refuse oral health care explained that these refusals were often due to patients finding the care painful and/or unpleasant because of neurological problems, or that they were a means of expressing distress' P2, p438

'Then they can't get to a dentist. Often if they're waiting on a waitlist of the dental hospital . . . I used to work in that area. They would be waiting and waiting and waiting and waiting.' P3, p502

'Because in the scheme of things, it doesn't always rank high as something they're worried about initially. They're like oh my God, I'm dying, and I've got pain, I've got this. The mouth really does get neglected until it really becomes an issue, and then it's harder to get on top of.' P3, p503

'No-one has looked in my mouth. The outreach nurses come, they say the same thing – just wash it out.' P5, p443

'Ah, no-one's actually come over and gone 'ahhh', you know. They've been sitting on that side of the table I've been sitting on this side of the table.' P5, p443

'...We would all have a bit more awareness (knowledge) in our area of expertise... when I see a patient, I don't automatically think 'Oh yes we need to look at his teeth....I have to admit my knowledge in dental issue is a bit patchy as well. Of course i

f it's related to my specialty then I'll be a bit more upfront with looking proactively." P6, p1333

'A palliative patient had tooth decay. She could not move, and we brought her to the nearby clinic. However, the dental service was on the 2nd floor and there was no elevator. So, it was difficult.' P6, p1334

'I think the difficulty of caring the patient is that, they might not be cooperative. Although the carers are trained and know what to do but sometimes the patients are not cooperative, so that might be difficult.' P6, p1334

'Once patient is diagnosed with cancer, unless it's oral cancer, their oral care seems to be left out... less priority. They are focusing on... their depression is

presentations to a dental clinic, was placed on a 2-year waiting list for lower denture replacement.' P5, p442

'Participants tended to stress they 'mentioned' their dry mouth, rather than 'reported' the condition. The causes for dry mouth as given by health professionals such as 'aftereffect of medication', or an 'age-related condition', seemed to reinforce to participants that the issue was not serious enough to pursue in its own right. Even when oral conditions persisted for extended periods of time, the ongoing examination of the mouth was minimal and sometimes only involved discussions around use and effectiveness of mouthwashes and/or antifungal preparations. Overall, the general impression to patients was that it was 'pointless' for professionals to look inside the mouth 'as there was nothing to see' and little the health staff could do to eliminate or ease their condition.' P5, p443

'From the perspective of the terminally ill participants, despite the extent and ongoing nature of oral difficulties encountered a deficit was noted, of thorough and structured assessment of interviewees' mouths by health professionals.' P5, p443

more towards the cancer... so their oral care is usually left out and not taken care of properly...' P6, P1334 'Tool is to guide us, how to do the assessment... so if there is no tool, it is like 'What should we do?'... Yes, now nothing...' P6, P1335 'Really it should be as the patient is admitted onto the ward when we're doing of the analysis of the focus group responses found that there Overcoming that first assessment... I don't know if it's a score that you get, from there you are issues that need to be addressed in order to reinforce challenges in would do this, from there you would do that. That would be like a guideline for caregivers' feelings of effectiveness in carrying out oral care oral care nurses... if it's there and it's guiding you and it's going to be like a tickbox, for patients in palliative care. Addressing these practical you're going to do it because you're going to look at A, B, C and D, It's going points can take different forms, such as exercises within and to be more completed rather than thinking, or open your mouth, on yeah. looks outside the clinical setting (e.g. role play of a patient refusing alright, done. P3, p502 oral care), identifying appropriate resources and their correct use, etc. During handover, discussions can take place 'maybe there could be like a nurse that comes around and assesses and then about the appropriate moment for oral care for both the they can judge from there if that person needs to see a dentist or something caregiver and the patient. A caregiver who feels at ease P3, p503 carrying out oral care can accompany another who feels 'You know how we have home doctors? We need home dentists. You know like uncomfortable. Also, explicit positive feedback can be elicited from patients, families, clinical specialists, managers, and other stakeholders.' P2, p439 'Focus groups involving oral caregivers showed that it is necessary for caregivers to feel that they and their colleagues are successful in carrying out oral care and to witness a positive outcome in order to feel convinced that good oral care is necessary. 'P2, p440 'Formal guidelines to assist in assessing the severity of peoples' oral health at the beginning of admission were also recommended to ensure a systematic approach to their assessment.' P3 502 'The results of this study are supportive of oral care for the terminally ill patient being raised to a clinical priority in hospice, acute hospital, and palliative community outreach settings to improve standards of professional holistic

palliative care.' P5, p444

Studies:

- P1 Bernardes Delgado et al. (2018)
- **P2 Croyere et al. (2012)**
- P3 Kong et al. (2020)
- P4 –Milligan et al. (2001)
- P5 Rohr et al. (2010)
- P6 Venkatasalu et al. (2020)
- p page number

Performing oral care

'Oral hygiene' and 'Promoting comfort': Palliative care patients, relatives and HCPs described brushing teeth, swabbing mouths, applying lip balms and using mouthwashes in order to keep the oral cavity clean, moist and ultimately comfortable and pain-free: *I used Difflam anaesthetic mouthwash to numb the ulcers for long enough to eat.* (Bernardes Delgado et al., 2018)

There is also the perception amongst caregivers that a clean mouth is not only comfortable to the patient but also more presentable to others. The 'Timing to perform oral care', the third sub-theme, is described by palliative care patients and HCPs. There is a change in routine from when patients are at home and go to a palliative care unit: At home... I was washing my teeth a lot. [In here] oh, well when they come to wash you, the first thing I do is clean my teeth... And then the same at night, when they come to put the lights out and turn me over... (Rohr et al., 2010) When patients depend on others for their oral care, it tends to be opportunistic, it happens as a response to oral symptoms. A lot of time, it's opportunistic, we are only alerted regarding the issue if family is concerned about any mouth ulcer, difficulties swallowing, or poor oral intake. (Venkatasalu et al., 2020)

The authors of four studies (Bernardes Delgado et al., 2018, Croyere et al., 2012, Kong et al., 2020, Milligan et al., 2001) also contributed to this theme. The authors provided an explanation as to why hygiene and comfort were important to nurses and how oral hygiene contributed directly to comfort: hygiene is seen as a principal nursing role and that for health-care assistants tooth brushing is seen as part of routine daily care and therefore it is their job to assist with it. (Croyere et al., 2012)

There seems to be opposite views regarding timing of oral care. Authors' concluded that HCPs argued that oral care should be provided systematically and following thoughtful organisation, rather than when patients chose (Croyere et al., 2012).

Effects on oral health

The sub-theme 'Oral symptoms' such as dry-mouth, ulcers, and thrush was experienced by patients and witnessed by their relatives. Xerostomia was the symptom mentioned more often by palliative care patients and relatives. The other oral symptoms came secondary to xerostomia such as: *his mouth is totally dry and obviously very unpleasant* (Bernardes Delgado et al., 2018).

Nonetheless, there is a 'Wider impact of oral symptoms'. Palliative care patients described being cross, short tempered and irritated about not being able to taste food and having difficulty eating and speaking. They were also conscious of the impact their mouth had on others, namely its potential smell: And also, I can be conscious about a smell coming out of my mouth... I clean it, I clean it of course... well I don't know if there's a smell. I can't smell myself. (Rohr et al., 2010) Nurses were also aware of the social impact of some oral symptoms ...having a dry mouth is affecting how they talk and communicate with their family. It might be - have an odour. So feeling more self-conscious and things like that... it's very socially isolating. (Kong et al., 2020)

Palliative care patients also described how to improve their symptoms: 'Improving oral symptomatology'. Drinking sips of water and certain mouthwashes seemed to be useful. However, often that was not the case, regardless of what was tried: *Nothing helps. I tried honey, and a cup of tea, and chamomile tea. It doesn't help. I tried all kind of lollies. It doesn't help.*.. (Rohr et al., 2010).

Challenges in palliative care

The 'Wider impact of oral care' relates to the effect performing oral care had on relatives and HCPs. Relatives described revulsion and worry at having done something that caused their loved one's harm: *As I removed the sponge every other person in the room reacted with revulsion* (Bernardes Delgado et al., 2018).

HCPs felt performing oral care violated theirs and the patients' personal space and there was also little reward in providing oral care (Croyere et al., 2012). Palliative care patients reported their loss of independence and what they perceived as being humiliating to them: *It's [staff assistance with oral care] humiliating... I'm so, I like to be independent... I'm a very independent person...* (Rohr et al., 2010)

The 'Barriers to oral care' included not knowing how to perform oral care, the confusion regarding guidelines and products, the refusal to accept oral care from some patients and the difficulty in accessing professional dental care. It was also not a priority and the oral cavity was seldom being assessed: *There was confusion over the choice of products and resources*. (Croyere et al., 2012), *No-one has looked in my mouth. The outreach nurses come, they say the same thing – just wash it out.* (Rohr et al., 2010) and *Then they can't get to a dentist. Often if they're waiting on awaitlist of the dental hospital...* (Kong et al., 2020)

'Overcoming challenges in oral care' is a sub-theme identified from the authors' comments and their conclusions from three studies (Croyere et al., 2012, Kong et al., 2020, Rohr et al., 2010) and nurses from one study (Kong et al., 2020). These were practical suggestions on how to overcome some barriers HCPs had in providing oral care. Examples included role playing of patients refusing oral care and identifying the appropriate resources and using them correctly. Authors also stated the importance of positive feedback and to witness a positive outcome from providing oral care. Furthermore, oral care to palliative care patients should be

given higher priority so professionals' standards could be improved. The results of this study are supportive of oral care for the terminally ill patient being raised to a clinical priority in hospice, acute hospital, and palliative community outreach settings to improve standards of professional holistic palliative care. (Rohr et al., 2010) In addition, there should be formal guidance on how to conduct an oral assessment: Formal guidelines to assist in assessing the severity of peoples' oral health at the beginning of admission were also recommended to ensure a systematic approach to their assessment. (Kong et al., 2020)

Discussion

The findings of the qualitative data synthesis were three themes: Performing oral care', 'Effects on oral health' and 'Challenges in palliative care'. Palliative care patients were the greater contributors to the themes and sub-themes generated by the thematic analysis, followed by HCPs. Patients were the participants of two of the six studies included (Milligan et al., 2001, Rohr et al., 2010) and their 'voices' were heard through their relatives in another study (Bernardes Delgado et al., 2018).

'Effects on oral health' was about what happens to them, including the 'oral symptoms', but also the 'wider impact of oral symptoms' and how to address 'oral symptomatology'. 'Oral symptoms' in particular were important for these studies' participants. It is known that oral health problems experienced by palliative care patients have a great impact on their quality-of-life (Aldred et al., 1991, Langmore et al., 2002). In addition, as systemic health deteriorates so does oral health (Chen et al., 2013). However, oral symptoms have a wider impact beyond the discomfort and pain caused (Bernardes Delgado et al., 2021). Patients' social interactions with others were compromised. There was difficulty talking and swallowing, but also how one presented himself/herself to others became complicated and was often embarrassing. The literature on palliative oral care focus on describing oral symptoms and how to manage these

(Quinn, 2013, Sargeant and Chamley, 2013, Wiseman, 2000, Wiseman, 2006). There is a lack of understanding and research on the wider impact of oral symptoms to palliative care patients and how they affect their quality-of-life (Fitzgerald and Gallagher, 2018). This study has provided an insight into the range of psychological consequences of oral symptoms.

There were conflicting statements on what worked and what did not work on addressing oral symptoms, which are also reflected in the literature. On one hand, it is recognised that simple oral care measures, such as tooth brushing, denture hygiene, moisturising, use of anti-fungals, are effective in improving oral health for palliative care patients (Kristanti et al., 2017, Nakajima, 2017). On the other hand, there is confusion on which guidance to follow and which products to use (Kvalheim et al., 2016). Oral care to these individuals is considered inadequate and dental professionals are seldom involved (Kvalheim et al., 2016, Saini et al., 2009, NHS Scotland, 2014). Palliative care patients contributed to other two themes 'performing oral care' and 'challenges in palliative care'. Their 'voices' were more subdued in these themes. They would clean their mouths and their teeth and would use certain products to mitigate some of the discomfort. However, their oral care routine changed as their health deteriorated and as they had to leave home. In addition, becoming more dependent on others for oral care was perceived as humiliating. Moreover, HCPs did not seem to care or assess patients' mouths. This was the patients' perception. The opposite of a person-centred approach to oral care seemed to be defended by HCPs. Oral care should be delivered in a systematic way and not when patients chose. Palliative oral care is often delivered in a unstructured and haphazard way and it is not evidence-based (Kvalheim et al., 2016). In addition, HCPs' priorities and what the individuals receiving oral care value is rarely taken into account (NICE, 2016).

Relatives also described oral symptoms they could observe for themselves. Although, this was often when oral health was already severely compromised. In terms of the 'challenges in palliative care' relatives described difficulties in providing oral care for someone else. This is

also the experience described by HCPs in providing oral care in other studies (Couch et al., 2013, Kvalheim et al., 2016).

HCPs contributed to all three themes. They were concerned with the notion of promoting comfort through oral care measures. However, the emphasis was on the challenges of providing oral care. It is a very personal care and some staff considered that it violates theirs and patients' personal space (Croyere et al., 2012). This care was not perceived as being rewarding by HCPs because they did not recognise its value on the individual's positive self-image. Although nurses were aware of the alienation and social isolation caused by oral symptoms (Kong et al., 2020).

There were also important barriers to the provision of oral care. HCPs were confused about what to do and what products to use. The literature reflects this aspect as most oral care procedures are not evidence-based and there are also staff and time pressures (Kvalheim et al., 2016). Authors added to the points mentioned above that patients were tired and fatigued which created difficulties with the oral care routine. Patients felt HCPs could not help. Therefore, there was no point in conducting an oral assessment. There was this sense of hopelessness from palliative care patients.

Nevertheless, echoing the recommendations offered by the authors of the included studies, the following strategies could be implemented in practice to overcome some of the challenges faced by HCPs, such as nurses, and carers. These are:

- Oral care exercises that include role-playing,
- Identify oral care resources and their correct application,
- Structured oral care training and guidelines,
- Positive feedback,

 Raise the awareness among HCPs and carers of the importance of oral care to palliative care patients in all settings.

Adopting, therefore, a patient centred approach in the provision of oral care amongst palliative care patients can ultimately enhance the experiences of patients and care providers alike, as well improve clinical standards.

Limitations of this qualitative systematic review should be acknowledged. Two of the six studies included were of poor methodological quality. However, we prioritised the relevance of the studies over their methodological quality. This approach is defended by Dixon-Woods et al. (2006). Data of the six included studies contributed to the thematic analysis identifying the themes and sub-themes.

Another limitation encountered was the fact it was not possible to describe the background of the findings fully. Most of the included studies provided limited information regarding context into which the studies took place and participants involved. Since limited information was given within this study, those that wish to transfer the findings to other sites are not likely to be able to judge the transferability of the results (Nowell et al., 2017).

Finally as the analysis is of secondary data, participants could not be probed, and the data collected may have less depth. However, rigour was ensured as a second experienced reviewer on qualitative research was involved in the analysis of the data.

Conclusion

The three themes identified from the six studies tell a story of what is important to palliative care patients, relatives, HCPs and authors regarding oral care. Despite similarities between the groups in terms of the oral symptoms experienced and observed and the goal of oral care procedures, this review identified differences among all stakeholders. The main priorities for

relatives and HCPs of delivering oral care seemed to have been cleanliness and comfort. The challenges experienced by the different stakeholders differed, namely in terms of the wider impact of symptoms and challenges to oral care. This confirms the need to investigate these topics further in relation to the different stakeholders and crucially to have consistent guidance for HCPs, relatives and patients in order to facilitate the provision of effective oral care.

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Appendix 1: Search strategy

Palliative oral care 31/08/2017

Embase (Ovid)	1472
Medline (Ovid)	1117
DOSS (EbscoHost)	417
CINAHL (EbscoHost)	723
AMED (EbscoHost)	80
PsycINFO (NHS HDAS)	110
Total before deduplication:	3919

T7	has 1074 to 2017 Amount 20								
	Embase <1974 to 2017 August 30> Date searched: 31/08/17 # Searches 1 terminal care/ 2 palliative therapy/ 3 palliative nursing/ 4 cancer palliative therapy/ 5 hospice care/ 6 hospice patient/ 7 hospice nursing/ 8 terminally ill patient/ 9 nursing home/ 10 nursing home patient/ 11 terminal care/ 12 palliative therapy/ 4 cancer palliative therapy/ 5 hospice are/ 13 (last year adj3 life).ab,kw,ti. 14 (terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti. 15 (cell* virtice il 2 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti. 15 (cell* virtice il 2 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.								
	te searched: 31/08/17	/							
#	Searches	Results							
1	terminal care/	30520							
2	palliative therapy/	69475							
3	palliative nursing/	477							
4	cancer palliative therapy/	20258							
5	hospice care/	8333							
6	hospice patient/	558							
7	hospice nursing/	43							
8	terminally ill patient/	7086							
9	nursing home/	48165							
10	nursing home patient/	4835							
11	nursing home*.ab,kw,ti.	33756							
12	(end* adj3 life).ab,kw,ti.	31578							
13	(last year adj3 life).ab,kw,ti.	766							
14	(terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.	15481							
15	(palliative adj3 (cancer* or care or healthcare)).ab,kw,ti.	38207							
16	(dying adj3 patient*).ab,kw,ti.	7877							
17	(close adj3 death).ab,kw.fi.	684							
18	(hospice* adj3 (care* or healthcare)).ab,kw,ti.	6964							
19	end stage.ab,kw,ti.	82012							
20	terminal stage.ab,kw,ti.	2723							
	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or	202407							
21	18 or 19 or 20	282495							
22	mouth hygiene/	21706							
23	mouthwash/	3342							
	toothpaste/	7064							
25	(mouth adj3 (health* or care or hygiene)).ab,kw,ti.	923							
26	(oral adj3 (health* or care or hygiene)).ab,kw,ti.	35184							
27	(dental adj3 (health* or care or hygiene)).ab,kw,ti.	24046							
28	(tooth adj3 (health* or care or hygiene)).ab,kw,ti.	692							
29	(teeth adj3 (health* or care or hygiene or clean*)).ab,kw,ti.	2367							
30	(mouthwash* or mouthrinse*).ab,kw,ti.	3818							
31	(mouth adj3 (wash* or rins* or swab*)).ab,kw,ti.	1817							
32	(toothpaste* or tooth-paste or dentifrice* or toothbrush*).ab,kw,ti.	9457							

33	((tooth or teeth) adj3 brush*).ab,kw,ti.	3114
34	dry mouth.ab,kw,ti.	6415
35	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34	81720
36	21 and 35	1472

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Date searched: 31/08/17

#	Searches terminal care/ palliative care/ hospice care/ "hospice and palliative care nursing"/ terminally ill/ nursing homes/ (end* adj3 life).ab,kw,ti. (last year adj3 life).ab,kw,ti. (terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.	Results
1	terminal care/	25990
2	palliative care/	49967
3	hospice care/	6244
<i>3</i>	"hospice and palliative care nursing"/	401
5	terminally ill/	6382
	nursing homes/	32385
6	nursing homes/	32383
7	(end* adj3 life).ab,kw,ti.	22617
8	(last year adj3 life).ab,kw,ti.	558
9	(terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.	12046
10	(palliative adj3 (cancer* or care or healthcare)).ab,kw,tio	24502
11	(dying adj3 patient*).ab,kw,ti. (close adj3 death).ab,kw,ti. (hospice* adj3 (care* or healthcare)).ab,kw,ti. nursing home*.ab,kw,ti. end stage.ab,kw,ti.	6292
12	(close adj3 death).ab,kw,ti.	549
13	(hospice* adj3 (care* or healthcare)).ab,kw,ti. nursing home*.ab,kw,ti. end stage.ab,kw,ti. terminal stage.ab,kw,ti.	5131
14	nursing home*.ab,kw,ti.	27626
15		57555
16	orimina sugeme, i. v, i.i.	2143
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	200214
18	oral hygiene/	11954
19	oral health/	13297
20	exp dental care/	30915
21	toothpaste/	3077
22	(mouth adj3 (health* or care or hygiene)).ab,kw,ti.	755
23	(oral adj3 (health* or care or hygiene)).ab,kw,ti.	34586
24	(dental adj3 (health* or care or hygiene)).ab,kw,ti.	23717
25	(tooth adj3 (health* or care or hygiene)).ab,kw,ti.	664
26	(teeth adj3 (health* or care or hygiene or clean*)).ab,kw,ti.	2346
27.	(mouthwash* or mouthrinse*).ab,kw,ti.	3546
28	(mouth adj3 (wash* or rins* or swab*)).ab,kw,ti.	1561
29	(toothpaste* or tooth-paste or dentifrice* or toothbrush*).ab,kw,ti.	9890
30	((tooth or teeth) adj3 brush*).ab,kw,ti.	2991
31	dry mouth.ab,kw,ti.	4372
32	18 or 19 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31	76517
33	17 and 32	1117