

Oral care experiences of palliative care patients, their relatives and healthcare professionals: A qualitative study

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ABSTRACT

Oral symptoms in a growing number of palliative care patients are often neglected. Dental professionals are not always involved in palliative care. Oral care is often inadequately delivered to palliative care patients while oral problems can affect quality of life.

A qualitative study was conducted to explore oral care experiences of palliative care patients, their relatives and healthcare professionals (HCPs). Four patients, four relatives and four HCPs were interviewed in a hospice.

Transcripts were analysed using thematic analysis and revealed three themes. Patients who were capable of *performing oral care* mainly brushed their teeth and looked after their dentures. Other care tended to be carried out by relatives and HCPs; adapted based on a person's level of consciousness. When describing *effects on oral health*, relatives and HCPs tended to focus on xerostomia, whereas patients provided detailed accounts denoting the psychological and social impact of oral symptoms. Perceptions of *enablers and barriers to oral care* differed between groups. Patients reported lack of access to professional dental care and patients' fatigue was the main barrier to oral care.

Nevertheless, there is great scope for further research into good oral care practices identified in this study and possible implementation in other settings.

KEYWORDS: palliative care; oral care; oral health; patients; family; healthcare professionals.

INTRODUCTION

Oral symptoms, such as xerostomia, mucositis and candidiasis are amongst the most common symptoms palliative care patients experience.^{1,2} According to the National Cancer Institute in the USA, 80% of individuals undergoing myeloablative chemotherapy develop oral symptoms.^{3,4} Additionally, oral mucositis and taste alterations are associated with drugs such as analgesics and bisphosphonates.^{3,4} Patients become unable to eat and oral symptoms can precipitate further life-threatening complications such as anorexia, malnutrition, cachexia and aspiration pneumonia.^{5,6}

Nevertheless healthcare professionals (HCPs) such as doctors and nurses seem less concerned with oral problems than other symptoms such as nausea and fatigue.⁵ In addition, the oral health of palliative care patients is a topic rarely explored from the dental perspective.⁷ This is astonishing when one considers how common oral symptoms are amongst palliative care patients and the predicted growth in palliative care need globally.⁸ Moreover, the National Quality Forum's framework and preferred practices for quality palliative and hospice care produced a consensus report in 2006 stating that palliative and hospice care should address the total needs of individuals. This includes symptom management, which requires the services of a coordinated interdisciplinary team.⁹

Despite this, oral complications are inadequately addressed by clinicians and dental professionals are not routinely involved in the care of these individuals.¹⁰ The oral care of palliative care patients is often neglected and inadequate.^{1,11} Some of the explanations given by nurses and frontline healthcare professionals are the lack of resources, lack of time and inadequate staff training.¹ Moreover, research in this field is scarce and oral care procedures are often not evidence-based.^{1,7,12}

In order to address this gap in knowledge, the aim of this study is to explore the experiences of palliative care patients, their relatives, and HCPs, such as nurses and healthcare assistants, regarding the oral care received or provided.

METHODS

Theoretical approach

This is a qualitative interview study designed to understand the oral care experiences of participants. In order to study the 'lived' oral care experiences of participants a phenomenological approach was adopted. Phenomenology is a theoretical position used in qualitative research when the aim is to provide insight into the 'lived' experiences of individuals.¹³ It is presented as an approach ideally placed when the focus of the research are human experiences and their meaning.¹³ It introduces the concept of perspective, in that there is a phenomenon when there is a subject who experiences it.¹³ The purpose of a phenomenological philosophy is the discovery of the essence of the participants' experiences, of the phenomenon being studied.¹³ The essence of a phenomenon can be described as its essential meaning, it is what makes the phenomenon what it is.¹³

Rather than seeking to make claims based on the statistical generalisability of the results, the aim of this primary research study was to generate rich, in-depth, multifaceted accounts concerning the oral care experiences of palliative care patients at a hospice in the South-West of England, the oral care experiences of their relatives and HCPs working at the same hospice. Ultimately, and in line with the phenomenological approach adopted, the aim was to discover the essence of the oral care experiences of the participants of the study and the meaning of these experiences.

Ethical considerations

Ethical approval was obtained from the University of Plymouth Research Ethics Committee (17/18-908).

Participants and recruitment

Participants were chosen due to their 'lived' experience of the phenomenon. Sampling was purposive in order to achieve this very aim. Additionally, the sample size was kept small so the richness of the individual experience could be accessed¹⁴ and the timeframe for the study adhered to.

Twelve participants were recruited and interviewed: four palliative care patients, four relatives and four HCPs at the hospice. This was the target for recruitment, due to expected challenges in recruiting patients and the time restrictions to conduct data collection. Twelve was also the total number of interviews considered adequate by the researchers to achieve the aims of the study. Participants were not excluded based on gender, age, health condition or number of years working at the hospice. Although the intended sample was to include a range of health conditions to ensure diversity of perspectives, all palliative care patients interviewed had a cancer diagnosis; a limitation of the study, due to most in-patients having cancer. Diversity and richness of individual experiences was achieved by interviewing three different groups. Participants included eight females and four males, their age ranged from 42 years old to 90 years old. In addition, year of diagnosis differed as did the number of years carers had worked with palliative care patients (Table 1).

Individuals were recruited with the assistance of staff members at the hospice. Participant information sheets were left in patient, relatives and staff areas. These forms included information about the study, the researcher's contact details, link to the study webpage and a

section that potential participants filled out and left with the receptionist if they wished to take part. The receptionist would then contact the principal investigator who attended the hospice and met potential participants. During this informal meeting the first author would describe the study, answer any questions and if both parties wanted to proceed to an interview then the consent process would take place and finally a consent form would be signed by both parties. An interview would then be arranged, and a private space would be booked. If patients were unable to move from bed some privacy would be created with curtains for example. However, this constituted a compromise and a limitation of the study.

Data collection

The method used to collect data was individual, face-to-face, semi-structured interviews. These were conducted, audio-recorded and transcribed verbatim by the first author, then uploaded into NVivo 12, a qualitative data analysis software programme.¹⁴

A phenomenological approach entails that data is collected free from preconceived ideas.¹³ A flexible, semi-structured format was utilised (Appendix 1), allowing participants the opportunity to discuss topics that mattered to them, which may not have been anticipated by the researcher.¹⁵ The researcher also took field notes on aspects that could provide additional insight into the data. This process enabled reflection on how the interviews were being conducted.

Data analysis

A phenomenological approach was adopted for this project as the researcher wanted to study the 'lived' experiences of participants regarding oral care, discover the essence of the phenomenon (oral care experiences) and understand the meaning of these experiences. The method employed to analyse the data was thematic analysis. Thematic analysis is not bounded

to any pre-existing theoretical framework, and as a consequence can be used within different theoretical frameworks such as phenomenology.¹⁵ Thematic analysis has a long history as a phenomenological method of data analysis particularly when the focus is on patterned meanings across the data-set and not so much on the distinctive characteristics of individual participants.¹⁵ Thematic analysis is a particularly useful method to describe and examine perspectives of different participants, to highlight their differences and similarities and subsequently lead to greater insight into the data.^{15,16} The phenomenological approach was part of the process of how the themes were identified, these were aspects of the lived experiences of participants regarding oral care.

The researcher followed the six stages described by Braun and Clarke¹⁵ to analyse the data:

1. Familiarisation with the data: the researcher transcribed verbatim the twelve interviews and uploaded the transcription files into NVivo 12. This process enabled the researcher to become familiarised with the data corpus and helped with data analysis. The researcher immersed in the data, read and re-read the data corpus in its entirety.

2. Generation of initial codes: the researcher 'listened' to what the data was telling her rather than applying prior categories from the literature or from the researcher's own experience. This was an inductive process in that initial codes, such as 'difficulty in getting to the dentist' and 'a home visit from the dentist would be helpful', were identified in a data driven way.

3. Search for themes: the analysis was re-focused at the broader level of themes. The researcher sorted the long list of initial codes into potential themes. For example, the two initial codes stated above were incorporated into a broader theme: 'access to dental professionals'.

4. Review of themes: potential themes were refined during this stage. Following the example above, 'access to dental professionals' became a sub-theme in the broader theme 'enablers and barriers to oral care'.

5. Define and name themes: during this phase the researcher identified the essence of what each theme was about.

6. Produce a report which is presented in this paper.

A second researcher was involved in the analysis and reviewed, questioned what was done, how it was done and the rationale for the decisions made. This process ensured the rigour of analysis.

FINDINGS

Thematic analysis of the interviews identified three themes regarding the oral care experiences of the participants: 'performing oral care', 'effects on oral health' and 'enablers and barriers to oral care'. In addition, within each theme further sub-themes were identified. Palliative care patients, relatives and HCPs contributed to all themes and most sub-themes.

Performing oral care

Participants described a range of oral care procedures and within this theme the researcher identified procedures done by the patients themselves i.e. 'oral care by self' and procedures done by others, i.e. 'oral care by others' (Table 2).

The four palliative care patients interviewed were still able to do a little for themselves. This may explain the reason why they did not appear to contribute much to the sub-theme 'oral care by others'. Their only contribution was from patient 3, stating that dental professionals, when they were at home, were looking after their teeth. Palliative care patients were able to describe what they were doing in terms of their self-care and this consisted mainly of brushing their teeth.

The relatives not only described how their loved ones looked after their teeth and mouths, but also how they cleaned their dentures. These participants described the oral care procedures with more detail than patients. In addition, relatives considered that ‘oral care by others’ was provided by dental professionals, HCPs and themselves.

HCPs seemed keen to encourage patients to remain independent. If patients were still conscious and able to do a little, they would encourage them to continue to brush their own teeth, albeit with some support, if required. HCPs seemed to adapt the oral care provided according to the patients’ needs and their own routine. The oral care would differ if a patient was conscious and independent or if a patient was unconscious and near the end-of-life. In addition, patients’ preferences were taken into account.

Furthermore, the oral care performed by patients or delivered by others was also to address specific oral symptoms such as xerostomia.

Effects on oral health

This theme is about the oral symptoms experienced by palliative care patients and observed by their relatives and HCPs (Table 3). Dry-mouth or xerostomia was a common complaint by patients. However, participants reported other oral symptoms such as mouth ulcers, thrush, difficulty in communicating, difficulty in swallowing, not being able to taste and also problems with dentures. The medication and their illnesses were exacerbating factors to oral symptoms.

There were simple, everyday measures, such as drinking water and ice chips, that patients tried in order to alleviate oral symptoms. Despite its everyday nature, these measures appeared to be promoted by HCPs and recognised as being helpful by all participants.

Enablers and barriers to oral care

All the sub-themes, ‘attitudes’; ‘training, guidelines and advice’; ‘learning from experiences’; ‘access to dental professionals’, within this theme except for the last one, ‘fatigue’, were viewed as both enablers and barriers (Table 4).

The attitude towards oral care varied amongst the participants. Oral care was being done by the patients interviewed. However, it seemed, particularly with patients 2 and 3, that it was not a priority. The HCPs at the hospice would encourage patients to brush their teeth so they did so. Nevertheless, oral care was often not important for patients. Patient 2 recognised that he did not have long to live.

Patient 3 on one hand appeared to acknowledge the association between good oral health and general health. However, he no longer perceived it to be a priority, due to his age.

Nevertheless, patients 1 and 4 seemed to prioritise oral care and the benefits associated with it, particularly in social interactions and for their own psychological wellbeing.

Relatives and HCPs seemed to share the view that for patients, oral care was often not a priority. All HCPs interviewed valued and prioritised oral care. This was despite some HCPs recognising an improvement in oral health was not always achievable. Some patients were very poorly and at the end of their lives and compliance with oral care was difficult. Nonetheless, for HCPs interviewed, oral care was an important part of holistic care. This was seen as the ethos of palliative care.

One of the relatives interviewed questioned her own society’s attitude towards individuals who are at the end of their lives; stressing the importance for her of a person’s dignity, which does not end when one becomes unwell.

In addition to training and advice on products, HCPs seemed to rely on their own professional experience and shared experience from colleagues. They either had a long history of performing oral care for palliative care patients, or they had been supported by other team members at the hospice.

Fatigue was a very 'loud' sub-theme and it is the only one within this theme that is clearly a barrier and not an enabler. Relatives and HCPs described some patients as being too fatigued to be bothered with oral care, having other priorities to save energy for or just not seeing it as important and worth the effort anymore. The patients interviewed did not contribute to this theme of fatigue. Nevertheless, the interviews were typically short as the interviewer was alert and responsive to the obvious signs of patient fatigue. For example, the interview with patient 2 lasted just over eight minutes and with patient 3 just over six minutes. The average of all 12 interviews conducted was over 16 minutes. In addition, the following extract of the researcher's field notes, following the interview with patient 2, indicates awareness of and sensitivity to the impact of fatigue on data collection: "*I just wanted to leave and stop the interview. I just wanted to leave you in peace and not disturb you any further... you are obviously struggling to talk... you need to rest.*"

DISCUSSION

Following the analysis of the data from the interviews, the researcher identified three themes: 'performing oral care', 'effects on oral health' and 'enablers and barriers to oral care'. The identification and interpretation of these themes contributed to the understanding of the essence of the phenomenon being studied: the participants' experiences of oral care.

Palliative care patients who were capable of *performing oral care* (self-care) mainly brushed their teeth and looked after their dentures. Other care tended to be carried out by relatives and HCPs; and it was often adapted based on a person's level of consciousness. Contrary to what

was reported in other studies,^{3,4} the oral care provided by HCPs was not opportunistic and it was part of their routine at the hospice. Given the setting HCPs were working in, they felt they had the time, resources and adequate in-house training to provide good oral care. This is in contrast with other studies, in which authors stated staff pressures, time pressures and inadequate training as barriers to oral care to palliative care patients.¹ The hospice where the interviews took place has a standard operating procedure for oral assessment of patients and oral care protocols. This is relatively rare as discovered through a survey of oral care practices conducted by the Multinational Association of Supportive Care in Cancer (MASCC) and the International Society for Oral Oncology.¹⁷

When describing the specific *effects on oral health*, relatives and HCPs tended to focus on dry mouth, whereas patients provided detailed accounts including difficulties with swallowing, taste and communication. Their descriptions were often vivid e.g. ‘feels like your mouth is going to collapse’ (effect of steroids an exacerbating factor) which highlights the psychological and social impact of oral symptoms. Indeed, other authors report the social and emotional impact oral problems have on palliative care patients.¹⁸

Thus, was oral care seen as a priority? For patients this varied, with some acutely aware of the knock-on effect for wellbeing and others downplaying the importance in relation to other aspects of illness and the end-of-life process. Relatives and HCPs shared the view that oral care is a priority and an important component of holistic person-centred care. For them the impact of care related to dignity and comfort.

Perceptions of *enablers and barriers to oral care* differed between groups. Although HCPs and relatives relied on valuable past experiences of caring, both groups perceived that education and training were lacking. Patients reported a lack of access to dental care in the hospice setting. One of the biggest barriers to self-care or other oral care was patient fatigue: a

barrier that relatives and HCPs found extremely hard to overcome. Fatigue and pain have been reported as the most prevalent and distressing symptoms for palliative care patients, with a cancer diagnosis, who are receiving end-of-life care.¹⁹ Therefore, it is not surprising that fatigue seemed to be so prevalent amongst patients in the hospice, who themselves had a cancer diagnosis.

Access to dental professionals was another barrier to oral care identified in this study. Palliative care patients and their relatives recognised the importance of accessing professional dental care and the challenges of doing so while staying in the hospice. Despite everyday oral care measures being recognised as effective to address oral symptoms by all groups interviewed, there was also the understanding certain oral complications, such as ill-fitting dentures, required professional care. Therefore, and as defended by some authors^{10,20,21} dental professionals should be involved in the care of these individuals. Indeed this is in line with National Quality Forum's framework and preferred practices for quality palliative and hospice care consensus report.⁹

LIMITATIONS

In order to evaluate the worth of this study, it is important to assess the trustworthiness of its findings.¹⁶ Transferability, credibility, dependability and confirmability are the criteria used to assess trustworthiness of findings. Data on palliative oral care is scarce and one could posit that this is in part since data is difficult to access, and this is a difficult group to identify and reach. Hence, the researcher attempted to overcome this difficulty by interviewing participants in a hospice. Nevertheless, not all palliative care patients need to be cared for in hospices. These individuals, as acknowledged by staff at the hospice, tend to be those with poorly controlled symptoms or receiving end-of-life care. Most palliative care patients are cared for in the community. Despite the researcher providing a description of the setting and

participants, this is a limitation and can impact on the transferability of the findings from the study.

In addition, the researcher did not check her analysis with participants, i.e. member checking. This was to avoid participant burden. Other techniques were employed to ensure credibility of findings. The researcher spent a prolonged period of time in the hospice before interviews took place. A second experienced researcher (S.G.: PhD, Research Fellow) reviewed the data analysis and interpretation, which ensured rigour. This was not to achieve consensus but to view the data from a different perspective and access its essence. Furthermore, the reviewer attempted to attain confirmability of findings by making it clear and transparent that the findings derived from the data and could be trusted.

Nevertheless, one could argue that the participants interviewed were not as diverse as initially anticipated. The researcher aimed to interview patients with cancer and non-cancer diagnoses, however all patients interviewed had a cancer diagnosis. It is recognised that cancer patients have a more predictable trajectory to their illness,^{22,23} making it easier to plan for their needs. This may explain why most in-patients had a cancer diagnosis.

Finally, the patients interviewed were very frail and fatigued. Therefore, three of them had to be interviewed in bed. This created problems with privacy as they shared a room with other patients. It is not possible to assess the impact this had on what was said during the interviews.

CONCLUSION

The findings of this study provide some insight into what the oral care experiences of palliative care patients, relatives and HCPs are in a hospice in the South-West of England. It appears that the care provided to patients was based on the following principles of evidence-based medicine: patients' preferences and values; knowledge, experience and skills; and the best available

evidence. The best available evidence was mainly based on expert opinion. Therefore there is great scope for further research into good oral care practices adopted locally and possible implementation in other settings. In addition and given that fatigue has such a big impact on the acceptability of oral care from palliative care patients, developing interventions to overcome or minimise fatigue in the delivery of oral care is another area to explore.

REFERENCES

1. Kvalheim SF, Strand GV, Husebo BS, Marthinussen MC. End-of-life palliative oral care in Norwegian health institutions. An exploratory study. *Gerodontology*. 2016;1-8.
2. NICE. Palliative care - oral. 2018; <https://cks.nice.org.uk/palliative-care-oral>. Accessed 17/02/2020.
3. Venkatasalu MR, Murang ZR, Husaini HA, Idris DR, Dhaliwal JS. Why oral palliative care takes a backseat? A national focus group study on experiences of palliative doctors, nurses and dentists. *Nursing Open*. 2020;7:1330-1337.
4. Venkatasalu MR, Murang ZR, Ramasamy DT, Dhaliwal JS. Oral health problems among palliative and terminally ill patients: an integrated systematic review. *BMC Oral Health*. 2020; 20:1-11.
5. Nakajima, N. Characteristics of oral problems and effects of oral care in terminally ill patients with cancer. *American Journal of Hospice and Palliative Medicine*. 2017; 34 (4): 430-434.
6. Hakeem F, Bernabe E, Sabbah W. Association between oral health and frailty: a systematic review of longitudinal studies. *Gerodontology*, 2019; 1 (11): 1-11.
7. Fitzgerald R, Gallagher J. Oral health in end-of-life patients: A rapid review. *Special Care in Dentistry*. 2018:1-8.

8. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, Murtagh FEM. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine*. 2017; 15 (102):1-10.
9. NQF. A National Framework and Preferred Practices for Palliative and Hospice Care Quality.2006;
[https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and Preferred Practices for Palliative and Hospice Care Quality.aspx](https://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx). Accessed 18/11/2020.
10. Saini R, PP M, Shete S, Saini S, Mani A. Dental expression and role in palliative treatment. *Indian Journal of Palliative Care*. 2009; 15: 26-29.
11. NHS Scotland. Scottish Palliative Care Guidelines - Mouth Care. 2019;
<https://www.palliativecareguidelines.scot.nhs.uk/media/86653/30-2019-mouthcare.pdf>
Accessed 25/02/2020.
12. Bernardes Delgado M, Burns L, Quinn C, Moles DR, Kay EJ. Oral care of palliative care patients - carers' and relatives' experiences. A qualitative study. *British Dental Journal*. 2018; 224(11):881-886.
13. Dahlerg K. The essence of essences - the search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health and Well-being*. 2006; 1(1):11-19.
14. Jackson K, Bazeley P. *Qualitative data analysis with NVivo*. third edition ed. London: SAGE 2019.
15. Braun V, Clarke V. *Successful qualitative research, a practical guide for beginners*. First Edition ed. London: SAGE; 2013.
16. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*. 2017; 16:1-13.

17. Barker G, Epstein J, Williams K, Gorsky M, Raber-Durlacher J. Current practice and knowledge of oral care for cancer patients: a survey of supportive health care providers. *Support Care Cancer*. 2005(13):32-41.
18. Ezenwa MO, Fischer DJ, Epstein J, Johnson J, Yao Y, Wilkie DJ. Caregivers' perspectives on oral health problems of end-of-life cancer patients. *Support Care Cancer*. 2016; 24:4769-4777.
19. Omran S, Khader Y, McMillan S. Symptom clusters and quality of life in hospice patients with cancer. *Asian Pacific Journal of Cancer Prevention*. 2017; 18(9):2387-2393.
20. Ohno T, Morita T, Tamura F, Hirano H, Watanabe Y, Kikutani T. The need and availability of dental services for terminally ill cancer patients: a nationwide survey in Japan. *Support Care Cancer*. 2016; 24: 19-22.
21. Hoeksema A, Peters LL, Raghoobar GM, Meijer H, Vissink A, Visser A. Oral health status and need for oral care of care-dependent indwelling elderly: from admission to death. *Clin. Oral Invest*. 2017; 21: 2189-2196.
22. Marie Curie. What are palliative care and end of life care? 2016; <https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care> Accessed: 25/02/2020.
23. Marie Curie. What does terminal illness mean? 2019; <https://www.mariecurie.org.uk/who/terminal-illness-definition> Accessed: 25/02/2020.

Table 1: Demographic data

Participants P: patient R: relative H: HCP	Age at the time of interview	Gender	Ethnicity	Diagnosis (patients only)	Year of diagnosis (patients only)	Number of years as a carer (relatives only)	Number of years working with palliative care patients (healthcare professionals only)
P1	50	Female	White British	Cancer	2015	n/a	n/a
P2	74	Male	British	Cancer	2 months before interview (2018)	n/a	n/a
P3	90	Male	British	Cancer	2016	n/a	n/a
P4	70	Male	White British	Cancer	June 2018	n/a	n/a
R1	42	Female	British	n/a	n/a	4 months	n/a
R2	75	Female	British	n/a	n/a	20 years	n/a
R3	62	Male	British	n/a	n/a	n/a	n/a
R4	57	Female	British	n/a	n/a	6 months	n/a
H1	42	Female	White British	n/a	n/a	n/a	10 years
H2	50	Female	British	n/a	n/a	n/a	2 ^{1/2} years
H3	58	Female	White British	n/a	n/a	n/a	31 years
H4	51	Female	British	n/a	n/a	n/a	27 years

Table 2. Theme: Performing Oral Care

Theme	Sub-themes	Palliative care patients	Relatives	Healthcare professionals
	Oral care by self	<p><i>'basically small amounts of toothpaste a couple of times a day and I used to have chewing gum cause when you have sugar chewing gum is meant to help you but I can't stand the taste of chewing gum anymore...'</i> P1</p> <p><i>'Nooo. I was on me own. Sometimes I did me teeth, sometimes I didn't do me teeth.'</i> <i>'The nurses remind me to do me teeth'</i> P2</p>	<p><i>'He has never been that fussy. He cleans them. He cleans them in the morning but he didn't always do it at night. I said you should (laughs)!'</i> R2</p> <p><i>'Well she would have looked after her own teeth at home.'</i> R3</p> <p><i>'toothpaste and cleaning yeah, gargle sometimes with listerine but not often.'</i> R4</p>	<p><i>'To encourage them. Yes if they are able to. Well you wouldn't expect them to get in there with the mouthwash and the swabs. And it's got grooves so we encourage them while they brush their teeth after gently to just stroke their tongue and over a period of normally 4 or 5 days you can see an improvement particularly if the top is coated and some of the medication leaves the tongue black.'</i> H2</p>
Performing oral care	Oral care by others	<p><i>'Hmm and when you were at home. Were you looking after your teeth at home? Yes doctor Xxx at Bovey Tracey was my dentist.'</i> P3</p>	<p><i>'But luckily she has had a dentist that has seen her regularly and maybe kept her on track.'</i> R1</p> <p><i>'Yeah... 10 days, about a week and then she was back in hospital. I think they were cleaning her teeth with toothbrush and toothpaste.'</i> R3</p> <p><i>'Yeah, yes, yeah I think the dry mouth is a bit better, but whether that's because they've been doing the oralieve in the morning...'</i> R4</p> <p><i>'at home I used to do her dentures for her... I did ask mum because she was still with it so she told me and did it exactly as she told me.'</i> R4</p>	<p><i>'If patients have thrush at the top of their roof of their mouths from wearing dentures we tend to clean their dentures put a bit of (inaudible) in the actual denture. Leave the denture to soak overnight in that. You also tend to take the denture out at night.'</i> H1</p> <p><i>'then normally finish with a little bit of oralieve gel on the tongue. And then Vaseline on the lips. If a tongue is very coated then either we use those twizzle sticks that you've got there or the back of the toothbrush whilst they are brushing their teeth. And then gently help them with that.'</i> H2</p>

Table 3. Theme: Effects on oral health

Theme	Sub-themes	Palliative care patients	Relatives	Healthcare professionals
Effects on oral health	Oral symptoms	<p><i>'I am getting dry mouth now even though I am drinking but I think that is again because of the tablets I am on.'</i> P1</p> <p><i>'Only solid stuff. Can't eat anything solid.'</i> P2</p> <p><i>'Yeah very dry.'</i> P4</p>	<p><i>'She couldn't wear them properly. They must have been too loose because they were falling off her mouth when she was trying to eat.'</i> R3</p> <p><i>'So I think the thrush it has affected her taste buds and how she's perceived food.'</i> R4</p>	<p><i>'They might be concerned if the person is known to have some oral candida or if it's very dry or maybe if the patient is not wearing dentures at the moment and is seen without them or so you know that sort of thing and yeah...'</i> H3</p>
	Exacerbating factors	<p><i>'Well before I used to use mouthwash but again it just the thought of having mouthwash hmm I just feel it would dry out my mouth a lot. So I haven't used that.'</i> P1</p>	<p><i>'She's had thrush for a little while, once her immune system started to get low and she's had various treatments for that, which I think to start with she wasn't doing it regularly enough, because she had a lot of medication and to do this 4 times a day on top and she is not a pill taker.'</i> R4</p>	<p><i>'It is not often that a patient will come into us and that their mouth... It might be quite clean but is not often that you get a lovely pink, clean, moist mouth. That doesn't happen very often... lots, lots of reasons a lot of it is drug induced yeah that doesn't happen very often. There is more often than not there is a bit of an issue with their mouths when they come in.'</i> H3</p>
	Everyday relieving factors	<p><i>'When I wake up in the morning my mouth is very dry and I have to have a good drink of water'</i> P3</p>	<p><i>'No no pain, but he just likes to keep it moist, that's it he is always sipping water more than he eats so...'</i> R2</p> <p><i>'I used to give him plenty of fluids, plenty of fluids again would give him plenty of fluids'</i> R2</p>	<p><i>'And we have lovely ice chips making machine which is wonderful... particularly if the tongue is really crusted or the lips are really dry. It just it's just something extra we can do. Is just another way of getting fluid and that's a bit more comfort to try and help'</i> H2</p>

Table 4. Theme: Enablers and barriers to oral care

Themes	Sub-themes	Palliative care patients	Relatives	Healthcare professionals
Enablers and barriers to oral care	Attitudes	<p><i>'Well I have always liked to look after my teeth because I have always had quite straight teeth.'</i> P1</p> <p><i>'Nooo not really. Mouth is mouth teeth are teeth. I don't know'</i> P2</p>	<p><i>'Because that's not a priority for her, she is so ill. Why bother? I think the only thing that would worry her would be having a smelly breath or something.'</i> R1</p> <p><i>'Yeah yeah I think with her it does make a difference. She's always been very well turned out shall we say, her hair, manicure.'</i> R4</p>	<p><i>'...if people are unconscious can clamp on the swabs so then you just wait for them to open their mouth and you would stop doing it and maybe doing it around their teeth rather than across their tongue and then sometimes you might go back and they may be alright with you doing it.'</i> H4</p>
	Training, guidelines and advice		<p><i>'We never had any input from health professionals other than us making appointments. It is only recently that she is in a place like this and had cancer that people started to be involved and someone mentioned teeth care and I think it was one of the Rowcroft staff.'</i> R1</p>	<p><i>'It is it is, there isn't an awful lot. I couldn't find mouth care when I was last looking. There is a lot about xerostomia in patients having chemo, but when it gets to here, no there isn't. There isn't anything new that I'm aware of. I couldn't find anything, it doesn't mean it isn't out there.'</i> H3</p>
	Learning from experiences		<p><i>'Only except when patients used to get thrush, they need medication for that. That's the one thing we used to look after. So you were aware of that? Mainly doing dressings, mainly. Oh that was during your professional life? Yes yeah'</i> R2</p>	<p><i>'Yeah you can normally tell by their faces because they are either raising their eyebrows or shut their mouths. If they don't like anything they will actually shut their mouths. Or hopefully raise their eyebrows to say...'</i> H1</p>
	Access to dental professionals	<p><i>'The bottom ones are alright not too bad hmm I used to have a private dentist so I find it difficult now even to get to the dentist, that's the problem.'</i> P4</p> <p><i>'Not not necessarily going to the dentist cause someone could visit me you know. That would be helpful having a home visit or something yeah'</i> P4</p>	<p><i>'I think she thinks it's ok, that's healthy, she goes to the dentist regularly, in fact very regularly. I think she thinks it's ok.'</i> R1</p> <p><i>'Because she lost so much weight they rattle about so much. She is having trouble speaking. She says "I need to the dentist".'</i> R4</p>	
	Fatigue		<p><i>'Not painful just hasn't the stamina, his stamina has gone and everything.'</i> R2</p>	<p><i>'Sometimes because they are really at the end of their lives, so they find it a struggle. They get fatigued by cleaning their teeth. Sometimes they can't be bothered to do it because they are too tired.'</i> H1</p>

Appendix 1: Interview guide - patients

Thank you for agreeing to talk to me today, before we get to my questions was there anything in particular that you wanted to say?

I would like to start by asking you how are you feeling physically today?

What about your teeth? How do your teeth feel today?

What about your mouth? How does your mouth feel today?

Are you experiencing any of the following: dry mouth, pain, difficulty swallowing, difficulty to eat, difficulty to taste food, problems communicating, concerns about mouth appearance?

Do your mouth/ teeth feel different today to how they felt last week?

How does it feel different?

Do you know why it might feel different?

Thank you for telling me about how your mouth and teeth feel. I would now like to ask you about what is done to look after them.

Who looks after your teeth/ mouth at the hospice?

Who looks after your teeth/ mouth at home?

What do they/you do to look after your teeth/ mouth?

How do you find that?

Are there any examples of things that you found useful or went really well regarding your mouth care since you've been not so well? Or the opposite?

Is there anything that could be done to improve your oral health? The way your mouth and teeth feel?

How important is caring for your mouth for your overall health? Why?

Thank you very much for answering everything I wanted to ask you, is there anything you would like to ask me?

Is there anything you were hoping to say today that you haven't had the chance to say yet?