

RESEARCH ARTICLE

Why oral palliative care takes a backseat? A national focus group study on experiences of palliative doctors, nurses and dentists

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Abstract

Aim: Poor oral care among frail older people at the end of life endangers quality of life. However, only few dying people have access to oral palliative care services. Therefore, this study aimed to investigate oral palliative care practices and referral patterns for palliative patients in the Brunei healthcare settings.

Design: An exploratory qualitative study.

Methods: Five focus groups were conducted among palliative care nurses ($N = 7$), palliative medicine doctors ($N = 4$), dentists ($N = 6$), oncologists ($N = 4$) and oncology nurses ($N = 4$). Verbatim was analysed using qualitative thematic analysis.

Results: Analyses revealed four distinct themes emerging as current oral palliative care assessment and referral practice in the Brunei healthcare settings: "taking a back seat," "opportunistic oral care," "they refused and refused" and "challenging healthcare resources and oral palliative care."

KEYWORDS

healthcare practitioners, oral, palliative, qualitative, terminally ill

1 | BACKGROUND

Palliative patients have been reported to have a high incidence of oral problems associated with their major ailment (Ohno et al., 2016; Saini, Marawar, Shete, Saini, & Mani, 2009). Medical management of palliative conditions such as chemotherapy is likely to produce oral complications among these patients because these drugs target cells with high mitotic rate (Saini et al., 2009). A national cancer institute has reported that 80% of patients receiving myeloablative chemotherapy develop oral complications, and drugs such as bisphosphonates and analgesics are usually responsible for oral mucositis and taste disturbances (Epstein, n.d.).

Evidence shows that 40% of palliative patients suffer from oral conditions for a prolonged period of time and lose their ability to communicate their oral health needs (Chen, Chen, Douglas, Preisser, & Shuman, 2013). These patients are unlikely to complain as they believe that it is an inevitable consequence of cancer treatments (Fischer, Epstein, Yao, & Wilkie, 2014). This may contribute to under-reporting of oral conditions among palliative patients; hence, health professionals may not completely appreciate and treat the problem.

Early diagnosis and systematic treatment of oral conditions among palliative patients could minimize their pain and suffering. Therefore, this qualitative study was designed to explore the perceptions of healthcare professionals regarding the oral problems and their care

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among palliative patients. The research question for this study was: "What are the perceptions of healthcare professionals regarding the care for oral conditions among palliative patients?" It is hoped that the findings from this study can be further used in redesigning oral care approaches to enhance the quality of life for palliative patients.

2 | METHODS

2.1 | Design and setting

An exploratory qualitative study design was applied as we were interested to understand the meaning of process, events, patterns and influences of oral palliative care practices, and to develop casual explanations among diverse healthcare practitioners. We used the 32-item checklist of the consolidated criteria for reporting qualitative studies (COREQ) for reporting of this study. Focus group discussions (FGDs) were used as a method of data collection which was conducted from 1 June 2018–30 October 2018 in three hospital settings providing specialist and general palliative care services.

2.2 | Participants and recruitment

All healthcare practitioners at selected settings received study information sheet and invitation letter through their respective heads of their department. Various healthcare professionals such as doctors and nurses from palliative, oncology, critical care, neurology and dental care services participated through purposive and convenience sampling. Respondents were approached through their heads of departments via email for obtaining mutual date, time and venue for their FGD participation and obtained verbal and written consent. We informed all participants about field specific such as FGDs with palliative nurses and FGDs with critical care doctors and role based FGDs such as FGD with nurses, FGD with doctors and FGD with dentists, to avoid the influence of power relationships and quality of FGD data. These FGDs collected a large variation in the data and helped us to reach theoretical sampling.

2.3 | Data collection instrument

Based on the experience and expertise of the research team (palliative care nurses, palliative care researchers, qualitative researchers and dentists) and based on the literature, a topic guide was developed to explore participants views on areas related to oral care among palliative patients (Table 1).

2.4 | Data collection procedures

The FGDs were conducted at a time and date convenient for participants' schedules and were held at their workplace settings.

TABLE 1 Topic guide to focus group discussions

Please can you share your experiences of providing oral care for palliative care patients?

Clinical practice on assessment and referral of palliative care patients to oral care services

Prompts:

1. What are common oral care problems that normally you encounter while you care for palliative care patients?
2. What are the current oral care practices for palliative care patients?
3. Are there any particular issues in making oral care assessment for palliative care patients? If any please specify?
4. How could/have these been overcome?
5. Are there any particular issues in making oral care referral for palliative care patients to oral care services? If any please specify?
6. How could/have these been overcome?

How does the oral care services work at present for patients under palliative care?

Prompts:

1. Were there any benefits of using oral care services for palliative care patients? (for you, for the patient, for the family carer)? If so, what are they? Can you give a specific example?
2. What are the issues around providing oral care for palliative care patients?
3. How do you feel about initiating oral palliative services for palliative patients? Is it an effective/efficient way of improving care for palliative care patients? If so, why? If not, why?
4. What impact do you think initiation of oral care services in your settings will make? How could it be improved?
5. Would you describe how far, present oral care services meets/match the needs and expectations of palliative care patients?
6. Have you faced any other challenges while delivering oral care for palliative care patients in your clinical settings? If so, what are they? Can you give a specific example? How could/have these been overcome?

Future components of oral palliative care for patients under palliative care?

Prompts:

1. How could the current oral care services be developed further to support palliative patients and their family?
2. How do you think future oral care practices related to patients undergoing palliative care should be designed to facilitate the palliative patient's and carer's choice from the perspective of patients and their families?
3. Are there any areas where improvements could be made?
4. Do you have any educational needs related to Oral Palliative Care Services? How could these be addressed/delivered?

Discussions were conducted in a mixture of English and Malay language to allow participants to comfortably express their ideas. All FGDs were conducted by experienced researchers as moderators (D.R. [PhD], A.H. [PhD], M.R. [PhD], J.S.D. [PhD] and Z.R. [PhD]) and was assisted by a scribe (Z.R.) who took field notes during the session, all who were interested in the research topic. Before the start of FGD, participants were briefed about the research, asked to complete a short form to record demographics and signed the consent form. Moderators also emphasized some ground rules for FGD participation that included maintaining confidentiality after FGD and equal opportunity for everyone to share their

views at the FGD. The participants were also informed that the discussion would be audio-taped for the purpose of data analysis and they were re-assured regarding the anonymity and confidentiality of the outcome from the discussion. Topic guide was used to lead the FGDs. Each FGD lasted approximately 45–60 min. FGD was repeated with new participants until no new information emerged.

2.5 | Data analysis

All recorded discussions were transcribed as verbatim which was counterchecked with field notes for accuracy. Malay words used, if any, were translated into English. Data analysis was done manually by the researchers. The six phases of thematic analysis (Braun & Clarke) were used for identifying, analysing and reporting themes in the data (Roockley, 2014).

Transcribed data were re-read several times individually by all researchers to get familiar with data (step 1) and developed several initial codes (step 2). Using constant comparison, all researchers met and reviewed these codes against each other that allowed for identifying initial themes (step 3). Once all themes were identified, all researchers reviewed and compared their codes and themes (step 4), enabling the development of refined themes (step 5) that followed writing this report (step 6). Audit trial was also conducted through checking themes against codes and codes against the verbatim. The researchers met several times to discuss the direction and quality of data analysis procedures during the analysis to establish the trustworthiness of the study.

2.6 | Ethical considerations

The study protocol was approved both administrative heads of selected hospital settings and also by the Institute of Health Sciences Research and Ethics Committee in Universiti Brunei Darussalam (IHSREC) and the Ministry of Health Research and Ethics Committee (MHREC) in Brunei Darussalam (MHREC/UBD/2018/2(1)).

3 | RESULTS

3.1 | Participants' demographic characteristics

In total, twenty-five ($N = 25$) healthcare professionals participated in five FGDs, of which 60% were females. Five separate FGDs were conducted with palliative nurses ($N = 7$), palliative doctors ($N = 4$), medical oncologists ($N = 4$), hospital dentists ($N = 6$) and oncology nurses ($N = 4$). Approximately, half of the participants (52%) had at least 15 years of experience working in their field and 68.0% of them were working in an acute care tertiary hospital (Table 2).

TABLE 2 Demographic characteristics of participants ($N = 25$)

Variables	N	%
Gender		
Male	10	40.0
Female	15	60.0
Professional qualification		
Nurse	11	44.0
Doctor	8	32.0
Dentist	6	24.0
Level of education		
Diploma	6	24.0
Advanced diploma	4	16.0
Bachelors	4	16.0
Masters	6	24.0
Doctorate	5	20.0
Years of experience		
0–5	3	12.0
5–10	4	16.0
10–15	5	20.0
15 above	13	52.0
Place of work		
Hospital 1	8	32.0
Hospital 2	17	68.0

Our thematic analysis formulated, four common themes that include: “Taking a back seat”; “Opportunistic oral care”; “They refused and refused”; and “Challenging healthcare resources and oral palliative care.”

3.1.1 | Theme 1: “Taking a back seat”

All the participants reported that they were generally aware of the importance of oral health in palliative settings to ensure high quality of care to these terminally ill patients. However, they admitted that oral care for these patients was not being prioritized unless the condition was alerted to them.

Turning a blind eye

Participants reported that their “main focus” was on the major diagnosis such as management of cancer and they tend to not or less prioritize oral care in palliative setting:

Our main focus is our area of interest. Let's say a patient comes to me with a cancer, all my focus is on cancer because I know that other people won't be able to advice, isn't it? Whether diseases are progressing or not, cancer is progressing or not, what are the issues... so I'll be more focused in my area.

(Samad, Focus Group 2 with palliative doctors)

Another doctor reported that lack of awareness about oral palliative care often made them turned a blind eye on oral care issues for palliative patients and they tend to focus only on their own area of expertise:

...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 if it's related to my specialty then I'll be a bit more upfront with looking proactively.

(Sofiana, Focus Group 2 with palliative doctors)

On the other hand, oncologists reported that lack of training about oral palliative care in their specialist courses was also identified as a major reason on why participants did not consider oral care as their priority:

We are not trained dentists to take care of oral thing so... the practice becomes secondary or tertiary to us.

(Faizal, Focus Group 1 with oncologists)

Nurses, on other hand, seem to rely heavily on doctors' orders for oral care by "only reporting to them" rather than taking responsibility:

We just alert, guide and then we will tell doctor, whatever we got, we will tell their oncologist or the medical officer. We just report.

(Jamal, Focus Group 5 with palliative nurses)

Unclear job scope and responsibilities

Participants reported that oral care often takes a back seat at healthcare settings as no one seem to take it as their scope of practice. Conceivably, they relied on other healthcare professionals to be responsible for the oral care.

Hospital palliative nurses who visit palliative patients' wards on referral reported that, although they make oral care assessments, they often rely on ward nurses, but were hesitant to request them to carry out any interventions for oral care issues.

Ana During a ward round, if there are issues with the oral then we check it... but since we are from specialist teams, usually we only ask the nurses in that ward to take action for those issues.

Sara Yes...we only do ward round and we don't stay with the patient.

Saiful ... but we have to be careful with how we say it to them (nurses in the ward) so we don't offend them. I'm afraid if they said that we are making use of them... it's not nice... because we come and go, but do not stay 24 hr in ward so we have to build rapport with the ward nurses.

(palliative nurses in Focus Group 1)

On the other hand, neither palliative doctors nor oncologists in this study accepted that oral care for the palliative patients is in their scope of job and responsibilities:

Well... I am not a dentist... that is a condition beyond my scope, isn't it?

(Sofiana, Focus Group 2 with palliative doctors)

The hospital dentists agreed that it was their role for oral care for all hospitalized patients. However, lack of referrals seems to disable them from providing professional care for palliative patients with oral care issues. They suggested that training nurses for oral palliative care will enable them to perform as their "part of daily routine":

I think the nurses in the palliative ward have to be trained. As part of their routine duty they also have to do look after the oral health of these patients and their care.

(Zaidi, Focus Group 3 with dentists)

3.1.2 | Theme 2: "Opportunistic oral care"

Healthcare professionals reported that oral palliative care was often provided as "opportunistic" rather than as a routine clinical practice for palliative patients.

Lack of clinical alerts

Participants reported that the patients' oral condition was not usually assessed by healthcare professionals unless the patients or the caregivers complained about oral discomfort or there were "noticeable" oral care issues in the patient's mouth. Thus, healthcare professionals seem to wait for "alerts" either from patients or family caregivers for initiating oral palliative care:

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.

(Lee, Focus Group 1 with palliative doctors)

If either the patient or usually the relatives or the carers complain that you know patient has some discomfort...

(Monica, Focus Group 3 with dentists)

Palliative nurses, on the other hand, were able to "pick" oral palliative care issues from their clinical assessment such as clinical signs of dry mouth, white spots or symptoms of lack of appetite:

Saiful Unless if the mouth is dry or when there are whitish spots, then it will be a concern.

Sofea ...usually if he or she complains of not wanting to eat

(Focus Group 1 with palliative care nurse)

Furthermore, oral care for palliative patients was also hindered due to the lack of integration between hospital dental services with

other hospital departments. Participants reported that transferring or making referrals between these services often incur charges for patients that seem to hinder oral palliative care. An oncologist viewed that “in-house” palliative oral hygienists or dentists may solve such issues:

In-house oral hygienists or dentists are crucial. Our unit is a separate entity but sometimes we have to refer our patients to other nearby facility and there will be a cost incurred to the patients that they may not necessarily afford.

(Dean, Focus Group 5 with oncologists)

Hospital dental services operating with an outpatient clinic reported about practical issues in providing oral palliative care for terminally ill and bed-ridden patients in the hospital. They said that oral care procedures which need patients to be transferred to “dental chairs” seem to be non-feasible for severely ill patients. Hence, dentists were only able to make basic assessments and ward based treatments rather than any dental interventions in the dental clinic:

Many of these patients who are terminally-ill are unable to come to the clinic... so we have to go and see them in the ward, they are bed ridden... all we can do is a basic examination, chart the teeth and record the conditions. But when it comes to treatment, only what is urgent and what can be carried out in the ward. So, if the teeth need to be taken out and we have to do it there, it is not going to be a holistic management.

(Zaidi, Focus Group 3 with dentists)

Similarly, oncology nurses also reported how practical issues related to transporting patients impeded to avail oral palliative care from dental services at the national cancer care hospital:

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.

(Jamal, Focus Group 5 with oncology nurses)

3.1.3 | Theme 3: “They refused and refused”

Most participants across the professional groups have reported on patients' views on oral care and it often remains as a challenge for better oral hygiene. The issue of patients being non-compliant and refusing to have oral care treatment were commonly shared across all the FGDs:

The question is patients' compliance. I think this is the main issue that we have... even if you give them a

thousand different types of toothbrush or different types of mouth gargles, they may not follow...

(Dean, Focus Group 4 with oncologists)

Dentists in this study reported that even if family carers were trained for oral care practices, performing oral care could bear significant challenges unless the patient agrees and cooperates:

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.

(Lina, Focus Group 3 with dentists)

Palliative nurses, on the other hand, shared physical resistance, at times fighting and biting by the patients if they enforce oral care practices for uncooperative palliative patients:

...(If) the patient refused...they will become uncooperative... they fight you... may also bite...

(Saiful, Focus Group 1 with palliative nurses)

Oncology nurses reported that patients “deprioritize” the importance of maintaining their oral hygiene as their focus remains on major events and implications that arose from their cancer diagnosis; such as attending chemotherapy, pain management and feeling depressed:

Zimah 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 more towards the cancer... so their oral care is usually left out and not taken care of properly...

Sharifah Their focus changes. From just as simple as oral care hygiene... to chemo, cancer, pain, all those stuff.

(Focus Group 5 with oncology nurses)

3.1.4 | Theme 4: “Challenging healthcare resources and oral palliative care”

Participants reported various challenges and constraints in providing a quality and holistic oral care for palliative patients. Firstly, limited number of dentists at hospital settings seems to challenge their interest to extend oral care services for hospitalized terminally ill palliative patients. They reported that hospital dentists were focused on managing dental emergencies across the hospitalized patients than providing specialist care for terminally ill patients:

In terms of the terminally ill patients, we just look at emergency treatments, what needs to be done, only the

basics and that's it. You don't look at the long term in maintaining, we don't have the manpower.

(Zaidi, Focus Group 3 with dentists)

Dentists, further, provided alternative solution as training nurses in providing oral care could replace and manage patients oral care needs:

Our manpower is probably sort of limited by how much we can provide as well. So part of our plan of trying to manage this patient would probably try and teach the medical nurses to look after the general care of that patient in the ward.

(Rizal, Focus Group 3 with dentists)

Palliative and oncology nurses, on the other hand, expressed the need of having appropriate clinical assessment tool and guidelines for oral care as a need of the hour to implement better oral palliative care:

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...

(Ana, Focus Group 1 with palliative nurses)

(Guideline) specifically for oral assessment, we don't have. We have this MSAS scale... that mentions oral care, but it is just a tick box...

(Jamal, Focus Group 5 with oncology nurses)

4 | DISCUSSION

To the best of our knowledge, this study is the first qualitative study in Brunei Darussalam designed to explore the perceptions of healthcare professionals towards oral care among palliative patients. This study revealed that all participants were aware of the importance of oral care in palliative setting to ensure good quality of life, but did not prioritize them due to their focused interest in treatment and training and the belief that oral health it is not their role. Although research on the perceptions of healthcare professionals of the importance of oral care in palliative setting is limited, a similar qualitative study among nurse managers in Sweden also found that the nurses considered oral health of patients to be important but a neglected part of nursing (Paulsson, Nederfors, & Fridlund, 1999). In contrast, a study on dental care of older people in nursing homes in Geneva found that only 32% of the caregivers (nurses and nurses' aides) found oral examination to be important, which shows an unawareness regarding the importance of oral care for residents in nursing homes (Chung, Mojon, & Budtz-Jørgensen, 2007). The same study also found that that most the caregivers felt inadequately trained on oral care, although they accepted that they are responsible for the oral health care for the residents. A systematic review which aimed to determine whether mouth care was effectively assessed in the palliative care setting also raised

concern about the lack of training and education among nurses in the setting (Gillam & Gillam, 2006).

Patients in end-stage diseases need special care and treatment which necessitates a group of specialists to render it and oral physicians are a definitive inclusion in this team (Mulk, Chintamaneni, Mpv, Gummadapu, & Salvadhi, 2014). However, our study found that oral care is usually an opportunistic care for the healthcare professionals as oral assessment was not part of their routine check-up for palliative patients. Similarly, an exploratory study on the experiences of terminally ill patients reported a lack of oral assessment from the healthcare professionals. It was also reported that they needed to inform the condition to the professionals for a check-up, only to be told that the issue was not serious enough to pursue in its own right as it is "after-effect of medication" or an "age-related condition" (Rohr, Adams, & Young, 2010). A study on oral care in Norwegian health institutions also found that terminally ill patients did not receive adequate oral care (Kvalheim, Strand, Husebø, & Marthinussen, 2016) and a review on oral care of hospitalized older patients in the acute medical setting reported that oral health is often separated from other nursing activities unless oral problems are obvious (Salamone, Yacoub, Mahoney, & Edward, 2013). However, a prospective cohort study among palliative patients in Italy reported that the average time spent by nursing staff to perform standard procedures of their mouth care was approximately 5 min for once or twice a day, which was in line with the Registered Nurses Association of Ontario (RNAO) guidelines on oral health, (daily mouth care should be performed at least twice a day even in patients with poor health conditions, decreased level of consciousness and in those without teeth) (Magnani et al., 2019). Recognizing a gap in oral assessment in the local context, this study has implications for palliative care teams, as effective assessment of the mouth is necessary for the appropriate implementation of care.

Besides that, our study also demonstrated the issue of compliance among palliative patients which has affected their oral health as they focused more on their illness and pain, neglecting their oral care. Similarly, a previous study found that the awareness for oral care was lacking among patients with long-term illnesses due to lack of perceived need (Yoshioka et al., 2016). Soileau and Elster (2018) also reported poor patient cooperation as an impediment in delivering oral care in palliative patients. Another study on the compliance of people with cancer in the self-administration of a pain assessment tool found that the mean compliance was only 58%, with reasons of not completing the form as psychological variables (44%), physical distress (26%) and absence of pain (16%) and lack of understanding of the method (1%) among the patients (Caraceni et al., 2004). In light of this, educating caregivers to comply with oral hygiene regimen is vital (Rozas, Sadowsky, & Jeter, 2017).

Finally, our study has found the barriers faced by healthcare professionals in providing high quality of oral care for palliative patients, mainly the lack of manpower and the absence of clear guidelines for oral assessment of these patients. A study by Soileau & Elster (2018) reported, lack of staff time as a barrier in delivering oral palliative care and inadequacy of healthcare providers as one of the core themes in the structural challenges of providing care to palliative patients (Khoshnazar et al., 2016). In addition, the same study reported

that the nonexistence of clinical guidelines and protocols in primary care is one of the barriers to providing effective palliative care. The use of a validated tool to assess oral condition and a specific protocol to follow in the daily clinical practice might help the healthcare professionals to identify, monitor and adequately treat mouth problems (Magnani et al., 2019). Soileau and Elster (2018) suggested that dentists can effect positive change for oral care of the terminally ill by ensuring that a proper protocol for oral care be developed, implemented and monitored (Soileau & Elster, 2018).

The strengths of our study lie in the qualitative method used, as it allowed the researchers to directly explore the experiences of healthcare professionals in providing oral care to palliative patients. As different healthcare professionals were involved consisting of doctors, nurses and dentists, their perception may vary, producing richer information on the researched topic.

4.1 | Limitations

The findings of this study have limited generalizability as only two healthcare settings were selected. In addition, constraints on openly giving opinion in front of colleagues may have biased participants' responses leading them to limit their truthful expressions.

5 | CONCLUSION AND RECOMMENDATIONS

The findings in this study have shed some light on the oral care of palliative patients by healthcare professionals by obtaining information of their perspective through FGDs. This paves a way for governmental health organizations in providing support for oral care of palliative patients to ensure high quality of care. This study suggests that related organizations or authorities should establish appropriate oral care guidelines specific for palliative patients. To help improve the effectiveness, a wider scope of the healthcare setting should also be considered and improved. For example, oral care can be made as a part of training for all healthcare professionals to counter the issue of manpower. These, coupled with the improved health policies in healthcare settings, might bring about a better result towards the provision of high quality of care for these patients.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

ZR prepared the drafts of this paper, and interpreted and analysed the data. KRV, AH, DRI and JSD commented for improvement in writing. All authors read and approved the final manuscript.

ETHICAL APPROVAL

Ethics approval and permission were obtained from Ministry of Health Research and Ethics Committee (MHREC/UBD/2018/2(1).

CONSENT FOR PUBLICATION

Consent for publication has been obtained from participants through consent form which stated that their personal identity will not be revealed.

DATA AVAILABILITY STATEMENT

The data sets used for the current study are available from the corresponding author on reasonable request.

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