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'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds

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"Death is difficult in any language": A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds

Abstract

Background: Ethnic minority patients have unique challenges in accessing health services. These include language difficulties, unfamiliarity with the health system, lower rates of cancer screening and survival, higher rates of reported side effects from cancer treatment and poorer quality of life. Little is known about this patient group when transitioning to palliative care.

Aim: To elicit the experiences of palliative care health professionals when providing care for patients from culturally and linguistically diverse backgrounds which differ from mainstream Australian language and culture.

Design: An emergent qualitative design, informed by theoretical and procedural direction from grounded theory research.

Setting/participants: Four focus groups held with palliative care staff (n=28) in a single specialist palliative care service in Australia.

Results: The following themes emerged: 1) determining the rules of engagement around discussion of diagnosis and prognosis; 2) navigating the challenge of language to patient understanding; 3) understanding migration experiences to establish trust; 4) maintaining the balance between patient safety and comfort care; 5) providing a good death experience through accommodation of beliefs; and 6) navigating the important role of family members while privileging patient preferences.

Conclusion: Underlying provider perceptions of caring for patients was that death is difficult in any language. Care was conceptualised as considering cultural and linguistic backgrounds within individualistic care. Understanding the migration experience and building trust were key elements of this individualised approach. Acknowledgement of the key role played by families in patient care and safety are strategies to minimise barriers and understand the concerns of this patient group. **Key words** Culturally and Linguistically Diverse; Palliative care; Health professionals; Qualitative

What is already known about the topic?

- Research suggests the need for cultural and linguistic considerations to inform palliative care while acknowledging the importance of avoiding decisions based on generalisations.
- There are a lack of empirical studies exploring the perceptions of multi-disciplinary palliative care teams in caring for patients from CALD backgrounds as a combined population group.

What this paper adds

- This study demonstrates a number of challenges, barriers and facilitators of providing end-of-life care to patients from CALD backgrounds and their families.

Implications for practice, theory or policy

- The global increase in older CALD populations will have significant implications for the planning and delivery of palliative care services. Strategies to minimise barriers and understanding the concerns of this particular patient group is central to providing good end-of-life care and support.

Introduction

The number of migrants living in countries in which they were not born is rapidly increasing worldwide,[1] accompanied by an increase in ageing populations[2] and chronic illness.[3] These trends have led to ageing populations within countries defined by growing cultural heterogeneity and numbers of people who do not speak the dominant language,[4,5] increasing the need for palliative care for Culturally and Linguistically Diverse (CALD) populations.[3] Culturally and linguistically diverse is a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics. In Australia, this term is used broadly and often synonymously with the term 'ethnic communities'. The increase in older CALD populations will have significant implications for the planning and delivery of palliative care services, particularly in Western countries.[6]

Disparities

CALD populations are particularly vulnerable to marginalisation[7,8] and can be less likely to access health services.[4,7] Migrants experience worse cancer outcomes[9] in relation to screening and survival rates,[4] reported side effects,[10] quality-of-life, and depression.[8,11] Patients from CALD backgrounds have been found to receive inadequate palliative care, report communication barriers,[12] and are vulnerable to inadequate assessment and management of pain.[13] Disparities are influenced by language proficiency,[13] familiarity with health systems, culturally determined beliefs and behaviours, and discrimination.[8]

Cultural and linguistic considerations

A number of cultural and linguistic considerations in providing palliative care have been identified. A key consideration explores the tension between Western ethical principles and contrasting principles in collectivist cultures. Respect for patient autonomy is one of the major ethical principles underpinning current palliative care in Western countries.[14-16] This mandates the disclosure of diagnosis and prognosis to patients, obtaining informed consent, and 'truth telling' by providers.[17,18] Collectivist cultures, such as those found in Asia, Latin America, the Middle East and Africa e.g. China, Brazil, Egypt and most African countries except South Africa which tends towards more individualistic characteristics, are argued to eschew the notion of individual autonomy in favour of viewing family members as a 'unit'.[19] Disclosure

of diagnosis and prognosis to patients can be challenged by family members advocating for non-disclosure on the principle that it may be emotionally harmful to patients.[14,20]

Communication is another key consideration.[21] Palliative care providers' report patient's limited proficiency in the dominant language as a significant barrier to communication.[22,23] Patients tend to return to their native language with increasing age.[6]

Research suggests that the encouragement of stoicism in some cultures influences how patients from those cultures express pain.[5,22] Other cultural values that may affect palliative care include the association of opioids with imminent death,[22] taboos around discussion of death, preference for home care and place of death, and use of complementary medicine.[4,12]

Adverse impact of generalisations

Parallel to the literature around the need for cultural and linguistic considerations, is acknowledgment of the importance of avoiding decisions based on generalisations. A sole focus on culture can lead to stereotyping and prejudice,[7] and assumptions about patients may lead to inappropriate outcomes.[10] Research suggests that tension can exist between the individual preference of patients and the preference of family members influenced by cultural values. A study of prognosis preferences in oncology patients from CALD backgrounds and patients from the dominant culture found that while it was rare for family members to support disclosure, many of the patients across all groups preferred disclosure.[10]

Exploring palliative care provision to patients from CALD backgrounds

Despite the global increase in older CALD populations and the implications for palliative care service provision, there are a lack of empirical studies on palliative care for patients from CALD backgrounds. The majority of Western studies focus on specific professions within palliative care such as professional interpreters[24,25] and nurses,[6,26] or individual CALD populations such as Chinese[27] and South Asian populations.[28] To our knowledge there are no empirical studies exploring the perceptions of multi-disciplinary palliative care teams in caring for patients from CALD backgrounds as a combined population group. The lack of empirical research in this area has led to increasing recognition of the need to better understand the influence of cultural and linguistic factors on palliative care.[5,6,16,26,29]

To help address the research gap, this study aimed to explore in-patient and community palliative care team members' perceptions of providing care to patients from CALD backgrounds.

Methods

Design

An emergent qualitative design was employed, informed by theoretical and procedural direction from grounded theory research.[30,31] A qualitative approach was chosen to facilitate exploration of the meanings attributed by providers to complex social phenomena through their own experiences.[32,33]

Setting

This study was set in a metropolitan region of New South Wales, Australia. Providers were recruited from a single specialist palliative care unit with a community palliative care service at a sub-acute hospital. The top five health care interpreter languages accessed at the hospital were Greek, Arabic, Chinese, Italian, and Macedonian.

Research team

EL was an experienced researcher with a background in psycho-oncology, behavioural science and palliative care. NJ was a social worker with additional qualifications in psychology and experience working in multi-disciplinary teams. AG was a university researcher with a background in social science and qualitative research.

Recruitment

A purposive sampling strategy was used to recruit participants. A letter of invitation, together with a participant information and consent form was emailed to medical, allied health or nursing staff who may have cared for patients who were not born in Australia and died in the specialist palliative care unit.

Data collection

Four focus groups were conducted at the hospital between January to March, 2016. To facilitate participation the focus groups were held at different times to cater for different shifts and in a room off the ward and in the community team office to reduce time away from clinical duties. Two groups involved palliative care ward nursing staff, one involved multi-disciplinary members of the community palliative care team, and one involved members of the palliative

care ward allied health team. Data was audio-recorded and transcribed verbatim. Focus groups ranged from 30 – 60 minutes. The focus groups with nurses in the in-patient setting tended to be shorter ~30 mins as staff felt the pull to return to patient care. EL and NJ moderated the focus groups; both were independent and did not hold a managerial or a clinical role with the teams. Data saturation was considered achieved when no new information emerged.

The moderators used a topic guide and open ended questions to prompt in-depth group discussion. Topic areas covered: care/support issues for patients, communication issues, the use of professional interpreters, concerns about food, hydration, and medications, and cultural and spiritual needs.

Data analysis

Data analysis took procedural direction from grounded theory and the constant comparative method.[30,31] Firstly, we undertook open coding of the transcripts in which three of the researchers (EL, AG, NJ) read and identified common and recurring themes. We reviewed and summarised the transcripts breaking them into units. We provided quotes to illustrate themes and to check on coding validity. Further conceptual domains were developed by describing comparisons between themes and within and between transcripts. Recurring data patterns and themes were identified using the constant comparison method.

Ethical considerations

Ethical approval for this study was granted by the Prince of Wales Hospital Human Research & Ethics Committee Ref No. 15/329 (NR15/POWH/603). All participants provided written consent to participate. It was made clear that participation was voluntary and that they could withdraw from the study at any time without affecting any relationships they might have with the researchers or the hospital. Data was de-identified to ensure confidentiality.

Results

Four focus groups were conducted with 28 multi-disciplinary in-patient and community palliative providers. The sample included doctors, nurses, social workers, pastoral care workers, occupational therapists and physiotherapists.

The overarching theme underlying provider experience of caring for patients from CALD backgrounds was that death is difficult in any language. Six key sub-themes emerged: 1) determining the rules of engagement around discussion of diagnosis and prognosis; 2)

navigating the challenge of language to patient understanding; 3) understanding migration experiences to establish trust; 4) maintaining the balance between patient safety and comfort care; 5) providing a good experience going into death through accommodation of beliefs; and 6) navigating the important role of family members while privileging patient preferences.

Death is difficult in any language

The overarching theme was that death was difficult in any language, reflecting a perception that while cultural and linguistic considerations were important, concerns related to approaching the end-of-life were universal. The approach to patient care was largely described as focused on the needs of individual patients, "*the care that I give is no different than any other patient",* irrespective of their cultural and linguistic backgrounds.

Within this approach to care, consideration of specific cultural needs was incorporated into the care of patients as individuals. *"I just meet them as a person, I talk to them to understand what they're thinking and feeling about their illness and learn their attitudes…I do recognise that some of what they're saying or their attitudes might have been because of their cultural background but I just don't go in with that initial framework oh you're from* [country] *therefore this is the sort of person you'll be". (Female, Allied Health In-patient Focus Group)* Thus the importance of not allowing care to be guided by cultural generalisations was highlighted.

Encompassing this approach to care was an understanding that palliative care involved consideration of broader social and cultural factors than those traditionally addressed in the bio-medical model of care. *"Their* [patient and family members] *focus isn't always on optimal care which is what our focus is, optimal care and safety, we've just got to recognise that there's other factors that are guiding the care". (Female, Allied Health In-patient Focus Group)*

Determining the rules of engagement around discussion of diagnosis and prognosis

Negotiating rules around engaging patients from CALD backgrounds and family members in discussions about diagnosis and prognosis was a prominent communication issue. "*That's one of the barriers almost we have when we introduce our service on the phone is that you know my mother doesn't know this and I don't want you to talk about the disease and it's interesting because that's the last thing that we do is go in and sort of have this full-on discussion about the disease, it's really getting to know them first and establishing a relationship". (Female, Community Multi-disciplinary Focus Group)* Tension was therefore

perceived over professional concern around patients' understanding of their conditions where family members' preference was for non-disclosure.

It was suggested that for providers working in the community setting, negotiating rules of engagement engendered specific dynamics related to providing palliative care especially in people's homes. *"The carers are there and if they've chosen to protect that person then we don't have a right to come in and just bypass all that ...when you walk into a household you're dealing with the family and the patient...we need to respect it whether we agree with it or not because without the family and the carers that person wouldn't be at home, so there's always a bigger picture"*. *(Female, Allied Health Focus Group)*

Other challenges to respecting family preferences around non-disclosure included ensuring successful transfer of information between nursing shifts and communicating with overseas family members about a patient's trajectory: *"I think there's an aspect of timing that's so difficult when people are overseas too like when to come...especially if they can't openly talk about prognosis but you're not sure that, they've communicated to someone if they don't come soon they may not get there or it's difficult when it can't be openly talked about"*. *(Female, Community Focus Group)*Although navigating family preference for non-disclosure could be challenging, providers demonstrated significant sensitivity in employing strategies to address these challenges. Providers observed that this preference was largely motivated by *"love"* and a wish to protect patients from emotional distress. They described actively re-adjusting their communication strategies. *"The term supportive care, I find that's actually really useful to make inroads with family, because often it's about selling a service, so it's almost like a marketing tool, I mean rather than talking about palliative care you talk about supportive care, and it actually works quite well"*. *(Male, Community Focus Group)* Thus certain terms were used, such as referring to 'disease' rather than 'cancer' or employing the term 'supportive' rather than 'palliative' care in describing their role.

Navigating the challenge of language to patient understanding

A key aspect of care for patients from CALD backgrounds concerned efforts to ensure their full understanding of factors related to their day-to-day care in light of varying levels of English language proficiency. *"I think that the language problem is an issue there because...you can miss out on snatches of conversations and things that can end up building up to this whole pool of knowledge about why we're managing the patient as we are...I think can be easier when there's been all those little conversations easily understood"*. *Female, Community Focus*

Group). It was perceived that basic proficiency didn't always equate to understanding. Conveying full understanding went beyond a basic understanding of English, to patients' having an underlying level of comprehension to gather and interpret information from daily interactions with providers.

Feeling that their needs were understood was perceived to translate into positive care experiences for patients. Trust was established through providers taking the time to attempt communication and enlisting staff members who spoke the same language to enhance understanding. *"Even if in the middle of the night when we've found* [staff member] *from a same speaking background to come up and understand the basic things, their face lights up, that thank goodness I can be heard, I'm understood and I can have some sort of comfort from that". (Nurse, In-Patient Focus Group)*

Day-to-day care for patients with limited language proficiency was largely mediated through family members. *"In palliative care we don't use the interpreter's service a lot and it's not because we don't respect what they can do and the value of that but you can't get an interpreter often within two days and so we do use the family members a lot more". Female Allied Health Focus Group)* Professional interpreters were mainly accessed for formal communication issues (e.g. consent, medical issues), and for some providers, rarely accessed at all. The length of time to book a professional interpreter was considered as impractical in the context of providing care. In these cases utilising family members to interpret was perceived as the most pragmatic option.

Accessing professional interpreters was particularly challenging when family members preferred to be used for interpretation. Providers perceived that for some families, an issue with the use of professional interpreters was connected to concerns around confidentiality if they were members of their communities. The use of family members as ad hoc interpreters raised ethical concerns for providers around the extent to which the full message was conveyed to patients. *"You don't know if the information is being guarded or people are trying to protect each other, and they may have good intentions but you don't know that your message is getting through 100 per cent". (Nurse, In-patient Focus Group).* In cases where family members wished to protect the patient from information, uncertainty arose around the accuracy of information transfer between a provider and the patient.

Understanding migration experiences to establish trust

Trust was a key part of delivering effective palliative care. Building trusting relationships with patients from CALD backgrounds and family members was associated with the need to have an understanding of unique experiences related to migration. *"Trust is extraordinarily important even beyond the lack of English language, that trusting relationship is really the most important".*

Respecting cultural differences was an important component in building trust as this example illustrates: *"A family not long ago, I was on night shift and the wife would stay overnight but once she took off her head gear she didn't want me to enter the room, you have to accept that". (Nurse, In-Patient Focus Group)*

Consideration of how potential traumas related to patients' experiences of migration may influence care was particularly important to building trust. Potential traumas included experiences of war, torture, and mistrust of mainstream systems from living under repressive regimes. *"I remember nursing an old man who wouldn't let me into the house…because where he'd come from* [country] *when he was a young man you didn't let people know where you lived because the police would come and terrorise the family for whatever your political beliefs were…so he brought all those suspicions with him".(Female, Community Focus Group)*

Routine clinical encounters such as family meetings could present a challenge due to previous experiences prior to migration: *"A lot of people that have been through a lot of interviews throughout the wars and after the war and then to this country, they've been through so many interviews and when you say okay let's go to the room for an interview, they're frightened because they've been through many hard times with interviews…I learnt that from their behaviour, from their attitude".(Male, Allied Health in-patient Focus Group)*

Understanding the impact of trauma was perceived as important for patients at the end-of-life due to it being a vulnerable stage where recollection of traumas could re-emerge. *"People don't want to talk about their history, so rather than go back through something painful we say ah we need to move forward not backward because that's too painful for the person to cope" (Male, In-patient Focus Group)* Experiences of discrimination in their native and adopted countries, particularly related to religious orientation, were also important to consider. Providers linked experiences of discrimination to instances where they perceived patients felt that they had to identify with a certain denomination to receive care. These participants explained: *"P1: (Nurse, In-patient Focus group) I often wonder how much being a Catholic hospital stops people of Islamic religion…P2: (Nurse, In-patient Focus Group) We have had*

a couple of Muslim families who felt that they should write down that they're Christian on their religion which is very sad that they feel like they've got to write Christian…P1: Their perception was because it was [palliative care service] *that the care would be different if they weren't Catholic".*

Maintaining the balance: patient safety and comfort care

Maintaining the balance between risks to patient safety and addressing family concerns around pain management and feeding was identified as a key factor in care provision. A prominent concern related to the administration of medication for pain relief, particularly around addiction and dosage. *"I looked after one patient, he was from a non-English speaking background and the family were like try not to let the staff give pain medication. And I find it's very unfair for the patient because the patient's in pain"(Nurse, In-patient Focus Group).* Providers perceived that underlying this concern was an association between administering medications for pain relief with patients approaching the end-of-life as *"Morphine equals death".*

Food was observed to be an important element of care with family members often providing home cooked meals for patients as *"food equals love".* The importance of food was linked to navigating family concern that patients would die if they did not eat. *"And that's the big issue with a lot of people that they're terrified, if this person doesn't eat they're going to die, therefore we have to feed them no matter what you say and it becomes a problem" (Female, Community Focus Group).* This emotional distress for families led to providers weighing up whether the risks to patient safety from allowing family members to feed patients were worth reducing the distress of family members. *"It's a balance between the risk of them aspirating and ending up with pneumonia or comfort feeds as they are at the end of life anyway….of what's medically advisable verses what we would do for their comfort to let them have their quality of life that they want knowing that there may be risks associated with that" (Nurse, In-patient Focus Group).* Determining whether to allow 'comfort care' in relation to feeding at the end-of-life was a key consideration for providers.

Providing a good death experience through accommodation of beliefs

Providing care at the end-of-life was approached by providers with awareness that accommodating different cultural and spiritual beliefs was an important part of giving patients a good experience going into death. Lack of awareness of cultural norms around dealing with

death could be challenging for providers, but attempting to accommodate beliefs was ultimately rewarding. *"There's a lot of challenges but I have to say it's lovely to think that you can give people from a different background a good experience going into a death…and to feel like you've negotiated those challenges and that they're feeling more comfortable, that's a very satisfying feeling"* (Female, Community Focus Group).

Understanding emotional cues and cultural sensitivities was not always easy for staff. So rather than viewing patient beliefs as barriers to care, providers attempted to accommodate different beliefs as much as possible. *"I find one of the big challenges is probably by lack of understanding of some of their cultures in the sense of- is it acceptable to cry, is it acceptable for them to talk about how they feel…with Australians I pick up the cues a lot better…while we're using the same words, the culture's very different and the values are very different and the expectations are very different, so just trying to not step on toes and support them at the same time".(Female, Community Focus Group)*

Accommodating cultural and religious rituals around death, such as following protocols around touching bodies, and facing bodies in specific directions were acknowledged and stories related: *"We had a* [cultural group] *family once who wanted us all to have our photos taken with them.* [Provider] *and I had to dress him and then have our photos taken with this man, then we had to take photos of the wife and the daughter with the dead gentleman, and that was all sent overseas".(Nurse, In-patient Focus Group)*

Aspects of care such as the use of equipment and preferences needed to be considered in some instances: *"The biggest challenge I had was a* [country] *family who needed a lot of equipment* [at home] *in the end but they would only buy new equipment…and it was to do with a superstition that if you had used equipment that someone else had passed away on that their spirit would enter the house". (Female, Allied Health In-patient Focus Group)*Accommodating cultural and spiritual beliefs at the end-of-life was described as a process of walking alongside the patient, *"through asking"* as well as *"talking with the families"*. This helped to provide spiritual and emotional care tailored to individual cases. Collaborating with pastoral care colleagues also assisted providers as they were perceived to have in-depth knowledge on how to accommodate cultural and spiritual beliefs. *"I see the pastoral care doing this very good because they* [go deeper] *into the different cultural ways. They asked whatever they needed for spiritual support".(Nurse, In-patient Focus Group)*

Navigating the important role of family while privileging patient preferences

Support from family members to assist with communication and provide companionship was identified as an integral aspect of care. Although support from family members was important, their role in care was observed to sometimes conflict with patient preferences. *"But then families are also the hardest part because they come in with all their love at all hours of the day and night, and it can unsettle them a little bit…it seems like they become unsettled when the family come". (Nurse, In-patient 'Focus Group)*

Providers noted the external influence of *"community expectations"*, *"duty"* and a *"sense of obligation"* on the role of family members in care provision. In relating one story, they highlighted the community expectations that certain family members would take on the role of primary carer were particularly relevant for patients from CALD backgrounds. *"P1 (Female, Community Focus Group): In the sense of I'm the daughter, I've got to care for her and if I don't want to…there's no option because everybody in the community will know you were a bad daughter. P2: (Female, Community Focus Group) Especially if they had a church affiliation where there's a tight-knit cultural community within a religious community sometimes, and all the friends and people dropping over and everybody knows and there's cultural and social and religious and family expectations all rolled into one at times".*

For providers, the interplay between meeting the needs and preferences of patients as individuals, navigating the role of family members in decision making and care, and acknowledging the influence of wider community expectations emphasised some of the complexity of providing palliative care for patients from CALD backgrounds.

Discussion

This study adds to the emerging empirical literature on palliative care provision to patients from CALD backgrounds in Western contexts. Care was conceptualised as considering needs related to their cultural and linguistic backgrounds within care of the patients as individuals. The findings support the use of the social-ecological framework[7] in exploring palliative care for patients from CALD backgrounds and the development of responsive models of care.

Death being difficult in any language was a prominent perception underlying care. Broom et al.[12] suggest that there are more similarities than differences across cultural groups in relation to experiences of palliative care. Fear of death and associated taboos around dying have been identified elsewhere as universal concerns.[14] Acknowledgement of shared universal concerns, within the context of developing sensitivity towards difference, is an important approach to

promote empathetic understanding between patients and providers from different cultures.[12,18,34]

A significant component of caring for patients from CALD backgrounds was navigating the important role of family members while privileging patient preferences. Family members are often the most important emotional and spiritual support resource for palliative care patients.[19,34] Consideration of the preferences of both family members and patients can be difficult for providers when they perceive these preferences conflict. There is a lack of training for providers around how to deal with 'moral distress' related to conflict between Western models of care and competing values from CALD populations.[18] Addressing these ethical dilemmas is important in ensuring the delivery of quality care.[21]

Ensuring that patients with limited English language proficiency understood factors related to their care was a prominent challenge, especially when the process was mediated through family members. High use of family members as ad hoc interpreters by patients from CALD backgrounds has been reported elsewhere.[9,13] Similar to our findings, palliative care providers in the United Kingdom have expressed concerns around the use of family members related to the accuracy of translation.[28] Engaging family members as part of the patient-provider therapeutic relationship is important to increasing the acceptability of end-of-life care for patients from CALD backgrounds.[16,22]

Maintaining the balance between patient safety and addressing family concerns around symptom management related to pain and feeding was a key aspect of care. A recent systematic review of Chinese cancer patient's perceptions of pain identified barriers to sub-optimal use of analgesics.[36] Similar to our study, barriers about fear of addiction and concerns on analgesic side effects were identified.[36]

Previous studies have identified the challenges caregivers of Chinese palliative care patients face with unfamiliar hospital food.[37,38] Palliative care providers have been urged to "look beyond the surface to recognise the deeper social, psychological, and emotional aspects that accompany the decision to continue feeding at the end of life." [39]

These concerns around opioid pain management and reduced food intake were perceived to be motivated by fear of approaching death. Addressing death related anxiety as a key part of service provision is reported elsewhere.[6] Research suggests that lack of formal training in providing culturally competent end-of-life care can lead to providers feeling unprepared to navigate these issues.[26]

Providers actively engaged in attempts to accommodate cultural and religious beliefs in providing a good experience going into death. Raising provider awareness of how to accommodate beliefs should involve the tailoring of education and information in collaboration with CALD communities.[35] Community out-reach programs targeted to community locations commonly accessed by cultural groups would be an important engagement strategy.[22]

It is noted that this study was conducted in a single Specialist Palliative Care Service and could only be generalised to the language groups in that area. There would be value in repeating the study in an area which has a different cultural mix as additional perspectives would further inform this topic, particularly the experiences of patients from CALD backgrounds, their family members, and wider communities. Future research in this area would assist with creating a nuanced understanding of palliative care provision to patients from CALD backgrounds.

Implications for practice

Strategies to minimise barriers and understanding the concerns of patients from CALD backgrounds are central to providing good end-of-life care. Recommendations for practice include:

- Provider education on how to access and work with professional interpreters.
- Establishing trusting relationships with patients and families to navigate concerns related to disclosure of diagnosis and prognosis.
- Cultural assessment of the patient and family on admission to assist in developing a patient-centred approach to care informed by cultural and linguistic considerations.
- Culturally appropriate terminology should be determined on an individual basis.

- Family members should be made to feel comfortable with administration of medication and ensure their understanding of the rationale.
- Communicate the risk of inappropriate feeding of patients to family members in a culturally appropriate way.
- Health professionals to consider and address the psychosocial impact of food and nutrition on both patients and carers at the end of life and consider the comfort culturally specific and familiar food can bring.
- As comprehensive pain assessment and appropriate pharmacological and non-pharmacological interventions are required to manage pain, sensitive conversations involving the patient, the family and an interpreter to allay fears and concerns are needed.
- Supporting family members to manage community expectations, such as developing strategies to support families with managing large numbers of visitors.

Conclusion

The increasing need for palliative care for CALD populations has significant implications for the planning and delivery of palliative care services. A range of cultural and linguistic considerations have been identified by palliative care providers in relation to providing care to patients from CALD backgrounds. Strategies to address these considerations while maintaining a focus on the needs of individual patients is central to providing quality end-of-life care.

Authorship

AG contributed to analysis, and manuscript drafting and revision. NJ contributed to conceptualising this study, data collection and analysis, and revising this manuscript. MG contributed to conceptualising this study and revising this manuscript. EL contributed to conceptualising this study, data collection and analysis, and manuscript drafting and revision.

Declaration of conflicts of interest

The Authors declare that there is no conflict of interest.

Research ethics and patient consent

Ethical approval for this study was granted by the Prince of Wales Hospital Human Research & Ethics Committee Ref No. 15/329 (NR15/POWH/603). Participants provided written informed consent documenting willingness to participate in focus groups and to have said focus groups audio recorded.

Data management and sharing

Raw data are contained within this manuscript in the form of focus group excerpts. The corresponding author is available to contact for further information.

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