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## Culturally and linguistically diverse palliative care patients' journeys at the end-of-life

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## **Culturally and Linguistically Diverse palliative care patients' journeys at the end-of-life**

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## **Culturally and Linguistically Diverse palliative care patients' journeys at the end-of-life**

### **ABSTRACT**

**Objective:** To understand the clinical and psycho-social journey of Culturally and Linguistically Diverse (CALD) palliative care patients.

**Methods:** This study was conducted at a sub-acute hospital with a specialist palliative care unit and a community palliative care service in a metropolitan region of New South Wales, Australia. Medical records of 100 deceased patients from CALD backgrounds over a 12 month period from 2014-15 were recorded on a Data Mining Tool. The cohort had transitioned to either community or in-patient palliative care services with a life limiting illness. We used descriptive statistical analyses to identify the patients' end-of-life journeys in the physical, psychological and social palliative care domains. Staff case notes were used to enrich the quantitative data.

**Results:** The most common symptoms burdening the patients were decreased mobility (82%), pain (77%) and poor appetite (61%). The majority of patients (87%) were diagnosed with cancer.

Language was a major barrier to the assessment and management of symptoms. The vast majority of patients were born in Europe and Asia. Twenty per cent of the patients preferred to use English. However, among patients who required an interpreter on admission, only 9% utilized professional interpreters.

Family distress around patients' lack of food consumption was prominent, along with provider concern when this led to families 'force feeding' patients. Only 5% of files documented patients', and 21% of files documented families', cultural wishes or needs. Care of the body after death was only documented in 20% of files.

**Significance of Results:** The increasing cohort of older people from CALD backgrounds will have significant implications for the planning and delivery of palliative care services. There is an emerging need to address the physical, spiritual, social and psychological palliative care domains in the end-of-life journeys of patients from CALD backgrounds to ensure the provision of quality care.

**KEY WORDS:** Culturally and Linguistically Diverse; CALD; palliative care

## INTRODUCTION

Due to global migration and ageing populations, older patient populations are increasingly defined by cultural heterogeneity and people whose native language differs to the dominant language of their host country (Butow PN, Sze M et al. 2011, Hanssen I and Pedersen G 2013). In Australia, the population of older Culturally and Linguistically Diverse (CALD) immigrants is expected to increase by 66%, compared to a 23% increase for those born in Australia (Johnstone MJ, Hutchinson AM et al. 2016, Johnstone MJ, Hutchinson AM et al. 2016). This trend will lead to an increased need of palliative care for CALD populations and have significant implications for the planning and delivery of palliative care services (Lau R and O'Connor M 2012, Johnstone MJ, Hutchinson AM et al. 2016).

Communication is a key issue in providing palliative care to patients from CALD backgrounds, especially for those with limited English proficiency (Chiu TY, Hu WY et al. 2009). Approximately a third of older immigrants in Australia are reported as having low levels of English proficiency (Johnstone MJ, Hutchinson AM et al. 2016). Cancer patients with limited English proficiency accessing palliative care are vulnerable to inadequate assessment and management of pain, and unnecessary emotional and spiritual suffering at the end-of-life (Butow P, Bell M et al. 2011). Limited English proficiency is also identified by palliative care providers as a barrier to communication (Shaw J, Zou X et al. 2015, Martin EM and Barkley Jr. TW 2016). Thus, improved communication between palliative care providers and patients from CALD backgrounds is essential to the provision of quality care (Chiu TY, Hu WY et al. 2000, Mitchison D, Butow P et al. 2012, Silva MD, Genoff M et al. 2016).

The importance of understanding the influence of cultural and linguistic considerations on palliative care is reflected in growing recognition of the need for further research (Ngo-Metzger Q, Massagli MP et al. 2003, Johnstone MJ and Kanitsaki O 2009, Hanssen I and Pedersen G

2013, Johnstone MJ, Hutchinson AM et al. 2016, Johnstone MJ, Hutchinson AM et al. 2016). Improved understanding is essential to removing barriers to accessing palliative care for patients from CALD backgrounds (Butow P, Bell M et al. 2011, Lau R and O'Connor M 2012). There has been significant development of specialist palliative care services within New South Wales (NSW), Australia. However, there is little information available at the patient level that describes how palliative care services impact on the type and quality of care provided. There is even less data on the preferences for place of care for patients from CALD backgrounds when entering the last days of life. The aim of this study was to understand the clinical and psycho-social journey of patients from CALD backgrounds who had transitioned from acute care facilities to either community or in-patient palliative care services. There are 8 domains of palliative care: physical, disease management, practical, psychological, social, spiritual, end-of-life care, loss and bereavement (Department of Health Western Australia 2008). This study explored the physical, psychological and social domains in the patients' journey, to identify what was occurring and opportunities for improvement.

## **METHODS**

Using an audit methodology we undertook a retrospective audit of the medical records of 100 consecutive deceased patients from CALD backgrounds over a 12 month period in 2014-15. The study cohort group had transitioned to either community or in-patient palliative care services with a life limiting illness. Patients from CALD backgrounds are defined as people born in a country other than Australia where the official language is not English.

This study was conducted at a sub-acute hospital with a specialist palliative care unit and a community palliative care service in a metropolitan region of NSW, Australia. The hospital is the main referral point for patients with a life-limiting illness in the region. The top five health

care interpreter languages accessed at the hospital were Greek, Arabic, Chinese, Italian, and Macedonian.

The data were collected by a researcher (NJ) at the Medical Records Department for the identification of relevant records. Eligible cases were identified from manually reviewing records on the top five health care interpreter languages accessed at the hospital and professional interpreter use. All medical record audit data were recorded on a Data Mining Tool to record the patients' end-of-life journeys (see Table 1 for data domains).

A short narrative of the patient journey at the end of each audit was also included. Qualitative data were collected from fragments of staff's case notes which NJ identified as relevant to different aspects of patient care. The majority of case note records were made by nursing and pastoral care staff (84% for communications with patients and 91% for communications with family). The forms were de-identified. No patients were involved. No medical records were removed and all chart audits were undertaken in the department. A second coder (EL) audited 10% of the data to assess the quality of data extraction.

### *Analysis*

An SPSS database was set up and all data resulting from the chart audits were entered. Descriptive statistical analyses were performed. Qualitative data relevant to different aspects of patient care from case notes were summarised. Data of the last seven days of patients' lives were analysed. The analyses focused on 7 days before the death of the patient (Day 7) and the day before the death occurred (Day 1).

## **RESULTS**

### *Characteristics of patient sample*

The mean age of patients was 75 years. Over half (54%) of patients were male. The majority (58%) had a partner. The patients were most frequently born in China (20%) (Graph 1). Although all of the patients were born in non-English speaking countries, 20% had English recorded as their preferred language (Graph 2). The majority (67%) of patients had affiliation with a Christian religion (42% Catholic, 16% Greek Orthodox and 9% Macedonian Orthodox) and 17% of patients indicated “no religion”. The vast majority (87%) of patients’ principal diagnosis was cancer with lung cancer (23%) the most common (Graph 3). More women than men were recorded as primary carers for their family member (29% were daughters, 25% wives, 16% sons and 15% husbands).

The median length of stay at the hospital on last admission was 7 days. More than half of the patients (53%) were recorded as admitted from a tertiary hospital in the region. Symptoms management was recorded as the reason for admission for 56% of the patients, 33% were admitted specifically for end-of-life care and 17% for respite. The most common symptoms burdening the admitted patients were decreased mobility (82%), pain (77%), poor appetite (61%) and weight loss (54%) (Graph 4).

On admission, 55% of patients were identified as requiring an interpreter, mostly by patients who were born in China, Greece, Macedonia and Italy. Professional interpreter services were utilized for only 9% of patients. Thirty seven percent of patients used their family members as ad hoc interpreters. For 11% of patients, bilingual hospital staff were used as ad hoc interpreters.

### ***Physical domain***

Typically, the first notations about patients’ CALD status were taken by nursing staff on admission. Limitations to communication with patients were noted in over a third (39%) of medical charts. Some patients (27%) were described as “non-verbal” or “unable to verbalize”,

of which only 5% were due to their medical conditions. For the remaining patients, the difficulties were attributed to the patients'/families' lack of English proficiency. A number of problems arose with patient communication due to language barriers. Some nurses reported struggling to properly admit patients and raised concerns about the quality of care being compromised, especially where levels of pain couldn't be properly assessed and addressed or safety education couldn't be delivered.

*“Patient is alert and of CALD background so unable to determine if orientated.” (Nurse)*

Some pastoral care workers reported not being able to assess patients or inform them about their rights and responsibilities. When that happened, the workers often chose to visit the patient at another time. Family members were either utilized as ad hoc interpreters, or the practitioners conducted the assessment directly with them, bypassing the patient.

*“Visited patient (...). Patient does not speak English. Hope to see family when they visit to do assessment.” (Pastoral care)*

The majority (61%) of patients received documented physiotherapy support, while 20% received nutritional support and 10% interacted with an occupational therapist. Speech Pathology support was received by 13% of patients.

Various issues around provision of food and hydration were significant. Some patients (ten entries) seemed to only tolerate home-made food. Food and dietary requirements were documented as discussed with 39% of families. Medical records reported some family members were upset at patient losing their appetite or ability to eat, which could be attributed to values associating ingestion of food with rehabilitation and well-being.

Six entries stated that families were attempting to force-feed patients. Nursing and pastoral care notes demonstrated consistency in trying to educate the families about the risks of force-feeding and the physiology of the end-of-life phase (losing appetite). The case notes also demonstrated that despite these repeated attempts, some families continued to feed patients.

*“Explained to family that we should not force patient to eat if she does not want to. Husband was feeding patient rice, but patient was pooling food in her mouth. Patient’s family were advised not to feed patient anymore food this evening. Family come, try hard to feed, patient not eating much.” (Nurse)*

Several families raised concerns about the medical staff ceasing the delivery of food or fluids to patients, who were either in terminal phase, unable to swallow or nauseous upon ingestion or fluid uptake. Consistent nursing staff, dietician and speech pathologist notations suggest that staff attempted to reassure families by explaining the rationale for these actions and the process of dying.

*“Nausea and vomiting when attempting to eat and drink. Patient says she’s hungry but she’s not allowed to eat. Family inquired re: ceasing fluids and explained same.” (Dietitian)*

Less than half (45%) of the patients were documented as experiencing overall physical comfort 7 days prior to their death. The comfort rates appeared to increase as they closer to death, with 86% documented as overall physically comfortable on the day of death. Almost half of the patients (48%) had hydromorphone and 21% of patients were administered morphine 7 days before death. On the day of death, more patients (59%) were administered hydromorphone and 27% morphine. Other comfort medications accessed were haloperidol, midazolam,

metoclopramide hydrochloride, glycopyrrolate, and other benzodiazepines (e.g. lorazepam, diazepam) (Graph 5).

Eleven families also raised concerns about certain medications administered to patients, specifically opiates and sedatives. Some family members were concerned that the medications were making the patients drowsy and less interactive. Others were worried that the medications were shortening the patients' life or otherwise contributing to their decline. The notes demonstrate the consistency of nursing staff educating the families about the actions of the medications and patients' need for sleep at the end-of-life. In one particular case the family forbid the doctors to increase the dose of the pain medications out of concerns that they were detrimental to the patient's health, while in other cases the families' concerns were diminished after talking to nursing staff or medical review.

*“Patient’s family unhappy with care. Son was very intrusive, following me and questioning what I was doing. Daughter questioned why pain relief increased and asked that it be reduced!! Family are very difficult to deal with and unfortunately I think they are probably compromising care as they do not fully understand the actions of the medications we are administering.” (Nurse)*

Almost all (98%) of patient records included Not-For-Resuscitation (NFR) documentation. However, patient participation in the NFR discussion was recorded in only 32% of records and family participation in 45% records. Only 38% of NFR documents were completed in their entirety.

Discussions with patients and their families around the place of care, should the patient remain stable or improve, featured consistently in the medical, social work and pastoral care notations. On ten cases the notations reported the patient vocalizing their desire to return home. On most

occasions this desire was in conflict with the patient's state of health (e.g. uncontrolled symptoms) or the wishes of the family, who stated that they were not able to care for patient at home. Some family members reportedly expressed their upset and disappointment with the expectations placed by other family members that they would care for the patient at home, potentially related to cultural norms.

*“Spent some time with daughter who spoke of her stress and exhaustion. (Daughter) is disappointed that there is an expectation that she will take care of mum and take her home, where she feels she cannot manage her care alone.” (Pastoral care)*

In a few cases (n=3) the patients and family members clearly communicated their concerns about being discharged from the hospital without further supports. Some family members considered the offer of utilizing services assisting in home care proposed by social workers.

Discussions about transfer to residential care were documented with 20% of families. For most of the patients it wasn't preferable. Some families (n=5) outright rejected the idea of residential care and communicated their keenness to care for the patient at home. The notes suggest that these family members often saw caring as their unquestionable responsibility, as well as something that they wanted to undertake.

Nevertheless, some patients and families (n=5) seemed more readily accepting of the possibility of moving to residential care. Those patients, who had been living alone and self-caring prior to their admission, reportedly demonstrated a pragmatic approach to their further care.

### ***Psychological domain***

The facility has a policy that all newly admitted patients are visited by the pastoral care worker. Some form of communication with the patient was documented in 90% of the records. Eighty

seven percent of patients were seen by a pastoral care worker, while 31% were seen by a social worker. Forty one percent of the patients had their spiritual or religious needs recorded, but only 5% had their cultural wishes or needs documented.

Communication with the patient's family was documented in 97% of the medical records. Family meetings were recorded as held for 41% of patients and their families. Proxy-decision maker or enduring guardians were documented in 53% of communications with the families. While 45% of family members had documentations of their or the patients' spiritual and religious wishes, only 21% had their family cultural wishes or needs documented.

Nine medical charts stated that the patients were not aware of their prognosis on their last admission at the hospital. It is difficult to deduce whether or when such lack of awareness resulted from their own wish not to know, the family's concern or both. Five entries reported that the patient's family members did not wish for them to know that they were dying. A couple of entries signalled that the family members were honouring their respective cultural traditions, in which advising the patient of a terminal illness or short prognosis was not practiced. These practices were considered as protecting the patient from bad news and not causing further harm.

*“Family aware of diagnosis and prognosis, however they have not told the patient as they state in their culture they protect loved ones and do not advise of serious illness.” (Pastoral care)*

However, fourteen patients were documented as aware of their end-of-life status, with some reported to show little or no anxiety in regards to dying. Other notes suggested that family members reported the patients openly communicating about their imminent death with their loved ones. Five entries clearly reported that the patients openly stated their wish to die. Several entries specifically focussed on the suffering experiences by the patients toward the end of their lives and their consecutive wish to end it.

Twenty seven percent of patients were documented as experiencing psycho-social distress 7 days before death and 10% had psycho-social distress on the day of their death. More family members appeared to have psycho-social distress in the last seven days of the patient's life than the patients. Thirty three percent of families were documented as experiencing psycho-social distress 7 days before the patient's death; raising to 48% a day before death and 40% on the day of the patient's death.

Pastoral care notes showed consistency in patients and their families requesting spiritual and pastoral care. Most frequently (30%), notations about local priests visiting the families or requests for pastoral care workers to organize priest visit were made. Several patients and families who identified as Buddhist inquired whether pastoral care was able to organise visits from monastics. The records suggest that this quest proved challenging, with the temples not being available.

*“Explored spiritual beliefs – Patient is Buddhist – he would like a monk to visit for blessings. He does not have contact with a particular person and is happy for hospital to organise. Buddhist nun from SGH visited patient this am, but language difficulty. I found a Cambodian monk from (suburb).” (Pastoral care)*

Eighty six percent of the families were documented as being prepared for the patient's death by the hospital team. The vast majority (91%) of families were seen by a pastoral care worker and 49% of families by a social worker. Bereavement needs were considered (e.g. by issuing a bereavement counselling referral) for 48% of families. Discussion about the preferred place of death took place in 45% of patients' documents. Discussions with the nursing staff about the care of the patient's body post-death were discussed in 20% of cases.

### ***Social domain***

Notations about visitors appeared consistently in the audited medical charts. Significant numbers of visitors coming to see patients in the last days of life were reported. The visitors were often close family members, sometimes travelling from interstate or another country, distant relatives, friends and people from patients' church communities.

However, 8 entries noted concerns, either from the immediate family or nursing staff, about the number of visitors. These were related to large numbers of visitors having a detrimental impact on the patient (tiring or upsetting them). In some instances immediate family members appeared torn between honouring their cultural customs and their families'/friends' desires to say good-bye to the patient, and the concern for the patient's energy level and comfort.

*“(Family) thought he was more comfortable with visits from immediate family, but long visits from people he hasn't seen a long time are tiring/stressing him out, but they are a cultural custom.” (Social worker)*

The notes demonstrate that in these cases nursing staff, pastoral care and social workers were consulted about the management of the visitors. Strategies, such as putting a notice at the door, or limiting visitors to two at a time, were suggested; however there was a dearth of documentation about their implementation.

## **DISCUSSION**

This study provides valuable insights into three domains of palliative care in the end-of-life journeys of patients from CALD backgrounds in Australia. The practice of palliative care involves physical, psychological, and social domains. Understanding the influence of cultural and linguistic factors on patient journeys at the end-of-life is an essential part of providing quality care. Cultural assumptions about patients, however, may lead to inappropriate outcomes (Mitchison D, Butow P et al. 2012).

Communication is key to balancing the needs of the individual and the needs of the family in palliative care. This study found language was a key barrier and inadequate access to professional interpreters. It is important to raise palliative care provider knowledge and awareness of the role of professional interpreters through education (Silva MD, Genoff M et al. 2016), such as through workshops.

Addressing concerns regarding disclosure of diagnosis and prognosis, while ensuring providers fulfil their duty of care related to truth telling requires the exchange of information in a culturally appropriate manner and establishing trusting relationships. The ethical dilemma faced by palliative care providers in respecting family preference for non-disclosure influenced by cultural values, as well as the Western ethical principle of patient autonomy, has been reported elsewhere (Chiu TY, Hu WY et al. 2009). This study found that the role of family members as intermediaries between patients and providers is in conflict with the Western medical emphasis on patient autonomy. To avoid negative outcomes from cultural generalisations, decisions related to disclosure should focus on the needs of the individual patient, reflecting a standard palliative care approach modified by cultural considerations (Tse CY, Chong A et al. 2003).

This study also found a lack of documentation of cultural wishes. Only 5% of files documented patients', and 21% of files documented families', cultural wishes. Only 20% of files had documented care of the body after death. Cultural assessment of the patient and family members on admission may help to inform a more patient-centred approach to care.

The administration of pain medication and adequate nutrition were documented as key concerns of family members. Working with family members to increase their knowledge and comfort with administration of pain relief through ensuring they understand the rationale is a key consideration. Concerns were also documented around family distress regarding patients'

lack of appetite and food consumption. To minimise the risk of inappropriate feeding, communication of this risk to family members should be done in a culturally appropriate manner.

Older people from CALD backgrounds will have a significant impact on palliative care provision. Cultural and linguistic considerations need to inform the planning and delivery of palliative care services to meet the needs of patients from CALD backgrounds and ensure the provision of quality care. Such care includes addressing physical, psychological, social and spiritual palliative care domains. When language is a barrier, a professional interpreter is required to assess physical symptoms, address cultural and spiritual needs including place of care and place of death. Other aspects may involve family education on pain control and symptoms of imminent death produced in different languages.

This study found that the role of the family in palliative care was strongly driven by community expectations, which was particularly evident around concerns related to the volume of visitors. Palliative care services should develop and evaluate strategies to support families with managing large numbers of visitors and manage community expectations more generally. Community out-reach programs to deliver educational interventions may help to increase awareness of palliative care among CALD communities (Martin EM and Barkley Jr. TW 2016). We call for the increased participation of CALD communities in the tailoring of education and information to developing cultural and linguistic considerations in palliative care.

### ***Limitations***

A limitation of this study is the quality and quantity of documentation, which in many cases was minimal. Qualitative research with palliative care providers exploring some of palliative

care domains would assist in providing a deeper understanding of care provision to patients from CALD backgrounds, their families, and wider communities.

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## Tables

**Table 1 Data Mining Tool domains**

<b>Domain</b>	<b>Data items</b>
Demographics	Age; gender; race/ethnicity; marital status
Disease specifics	Principal and additional diagnoses; disease recurrence
Treatment	Chemotherapy and/or radiotherapy; surgery in the last 30 days; number and type of procedures and interventions; number of days between commencement of treatment and the date of death
Documentation	Statements or assessments that identify the persons journey (i.e. the prognosis; routine pain and comfort assessment; extent of any uncontrolled symptoms; family meetings or other discussion to review prognosis and discuss options for care including possibility of home death; Advance Care Directives; NFR; documented proxy decision-maker; documented review and cessation of non-essential medications and interventions; documentation of deactivation of ICDs. Issues that may relate to specific cultural groups such as the provision of food, hydration or place of care will be recorded
Communication	Documented conversations regarding prognosis with patient and family; documentation of organ and tissue donation discussions and decision; calling the family because of deterioration or imminent death; psycho-social support e.g. pastoral care, social work
Psycho-social	Documentation of religious and spiritual needs of the patient and family; documentation of cultural needs/wishes of the patient and family