Manuscript Details

Manuscript number	COLL_2018_98_R1
Title	Cultural considerations at end of life in a geriatric inpatient rehabilitation setting
Article type	Research Paper

Abstract

Aim To explore the impact of cultural factors on the provision of end-of-life care in a geriatric inpatient rehabilitation setting. Background Australia's ageing population is now also one of the most culturally diverse. Individuals from culturally and linguistically diverse backgrounds may have specific care needs at the end of life according to various aspects of their culture. Design A mixed method approach using a retrospective audit of existing hospital databases, deceased patients' medical records, and in-depth interviews with clinicians. Findings Patients' and families' cultural needs were not always recognised or facilitated in end-of-life care, resulting in missed opportunities to tailor care to the individual's needs. Clinicians identified a lack of awareness of cultural factors, and how these may influence end-of-life care needs. Clinicians expressed a desire for education opportunities to improve their understanding of how to provide patient-specific, culturally sensitive end-of-life care. Conclusion The findings highlight that dying in geriatric inpatient rehabilitation settings remains problematic, particularly when issues of cultural diversity further compound end-of-life care provision. There is a greater need for recognition and acceptance of the potential sensitivities associated with cultural diversity and how it may influence patients' and families' needs at the end of life. Health service organisations should prioritise and make explicit the importance of early referral and utilisation of existing support services such as professional interpreters, specialist palliative care and pastoral care personnel in the provision of end-of-life care. Furthermore, health service organisations should consider reviewing end-of-life care policy documents, guidelines and care pathways to ensure there is an emphasis on respecting and honouring cultural diversity at end of life. If use of a dying care pathway for all dying patients was promoted, or possibly mandated, these issues would likely be addressed.

Keywords	Culture; Diversity, End-of-Life Care; Geriatrics, Nursing, Older Person, Palliative Care; Rehabilitation
Taxonomy	Nursing, Cultural Care, Cultural Issues, Older People, Palliative Care Nursing, Rehabilitation in Care Setting

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Suggested reviewers	Patsy Yates, Jane Seymour, Susan Lee, Merryn Gott

Submission Files Included in this PDF

File Name [File Type]

Cover Letter 06062018.docx [Cover Letter]

Response to Reviewers 06062018a.docx [Response to Reviewers (without Author Details)]

Title Page 06062018.docx [Title Page (with Author Details)]

Revised Manusript 06062018.docx [Manuscript (without Author Details)]

Conflict of Interest.docx [Conflict of Interest]

Ethical Statement 09042018.docx [Ethical Statement]

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Research Data Related to this Submission

There are no linked research data sets for this submission. The following reason is given:
The authors do not have permission to share data

6th June, 2018

Professor Lisa McKenna
Editor in Chief
Collegian

Dear Professor McKenna

I am pleased to submit this revised manuscript titled to ***Cultural considerations at the end of life in a geriatric inpatient rehabilitation setting*** to Collegian for review and possible publication.

This manuscript is the original work of the authors, has not been published, nor is it under consideration for publication elsewhere. All authors have contributed to the research and preparation of the manuscript and have approved the final version of this manuscript.

Conflict of Interest - There are no conflicts of interest to report.

Declaration of Financial Support - The authors disclose receipt of financial support from the Centre for Quality and Patient Safety Research at Deakin University, Australia.

Regards

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	✓
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	✓
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	✓
Objectives	3	State specific objectives, including any prespecified hypotheses	✓
Methods			
Study design	4	Present key elements of study design early in the paper	✓
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	✓
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	✓
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	N/A
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	✓
Bias	9	Describe any efforts to address potential sources of bias	N/A
Study size	10	Explain how the study size was arrived at	✓
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	N/A
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	N/A
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	N/A
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	N/A

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	✓
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	✓
		(b) Indicate number of participants with missing data for each variable of interest	N/A
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	N/A
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	N/A
		Cross-sectional study—Report numbers of outcome events or summary measures	✓
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	✓
Discussion			
Key results	18	Summarise key results with reference to study objectives	✓
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	✓
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	✓
Generalisability	21	Discuss the generalisability (external validity) of the study results	✓
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	✓

COLL_2018_98
Response to Reviewers

Reviewer 1	
The area of EOL and cultural diversity is a topical health issue which requires acknowledging. The claims within this paper require further discussion and refining as in the present format it is not concrete.	Thank you. In light of both reviewers' comments, a number of changes have been made including revision of the Introduction to include further relevant literature. The content and terminology has also been revised to ensure it will make sense to an international audience. Headings have also been added to the Findings and Discussion to guide the reader. The Discussion has also been refined to make the key messages more clear.
It needs to be clear that this is not a generalisation and that there are clinicians who are confident in providing EOL care specific to cultural beliefs.	Thank you for your comment. The authors do not attempt to claim that the findings are to be universally applied. In the Limitations section (page 12) it states: *It is also important to acknowledge that this study was conducted in one setting in Melbourne, Australia. Therefore, the findings may not be transferable across other settings or patient groups.*
The literature referenced could be broader and a comparison made to organisations which do have specific cultural resources, and note the wide use of Bloomer et al.	Thank you for this comment. The literature has been reviewed and revised accordingly. Bloomer et al.'s work featured because of their recent work in a similar setting, with older people at end of life. Several references have now been removed and/or replaced with others. The following papers have also been integrated into the literature presented: Betancourt, J., Green, A., Carrillo, J., & Ananeh-Firempong, O. (2016). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public health reports, 118*(4), 293-302. Broom, A., Good, P., Kirby, E., & Lwin, Z. (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal, 43*(9), 1043-1046. doi:10.1111/imj.12244 Lloyd, L., White, K., & Sutton, E. (2011). Researching the end-of-life in old age: cultural, ethical and methodological issues. *Ageing & Society, 31*(3), 386-407. Periyakoil, V. S., Neri, E., & Kraemer, H. (2016). Patient-reported barriers to high-quality end-of-life care: A multiethnic, multilingual, mixed-methods study. *Journal of Palliative Medicine, 19*(4), 373-379. doi:10.1089/jpm.2015.0403
It is clear this is a sub study, though I find it difficult to arrive at that same conclusion as evidenced in the claims this study presents on page 4.	Thank you for your comment. The statement which commenced with *'Currently there is a dearth…,'* has been removed.
I acknowledge this is also a retrospective audit analysis and that documentation is never of value within the progress notes of a deceased patient.	Retrospective audits are inherently challenging and flawed. It is acknowledged in the 'Limitations' section (page 12) that the main limitation of a study of this type is the quality of the available evidence. It is possible that the audit data does not accurately reflect what occurred, but there is no way of validating this. There still are, however,

	some key learnings to come from this audit, as are presented in this paper.
ACP is an area to focus on. It is difficult and reasonable that during the night, when staffing resources are at the minimum, cultural traditions may be impacted on if it is not a palliative care unit or hospice. Be mindful of the distress of other patients. It cannot be undervalued the limits on service provision in acute care facilities.	Thank you for your comments. We agree wholeheartedly. Advance Care Planning is an area that needs significant attention. If rates of uptake for ACP were higher, it may be that many of the challenges associated with inpatient end-of-life care arise less frequently, or that certain individuals are not admitted to hospital at all. This means that further consideration for aged and residential care services and other care settings is required, to ensure appropriate recognition of those approaching the end of life and that care aligning with the person's wishes is planned proactively.
It is a suggestion to the authors to consider refining and present key findings supported by the literature within a table or specific themes.	The Findings (commencing page 6) have been refined and revised to now include sub-headings to guide the reader.
I note the comment on page 10 and question the comparison with NZ and the depth this would bring to the discussion. All the best.	Thank you for this suggestion. We have added further international literature (page 10) to improve the depth of the discussion.
Reviewer 2	
Background: given the international readership of this journal it is important that the terminology is clearly defined. I am unclear what is mean by a "sub-acute" setting.	Thank you for this comment. Whilst the term 'subacute' is likely familiar to Australian readers, it is acknowledged that this term may not be familiar to an international readership. Therefore it has been replaced with 'geriatric inpatient rehabilitation' for ease of understanding.
The authors refer to it as a "hospital" at times and describes it as focusing on "rehabilitation, functional restoration, transitional care, aged and mental health care" with no mention of palliative or end of life care. Are the patients residing in this care setting permanently or temporarily? Is the setting the same as what is often described as a care home or raged care facility?	This study was conducted in a geriatric inpatient rehabilitation facility. It is part of a hospital, not residential care. Information in the Introduction (pages 3-4), has been edited to make this more clear: *For older people with more complex care needs who require hospitalisation, care may be provided in geriatric inpatient rehabilitation settings (Visser et al., 2014), where multidisciplinary care is focused on optimising patient functioning (Australian Institute of Health and Welfare, 2013).*
Data collection: how were the clinicians recruited to the study? How as the data collected - face to face individual interviews?	Further detail has been added to the 'Data collection' section (page 5)to explain recruitment. It now reads: *Convenience sampling was used to recruit nursing, medical and allied health clinicians, who were permanently employed in this setting, and had cared for at least one patient who had died. Face to face semi-structured interviews were conducted to explore end-of-life care provision in this setting.*
Were they recorded and transcribed verbatim?	Detail about interview transcription has been added to the 'Data Analysis' section (page 5): *Clinician interviews were transcribed verbatim*

Was an interview schedule used and if so, could this be included as supplementary information	An interview schedule was used to guide the interviews. However the interview schedule relates to a larger study (reported elsewhere). The cultural aspects reported in this sub-study were offered up by participants organically, rather than in response to specific or targeted questioning. Hence it would not be helpful to include the interview schedule here.
Data analysis: more detail is required on how the qualitative data was analysed	The data analysis section (page 5) has now been amended to include the following:- *Clinician interviews were transcribed verbatim and analysed using inductive content analysis, where themes were derived directly and inductively from the interview data (Moretti et al., 2011). Inductive content analysis limits the influence of subjective interpretation by the researcher (Moretti et al., 2011), and hence was considered most appropriate for this study. The trustworthiness of the process and findings was ensured by having a second researcher read the interview transcripts and derived themes to ensure congruence. The findings were then shared amongst the entire team for discussion and final themes were agreed upon.*
Findings: what was the mix of clinicians in relation to their professional background and culture. This is an important factor as our cultural background impacts on how we care for those who come from different cultures. Age, gender, ethnicity and discipline/training is important to include.	Given that this paper reports on a sub-study of a larger study, in which the focus was not cultural considerations, data were not collected about clinician participants in terms of age, gender or cultural diversity. However further detail has been added to the 'Clinician Perspectives' section (page 7) which reads:- *Nineteen clinicians participated in semi-structured interviews including registered nurses (n=8), enrolled nurses (n=4), allied health clinicians (n=5) and medical staff (n=2). Participants had an average of 15 years (range 1 – 40 years) experience in this setting. Further demographic data about clinician participants was not collected, as a way of protecting participants' identity.*
Discussion: Overall the discussion has been written well and draws upon relevant literature however there are a couple of points that need to be made which will strengthen the discussion. Firstly, in many English speaking countries, palliative care is provided predominantly by a European workforce. Is this the same in Australia? How does a lack of cultural diversity in the healthcare workforce impact on the way in which care is provided to the CALD population? It would be interesting to integrate this literature into the discussion and use it in the	Thank you for this interesting comment. This paper represents a sub-study of a larger study. Issues of cultural and cultural diversity were not part of the larger study, hence detail about the cultural backgrounds of clinicians was not collected. Furthermore, in accordance with ethical approvals and the need to protect the identity of those who did participate, limited demographic data about clinician participants were collected. This means that we cannot definitively comment. What we have done, however, is add information to the discussion (page 11) about this: *Previous studies have shown that cultural awareness is improved when the clinician group is also culturally diverse, and includes individuals from similar and diverse cultural backgrounds (Komaromy et al., 1996; Saha, Taggart, Komaromy, & Bindman, 2000). In this study*

recommendations for practice improvement and policy development. http://journals.sagepub.com/doi/abs/10.1093/phr/118.4.293.	*however, the potential impact of clinician culture was not considered.* Reference to the work of Betancourt, Green, Carillo & Ananeh-Firempong (2016) has been integrated into the Introduction and Discussion.
Secondly, what about the use of cultural liaison or support teams? This is being increasingly used in health care settings globally and they can be a useful cultural broker to the effective provision of care particularly when the health care professional's cultural background differs to that of the patient and family.	Thank you for this comment. The role of the cultural broker is an interesting one, but not a role or focus of any clinician group in this setting. Reference to clinicians as cultural brokers has been integrated into the discussion (page 11):- *More recent research has emphasised the potential for clinicians to act as cultural brokers, who can provide various links and support to minimise cultural boundaries (Crawford, Stein-Parbury, & Dignam, 2017; Lindsay, Tétrault, Desmaris, King, & Piérart, 2014). But this suggestion assumes that clinicians are culturally aware and have the know-how for providing culturally sensitive care. The findings of this study suggest clinicians in this study were unlikely to be prepared for a cultural broker role.*
Conclusion: I wonder why this section starts with the statement: "there is little doubt that in Australia, like many other Western cultures, dying in hospital remains problematic" - I am not sure how this relates to the aim of the study or why hospitals are more problematic in relation to caring for the CALD population than other care settings.	Thank you for this comment. The statement has been amended (page 12) to now state:- *There is little doubt that in Australia, like many other Western cultures, dying in geriatric inpatient rehabilitation settings remains problematic*
It also leaves me confused about the type of care setting when hospital and sub acute care is used interchangeably.	As per a previous suggestion, the setting is now described as a geriatric inpatient rehabilitation setting, to make more sense to an international audience.

Title Cultural Considerations at end of life in a geriatric inpatient rehabilitation setting

Running Head Cultural consideration at end of life

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Conflict of Interest

No conflicts of interest have been declared by the author(s).

Funding Statement

The authors disclose receipt of financial support from the Centre for Quality and Patient Safety Research at Deakin University, Australia.

Cultural considerations at end of life in a geriatric inpatient rehabilitation setting

Abstract

Aim

To explore the impact of cultural factors on the provision of end-of-life care in a geriatric inpatient rehabilitation setting.

Background

Australia's ageing population is now also one of the most culturally diverse. Individuals from culturally and linguistically diverse backgrounds may have specific care needs at the end of life according to various aspects of their culture.

Design

A mixed method approach using a retrospective audit of existing hospital databases, deceased patients' medical records, and in-depth interviews with clinicians.

Findings

Patients' and families' cultural needs were not always recognised or facilitated in end-of-life care, resulting in missed opportunities to tailor care to the individual's needs. Clinicians identified a lack of awareness of cultural factors, and how these may influence end-of-life care needs. Clinicians expressed a desire for education opportunities to improve their understanding of how to provide patient-specific, culturally sensitive end-of-life care.

Conclusion

The findings highlight that dying in geriatric inpatient rehabilitation settings remains problematic, particularly when issues of cultural diversity further compound end-of-life care provision. There is a need for recognition and acceptance of the potential sensitivities associated with cultural diversity and how it may influence patients' and families' needs at the end of life. Health service organisations should prioritise and make explicit the importance of early referral and utilisation of existing support services such as professional interpreters, specialist palliative care and pastoral care personnel in the provision of end-of-life care. Furthermore, health service organisations should consider reviewing end-of-life care policy documents, guidelines and care pathways to ensure there is an emphasis on respecting and honouring cultural diversity at end of life. If use of a dying care pathway for all dying patients was promoted, or possibly mandated, these issues would likely be addressed.

Summary Statement

Why is this research or review needed?

- Australia's population is ageing and becoming increasingly culturally diverse.
- There are significant disparities in end-of-life planning, decision making and care for older people from culturally and linguistically diverse backgrounds compared with those from the mainstream population.
- Clinicians typically feel overwhelmed and underprepared to provide end-of-life care, particularly when they may have little understanding of what constitutes culturally responsive or appropriate end-of-life care for older people.

W**hat are the key findings?**

- Patients' and families' cultural needs before and after death were not always accommodated; influence by organisational constraints and inadequate communication.
- Clinicians typically lacked cultural awareness and the potential breadth of cultural practices, rituals, and other needs considered essential to the provision of culturally sensitive end-of-life care.
- Clinicians identified a need for further education to improve understanding of how to address cultural needs for older people and their families at the end of life.

How should the findings be used to influence policy/practice/research/education?

- There is a need for greater recognition and acceptance of the potential sensitivities associated with aspects of cultural diversity and how it may influence patients' and families' needs at the end of life.
- Health service organisations should make explicit the importance of early referral and utilisation of existing support services, such as professional interpreters, palliative care and pastoral care personnel, in the provision of end of life care.
- Health service organisations, particularly policy-makers, should consider reviewing end-of-life care policy documents, guidelines and care pathways, to ensure there is an emphasis on respecting and honouring cultural diversity and facilitating culturally appropriate care at the end of life.

Keywords Culture, Diversity, End-of-Life Care, Geriatrics, Nursing, Older Person, Palliative Care, Rehabilitation

Introduction

Like many other developed countries, Australia's population is rapidly ageing (Australian Bureau of Statistics (ABS), 2013). The World Health Organization (WHO) urges governments to ensure health care systems and services are centred on the needs and rights of older people, right up until their death (2017). In Australia, a national consensus statement (the Statement) was released, providing recommendations for the delivery of safe, timely and high quality end-of-life care (ACSQHC, 2015). However, the Statement relates specifically to acute care settings and fails to address the unique and often more complex needs of older people approaching the end of life in other inpatient settings. Given Australia's ageing population, the likelihood of a frail older patient's decline and death should be more readily acknowledged and planned for (Bloomer, Botti, Runacres, Poon, & Barnfield, In Press), irrespective of the care setting.

Not only is the population ageing, but Australia is now also one of the most culturally and linguistically diverse (CALD) countries in the world. Recent statistics show that 28% of Australians were born overseas (ABS, 2017), 26% speak a language other than English at home and approximately 130 religions are followed (Victorian State Government, 2016a). Yet a person's culture is about more than ethnicity, language and religion. Culture is also a system of shared valued and practices (Lloyd, White, & Sutton, 2011), representing who an individual is, how they connect with others, their sense of identity and belonging (FECCA, 2015). Culture also influences the meanings, cultural norms and values people attach to death and dying (Lloyd et al., 2011).

When accessing health care, a person's cultural practices, traditions and norms may be poorly understood by clinicians, and language barriers are a common source of difficulty (FECCA, 2015). As a result, older people from culturally diverse backgrounds receive poorer quality care and are less likely to access appropriate health care when needed (Periyakoil, Neri, & Kraemer, 2016), instead relying on family networks for increased support and informal care (Australian Government, 2017; Lloyd et al., 2011). Acknowledging this, there is an increasing emphasis on ensuring culturally responsive, respectful and accessible services are provided for older people from CALD backgrounds (Australian Government, 2017; Broom, Good, Kirby, & Lwin, 2013). To provide such services, significant changes to health care environments are required (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2016). Health care providers and individual clinicians are encouraged to seek to understand a person's cultural background and how it may influence their care needs and preferences, and be inclusive of family/significant others (Betancourt et al., 2016; Victorian State Government, 2016b).

For older people with complex care needs who require hospitalisation, care may be provided in geriatric inpatient rehabilitation settings where multidisciplinary care is focused on optimising patient functioning (Australian Institute of Health and Welfare, 2013; Visser et al., 2014). Irrespective of the type of inpatient setting, hospitalisation is a highly stressful event for an older CALD person and their family, particularly as the older person approaches the end of life (Johnstone, Hutchinson, Rawson, & Redley, 2016). Significant disparities in end-of-life planning, decision making and care exist for older people from CALD backgrounds compared with those from mainstream English-speaking backgrounds (Betancourt et al., 2016; Johnstone & Kanitsaki, 2009). This is complicated further when end-of-life care is provided in an inpatient setting that is not intended for that purpose (Bloomer et al., In Press).

The provision of culturally sensitive end-of-life care requires clinicians to have an awareness of how an individual's culture shapes their beliefs and needs (Crawley, Marshall, Lo, & Parkin, 2001). In the absence of this awareness, assumptions are made about death and dying, and about patients' and families' cultural needs as death approaches (ACSQHC, 2015). Yet, a recent review highlighted that the idea of what constitutes a good death varies considerably between and within cultures (Lloyd et al., 2011). Although clinicians can make a profound difference in how patients and their families experience and process patient death (Johnstone et al., 2016), recent evidence suggests that clinicians can feel overwhelmed and underprepared to provide end-of-life care (Bloomer et al., In Press) and not know how to initiate communication with patients and families about end-of-life care (Bloomer et al., In Press; Periyakoil et al., 2016). Another study found that nurses had little knowledge or understanding of what constituted culturally responsive or appropriate end-of-life care (Johnstone, Hutchinson, & Redley, 2015).

This paper presents the findings of a sub-study embedded in a larger mixed methods study. The aim of the larger study was to explore (i) how patient deterioration and dying are communicated amongst clinicians involved in care, and with families; and (ii) how this communication influenced decision-making and care. During the larger study, it became apparent that due to the cultural and linguistic diversity of the patient cohort, cultural factors influenced end-of-life care.

Aim

The aim of this sub-study was to explore the impact of cultural factors on the provision of end-of-life care.

Setting

The data relate to a study conducted in a 180-bed geriatric inpatient rehabilitation facility providing a range of multidisciplinary services including rehabilitation, functional restoration, transitional care, aged and mental health care in metropolitan Melbourne, Victoria, Australia. The population served by this facility and the greater healthcare organisation is rapidly ageing, with more people aged over 65 years and 85 years than the rest of Melbourne. The population is also culturally diverse with almost half the population not speaking English as their first language and 32 religions represented.

Design

Ethical approval was granted by the Human Research Ethics Committee of the healthcare organisation (RES-16-0000491L) and the University (2016-355), for a two-stage mixed method study including a retrospective audit of existing hospital database sources and exploratory semi-structured interviews with clinicians.

Sample

Stage One involved 54 inpatients who died in the geriatric inpatient rehabilitation facility between 01/07/2015 and 30/06/2016. Stage Two involved semi-structured interviews with 19 clinicians (including nursing, medical and allied health), working in the same setting, who had been involved in the care of an inpatient who died.

Data collection

Multiple sources of data were used. Demographic data related to the 54 deceased patients were collected from existing hospital databases. The medical records for each patient's final admission were also examined for evidence of communication, decision-making and end-of-life care planning.

Convenience sampling was used to recruit nursing, medical and allied health clinicians, who were permanently employed in this setting, and had cared for at least one patient who had died. Face to face semi-structured interviews were conducted to explore end-of-life care provision in this setting.

Data analysis

Descriptive statistics were used to analyse demographic data. Textual data from patient medical records were analysed using qualitative content analysis to address the aim of this sub-study. Clinician interviews were transcribed verbatim and analysed using inductive content analysis, where themes were derived directly and inductively from the interview data (Moretti et al., 2011). Inductive content analysis limits the influence of subjective interpretation by the researcher (Moretti

et al., 2011), and hence was considered most appropriate for this study. The trustworthiness of the process and findings was ensured by having a second researcher read the interview transcripts and derive themes to ensure congruence. The findings were then shared amongst the entire team for discussion and final themes were agreed upon.

Findings

Data from the retrospective audit included data related to patient demographic characteristics and clinician entries in the medical record which demonstrate acknowledgement of patient and/or family cultural needs. Content from clinician interviews that explored cultural issues and considerations is also presented.

Patient demographic characteristics

Fifty-four inpatient deaths occurred in the one year study period. The average age was 83 years (SD=9) with 55.6% males (n=30). Most patients (n=49, 90.8%) were admitted from an acute hospital ward. Falls (n=15, 27.8%) and diseases of the circulatory system (n=13, 24.1%) were the two most common reasons for admission and almost half (n=23, 42.6%) had a comorbid diagnosis of cognitive impairment. No patients had a completed Advance Care Plan, and none were identified as terminal or actively dying at time of admission. Next-of-kin was most commonly an adult child (n=32, 59.3%) with only 10 patients (18.5%) identifying a spouse as next-of-kin. The most common religion was Roman Catholic (n=19, 35.2%), followed by Greek Orthodox (n=7, 13.0%), other Christian (n=4, 7.4%), Buddhist (n=3, 5.6%) and Jewish (n=1, 1.9%), with 17 (31.5%) reporting no religious affiliation and in three cases (5.6%) the patient's religion was not recorded.

Acknowledgment of Cultural Needs in Medical Records

In several cases, there was evidence of clinicians' acknowledgement of a patient's and family's cultural needs. In Case 11, the case of an 80-year old Jewish male, a medical officer acknowledged the patient's and family's religious needs by writing *"…son has made preparations for Rabbi to attend for end-of-life matters"*. A subsequent entry by a social worker notes that the patient's family have requested *"…a traditional Jewish burial as soon as possible after father's death"*.

In Case 50, the patient was an 89-year old Buddhist male. His daughter was his next-of-kin and at the time of death, she expressed the family's religious needs to the allocated nurse as noted by this entry in the medical record: "[Patient] *passed away at 2305hrs… family in attendance… Family insisted nursing staff not to wash or do last offices for [patient] as they want to do prayer for the next 7-8 hours. Special Buddhist priests are in attendance and prayer is in progress. Nursing staff discussed with NCO [nurse-in-charge] and Security if it's ok to allow for prayer for next 7-8 hours and*

keep body in ward and NCO advised that we need to respect their wishes and allow them to pray as their wish".

However, specific cultural needs of the patient and/or family were not always acknowledged or accommodated. In Case 47, an 88 year-old Buddhist male was admitted following a fall 13 days prior to his death. There was evidence in the medical record of multiple written clinician entries regarding the patient's condition, poor prognosis, care plan and communication with his daughter, his nominated next-of-kin. In anticipation of his death, the daughter reported specific religious requirements, which were documented by a palliative care clinician, three days prior to his death: *"Patient of Buddhist faith. Family request Buddhist monk attend and candles and incense be lit following patient's death. Family will arrange and liaise with nursing staff"*. At the time of the patient's death however, their specific requests were not accommodated, as noted in the final nursing entry: *"Family advised he was no longer breathing… family clustered. I noted candles and incense, advised them sorry they could not use them. They were also calling in all immediate family, 80 in total, I advised them no they couldn't have that many overnight"*.

Clinician perspectives of cultural issues and challenges

Nineteen clinicians participated in semi-structured interviews including registered nurses (n=8), enrolled nurses (n=4), allied health clinicians (n=5) and medical staff (n=2). Participants had an average of 15 years (range 1–40 years) experience in this setting. Further demographic data about clinician participants was not collected, as a way of protecting participants' identity.

Caring for any dying patient and their family was acknowledged as challenging, particularly in relation to communication, decision-making, comforting and supporting family. One participant reflected however, that even with the challenges associated with caring for a dying person and their family, end-of-life care should be viewed as more than just a negative experience:

> *"… It's part of life, it's part of the life cycle. It should be a bit of a sacred passage and I don't mean sacred in a necessarily religious way. It's whatever belief system you follow but it should be a special time and I think too often, it becomes a traumatising time for the family and sometimes the patient, and I think we can do so much better than that"* (Interview 4, Allied Health).

When the patient and/or family are from a culturally diverse background, providing culturally sensitive end-of-life care can be challenging. Interview participants identified some of the challenges associated with providing end-of-life care in the context of various cultural influences,

and how these could be improved. Identifying the need for a unified approach to family communication, led by the medical officer, one participant said:

> *"I think we need to have a clear cut conversation, which can be a team approach or a medical approach, directly to the families because in most of the cultures they take medical words (information from a doctor) more effectively than nursing"* (Interview 1, Registered Nurse)

Another suggested that existing supportive personnel and services were underutilised. Speaking of pastoral care and religious support, a participant said:

> *"We have to have the support network in place to help families, staff, whoever with that. I personally don't believe pastoral care is used nearly enough... I documented on my patients that are dying, that the family would benefit from having a pastoral care...doesn't matter what religion they are or you know we've got a lot of Greek and a lot of Italians so an orthodox minister, can we get them in?"* (Interview 10, Registered Nurse).

Another commented that professional interpreter services were underutilised, potentially impacting communication with patients and families who may who speak languages other than English:

> *"We have the use of interpreters, though, I feel in my two years here it's becoming a bit more and more precious with that resource, so we have a process, now, where they make sure that at least two other staff members need that interpreter to come in, and it's really difficult because often our patients are cognitively or hearing impaired, plus the language"* (Interview 14, Allied Health)

The issue of culturally appropriate food was also raised, given that it may provide a sense of comfort for the dying person. A dietitian participant offered:

> *"So we do have halal, kosher, we do have some multicultural meals.... well I suppose a multicultural kind of menu available, probably not extensive, but it is available for clients, a certain number of dishes"* (Interview 13, Allied Health).

Even though some multicultural meals were available, another suggested she was unsure that culture was considered when planning meals for a patient:

> *"I guess I don't think we consider it when we're organising food, but we do have family members bring food in"* (Interview 14, Allied Health)

When it came to reflecting on the care provided by the members of the treating team, several issues were raised. One suggested that even with a culturally diverse workforce, cultural needs were not always understood, impacting clinicians' care and relationship with the patient and/or family:

> *"We have a lot of culturally different nurses. I wouldn't say it's embraced, but it's not repelled either, if that's the opposite. It's kind of in the middle. We're aware of different cultures; where we can, and where we know there's a difference we try and work around it, work with it. But where we don't know, and I'm sure there's some colossal mistakes we make with religion, where we don't know then we make the mistake and then the family look sideways at you. But we do try. Most of the nurses will ask if there's anything that we need to do, that we shouldn't be doing, or with something we shouldn't be doing"* (Interview 12, Registered Nurse)

The potential for clinicians to learn about end-of-life care and cultural diversity was identified as a way of potentially improving care. One nurse reflected on her own learning:

> *"I think you just have to understand the culture. If you make an effort to understand it a little bit more, I can sometimes see where they're coming from, I really can… so I've always been fascinated by not just religion but, you know, the culture of it too. But I think if you try and make an effort to understand and come to some sort of common consensus…"* (Interview 3, Registered Nurse)

Another described the actions she took to address her need for greater understanding:

> *"…there's no training in cultures. You know, you've got different cultures, and different cultures do different things with, you know when someone's dying. They might want a priest to come, or they might want someone to come and do something before they die or they, there's so many different things come into play. Or they might want the body to be buried straight away. And, well we're not taught that, and you have to research, sometimes I've actually gone onto the internet and Googled it, you know so I know. Because I don't want to go into the family and say, oh well what do you want us to do with the body? Or what do you want us to do?"* (Interview 2, Registered Nurse).

From an organisation standpoint, it was also suggested that more could be done to increase clinician awareness and understanding of end-of-life care:

> *"I think for everybody. I think it should be part of, like we do a mandatory basic life support, we do a mandatory vitals and recognising the deteriorating patient. I think it's absolutely*

imperative that we have some sort of education that is mandatory every 12 months for end of life as well. And hopefully people, it gets people talking, it gets people thinking a different way and hopefully things can get done better. It will be a very slow process but I think it's important" (Interview 10, Registered Nurse)

Yet, given the potential for death to be an emotive topic, when considering the idea of end-of-life care education, the participant reflected:

"I found it enlightening to learn of the Buddhists and the Jewish and what have you, and accepting their ways… I'm cool with death. I don't like it of course, but … And so I will learn and become a sponge, but others don't want to do that…for whatever their reasons, and you've got to be careful because you can almost come across as bullying and intimidating when you're asking them" (Interview 10, Registered Nurse)

Discussion

This study demonstrates the impact of cultural factors on the provision of end-of-life care in a geriatric inpatient rehabilitation setting. What is evident is that a one-size-fits-all approach to end-of-life care for patients from diverse cultural backgrounds and groups is inadequate. When sociocultural differences between patients and clinicians are not fully appreciated, explored or understood, is when the impact may be most significant (Betancourt et al., 2016). Experiencing dying and death can be highly emotive and a traumatic experience for patients, families and clinicians, complicated further by the fact that poor health and death can have different meanings and prompt different responses according to various cultural factors (Johnstone et al., 2015; Lloyd et al., 2011). Similar issues have been identified in healthcare settings internationally, with sociocultural barriers contributing to healthcare disparities (Betancourt et al., 2016). In a study of patient-reported barriers to end-of-life care in the USA, the majority of patients from a diverse multi-ethnic cohort reported challenges in receiving culturally appropriate end-of-life care (Periyakoil et al., 2016). In New Zealand, higher rates of older people from various cultural groups has increased the need for clinicians to be supported to provide culturally sensitive end-of-life care (Bellamy & Gott, 2013).

Organisational constraints

Whilst providing for the cultural needs of patients and families is just as important as meeting their physical needs at end of life (ACSQHC, 2015; Lloyd et al., 2011), these findings demonstrate that in this setting, cultural requests before and after death were not always accommodated. Limited

access to professional interpreters likely impacted opportunities for patients and families to express their specific cultural needs for end-of-life care. In end-of-life care, professional interpreters enable open communication regarding prognosis and specific needs in end-of-life care (Douglas et al., 2011) and lack of use or access to professional interpreters is associated with patient dissatisfaction (Betancourt et al., 2016). Hence the use of professional interpreters, rather than family or other staff is a best practice recommendations for communicating with patients and families from diverse cultures (Douglas et al., 2011).

Clinicians' concerns with the length of time the deceased person and their family remained in the ward area after death is another example of organisational constraints influencing the end-of-life experience. Previous research has identified that the demand for beds and push to remove the deceased and prepare for the next admission, impacted upon the way families were able to grieve after a death (Bellamy & Gott, 2013; Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2013).

Cultural awareness

The findings also suggest that clinicians' lack of awareness of various cultures. Previous studies have shown that cultural awareness is improved when the clinician group is also culturally diverse, and includes individuals from similar and diverse cultural backgrounds (Komaromy et al., 1996; Saha, Taggart, Komaromy, & Bindman, 2000). In this study however, the potential impact of clinician culture was not considered. More recent research has emphasised the potential for clinicians to act as cultural brokers, who can provide various links and support to minimise cultural boundaries (Crawford, Stein-Parbury, & Dignam, 2017; Lindsay, Tétrault, Desmaris, King, & Piérart, 2014). But this suggestion assumes that clinicians are culturally aware and have the know-how for providing culturally sensitive care. The findings of this study suggest clinicians in this study were unlikely to be prepared for a cultural broker role.

A lack awareness or understanding about how to provide culturally sensitive care also led to missed opportunities in end-of-life care. Whilst the obvious solution might be to create educational opportunities for clinicians to increase clinicians' knowledge and awareness of various cultural groups and their needs, how this is conceptualised and actualised is important. Given that so many factors including ethnicity, religion, language and beliefs contribute to a person's cultural identity (FECCA, Australian Government, 2017; 2015), caution should be taken against making assumptions about individuals based on their identified culture alone (Australian Government, 2017; Reid, 2005). Whilst cultural factors can shape a person's preferences for care, particularly at the end of life, it is important that clinicians are mindful not to standardise an individual's care plan based on their assumed culture (Bellamy & Gott, 2013). Doing so may only serve to restrict dialogue or

understanding to a pre-determined list of attributes and practices and end-of-life care beliefs (Koffman, 2011; Williamson & Harrison, 2010) rather than a more individualised approach that engages patients and families.

Education opportunities

Education opportunities should be designed to assist clinicians in understanding and being sensitive, respectful and responsive to the complexities of the patient's and family's preferences and needs (ACSQHC, 2015; Broom et al., 2013). With this in mind, educational interventions should not be aimed at producing a prescriptive list of information for each ethnicity or religion (Bellamy & Gott, 2013) as this 'cookbook' approach is short-sighted and limiting (Jones, 2005). Rather, the design of educational interventions should first seek a multi-stakeholder understanding of CALD community experiences of end-of-life care and communication (Broom et al., 2013), then focus on equipping clinicians with the skills and confidence to communicate their openness and desire to provide optimal and culturally sensitive care by seeking information and guidance directly from the patient and/or their family.

Limitations

There are several limitations to this sub-study. A retrospective audit is limited by the quality of the evidence. Hence, it is possible that the medical record audit data did not accurately reflect culturally-specific conversations or how the cultural needs of dying patients and their families were accommodated. This paper represents the findings of a sub-study of a larger study. Given that aspects of culture were not the focus of the larger study, data relating to ethnicity or language preference were not collected. Rather this paper reports only on the data available according to the larger study. It is also important to acknowledge that this study was conducted in one setting in Melbourne, Australia. Therefore, the findings may not be transferable across other settings or patient groups.

Conclusion

There is little doubt that in Australia, like many other Western cultures, dying in geriatric inpatient rehabilitation settings remains problematic. When the goal of care is ultimately about life prolongation, dying does not fit. Furthermore, with increasing rates of specialisation amongst clinicians coupled with the multidisciplinary approach to care as seen in this geriatric inpatient rehabilitation setting, coordination of end-of-life care in settings other than specialist palliative care settings appears to be lacking. Issues of cultural diversity further compound this. These findings

highlight the need for greater recognition and acceptance of the potential sensitivities associated with aspects of cultural diversity and how it may influence patients' and families' needs at the end of life.

This study has emphasised the need for health service organisations to prioritise and make explicit the importance of early referral and utilisation of existing support services, such as professional interpreters, specialist palliative care and pastoral care personnel in the provision of end-of-life care. If use of a dying care pathway for all dying patients was promoted, or possibly mandated, these issues would likely be addressed.

Recommendations

Rather than anticipating a patient or families' needs according to any identified cultural factor or assumed practice, clinicians should be supported by health service educators, managers and policymakers to take an individualised approach to care; seeking information about end-of-life care preferences from patients and/or families. Health service organisations should consider reviewing end-of-life care policy documents, guidelines and care pathways, to ensure there is an emphasis on respecting and honouring cultural diversity at end of life and prioritising patient and family cultural needs and preferences, integral to high-quality care.

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Conflict of Interest

There are no conflicts of interest to report.

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