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Abstract

Background: Death anxiety is a known phenomenon in older people of culturally and linguistically diverse backgrounds (CALD) hospitalised for end-of-life (EOL) care. Little is known about how nurses assuage death anxiety in this population.

Aims: This study investigates the strategies used by nurses to help assuage death anxiety and facilitate a “good death” in older CALD Australians hospitalised for EOL care.

Methods: This study was undertaken as a qualitative descriptive inquiry. A purposeful sample of 22 registered nurses was recruited from four healthcare services located across metropolitan Melbourne and regional Victoria. Interviews were transcribed verbatim and analysed using thematic analysis processes.

Findings: Data revealed three key strategies nurses use: recognising death anxiety; delineating its dimensions; and initiating conventional nursing caring behaviours to help contain it. Contrary to expectations, cultural similarities rather than differences were found in the strategies used by nurses for assuaging death anxiety in older CALD Australians.

Conclusions: Cultural similarities can be just as important as cultural differences when caring for hospitalised older CALD people and assuaging their death anxiety.

Keywords: aged, immigrants, anxiety, death, terminal care, hospitalisation, nurses, Australia
Introduction

International research is increasingly showing that immigrants and ethnic minorities experience significant barriers to receiving high-quality end-of-life (EOL) care compared with the majority population of the countries in which they live (Gysels et al., 2012; Periyakoil, Neri & Kraemer 2015; Seeleman, Essink-Bot, Stronks & Ingleby 2015; Smedley, Stith & Nelson 2003). Moreover, as a consequence of these barriers, immigrants and ethnic minorities also experience disparities in the outcomes of their EOL care, which extends to their being enabled to experience a “good death”. In an attempt to redress this problem, there has been mounting recognition by researchers and health service providers alike of the need to better understand the influence of culture on patient and family-centred EOL care and on the processes that can be used to help enable immigrant and ethnic minority patients to experience a good death at the end of their lives (Cheng et al., 2015; Gysels et al., 2012; Kagawa-Singer & Blackhall 2001; Periyakoli, Neri & Kraemer 2015; Seeleman, Essink-Bot, Stronks & Ingleby 2015).

Australia has one of the most culturally and linguistically diverse populations in the world. According to the 2011 Census, Australia’s population is comprised of people originating from more than 200 countries, speaking more than 220 different languages other than English at home, and practising more than 120 religions (Australian Bureau of Statistics, 2011). Australia also has an aging population, with the Australian Institute of Health and Welfare (AIHW) estimating that people over the age of 65 years will increase by 21% within the next 40 years (AIHW, 2015). As of 2011, more than one third (36%) of Australians over aged 65 years were born overseas, with 14% being from main English-speaking countries and a disproportionate 22% from non-main English speaking countries (AIHW, 2013). Of those from non-main English speaking countries (to be referred to herein as older immigrants of culturally and linguistically diverse (CALD) backgrounds), the largest birthplace groups
originate from Italy, Germany Greece, China, the Netherlands, Croatia, Malta and Poland (NSAPAC, 2011). Significantly, the population of older immigrants of CALD backgrounds is projected to increase by 66%, compared with just 23% for the older Australian-born population in the forthcoming years (AIHW, 2004). Moreover, according to the National Seniors Australia Productive Ageing Centre (NSAPAC), some overseas birthplace groups (even those who have lived in Australia for many years) will have relatively low levels of English language proficiency (NSAPAC, 2011). Some have estimated that as high as 34% of older immigrants of CALD backgrounds lack proficiency in the English language. Adding to this, for those who do have English language proficiency, this proficiency tends to decline with increasing age and as the older person reverts back to using their first language (NSAPAC, 2011).

In Australia most people who are expected to die, will die in hospital (AIHW 2014; Clark, Collier, & Currow, 2015). Although the place of death for those in the older age groups (i.e., older than 65 years of age) will gradually shift from hospitals to residential aged care facilities (Broad et al., 2013), a significant number of older people will nonetheless die in hospital. This is because when ill and dying, the EOL care supports required by people are not readily available outside of the hospital setting (AIHW 2014; Clark et al., 2015; Swerissen & Duckett, 2014).

In the cultural context of Australia, family members of older immigrants of CALD backgrounds have often successfully assumed the primary care of their older relatives with a chronic illness over an extended period of time (Federation of Ethnic Communities Councils of Australia, 2015). However, as older relatives approach the end of their lives and their symptoms become unmanageable at home it becomes necessary for them to be admitted to hospital for EOL care. It has been conservatively estimated, for example, that between the years of 2011 and 2025, the number of older immigrants of CALD backgrounds aged 65
years and older in Australia will increase from approximately 650,000 to around 950,000 (NSAPAC, 2011). There is emerging evidence to suggest that this population will have higher rates of hospital admissions and hospital bed utilisation in the last year of life compared with the Australian-born population (Chan et al., 2003; Rao, Warburton, & Bartlett, 2006).

The “terror of death”

There is one thing in life that is certain: we are all going to die. Acknowledgment of this fundamental universal truth about the human condition has the capacity to cause in people paralysing fear and anxiety – commonly termed “death anxiety”. As Ernest Becker (1973) has famously written, the knowledge that “one is food for worms” gives rise to a profound terror of death, which he describes in the following terms:

This is the terror: to have emerged from nothing, to have a name, consciousness of self, deep inner feelings, and excruciating inner yearning for life and self-expression – and with all this yet to die (p. 87).

The terror of death that human beings have, their desire to transcend this terror, and the strategies they use to keep their death-related fears and anxieties contained have all been well documented (Bauman, 1992; Becker, 1973, 1975; Firestone & Catlett, 2009; Kubler-Ross, 1969; Ma-Kellams & Blascovich, 2012; Rudert, Reutner, Walker, & Greifeneder, 2015; Solomon, Greenberg, & Pyszczynski, 2015). A principle mechanism by which people keep their terror of death and related anxieties contained is human culture, which, as Solomon et al. (2015) have shown, serves to infuse people’s lives with order, stability, significance and purpose. If, for some reason, the death-anxiety buffers that human culture provides fail, people’s terror of death can break through (Becker 1973, 1975). This is because without the necessary buffers that human culture provides and the shared cultural worldviews (ultimate
values and beliefs) it makes possible, people are confronted by reminders of their own inevitable mortality, which in turn can leave them feeling vulnerable, helpless, insignificant, and uncertain (Becker, 1973; Johnstone, 2012).

It is well established within the field of social psychology that the capacity of different people to manage their death anxiety is “culturally contingent and a by-product of culture-specific epistemologies” (Ma-Kellamns & Blascovich, 2012, p. 773). In other words, how different people and groups respond to and manage their death anxiety is profoundly influenced by cultural factors (Simon, 2014). This perhaps helps to explain why people from diverse cultural and language backgrounds, even when old and anticipating death, may have their death-related anxieties (e.g., about their significance, dignity and worth as human beings) amplified when admitted to hospital for EOL care (see Bowling et al., 2010).

Hospitals are potent reminders of one’s inevitable mortality (Johnstone, 2012). A person’s cultural worldviews which would ordinarily buffer them against their terror of death may be threatened, either advertently or inadvertently, by the normative contours and normalised practices of “the system” (see also Bosma, Apland & Kazanjian, 2010; Johnstone, 2012). In other words, by their very nature, hospitals constitute “mortality salient” environments – that is, their very setting, situation, and symbolism all serve as powerful reminders of the inevitable mortality of human beings (Johnstone, 2012). The mainstream cultures of hospitals and the health care professionals working within them can sometimes seem threatening to people whose cultural worldviews differ from those reflected in the cultures of the hospital environment and staff (Johnstone, 2012; Johnstone & Kanitsaki, 2009). In clinical contexts where EOL care is provided the “threats” posed by the system can seem even greater and can risk undermining processes otherwise essential to patients being enabled to experience a good death.
International research suggests that the fear of death and related anxieties in ethnically diverse populations are greater than that experienced by more homogenous populations. A UK study, for example, has found that ethnically diverse people were more likely than their British counterparts “to express fears about death and dying on all measures” (Bowling, Iliffe, Kessel & Higginson, 2010, p. 197). Contrary to expectations and myths about older people (e.g., that they are accepting of death) and ethnic minorities (e.g. that they always “look after their own”), the study also found older people had more anxieties about death and dying than did their younger counterparts, and that having family support was not necessarily protective against death anxiety (Bowling et al., 2010).

The cultural and language diversity of Australia’s aging population has significant implications for the planning and delivery of culturally appropriate EOL care for older immigrants of CALD backgrounds admitted to hospital at the end of their lives. Despite a growing recognition of the importance of providing EOL care that is “culturally appropriate” for patients of diverse cultural and language backgrounds, there is a lack of Australian research systematically investigating cross-cultural considerations in EOL care for older immigrants of CALD backgrounds and the influence that culture might have on the provision of appropriate care (Broom, Good, Kirby & Lwin, 2013; Hiruy & Mwanri 2013; Johnstone, Hutchinson, Rawson & Redley, 2015; McNamara, Martin, Waddell & Yuen, 1997). This is so despite calls by some international researchers for “culture” to be made a priority in EOL care research (Gysels et al., 2012).

There have been only a limited number of Australian studies specifically investigating issues concerning the nursing care of older immigrants of CALD backgrounds in acute care settings (Cioffi 2006, 2013; Johnstone, Hutchinson, Rawson & Redley, 2015). There are also gaps in knowledge about what has been termed “culturally conscientious thanatology” which
entails a “conscientious appreciation and awareness of diversity” when working with people who are dying and the bereaved (Bordere, 2009, p.1).

Of the reported Australian studies located in the context of this study, only one (Johnstone, Hutchinson, Rawson & Redley, 2015) has had as its focus older immigrants of CALD backgrounds admitted to acute care hospitals for EOL care. Thus little is known about the kinds of strategies nurses use to identify and help ease the terror of death and related anxieties that older immigrants of CALD backgrounds may experience when hospitalised for care at the end of their lives. Adding to this, death anxiety itself (the factors contributing to it, how it is experienced, how practitioners manage it) stands as an under-researched area in nursing as it is in other fields concerned with the provision of quality EOL care, including palliative care (Simon, 2014).

Nursing care provided during the final days and hours of life can have a profound effect on the patient and his or her family, and whether or not the patient experiences a good death. Because of being at the bedside during the dying process, nurses are able to assess, identify and respond in a systematic way to patient and family fears (both existential and practical) about dying and the inevitability of death (Adams, Bailey, Anderson, & Docherty, 2011; Huang, Yates & Prior, 2009; Leung & Esplen, 2008). However, just what nurses do to identify and help manage death anxiety in older immigrants of CALD backgrounds hospitalised for EOL care is unknown.

**Aim of the study**

This paper is drawn from the findings of a larger study that aimed to explore and describe nursing roles and strategies in EOL decision-making involving older immigrants of CALD backgrounds hospitalised for EOL care (Johnstone, Hutchinson, Rawson & Redley, 2015). The specific aims of the larger project were to explore and describe:
• What nurses know and understand about culturally responsive EOL care.
• What nurses perceive and understand their roles to be in EOL decision-making concerning older immigrants of CALD backgrounds admitted to hospital at the end of their lives.
• What strategies nurses use to engage in EOL decision-making concerning older immigrants of CALD backgrounds admitted to hospital and needing EOL care.
• What nurses perceive and understand to be the relationship between their EOL decision-making and the “quality of death” outcomes for older immigrants of CALD backgrounds and their families in hospital contexts.

A serendipitous finding made in the larger study was that nurses perceived they played a fundamental role in identifying and assuaging the “terror of death” and related anxieties in the hospitalised older immigrants of CALD backgrounds they were caring for. The aim of this current paper is to describe and report the strategies nurses used to identify and help assuage the terror of death and related anxieties they perceived their older immigrant patients and families experienced during periods of hospitalisation for EOL care.

Methodological issues

Method

The larger project was undertaken using a qualitative exploratory descriptive (QED) design informed by the works of Lincoln and Guba (1984) and Patton (2002). This approach was chosen because it is a highly pragmatic approach that enables “quite concrete and practical questions to be addressed by people who are working to make the world a better place (and wondering if what they are doing is working)” (Patton, 2002, pp. 135-136). Full details of the larger study have been reported elsewhere (Johnstone, Hutchinson, Rawson & Redley, 2015).
Setting

This study was conducted in the Australian state of Victoria. This state has the second largest multicultural population in Australia, with 26.2% of its population born overseas in more than 200 countries and more than 22% of its population speaking a language other than English at home (Victorian Multicultural Commission, 2013). Participant recruitment occurred across four major health services located in metropolitan Melbourne and regional Victoria, Australia. A purposeful sample of 22 registered nurses was recruited from these sites.

Participants

Participants were recruited via a range of strategies including: the placement of advertisements in the newsletters and on the homepages of professional nursing colleges and associations, news reports on the project in the nursing media, direct invitation via seminar presentations at the participating health services, and snowballing technique via professional networks. Those who expressed an interest in the project were contacted by email or telephone and provided with a letter inviting them to participate. They were also given a plain language statement explaining the project and what their involvement would entail. If requested, further information was provided at the time of interview. The selection of participants was based on the following inclusion criteria: holds current registration as a nurse; practising in a hospital in the State of Victoria; and has been and/or is involved in the care of immigrants of CALD background aged 65 years and older admitted to hospital during the past five years for EOL care. Of the 22 nurses recruited to the study, 11 worked in medical-surgical wards and critical care (coded AC), eight worked in acute palliative care (Coded PC), and three worked in the aged care sector (Coded AG). The final number of participants interviewed was determined by the point at which data saturation was achieved.
As has been previously reported, the majority (91%) of participants were female and, of those who completed the demographic questionnaire, most (82%) had been in their current position more than 5 years (range 1-20 years). Eleven participants indicated they had undertaken postgraduate studies (postgraduate certificates [n=3], postgraduate diplomas [n=1], master degrees [n=7]), with four (20%) indicating that they had completed their highest professional qualification in the last five years. None of the participants had undertaken any formal education on cross-cultural considerations in EOL care.

**Ethical considerations**

Ethics approval for the study was granted by the University Human Research Ethics Committee as well as by the institutional ethics committees of the four participating health services from which recruitment occurred. All participants gave their informed consent prior to their inclusion in the study. Subsequently all identifying information such as names and institutional affiliations was deleted from the transcripts and replaced with codes.

**Data collection**

Data collection occurred throughout the duration of the study which was conducted over the calendar year of 2014. Two sets of data were collected: *demographic data* – obtained by participants completing a demographic data sheet developed by the research team; and *interview data* – obtained via in-depth, semi-structured individual interviews conducted either face-to-face (n=13) or via telephone (n=9). Interviews were conducted in a conversational style and guided by 14 broad open-ended interview questions, which have been reported previously (Johnstone, Hutchinson, Rawson & Redley, 2015). Interviews lasted between 35 and 90 minutes (average length of time 60 minutes). All interviews were audio-recorded and transcribed verbatim by a professional transcriber.
**Data analysis**

Data were analysed using the content and thematic analysis strategies described by Patton (2002) and involved the following steps: verbatim transcription of the audio-recorded interviews; active reading of the data (asking questions while the transcripts were being read); annotating data; and creating and assigning categories. In using these steps, data were searched for patterns, linkages and plausible explanations (Patton, 2002). Initial data configurations were reconfigured in an attempt to find other ways in which the data could be interpreted or organised and which might have led to different findings. Rival configurations and organisation of themes or competing explanations that were not supported by the data were either dropped or modified (Patton, 2002). Conversely, configurations, themes and explanations that were supported by the data were judged to have the best “fit” namely between data and analysis, and were retained (Lincoln & Guba, 1985; Patton, 2002).

**Rigour**

To ensure the methodological rigour of the study, due attention was given to upholding the principles of credibility, fittingness, auditability, confirmability, and triangulation as described by Patton (2002). In the case of triangulation, two forms were used. The first of these, *source triangulation*, was achieved by recruiting participants from across several geographic sites and two areas of practice (acute care, acute palliative care) and examining the consistency of different data sources within the same method. The second form, *analyst triangulation*, was achieved by the four named co-authors of this report analysing the data and comparing their respective individual findings.

**Findings**

Analysis of the data revealed that nurses used three core strategies to help allay the death-related anxieties (including fear of the dying process itself) that older immigrants of CALD
backgrounds and their relatives were perceived to experience during episodes of hospitalisation for EOL care. Detailed findings are presented under the following themes: recognising death anxiety; delineating the dimensions of death anxiety; and initiating conventional nursing caring behaviours to help contain the death-related anxieties that had been discerned in the hospitalised older immigrants and their relatives.

**Recognising death anxiety**

Essential to participants assuaging their patients’ death anxiety was recognising behaviours that were indicative of their terror of death. Participants recounted several cases in which they had correctly recognised that either an older immigrant patient or his/her attending family members were consumed by fears and anxieties related to the dying process and the death that was imminent. One standout example involved the case of a Greek-born man who did not speak English. Remembering this man, a palliative care nurse participant reflected:

You could see the anxiety around 'I'm dying, I'm dying, I'm scared' - he had a fearful component to that [...]. He was making the sign of the [orthodox Greek] cross on multiple occasions and saying 'I'm terrified' (PC03, p. 5).

**Delineating the dimensions of death anxiety**

Participants believed that the terror of death and related anxieties experienced by older immigrant patients and their families during hospitalisation encompassed three key dimensions: fear of the unknown, fear of not having lived a meaningful life, and fear of leaving behind loved ones.

*Fear of the unknown*
Participants believed that a key component of the fear of dying experienced by older immigrant patients and their families was a fear of the unknown; as two participants working in acute care stated respectively:

I think people are afraid of the unknown (AC09, p.23)

Whether it's the family or the patient - it's usually fear - fear of the unknown (AC04, p.25).

*Fear of not having lived a meaningful life*

Participants revealed that they commonly encountered situations in which the most pressing issue for their patients was reconciling the meaning of their lives and determining whether their lives had “mattered”. They revealed that many immigrants who had left their country of birth 40 or 50 years earlier in order to build a better life for themselves and their children often pondered whether their immigration had been “worth it”. In response to their patients’ existential reflections, respondents would embark on a process of “tracing over the patient’s life-journey” from their early lives in their country of origin to their later new lives in Australia. As one palliative care nurse participant recounted:

What I will sometimes do is explore the meaning of the patient’s life – what did they do? What sort of work did they do? And children, family. Often when they start to talk about the meaning of their lives they start to reflect ‘Gee, in actual fact, I have achieved a lot, there’s a lot I can be proud of’ (PC01, pp.11-12).

Participants acknowledged that sometimes, despite their best efforts, they could do nothing to ease the death anxiety of their patients. As one palliative care nurse explained:

Sometimes people find it really hard to actually get any sense of having achieved anything [in their lives] and that’s more difficult. That’s really hard. I have had that situation where people feel that they’ve been a failure (PO1, p.12).
Helping to assuage death anxiety in these and other patients was particularly challenging when they were contemplating the reality that soon they would not exist anymore:

It's often about not being here, not existing anymore and that's a really hard one. I can't just wave a magic wand and make that better [...] I'm thinking of a patient just recently who was really angry about the fact that he wasn't going to be here ... and he said 'Well, I'm dying. WHAT DO YOU THINK?' He was quite nasty in his response, asking those questions (PC01, p.11).

The participant involved in this case went on to recount, however, how she got the patient transferred to a palliative care unit and promised that she would “drop in and see him”:

I popped down one day after work. He was so pleased to see me, he burst into tears. He couldn’t apologize enough for the way he spoke to me [previously]. ... He was so proud of his boys and he was just so grateful that I was actually able to allow him to put some words around that (PC01, pp. 11-12).

**Fear of leaving behind loved ones**

A concomitant dimension which participants had deduced from their years of practice in providing EOL care was that once either the patient or family had recognised that death was imminent they began to fear the commensurate loss that would inevitably follow. Specifically, either the patient could not face letting go of the living (their family) or, conversely, the living (the family) could not face letting go of the dying (their loved one). As explained by two acute care nurse participants:

I think people's fear of death [involves] their not wanting to leave the family. That is from all ages - from the 25-year-old girl who has just become a mother and got a terminal illness to the 89-year-old man who has got a tumour bulging out of his eye. Every single person is the same (AC09, p.23).
Sometimes it is that they can't let go, that they don't want to see that patient drowsy, they still want to talk to that patient. [...] Sometimes they just want to take [the morphine] away and they think if we take that away the patient is going to come back to us (AC07, p.10).

**Assuaging death anxiety**

To help ease the death anxiety they had recognised in their older immigrant patients of CALD backgrounds and families, participants used three key nursing-specific strategies: having a discernible presence at the bedside (also termed “presencing”), providing iterative explanations, and giving reassurance.

**Presence at the bedside**

As previously reported, participants in the larger study believed it was extremely important for both patients and families not to be left feeling as though they were having to deal with the dying process “on their own” (Johnstone, Hutchinson, Rawson & Redley, 2015). In the component of the study being reported here, participants identified a range of nursing-specific behaviours they believed helped alleviate the loneliness of and related fears concerning the dying process and the inevitability of death. These included: being “readily available”, “having a discernible presence at the bedside”, “making gentle inquiries about the patient’s wellbeing”, “constantly checking yet, at the same time, ‘giving space’ to the patient and the family”, and “providing attentive care so family can feel everything is still being done”. Participants clarified, however, that having a discernible presence at the bedside did not mean that nurses had to be constantly in attendance. As one acute care nursing participant explained:
You don't need to be there [all the time]. Give them their space. Don't watch over them, don't hover around them. Give them their space. *But [let them] know that you're there and just pop back in [to the room] every so often so they know that you're there and ask ‘Can I do anything?’* (AC11, p.15).

*Providing iterative explanations*

Participants strongly believed that an essential part of assuaging a patient’s or a family member’s terror of death and the dying process was providing frequent and ongoing explanations about what was happening, the cares that were being planned and/or provided, and why. One of the reasons for this was that, in their view, most of the families they had dealt with had had a naïve view about death and the dying process. Participants believed that the various views that family members held about death and dying tended to be informed by dramatic death scenes played out in film or various mainstream television shows, not life experience. Accordingly, it was necessary for them to provide family members with iterative explanations about the dying process and what to expect. As two acute care nurses reflected:

> Having someone [i.e., the nurse] who would [help them to] understand the nature of death – that you become sleepier, you spend more time in bed, you eat less, that that's all natural. So they [the family] wouldn’t be traumatised by weight loss, changes in breathing (AC01, p.7).

> So [we] might be telling them about breathing – that it might be getting a little bit noisy but it's not making them uncomfortable; or it might be about pain or it might be about colour changes in the skin. Being able to honestly answer questions that the family have about what's happening and why it's happening and to actually be able to help them through it (AC02, pp.9-10).
Another participant sought to allay the fear she observed in family members by constantly, but discreetly checking on the patient's condition, and inquiring gently, “See there's a little bit of restlessness happening. Do you think morphine should help her? How do you feel about it? Should I give her morphine?” (AC06, p.15).

Participants acknowledged, however, that it was often difficult to help patients come to terms with their existential anxiety about dying when they did not speak the same language as their patients. As one participant reflected:

They're facing death and probably can't communicate that to many people in their language. I think if I had to communicate fear in Italian or Greek, having learnt it from the age of 30 or something, it would be horrendous, because I've got to use the words that would come from my heart. Your mother's language is your emotional language. So if you can't use that language, you can't express yourself (AC01, p.9).

Offering reassurance

In addition to the above strategies, participants believed it was essential to constantly provide patients and families with reassurance, which basically entailed providing families with the opportunity to ask questions and to be given honest and satisfying answers:

I sometimes ask the family ‘How can I help you? Is there any more information that you need? Is there anything I can do? Is there anything that your father would like, prefer? Do you need some more information about what's going on?’ (AC04, p. 26).

Sometimes this approach required nurses to repeatedly answer the same or similar questions raised by different family members:

I do find they [families] may keep asking different nurses the same question. Some nurses will say the same things, some nurses they have different views and different opinions (AC07, p.10).
It was recognised, however, that with some cultural groups – particularly those that operated on a collective family decision making model – this repeated questioning by family members was a means of seeking reassurance that their loved one was being well cared for:

Generally everybody is on the same page, we all want to give that patient peace … Maybe they [the family] want to get a clear idea, they want to make sure everybody is on the same page, they want to make sure we're doing the right thing for the patient (AC07, p.10).

It was also recognised that not all patients or their families wanted to engage in deep existential conversations about death and/or the prospect of dying. As one palliative care nurse participant explained:

Some people can get a bit evangelical in palliative care, you know ‘patients must discuss their fears and patients must discuss this and that’. But over the years I've just come to see such variety and diversity that to me, it's not about ticking boxes about what ‘must’ be discussed. It's just about allowing opportunities and helping staff have the skills so that if an opportunity arises for an important discussion, they're going to be comfortable [with that]. Because those important discussions, as we know, can come up at any moment and not necessarily when the health professional goes to the bedside ready to give that opportunity for the discussions to happen (PC02, p.19).

Discussion

The findings of this study were a surprise as they we not in keeping with what we had expected. When progressing the component of the study being reported here we had anticipated that our findings would emphasise important cultural differences rather than similarities in the management of the death-related anxieties that participants had observed in their patients. We had also thought that they would reveal the use of “culturally tailored”
nursing strategies to help assuage the death-related anxieties discerned in their patients. While it is noted that the issues of language differences between nurses and patients, patients coming to terms with whether their immigration to Australia “had been worth it”, and collective family decision making were identified as salient areas of concern, they were not preeminent. Instead, what was revealed was a shared and common human reality in regard to the universal terror of death (discussed in the introduction to this article) and the universal cultural mechanisms that nurses might use to successfully help assuage this terror and related anxieties when caring for older immigrant patients from CALD backgrounds. It is noteworthy that a similar finding was made by McGrath, Vun and McLeod (2001) and, taken together with the findings of this study, underscores what transcultural nurse theorist Madeleine Leininger (1988) has described as “culture care universality”, that is, the “common, similar, or uniform meanings, patterns, values, or symbols of care that are culturally derived by human beings for their wellbeing or to improve a human condition and lifeway or to face death” (p. 156).

The above finding highlights an important although often understated observation made by McGrath et al. (2001) that “there is a danger inherent in too exclusively focusing on ethnic difference” which may inadvertently “disguise the essential similarities in the dying experience across cultural groups” (p. 311) – an observation also made by Bosman et al. (2010). It also highlights that cultural similarities can be just as important as cultural differences when caring for people from diverse cultural backgrounds and which can be meaningfully appealed to in order help to assuage the existential anxieties patients may experience when confronting the inevitability of their own mortality.

Managing death anxiety has been identified as an important element of EOL nursing care and as being essential to achieving patient comfort and “quality death” outcomes (Lodhi et al., 2014; Huang et al., 2009). Suggested nursing interventions for achieving a quality
death in patients who are dying include, but are not limited to, what are in essence universal cultural practices: providing emotional support, symptom management, grief work facilitation, presencing, active listening, family support, mood management, patient and family education, bibliotherapy, reminiscence therapy, culture brokerage, and several more (Bulechek, Butcher, Dochterman, & Wagner, 2013, p.484). These and other EOL care nursing interventions are aimed primarily at making the dying process as comfortable as possible for the individual and those around him or her (including family, friends and caregivers) and to render their deaths “culturally meaningful” in human terms (Timmermans 2005, p.993).

The strategies used and described by participants in this study were strongly aligned with conventional nursing interventions used in the provision of EOL care. However, they were also consistent with the lesser known process called “death brokering” (Timmermans 2005). According to Timmermans (2005, p.993) death brokering is a process whereby, as death approaches and occurs, health professionals help negotiate “a culturally acceptable passing” and “broker” or negotiate “the existentially frightening and ambiguous aspects of death and dying”. In short, it is a process whereby patients and their families are helped to negotiate the “ambiguity of finite living” (Timmermans 2005, p.995).

Although not clearly articulated as such, the interventions described by participants in this study were perceived to work by helping their older immigrant patients of CALD backgrounds to regain a sense of order, stability, significance and purpose in their lives, all of which had ostensibly been threatened by their admission to hospital and the salient reminder their hospital admission represented apropos their inevitable mortality. There is scope to suggest that the conventional (“universal”) nursing interventions that the participants used (notably of giving presence at the bedside, providing iterative explanations about what was going on, and offering constant reassurance) helped to assuage the death anxiety their patients
were experiencing by virtue of buffering the feelings of vulnerability, helplessness, insignificance, and uncertainty they were experiencing.

Being present with patients – also called “presencing” (Benner. 1984, p.57) – has long been recognised as being pivotal in the nurse-patient relationship and as an effective nursing intervention for helping to ameliorate the suffering and vulnerability of patients when hospitalised for care (Boeck, 2014; Hessel 2009; Osterman & Schwartz-Barcott, 1996; Zerwekh, 1997; Zyblock, 2010). Although a contested notion, it is generally agreed that both the value and act of being present rests on

the ability of the nurse to create a space where the patient can be in deep contact with his or her own suffering, to allow the patient to share with a caring individual, and to assist the patient to find his or her own way forward through the health experience (Zyblock, 2010, p.120).

In this study, and in keeping with the theoretical literature on presencing, by consciously and mindfully engaging in presencing – i.e., “being there, listening, feeling close, touching, and attentively giving physical care” (Zerwekh, 1997, p.261) and giving their patients “space”– the participants were able to: affirm the dignity and worth of their older immigrant patients, help their patients to create a sense order and stability out of chaos (McKirvegin & Day, 1998) and, ultimately, empathically ameliorate the vulnerability that their patients and attendant families were experiencing (Boeck, 2014).

Providing iterative explanations has been identified in the health professional literature as a process that is essential to a nuanced and appropriate response to helping patients deal with the existential anxieties raised by hospitalisation for EOL care (Dose et al., 2015; Lehto, 2012). As a process, it encompasses ensuring that the patient and family receive “clear and relevant information”, that the necessary time is taken “to listen and to understand the situation from the patient’s point of view”, and that health care providers tailor their
communication in accordance with the patient and family’s understanding of what is happening. Such an approach has been identified as also being helpful in providing quality EOL care to individuals who have unresolved regrets and concerns about the past (see also Rudert et al., 2015), who are finding it difficult to reconcile the ambiguity of a finite existence, and who are otherwise struggling to find meaning and purpose in their lives before they die (Lehto, 2012; see also Ma-Kellams & Blascovich, 2012). The findings of this study affirm this view. By taking the time necessary to listen and to understand the situation from the patient’s point of view and tailoring communication in accordance with the patient and family’s understanding of what is happening, participants in this study were able to help their older immigrant patients to reflect on their lives and to recognize that these had not been in vain (recall the case of the angry man who discovered and was able to name the pride he felt in his sons). This outcome is in keeping with what has been theorised as “esteem building” (Solomon et al., 2015) and which enables people to feel that their lives had purpose and meaning, and that they had dignity and worth as human beings.

Providing “calm and empathetic reassurance” has also long being recognised in the literature as being critical to helping patients and families in the last hours of living (Ferris, von Gunten, & Emanuel, 2003; Billings, 2011). Making patients and families feel confident that they will not be abandoned as death approaches and that the nurses will take as much time as is needed to care for them during the dying process are also essential to providing reassurance (Reinke et al., 2010). Through their presencing and providing iterative explanations of what was going on, participants in this study believed that they were able to reassure their patients that they would not be left alone to deal with what was unfolding around them and to temper their sense of vulnerability and uncertainty as they grappled with the ambiguity and inevitability of their mortality.
As previously reported, participants in the larger study had not received any formal education of how to provide culturally responsive EOL care and worried that they would “do the wrong thing” (Johnstone, Hutchinson, Rawson & Redley, 2015). As one participant had commented: “I didn't want to be responsible for this person going to hell […] Or their spirit not being pure because of something that I'd done through ignorance” (AC.04, pp. 9 & 10). Even so, participants were willing to engage with their older immigrant patients of CALD backgrounds, despite their cultural differences. Moreover, the data suggests that the participants had no reservations about dealing with death anxiety per se or their capacity to provide high-quality care that was inclusive of strategies aimed at mitigating the impact of their patients’ death anxieties despite the cultural differences at play. This is in contrast to other studies which have suggested that nurses often feel inadequate in the provision of EOL care generally (let alone with patients from diverse cultural and language backgrounds), experience stress and fatigue as a result of providing EOL care, and often feel a sense of incompetence when caring for a significant number of dying patients (McCourt, Power, & Glackin, 2013). One explanation for this may be found in the fact that the majority of participants in this study had a palliative care nursing background. Research in this area suggests that nurses who have had a specific palliative care education tend not to have a fear of death and experience less difficulty than do other nurses in managing death anxiety in patients (Peters et al., 2013a, 2013b; Simon, 2014). Another explanation can be found in what has been previously reported, namely, the participants exhibiting “cultural humility” when caring for patients whose cultural lifeways were unfamiliar to them (Johnstone, Hutchinson, Rawson & Redley, 2015; see also Frondona, Baptiste, Reinholdt, & Ousman, 2015; Tervalon & Garcia 1998).

In the case of the fear the participants otherwise had of “getting it wrong” when caring for patients whose cultural lifeways were unfamiliar to them (reported previously – see
Johnstone, Hutchinson, Rawson & Redley, 2015), contrary to Gunaratnam’s (1997, 2008) theorised view that multiculturalism in palliative care and fears of “getting it wrong” can erode caregivers’ emotional and moral engagement with patients, our study found the opposite. Concerns about “getting it right” actually emerged as the primary driver for participants to “give a little bit of themselves” (Johnstone, Hutchinson, Rawson & Redley, 2015) and to engage emotionally and morally with their patients and families.

**Strengths and limitations**

The key strengths of this study are twofold. First is the contribution it makes to highlighting assuaging the terror of death and related anxieties as an essential ingredient of quality EOL care for older immigrant patients of CALD backgrounds. Second, is the contribution it makes to a deeper understanding of the interventions used by nurses to identify and help assuage the death anxiety that older immigrant patients of CALD backgrounds and families may experience during episodes of hospitalisation for EOL care. Analysis of the data revealed that through their interventions, the nurses in this study co-created a context of care and shared cultural meanings within the hospital setting, which fostered in the patients and their families a sense of certainty and stability. This contextualisation, in turn, was perceived as helping to soothe the fear, uncertainty and isolation that patients and their families initially felt upon encountering the unfamiliarity of the hospital environment. A limitation of the component of the study reported here is that it has had as its focus the views and accounts only of nurses involved in the EOL care of older immigrant patients of CALD backgrounds. Future comparative studies investigating the views of older immigrant patients of CALD backgrounds themselves and their families would help validate the findings made and conclusions drawn. A deeper inquiry into the particular cultural nuances and worldviews that help assuage the death anxiety that older immigrant patients of CALD backgrounds and their
families experience in the context of hospitalised care would also strengthen the knowledge base of nursing practice in this domain.

**Conclusions**

In this study participants described three key strategies which they used to help assuage death anxiety in older immigrant patients of CALD backgrounds hospitalised for EOL care. These were: recognising death anxiety; delineating the dimensions of death anxiety; and initiating conventional nursing caring behaviours to help contain the death-related anxieties that had been discerned in the older immigrant patients of CALD backgrounds being cared for. While these strategies were used in the specific context of giving EOL care to older immigrant patients of CALD backgrounds, the insights gained and the lessons learned are amendable to being applied to older people from all (not just “minority”) cultural backgrounds when hospitalised for EOL care. Meanwhile, although the findings of this study contribute to the growing body of knowledge on providing culturally responsive EOL care to immigrants and ethnic minorities, it does not fill the gaps that currently exist in regard to how nurses identify and manage death anxiety in older immigrant patients of CALD backgrounds hospitalised for EOL care. A dedicated program of internationally comparative, cross-cultural collaborative research redressing these gaps would improve both knowledge and practice in the EOL care of older immigrant patients of CALD backgrounds. Since the phenomenon of death anxiety and the existential questions it raises are extremely complex – and indeed far too complex to be addressed by a single discipline (e.g., nursing, social psychology, etc.) or profession (e.g. nursing, medicine, etc.), within a single cultural context (e.g. Australia, UK, USA, etc.) – a cross-disciplinary collaborative approach is also called for. We hope that the findings presented in this paper provide a catalyst for a robust and long overdue program of research to be developed and progressed in this area.

**References**


Cultural-Study-on-Behaviors-When-Death-Is-Approaching-in-East-Asian-Countries-
What-Are-the-P


Peters, L., Cant, R., Payne, S., O’Connor, M., McDermott, F., Hood, K…. Shimoinaba, K (2013b). Emergency and palliative care nurses’ levels of anxiety about death and coping


