

## What are the priorities for developing culturally appropriate palliative and end-of-life care for older people? The views of healthcare staff working in New Zealand

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### What is known about this topic

- Similar to the worldwide trend, New Zealand's ageing population is predicted to increase to 25% by 2051.
- Good end-of-life care is fundamental to all, regardless of age or cultural heritage.
- Cultural factors can shape care preferences at the end of life.

### What this paper adds

- Making assumptions about end-of-life care preferences based on cultural heritage reinforces stereotypical beliefs and masks individual preferences.
- Enabling family to provide end-of-life care may require health and social care staff to take a step back and relinquish their role as 'expert provider'.
- Care staff can provide an educative role and support the family to provide 'hands-on' care.

### Introduction

In common with many other developed countries, New Zealand is ethnically and culturally diverse. Whilst 67.6% of the population self-identifies as European, significant numbers report a non-European ethnicity including Māori (14.6%), Asian (9.2% – the majority of whom are Chinese and Indian) and Pacific Islanders (6.9% – the majority of whom are Samoan, Cook Island

### Abstract

This paper explores the views of healthcare staff regarding the provision of culturally appropriate palliative care for Māori, Pacific Island and Chinese elders living in Auckland, New Zealand. The ageing population is culturally and ethnically diverse and, along with other developed countries experiencing high levels of migration, the challenge is balancing the rise in numbers of older people from different ethnic and cultural groups with end-of-life care, which reflects personal values and beliefs. Two joint interviews and ten focus groups were conducted with eighty staff across a range of primary, secondary and speciality care settings in 2010. The findings demonstrated that participants viewed the involvement of family as fundamental to the provision of palliative care for Māori, Pacific Island and Chinese elders. For Māori and Pacific Islanders, healthcare staff indicated the importance of enabling family members to provide 'hands-on' care. The role of family in decision-making was fundamental to the delivery of and satisfaction with care for older Chinese family members. Care staff highlighted the need to be cognisant of individual preferences both within and across cultures as a fundamental aspect of palliative care provision. The role of family in 'hands-on' palliative care and decision-making requires care staff to relinquish their role as 'expert provider'. Counter to the prioritisation of autonomy in Western health-care, collective decision-making was favoured by Chinese elders. Providing families with the requisite knowledge and skills to give care to older family members was important. Whilst assumptions are sometimes made about preferences for end-of-life care based on cultural values alone, these data suggest that care preferences need to be ascertained by working with family members on an individual basis and in a manner that respects their involvement in palliative care provision.

**Keywords:** culture, end-of-life care, ethnicity, older people, palliative care

Māori and Tongan) (Statistics New Zealand 2006). Those who identify as non-European are predicted to increase in numbers over the next 20 years, particularly within older age groups (Statistics New Zealand 2010). This diverse ethnic mix will need to be considered in the development of palliative care services (Palliative Care Council of New Zealand 2011). According to Voltz *et al.* (1998), attitudes and beliefs towards death and dying can vary markedly and the provision of appropriate

palliative and end-of-life care for different cultural groups requires healthcare staff to be aware of, and sensitive to, an individual's values, norms and beliefs and those of their family and whanau (the Māori term to describe extended family members) and significant others (Clark & Phillips 2010).

The challenge in New Zealand is to balance the rise in numbers of older people from these ethnic groups with the provision of end-of-life care, which reflects their unique cultures, values and beliefs. According to Robinson & Ingleton (2011), however, it may not be easy to deliver a dominant 'Western' healthcare environment, in a manner that is acceptable in terms of their cultural heritage. Within the New Zealand context, the Treaty of Waitangi, signed between the British Monarchy and the Māori people, set the precedent for the way in which health services are now delivered. Based on the principles of partnership, participation and protection (Durie 1989), the Treaty underpins all social and economic policies in supporting the rights of indigenous peoples (against a colonial legacy), but is yet to be realised in terms of actual health gains for Māori (Ellison-Loschmann & Pearce 2006). Indeed, a number of disparities between Māori and non-Māori across a range of social, economic and major health measures have been reported (Robson & Harris 2007).

This paper draws upon focus group and interview data to explore the views of generalist and specialist palliative care providers working across a variety of settings, regarding the provision of culturally appropriate palliative and end-of-life care for older people in New Zealand who identify as non-Pākehā. Pākehā is a Māori term for New Zealanders who are not of Māori descent. They are mostly descendant from British and, to a lesser extent, Irish settlers of the 19th and 20th centuries, although some Pākehā have Dutch, Scandinavian, German, Yugoslav or other ancestry. The term 'generalist' refers to those who provide care to individuals affected by a life-limiting illness as an integral part of clinical practice by any care professional. 'Specialist' refers to those who have undergone specific training and/or accreditation in palliative care or medicine (Ministry of Health 2009). The views of healthcare staff are given precedence on the basis that the need to improve 'generalist' palliative care management is well recognized (Ministry of Health 2001) to help understand and develop new and innovative ways of working.

## Background

For the purposes of this paper, 'culture' is defined as the multiplicity of views that exist among individuals and groups and the internal and external manifestation of a person's values and norms that are learnt throughout the

course of a lifetime (Barnum 1998). The provision of culturally sensitive palliative and end-of-life care involves healthcare staff developing an awareness of how these norms and values can shape beliefs so that care can be provided in an appropriate manner (Crawley *et al.* 2002).

However, as Koffmann (2011) maintains, when applied to palliative care, 'culture' may serve only to restrict dialogue to 'an interpretative list of end of life care beliefs and practices from a range of so-called 'cultural' groups' (p. 117). Others have raised concerns about the deterministic links between cultural, ethnic or religious factors and end-of-life care preferences (often referred to as 'the cookbook' approach) (Jones 2005). Adopting this approach is one solution to caring for individuals from different cultural backgrounds; however, this may serve to foster new myths or stereotypes (Johnson & Jones 2002). As Kagawa-Singer & Blackhall (2001) note, there can be a wide variation in the beliefs and behaviours within any given population. From a Māori perspective, this is endorsed by Reid (2005) who warns of the dangers of making generalisations about individuals and groups based on their cultural identity alone. Rather, as Koffmann (2011) asserts, it is important to maintain a twofold approach to end-of-life care that acknowledges cultural values, but at the same time focuses on the individual, their care preferences and those of their family and significant others.

Originating in New Zealand, cultural safety was a concept first introduced into health-care to address Māori consumer dissatisfaction and reduce the impact of colonisation and culturally inappropriate practices in health-care in the 1980s (Dowell *et al.* 2001, Jacobs & Boddy 2008, Papps & Ramsden 1996). It has been identified as a framework that, when used by health and social care professionals, gives recognition to power imbalances, which are often inherent between care providers, the recipient and members of their family (Phiri *et al.* 2010). With cultural safety fundamental to philosophies of care for over three decades now, we argue that New Zealand, with its cultural diversity, is well placed to provide other developed countries experiencing high numbers of migrants with some major insights and strategies to help ensure culturally safe palliative and end-of-life care.

Few studies have examined the palliative and end-of-life care needs of Māori, Pacific Island and Asian populations in New Zealand. Research conducted in relation to Māori and Pacific Island populations has focused predominantly on barriers to specialist palliative care. These studies have highlighted a preference for the provision of end-of-life care at home by family members (Mann *et al.* 2004, Ryder-Lewis 2005, Little 2009, Lawrenson *et al.* 2010), the use of traditional medicines (Lawrenson *et al.* 2010) and the importance of

good communication skills for clinicians, particularly when dealing with large and often extended family groups (Ministry of Health 2003, Lawrenson *et al.* 2010). The work of Ryder-Lewis (2005) has also highlighted the extent of Māori and Pacific Island family involvement in the care of a dying family member and the challenges they face, as well as those encountered by care staff within institutional care settings.

Similarly, few studies have examined the experiences of Chinese elders in New Zealand regarding culturally appropriate end-of-life care. International studies have identified the involvement of family in decision-making and place of care as central to good end-of-life care; a preference for family members to make decisions about the patient's care and treatment has been reported (Bowman & Singer 2001, McGrath *et al.* 2001), as well as a tendency to withhold prognostic information on the basis that it might cause a loss of hope (Bowman & Singer 2001, McGrath *et al.* 2001, Chan & Kayser-Jones 2005, Hathaway 2009). Chinese participants in one study were less likely than their European counterparts to want the truth revealed about a terminal diagnosis (Waddell & McNamara 1997). The concept of individual rights has only recently begun to take influence amongst Asian populations; commentators have noted a preference for a concept of self enmeshed within family networks. This has been deemed a particularly important aspect for Chinese elders (Ho 1995, Fan 1997).

A common finding reported in the international literature is a preference within most Chinese families for a hospital death (McGrath *et al.* 2001, Seymour *et al.* 2007, Hathaway 2009). Reasons identified vary and include not wanting to be a burden to family, the accessibility of nursing staff and the maintenance of hope in the face of illness (Seymour *et al.* 2007). Death at home has been identified as something to be avoided because of family members' fears of 'contamination' (McGrath *et al.* 2001, Seymour *et al.* 2007). There is also evidence to suggest that hospice was considered an inappropriate place to die on the basis that admission could cause the individual to lose hope and a fear that they may be influenced by the spirits of those who had died there (Seymour *et al.* 2007, Bennett 2008, Hathaway 2009).

## Methods

These data were generated as part of a larger study of palliative care management in New Zealand and took place in 2010. Fundamental to this study was a consideration of the barriers to, and facilitators of, palliative care provision by both generalist and specialist providers. Eighty participants working in specialist (hospice and specialist palliative care teams  $n = 26$ ) and generalist palliative care settings (comprising GP surgeries, hospital-

based teams and residential aged care facilities  $n = 54$ ) took part in 10 focus groups and two joint interviews in Auckland, New Zealand. Healthcare staff working in aged residential care facilities ( $n = 30$ ) were specifically targeted as these represent critical settings for palliative care provision for older people. Sample size was determined by the principles of data saturation. Ethical approval for the study and written informed consent to interview participants were obtained prior to data collection. A specific question was posed in relation to the views and experiences of care staff regarding the provision of palliative and end-of-life care for Māori, Pacific Island and Asian populations – with a particular emphasis on Chinese elders. Participants were recruited from a range of care settings and disciplinary backgrounds (Table 1).

## Analysis

Focus group and interview transcripts were recorded and transcribed verbatim. A short background questionnaire containing a number of demographic details was also completed. Analysis incorporated key elements of a modified grounded theory approach (Charmaz 2006). Both researchers (GB and MG) read the transcripts

**Table 1** Participant demographics

Gender (%)	
Male	9 (11.25)
Female	68 (85)
Not recorded	3 (3.75)
Age range	20–69 years
Ethnicity (%)	
NZ European	44 (55)
Māori	3 (4)
Cook Island	1 (1)
Indian	6 (8)
Chinese	2 (2)
Other	22 (28)
None	1 (1)
No details	1 (1)
Job title (%)	
Consultant	5 (6.25)
Junior doctor	3 (3.75)
General practitioner	6 (7.5)
Practice nurse	4 (5)
Clinical nurse specialist	6 (7.5)
Other nurse	39 (48.75)
Allied health professional	4 (5)
Other	12 (15)
No details	1 (1.25)
Place of work (%)	
Acute hospital	5 (6.25)
General practice	12 (15)
Specialist palliative care unit	26 (32.5)
Aged residential care	30 (37.5)
Education/research	7 (8.75)

noting the core themes that emerged. Each researcher took the lead to identify further subthemes. The qualitative data analysis programme, NVivo (QSR International, Victoria, Australia), was used to manage and code the data. The coding frame developed was grounded in the data rather than decided a priori. These data highlight the pivotal role of family both in the provision of 'hands-on' care and in the decision-making process. They also demonstrated the need to take into account individual end-of-life care preferences which, according to the views expressed by participants, are integral to good care.

## Findings

The pivotal role of family: *'Having your family around you is greatly important'*

In ideal circumstances, participants indicated home as the preferred place of care in the final stages of life for Māori and Pacific Island elders, and highlighted the pivotal role played by family members in the provision of care. However, home was often described in symbolic terms – its meaning imbued with more than just a physical location:

They (Māori elders) want to be at home, they want to be surrounded by their familiar things, you know, pictures on the walls. If you go into Māori homes there's usually lots of photographs on the walls, you know their children, and grandchildren and parents and aunties and uncles. You know people that have passed on and people that are still here; they want to have all of that around them, all of their familiar stuff. (Hospice worker)

The importance placed on the role of older family members within extended family networks as carers for younger members was also identified as a reason why home was viewed as the preferred place of care. As the following excerpt illustrates, it is common place for some Māori and Asian families to live together in ways that enable them to carry out their duties of care:

...they [older family members] might still have childcare responsibilities where they're looking after their grandchildren while their children go out to work. You know because they all live together in the same house, which I think is something you don't see very often in non-Pacific Island or non-Māori families. I suppose you see it in Asian families too, they have the extended family situations, grandparents caring for grandchildren. (Māori Support Worker)

Within the context of institutional care settings, the enabling of family members to provide 'hands-on' care to their older relatives was a matter that participants saw as important. Rather than allowing staff to perform personal care, participants reported that family members

would work together, often forming a rota to undertake the role of main carer:

They (older Māori) don't like the nurse to do the cares and that sort of thing, they don't like people coming in and intruding and doing it, they do it their way. (Residential aged care worker)

Whilst this often worked well, participants also reported instances where their professional knowledge and duty of care ran counter to what they considered poor care being provided by family members. Accordingly, participants identified the importance of providing ongoing support to equip families with the necessary skills to provide care to dying elders:

I don't think there's enough on palliative care of Islanders, Māori, the Asian cultures there's not enough education for the families so that the families can do the care. Some of that care is quite specialist and they go in there gun ho and turn them over and they could be quite in pain. There's a lot to do with positioning and things like that and then managing the pain pump and you know, you need to have, the nurses need to be able to educate the family and then leave the family to it with support from the sideline. (Residential Aged Care Manager)

An appreciation of how family members experience the end-of-life care of a loved one, within the context of institutional care settings, can pose a challenge to health-care workers in determining whether service provision, characterised by the 'expert provider' philosophy of care, adequately and sensitively meets the needs of families. As the above excerpts highlight, providing family caregivers with appropriate support and education *'from the sideline'* so that they are able to participate in, rather than just observe end-of-life care is seen as fundamental to overall satisfaction. Whilst the role of family has been widely documented with respect to their involvement in paediatric palliative care (see e.g. Rosenbaum *et al.* 1998), these findings highlight the role that family can play in caring for older dying relatives, in enabling them to provide hands-on care in what can be a difficult and yet potentially rewarding time for those involved (Steinhilber *et al.* 2001).

Views associated with institutional care settings: *'Places like that really aren't set up to cope with large numbers of family'*

In spite of the pivotal role of family members highlighted previously, accommodating large family groups keen to be involved in care whilst balancing the needs of other people in institutional care settings was reported by participants to be challenging. Indeed, the ability to accommodate the needs of diverse groups within care settings was perceived as critical in supporting a positive experience:

For our Māori and Pacific Island families at [hospice] we have adjoining rooms so that we can open up rooms so that your family can be in one room, you're in the other room and there's an adjoining door so that, you know the family can be close by. We've had a few families that have taken advantage of that. You know we have a motel room sort of thing where families can be...not necessarily be in the room with them, but they're right on the spot if they're needed in a hurry. (Hospice worker)

In the case of hospice, accommodating large family groups was often achieved through the use of adjoining rooms while in residential aged care facilities, it was achieved by accommodating larger family groups away from other residents. This enabled families to remain close at hand to provide support and care but not intrude on other patients:

...the entire extended family comes in and, you know forms around the person who's deceasing and stay with them the whole time. And so we worked to make it so that they could do what they do really, but also not effect, as much as possible, the other clients. So what we tried to do was have this man's room, one of the rooms upstairs that is further toward the back, with excellent views of course, but separated a bit from some of the other rooms. So that when this huge group was coming in and out (laughter) they'd be privacy for other people and things like this. But they were very good about understanding too that there were other people there who were there who were unwell, and that they needed to observe other people's rights and things like that, so that worked out well. (Residential Aged Care Manager)

The physical environment of some institutional care settings was perceived to be a barrier to the provision of culturally appropriate palliative and end-of-life care. Participants claimed that hospice in particular was seen as an unwelcoming environment for some cultural groups, having historically served the needs of those from primarily white, Christian middle class backgrounds:

It's very hard from my experience of being in the community and the hospice...we definitely didn't have a large population of Māori patients on the books...maybe hospice was sort of seen as elite or the buildings, it just didn't seem to appeal. I think [hospice] have done really well with getting their Māori, they are very engrossed in it, in the Māori culture but [hospice] is seen as quite white, middle class... (Specialist Palliative Care Team)

...you were just saying that [Hospice] has made some important in roads but it still looks like a very, it still has got lots of crosses and things around and it still looks like a Catholic institution doesn't it? (Specialist Palliative Care Team)

Connecting with other diverse groups and adapting to the look and feel of the environment were considered

fundamental to the provision of culturally appropriate care. Initiatives to transform the environment were simple and, after consultation with Māori and Pacific Island groups in particular, had the effect of making hospice a more 'friendly' and welcoming environment for those groups, who historically have been underrepresented as hospice users:

With [hospice], we're just going through the process of redesigning our entranceway and they've asked me to have some input into that. And the main thing I've said to them is around making it more accessible and more Māori friendly, if you like, you know with native planting and, you know perhaps some artwork in the garden, in the entranceway there. And running water, and things like that, just to give it a more accepting feel. (Māori Support Worker)

*Autonomy versus dependence: 'Don't talk about it in front of Mum. Come out and talk in the lounge'*

In Western culture, full disclosure of health information to patients is considered important to enable individuals to make an informed decision about future care and treatment options (Beauchamp & Childress 1994). However, participants in this study identified different preferences surrounding the disclosure of health information. For example, participants expressed the view that Chinese patients in particular were not often in favour of receiving a prognosis of a life-limiting illness and preferred that this information be channelled through a family member acting as intermediary. This preference for withholding information from older family members was perceived as a particular challenge for some participants. Indeed, the rising population of Asian patients in the New Zealand healthcare system raised issues for participants concerning language, cultural practices and religious and health-related beliefs that ran counter to the western model of patient autonomy:

Well they're (Chinese) more family-oriented, like with one of our residents, we worked really well with the family um, you know, just in order to provide the care, well what the family wants for the resident rather than what the resident wants for themselves. (Residential Aged Care Worker)

Whilst informing the patient's relatives of a life-limiting illness prior to the patient himself/herself is a breach of the New Zealand Code of Health and Disability Commissioner (1996), participants noted the varying expectations and mix of involvement of patients, healthcare professionals and family, which posed significant challenges for care staff:

And they're [Chinese] over here, they don't speak the language at all, most of the problems with communication

around palliative care, you know, you need to be able to understand where someone's coming from...But try and do that with Asian families and they've got the culture of not wanting to go through the resident or the patient, you have to go via the family. It's a collective society, it's huge, huge, so for me, that, I have more of a concern about our Asian population, which is growing. (Nurse Educator)

Conversely, participants claimed that caring for Māori and Pacific Island elders was made easier by their belief system, which views death, dying and bereavement as central to life (MacLeod 2008). Heterogeneity of views across cultural groups was identified as a challenge to care delivery, but, at the same time, it was acknowledged that care staff should be cognisant of widespread variations both across and within those groups to facilitate culturally appropriate end-of-life care:

Whereas I think Māori and Pacific people are much better at, in general, in talking about death and, and prognosis and how much time have you got left. But yes, for the Asian people though, they very much want to, 'don't talk about it in front of mum,' you know? 'Come out, come out and talk in the lounge. (Nurse, General Practice)

The importance of individuality: *'Everybody that comes through our door needs something different from us'*

Whilst an appreciation of common cultural practices was helpful in being able to inform the delivery of care at the end of life, participants claimed that it was important not to make assumptions based on cultural heritage alone. Rather, they talked of the importance of maintaining an individualised approach:

...all I'm really saying there is that rather than make a generalisation that applies to everyone, you just have to individualise it and sometimes you get surprises. (General Practitioner)

Because some of those Māori patients will say they're Māori ethnically but that they do not recognize the Māori culture. (Hospice Nurse)

Although the care giver needs to establish how important cultural factors are to the individual concerned, too heavy a reliance may serve to obscure important individual differences. As the following participant alludes, the role and views of family are significant in establishing care based on need with the right mix of cultural awareness:

Well I think whenever you get a culture that is different whether it is someone that is deaf or Pacific Island or different to us the risk is that we treat people differently and I think we see that happening in hospital and yet what happens when we sit down with the family we find in the end we do the same work with those families it is about sitting down, finding where they are coming from, finding out what is impor-

tant to them, finding out how their family works, finding out what's the way this family normally structures things, who we need to talk to and actually that is the same we do with a Pakehā family. (Registrar, Specialist Palliative Care Team)

## Discussion

This study has explored the views of care staff regarding the provision of palliative and end-of-life care to Māori, Pacific Island and Chinese elders. Corresponding to Ryder-Lewis (2005), our findings reveal the extent to which Māori and Pacific Island families play a fundamental role in caring for an older dying relative. In line with Ryder-Lewis (2005), family is referred to in the broadest sense. They are not necessarily the nuclear family and might include cousins, aunts, uncles, neighbours, friends and even church groups as well as immediate family members. In line with the Treaty of Waitangi, this paper highlights the importance of working in partnership with family members as a way of ensuring culturally safe palliative and end-of-life care. Whilst some participants expressed anxieties in relation to relinquishing their duty of care to family members, working in partnership with families was considered fundamental. Participants expressed anxieties in relation to the constraints posed by the physical environment in accommodating extended families at the same time as balancing the needs of others being cared for in hospice, hospital and other institutional care settings. While Ryder-Lewis (2005) notes similar difficulties within the intensive care unit environment, our participants were able to manipulate the environment and accommodate larger families in residential aged care facilities and hospice. This was seen as key to good quality end-of-life care for Māori and Pacific Island families.

These findings resonate with the work of Reid (2005) who cautions against homogenising individuals based on their cultural heritage alone. A number of authors have argued that meeting an individual's 'cultural' needs forms only part of the bigger picture (Jones 2005, Payne *et al.* 2005, Elkan *et al.* 2007), but can, nonetheless, inform the delivery of end-of-life care (Cox *et al.* 2006).

In line with Searight & Gafford (2005), we have highlighted the extent to which cultural factors shape preferences around decision-making, receiving bad news, and end-of-life care. The Western moral imperative of autonomy, informed consent and truth telling is often at odds with the beliefs of cultural groups who place a much greater emphasis on the role of family in decision-making. In relation to Chinese patients with a life-limiting illness, participants noted that there was a preference for a much greater family involvement in decision-making. According to Windsor *et al.* (2008), however, determining how much information to give patients from different ethnic groups with a life-limiting illness is not

straightforward and 'one size does not fit all'. Research conducted in China would suggest that most patients want to be informed of a cancer diagnosis, although few would want to be informed about a cancer diagnosis with poor prognosis (Yun *et al.* 2004, Jiang *et al.* 2007). Seymour & Gott (2011) note similar discrepancies and argue that 'older people tend to take heterogeneous stances towards decision-making and that their abilities (and indeed wishes) to be autonomous often depend on the context in which they find themselves' (p. 48). As a result, care professionals should be mindful that some individuals may make a decision not to be autonomous in relation to future care and treatment and would rather entrust their care to their doctor or family members.

This paper offers an important contribution to the literature regarding the views of care staff who provide palliative and end-of-life care to growing numbers of non-Europeans within a dominant 'Western' healthcare environment. We have highlighted the important role that families play both in the delivery of care and in decision-making, as well as the ways in which their experiences of caring for older dying relatives can be improved with appropriate support, education and 'coaching' from care staff (The National Palliative Care Program 2003). Further research is required to explore the views of older non-European elders and their families regarding end-of-life care preferences and to develop a framework to guide end-of-life care preferences and decision-making, rooted in the values that they consider important.

This study has several limitations. The views expressed are only of those who identify as professional carers. We did not include the views of family members with experience of caring for older dying relatives in institutional care settings. This is an area that warrants further research, given the ageing population in New Zealand and the fact that over 60% of deaths on a national basis occur in hospital and residential aged care settings (Statistics New Zealand 2010). Furthermore, we do not consider our findings to be representative of the views of all care staff and make no claims to generalise the findings beyond our sample. However, this study provides a detailed insight into the views of care staff with experience of providing palliative and end-of-life care to older adults across a range of settings and the importance of cultural safety in determining good palliative and end-of-life care for older adults and members of their family across a range of different care settings.

## Conclusion

This study has highlighted the importance of the role of family in both the provision of hands-on care and their role in collaborative decision-making for older members with a life-limiting illness. Whilst cultural factors can

shape care preferences and decision-making at the end of life, healthcare staff need to be mindful not to 'homogenise' an individual's care based on cultural heritage alone and should remain cognisant of individual differences. Enabling family to provide end-of-life care requires care staff to take a step back and relinquish their role as 'expert provider'. Care staff can provide an educative role and support the family to provide 'hands-on' care from the sidelines and in a manner which is informed by individual and family preferences. Whilst we have highlighted the fundamental role that family can play in caring for older members, family too may vary in their ability and confidence to support and provide direct care. It is important to ascertain the wishes of both the individual older person and family members are met to ensure that preferences are met through individualised assessment – a hallmark of good practice.

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