Palliative Care NEW SOUTH WALES | Palliative Care Volunteering

Research Report

It Takes A Village: Discussing the challenges of managing cultural diversity and volunteering in palliative care services

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Background

Australia is a multicultural society with an ageing population. As the proportion of older people who come from culturally and linguistically diverse backgrounds increases so too will the need for culturally competent and sensitive palliative care. This research investigates how the culturally and linguistically diverse (CALD) populations are catered for in the field of palliative care within the Sydney Metropolitan area of New South Wales, and how services that utilise volunteers are ensuring they are addressing the needs of this group. This research also attempts to understand how services engage and manage volunteers from CALD backgrounds and through an informal self-assessment and investigate whether they believe they are meeting the specific needs of the communities in which they operate.

Culture: What is it? What role does it play in death and dying?

Culture can be defined as a "system of shared ideas, concepts, rules and meanings that underlie and are expressed in the way that human beings live" (Keesing in Lickiss, 2003). It is important to understand culture as more complex and diverse than simply ethnicity or language groups, although these characteristics form part of the overall culture of an individual. This is particularly important in understanding matters around death and dying, where there may be distinct differences even within groups that share a language or ethnicity.

It is important to understand the broader social factors that influence individuals and the culture with which they associate. As Lickiss (2003, p14) illustrates in the paper *Approaching death in multicultural Australia*, the ethnic group a second generation immigrant may be nominally associated with may not necessarily be the culture that reflects their views or attitudes about death and dying if they have come to relate to the current trends within their country instead. This is important when recognising the importance of individualising care in the palliative setting.

While all palliative care should address the specific needs of the individual it is crucial to acknowledge how equity of access across a service can be extended to support patients and their families from non-English speaking and culturally diverse backgrounds. In a society where there are acknowledged disparities among ethnic groups in their underutilisation of the health care system overall, it is of great importance that palliative care is not only provided to these groups but that it is effectively promoted as well (Lau & O'Connor, 2012).

To achieve both equity and effectiveness of delivery, palliative care must pay attention to how each CALD community experiences suffering and loss. The modern palliative care movement commenced as a reaction to the observed neglect and suffering of people at end of life, and palliative care clinicians advocated for attention to both physical and existential forms of suffering. Volunteering in palliative care grew from a desire to include members of the community (volunteers) not only as companions but as custodians of community wisdom whose presence would bring comfort and so ease the experience of existential distress and suffering. The experience of comfort is dependent on the beliefs and worldviews of the community,

and so it follows that ideally volunteers in palliative care ought to be selected from within those same communal beliefs and worldviews as the people they support.

The way in which formal and informal care is experienced varies within the anthropological spectrum of communities and cultural influences. The Anglo-centric community is more likely to accept the formality of care provided by volunteers. By contrast communities which emphasise communal or collective familial support are less likely to be as accepting of volunteers. For example the Aboriginal community are well known for the importance of including the mob at the site of care. Likewise for some African communities the notion of volunteers as a substitute for familial 'community' support is contrary to their cultural norms.

> *'Here you call it volunteering, we call it community.'*
>
> Woman from Sierra Leone (PCNSW, 2016)

It is worth noting that even normative assumptions about cultural traditions and identity may be problematic in informing formal care. Kellerhear (2007) in his exploration of the social history of dying notes that we are often too willing to refer to 'tradition' as if to an amorphous body of truth about a group and less willing to untangle and differentiate those meanings in the context of history. Merely because a person identifies with a particular group really tells us little about how they embrace that identity or the traditions of that group, and in turn how they value normatively-designed systems of formal care. Understanding the various constructs of formal and informal care networks for each cultural group is beyond the scope of this paper but is conceptually relevant to the attractiveness and uptake of palliative care volunteer support by CALD communities.

Palliative care volunteers are typically embedded in palliative care as part of the formal care network, groups that value familial support are likely to regard volunteer support as intruding on their informal care networks. These informal care networks can often be well organised and deeply embedded within CALD communities in Australia, as illustrated by the research paper *Death and dying in Australia: perceptions of a Sudanese community* (Sneesby, Satchell, Good & Van der Riet, 2011). This research identified, that even once the concept of palliative care was understood by members of the Sudanese community living in Australia, cultural practices that prevent bad news being given to someone without the protection and support of community leaders such as elders, church ministers, welfare officers and African support workers would make it difficult to impose formal care structures into this network (Sneesby et al, 2011: 2698).

Further to this, the recent shift in thinking away from the professionalisation and medicalisation of palliative care to a more holistic approach that seeks to engage the community (Rosenberg, Horsfall, Leonard & Noonan, 2015: 31) could have much wider appeal to CALD communities who have cultural practices that reflect this ethos.

Method

Palliative Care NSW interviewed palliative care volunteer managers across a variety of volunteer services within the Sydney Metropolitan Area to gain an insight into how different services provide palliative care to CALD patients and their families, how they utilise CALD volunteers, and explore attitudes on how culturally and linguistically diverse needs are addressed within palliative care in the context of death and dying.

The interview consisted of 18 semi-structured questions for services that had volunteers working directly with residents, with open ended responses encouraged to clarify attitudes and preferences throughout the interview. A total of 6 respondents were interviewed over the telephone. All of these respondents identified some of their patients to be from various CALD communities and backgrounds. When asked about their volunteer base, all respondents acknowledged that at least some of their volunteers were from CALD backgrounds.

Participation in this research was voluntary, and invitations were emailed to volunteer coordinators across Sydney Metropolitan area. Follow up phone calls were made to arrange interview appointments with those interested in taking part.

A variety of services were represented in this sample, the smallest having 4 active volunteers in hospital and 10 in the community, and the largest cohort of active palliative care volunteers being 42 in one service. These services were from various locations, some operating multiple facilities within the Sydney Metropolitan area, and included in-patient and community volunteering programs.

Findings

CALD groups – How are they identified within palliative care services? Is this problematic?

Respondents were asked "what are the main CALD groups living in your catchment area?" (Question 3), this provided the first insight into how respondents identified different cultural groups, whether by language group, country of origin or religious affiliation. These identifiers were offered by the respondents without prompting by the interviewer:

Identifier	# times mentioned
Arabic	4
Mandarin	1
French	1
Vietnamese	3
English	1
Aboriginal and Torres Strait Islander	3
New Zealand	1
India	1
African	1
Germany	1
Italy	3
Scotland	1
Greece	2
Sri Lanka	2
Asian	2
Pacific Islander	1
Hindu	1
Muslim	2
Spanish	2
Teocheo	1
Hungarian	1
Turkish	1
Macedonian	2
Chinese	2
Dutch	2

(Responses from Question 3)

Ensuring equal access to palliative care, and an equal level of service for patients from CALD backgrounds requires an acknowledgement that this patient group may have unique needs, both cultural and personal that may not be accommodated by current programs. There is general consensus in the literature that many health services are underutilised by those from ethnic minorities and this applies to palliative care as well. Poor access has been attributed to "lack of knowledge and awareness of palliative care services… communication difficulties and mistrust between services providers and users; and lack of cultural sensitivities among service providers" (Lau & O'Connor, 2012: 57). This research project supported the findings of previous research - when respondents were asked how they assessed patients as CALD, there were a variety of responses:

a) ***"For me it's about recognising a surname sometimes"*** – This is hugely problematic in assessing the specific needs of a CALD patient, while it may be indicative of a patient's ethnic background it could also be quite prejudicial, and it does not indicate a person's cultural belief, religious background or even potential language differences.

b) ***"We're not really focused on meeting the CALD needs, we do respite and companionship, the nurses need to do that not the volunteers… for me I meet all their needs individually, I don't give anymore to that [CALD] group than any other"*** – Again, this attitude is problematic, as it fails to address how a service can provide an equitable level of companionship to a patient who speaks English on one hand and a patient who has specific language and cultural beliefs that need to be met on the other if they

are given "the same service". Respite and companionship are crucial elements of palliative care, and special needs do not necessarily mean special treatment. It means providing the same level of care differently to ensure an equitable outcome. As another respondent acknowledged ***"initially all residents are treated the same irrespective of their language or cultural background, it is part of treating all residents equally – but in order to provide the same quality of care for a resident from a CALD background it may be that we need to find a volunteer that speaks their language too, so that would be how it differs"***

c) ***"There is a spot I can write it down on the forms... there is a field for it... It usually asks what is the first language spoken at home"*** – This tendency to focus on language when assessing CALD patients is problematic because of its narrow focus, and the failure to address cultural and religious diversity across language groups.

It is crucial that there is acknowledgement of cultural differences so that CALD patients can be assured that their wishes and needs will be understood and met as best they can. This is particularly so within a system that is designed around western medical ethics and traditions and when discussing emotive topics such as death and dying, this also applies to services that engage volunteers to provide support to palliative care patients.

Palliative care volunteering and cultural diversity – How is this being managed? How could we do it better?

Palliative care volunteers occupy a diverse range of roles, assisting the clinical team in providing psycho-social, spiritual and physical support for patients and their families, however, most commonly they provide companionship, the opportunity to have a cup of tea and a chat. The ability to communicate is a challenge for many palliative care patients, felt more acutely by those for whom English is a second language. This research illuminated some interesting examples of the unique companionship needs of CALD patients and their families, and some creative responses by volunteers in order to meet the needs of CALD patients, where language and communication are a challenge.

Example 1: Where there's a will there's a way

"There was one case, where a patient, a gentleman who only spoke Italian had an Australian/Lithuanian volunteer, they couldn't communicate with the same language, but the gentleman understood that he [the volunteer] was there for him.

Then one day, the volunteer brought in his neighbour, who was Italian to come and talk with the patient in his own language – Where there's a will there's a way"

This example beautifully highlights how a service can encourage innovative and creative thinking from their volunteers to provide a better level of palliative care to patients. It also highlights the importance of communication and language in order to provide an equitable level of care across diverse cultural groups. Although the patient felt supported by his volunteer

despite their inability to communicate verbally, the opportunity to speak in his own language must have been a pleasant surprise and in some ways a relief. In contrast, this anecdote also highlights the possibility that there was a potential breach of confidentiality by the volunteer by effectively revealing patient information to a person outside of the volunteer's 'circle of confidence' by inviting the person into the inpatient setting. It could be argued that this is a complication unique to the Anglo-centric values inherent in the formal care network, but it is one within which volunteer services must work. Volunteer practice must encourage cultural literacy but also respect normative standards. There is existing research that suggests palliative care professionals feel significantly more confident in delivering care to an Anglo-Australian patient (McNamara, Martin, Waddell & Yuen, 1997: 363), with a shared cultural understanding this seems a logical conclusion, however with the increasingly culturally diverse community that will be seeking palliative care services in the future it is crucial that volunteers and professionals alike can feel more competent in their abilities to deliver an equitable service to CALD patients and families, cultural literacy is one way this can be achieved, and broadening the volunteer base to include members of CALD communities would also prove beneficial.

Example 2: Understanding language versus understanding culture

When asked – Have your patients ever requested a volunteer from a CALD background?

"Yes, a Dutch lady. She requested Dutch speaking people, she said 'I want to speak with someone who understands Holland', she wanted someone who could talk about the culture, history and things that were meaningful to her".

This example highlights how important meaningful communication is for patients. It is not simply about providing an interpreter to address language barriers, but is instead about providing the opportunity for patients to connect with their culture and their personal history.

Example 3: Chinese Whispers in the Maltese Community

When asked – Have your patients ever requested a volunteer from a CALD background?

"I don't think they have.... I would say probably not... although some have asked for someone not from a particular CALD background, they didn't want someone from the same background as them because of "Chinese whispers" in their community."

This example demonstrates the complexities of caring for people from various cultural backgrounds, were social norms and expectations can differ greatly. It is crucial that staff and volunteers at least have an awareness of these differences in order that they can better provide a service that is culturally sensitive.

A similar sentiment was expressed by clinical staff involved in the delivery of palliative care to people in rural settings, where there was an expressed concern that they would prefer a person from outside their (small rural) community rather than someone local (Huntir, 2016). In both examples 'from the same community' assumes the pejorative sense of being detrimental to care.

Example 4: Bringing IN Cultural Diversity by Reaching OUT to CALD Communities

Encouraging people from diverse backgrounds to utilise palliative care services is problematic for a myriad of reasons, however, one way this can be overcome is by improving the cultural diversity of volunteers through community engagement.

When asked - How has cultural diversity been managed if at all, with regards to service provision/recruitment of CALD volunteers/training of staff/ training of volunteers?

"Just recently colleagues and I met with 3 women from the Muslim community here locally, who are very active - and talked to them about palliative care volunteering... we have asked them to look at the application, training and suggested they attend training next March."

This service effectively identified a gap in their volunteering base and have proactively sought to address it by engaging with the community, introducing them to the concept of palliative care, educating them on how they can be part of it, and simultaneously educating a community about how they can access it as patients. As Rosenberg et al (2015:15) illustrate "the place of the whole community in supporting its dying members is gradually being reconsidered as an integral component of a more complete response to EoLC [End of Life Care]". Community engagement and education are key to ensuring to ensuring this, particularly in CALD communities that have strong informal care networks that can be utilised and embraced to provide high quality palliative care.

Example 5: Where to die? In-home vs in-patient: How can we accommodate CALD patients more effectively?

Building on from the previous example is the concept that in-home care may appeal more than in-patient care to CALD communities. With many CALD communities utilising established informal care networks already the extension of this to include palliative care seems like a logical progression

When asked – How is the cultural diversity of your area reflected in the patients you see in your service?

50% of services did not believe their local demographic was accurately represented by the patients accessing their services and similarly by those volunteering.

"We have a big indigenous population, they would be the 2nd largest CALD group, but this is not reflected in our services as either patients or volunteers... perhaps in the hospital more so, but not in the home at all."

This example highlights previous research that states that "Aboriginal and Torres Strait Islander peoples are known to be generally ambivalent about the use of western health care and are particularly reluctant to use palliative care services (The National Rural Health Alliance Inc (ND): Sullivan, 2003 in Lau & O'Connor, 2012: 57).

Further research should attempt to understand how cultural preferences and available resources could be better understood to improve access to palliative care, as well as increasing engagement in community based and informal palliative care networks. Further investigation could provide an invaluable insight into how culture, family and palliative care volunteering are inextricably linked and can be promoted and nurtured into the future.

Discussion

In the context of death and dying, the cultural needs of these groups vary immensely, and some descriptions cover not only multiple nationalities, but also multiple religious groups with vastly different beliefs and traditions. In 2014 the population of NSW was 7 518 472 (ABS, 2017) with 31.4% of the population having been born overseas (ABS, 2017), and 22.5% of people speaking a language other than English at home. These numbers suggest that CALD groups form a large section of the population now and will continue to do so into the future and will require access to culturally appropriate health care on a broad scale, and more specifically palliative care. When these numbers are viewed in light of population projections that suggest the number of people over 85 years of age will double in the next 20 years it is crucial that CALD patients are supported appropriately within the palliative setting.

A limitation of this research was that it did not attempt to assess overall awareness of palliative care services within the CALD community, the fact that 50% of the services interviewed did not believe that the number of CALD patients accessing their services accurately represented the cultural diversity of their community suggests a need to increase awareness of and access to palliative care services to the CALD community, and perhaps improve overall perceptions and attitudes towards palliative care as well.

Developing an increasingly social approach to death and dying could lead to better engagement with CALD communities, as both patients and volunteers. This research was designed to illuminate the trends in how palliative care services address CALD needs and how volunteers are incorporated into these plans at present across Metropolitan Sydney.

With this in mind the report offers a number of thematic observations.

This research highlighted some concerning gaps in palliative care provision within an ageing and multicultural society. When considering how inextricably linked culture is to death and dying it is problematic that there is currently minimal policy and programme focus on this in the field of palliative care provision and volunteering. There was no consensus on how to identify a patient as CALD across the services interviewed, whether it be by language spoken at home, country of origin or religion, each service and even individual respondents used their own discretion to identify these patients. While there was some discussion about treating all patients equally, despite their CALD background, little has been done to address the problem that 50% of services did not believe that the patients they cared for accurately represented they diversity of the community in which they operate. This is one of the most concerning aspects, how are these patients dying if they are not accessing palliative care services? Is it a lack of awareness, or a concern that they will not have their unique cultural or religious needs met within the formal care network? While fully exploring these questions was outside the scope of this research, the acknowledgement of this lack of diversity indicates a need for further investigation.

It must also be acknowledged that there is no "one size fits all" solution to engaging different cultural groups in palliative care uptake as patients or as volunteers. However, moving away from an Anglo-centric model of medical ethics and towards a more social and community based approach to death and dying may not only destigmatise death and dying more broadly across society but also encourage the participation of CALD groups in formal care networks. Having those groups involved as palliative care volunteers could benefit the members of their own community. While more broadly formal health networks in palliative care would also benefit from greater cultural diversity.

In summarising, what will be important to ensure the equitable provision of palliative care across an ageing and multicultural society in the future will be based on recognising and respecting the culturally specific needs of some communities in order to meet their palliation requirements, while simultaneously embracing and recognising their roles as members of society to engage in providing palliative care as volunteers and members of the palliative care team within the hospital and community setting.

While this research demonstrates room for improvement, it should be acknowledged that in 2017 palliative care is still poorly understood in general, and access and utilisation is often hindered by the existing stigma surrounding palliation, death and dying. With further community education that seeks to demystify the role of palliative care there will be more equitable access for all. For CALD communities that have additional hurdles to overcome, including language barriers, isolation, racism or religious discrimination this task will be more challenging but not impossible. Palliative care services will need to develop policies and programmes that work with emerging and ever changing societal trends such as ageing and increasing cultural diversity by embracing the uniqueness of Australian society.

End notes

The Volunteer Support Services Program

This paper has been prepared as part of the Volunteer Support Services Programme which is hosted by Palliative Care NSW and funded by NSW Health. The Volunteer Support Services Programme seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW (www.volunteerhub.com.au).

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