

What Matters in the End

Understanding the End-of-Life needs of Culturally & Linguistically Diverse and Aboriginal communities in Western Sydney Local Health District

ما يهم في النهاية ... فهم احتياجات مرحلة نهاية الحياة لدى المجتمعات المتنوعة ثقافياً ولغوياً ومجتمعات السكان الأصليين في المنطقة الصحية المحلية في غرب سيدني.

आखिर में क्या मायने रखता है...वेस्टर्न सिडनी लोकल हेल्थ डिस्ट्रिक्ट (पश्चिमी सिडनी स्थानीय स्वास्थ्य डिस्ट्रिक्ट) में सांस्कृतिक और भाषाई रूप से विविध और ऐबओरीजिनल समुदायों के जीवन के अंत की आवश्यकताओं को समझना

最终什么才重要... 了解西悉尼地方卫生区文化和语言多元化群体和原住民社区的临终需求

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With respect for Aboriginal cultural protocol and out of recognition that its campuses occupy their traditional lands, Western Sydney University acknowledges the Darug, Eora, Dharawal (also referred to as Tharawal) and Wiradjuri peoples and thanks them for their support of its work in their lands (Western Sydney and beyond).

WARNING ABOUT IMAGES

Aboriginal and Torres Strait Islander people are warned that this publication contains images of people who are deceased.

Image, front cover: Vanessa (photovoice participant)

Image, back cover: Marine (photovoice participant)

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ABOUT THE RESEARCH

This research report (*What Matters in the End*) and companion report (*Stories of Care*), document findings from a research project funded by the NSW Ministry of Health: *Understanding the End-of-Life Needs of CaLD and Aboriginal Communities in Western Sydney Local Health District*. The research was undertaken by investigators from the Western Sydney University Caring at End-of-Life Research Program in collaboration with the Western Sydney Local Health District Advisory Board and research partners.

Both reports are available online at the following links:

What Matters in the End: <https://doi.org/10.26183/cnxj-nw28>

Stories of Care at End-of-Life: <https://doi.org/10.26183/w66h-qn16>

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REFERENCING GUIDE

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Executive Summary

Overview

This report, *What Matters in the End* (<https://doi.org/10.26183/cnxj-nw28>), details a population-based end-of-life needs analysis for people actively living with and dying from a life limiting illness in Culturally and Linguistically Diverse and Aboriginal communities in Western Sydney. The research, funded by the NSW Ministry of Health, was designed to directly engage with communities, giving voice to those who are marginalised, vulnerable or disadvantaged. It focuses on understanding cultural needs, and the ways in which end-of-life care can be provided in culturally safe ways for the Aboriginal community, and people from Arabic, Hindi and Mandarin speaking backgrounds. Based on the findings generated by the research, the report makes clear and achievable recommendations for service systems to better support people who are experiencing end-of-life, as well as their carers and communities. Although the research was focused on Western Sydney, its implications are much broader, with the potential to make a significant contribution to culturally attentive models of care for other communities living in urban regions of Australia.

The primary aim of the research was to understand what diverse communities need from Western Sydney Local Health District (WSLHD) end-of-life services, and what can be done to make these services culturally safe. This includes advocacy and support for people to die at home if they choose to do so. These aims were facilitated by focused research questions that sought to understand the cultural aspects of end-of-life, including bereavement; the extent of death literacy; what communities have that already works; the supports and services communities have found useful; what other supports or services people need and who is best placed to provide them; and the ways existing services and supports need to change in order to be culturally appropriate. The research was conducted by Western Sydney University's Caring at End-of-Life Research Program in collaboration with the WSLHD Advisory Board led by representatives from Supportive and Palliative Care, Aboriginal Health, and Multicultural Health. Consultations with individual cultural advisors from local communities were also undertaken as part of the research design.

The research engaged healthcare professionals and community members in a comprehensive multi-method design that elicited both qualitative and quantitative data for analysis. Table 1 summarises the methods of data collection and participant profiles:

Table 1. Study design

Key informant interviews	Structured and recorded qualitative interviews with healthcare professionals within supportive, generalist or palliative end-of-life care working within the WSLHD catchment area and in relevant bereavement service spaces.
Death Literacy Index (DLI) online survey	Quantitative online survey of adult community members from an Aboriginal, Arabic, Mandarin, or Hindi cultural/linguistic background living in the WSLHD catchment area. The survey was translated into language for Arabic, Mandarin and Hindi speaking respondents, who could elect to answer questions in language or in English.
Focus groups	Face-to-face, semi-structured, recorded discussions with adult community members from an Aboriginal, Arabic, Mandarin, or Hindi cultural/linguistic background with end-of-life caring experience and living in the WSLHD catchment area. Aboriginal support workers and bi-lingual interpreters were available at each of the relevant focus groups to assist participation.
Photovoice interviews	Semi-structured and recorded photovoice interviews with individual adult community members with end-of-life caring experience of more than six months prior and living in the WSLHD catchment area. Interviews held online with an English-speaking researcher and option for a nominated bi-lingual support person to attend, if needed.

Following completion of the data collection phase and data analysis, public forums were held in the community to present the interim findings. This process provided community members with the opportunity to comment on the research findings and to make further suggestions for addressing cultural needs at end-of-life. The key themes and/or issues distilled from the research data are identified in Table 2:

Table 2. Key themes

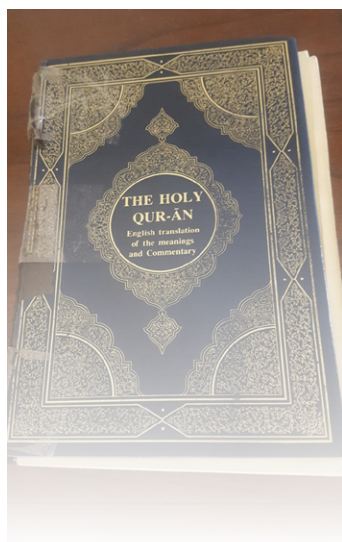
1. Cultural practices and rituals are important aspects of end-of-life and bereavement care	2. Relational trust is fundamental
3. Ways to provide community input for culturally appropriate care	4. Building knowledge and understanding of end-of-life services
5. Making the most of hospital-based services	6. Increasing culturally safe end-of-life and bereavement services in the community

These themes are discussed here (in brief) under 'Key Thematic Findings'. They are fully detailed below in the 'Findings and Discussion' section of this report which documents the end-of-life needs identified by people from the Aboriginal community and Arabic, Hindi and Mandarin speaking backgrounds within WSLHD, as well as healthcare professionals working in the end-of-life space.

Key Thematic Findings

1: Cultural practices and rituals are important aspects of end-of-life and bereavement care

In all four cultural groups, the cultural practices and rituals related to end-of-life were important for providing comfort and peace for people who are dying, as well as their family and friends. If spiritual or religious needs remain unmet, ongoing suffering and complications with the grieving process may result for the bereaved family and community. However, there are diverse beliefs and practices between cultures and the variations within cultures were equally important. For example, people from any of the four groups might have a Christian faith due to personal interest or family background. Generational differences were reported in willingness to care and to follow traditional rituals. The Death Literacy Index (DLI) survey revealed that the number of years people had been in Australia was the most significant demographic for predicting people's death literacy and was a more important indicator for this than their cultural background. The diversity in cultural practices on the one hand, and differences in death literacy on the other, means there are no 'easy recipes' for identifying peoples' end-of-life needs. Awareness of some of the diversity of practices and appreciation of the values that underpin those practices is needed to maximise health professionals' capacity to work with patients and families to provide culturally appropriate patient centred care that avoids making assumptions about the path that the end-of-life and bereavement journey follows.



2: Relational trust is fundamental

The message from our participants was that trust was essential. The need to build relationships of trust underscored other themes in the findings. Without trust people would not talk about sensitive topics such as death and dying, would not hear messages about the available services, and would not access services if they could not believe their needs would be addressed. Trust was particularly important for bereavement counselling where people were already struggling with their grief. The capacity to build trusted relationships within existing services was significantly impacted by systemic issues relating to discontinuities in care. The necessity to navigate an unknown health system with a multitude of disconnected systems, services, and staff was distressing and disempowering. There was insufficient time or opportunity to develop trusted relationships. When people are at their most vulnerable, consistency and familiar faces amongst medical and supportive care staff was understood as critical. However, patients and families were required to repeat their story multiple times to different health staff in different parts of the system. The major end-of-life system discontinuities identified were: (1) the separation of doctors in private practice (GPs) from the hospital system; (2) the outsourcing of palliative care in the home to a private provider; (3) the separation of medical services from grief and bereavement services; and (4) the separation of formal health services from NGOs, religious and other organisations providing support in the community.

3: Ways to provide community input for culturally appropriate care

Barriers to good end-of-life and bereavement support are presented in Theme 1 on the need to respect cultural differences in end-of-life practices and rituals and Theme 2 on the difficulties of building trusted relationships across the silos in the health system. Together they show some of the difficulties faced by Aboriginal and culturally and linguistically diverse (CaLD) people in obtaining the support they might need. Being willing to seek help and knowing who to ask, or how to ask, can be challenging. Theme 3 addresses the organisations, programs, services and informal networks that already exist outside NSW Health and ways that they could connect to end-of-life and bereavement services. Respondents suggested that the barriers to connecting with these services could be addressed by: (1) extending and networking community-related support; (2) building awareness amongst Aboriginal and culturally

diverse communities on the range of support options available; and (3) having specific community liaison contacts who can help to respond to and navigate the end-of-life journey for families and patients and their carers.

4: Building knowledge and understanding of end-of-life services

Many people do not want to talk about end-of-life, whether it be from holding on to hope, wanting to avoid summoning death, or just being uncomfortable with the topic. Low health literacy and understanding of bodily functions, being stressed, or feeling vulnerable are all factors that can further hinder people's knowledge or understanding of end-of-life services. However, without understanding what services are and what they do, people can miss out on the end-of-life help they need. There can be further obstacles grounded in language differences, cultural differences, and unfamiliarity with the health system. Concepts such as 'palliative care', 'counselling', 'formal volunteering' and 'dementia' were reported to be unfamiliar to many culturally diverse and Aboriginal people. There is a need to sensitively understand these obstacles in order to drive suggestions for where services can be introduced or improved to provide culturally sensitive support to those at end-of-life, their families, and other carers.

5: Making the most of hospital-based services

People often present to palliative care when it's 'too late'. Providing patients and families with an early introduction to supportive and palliative care reduces the occurrence of unplanned or emergency admissions by encouraging uptake of care pathways that reflect the individual's condition, needs and social circumstance. However, due to the silos in the health care system (Theme 2), health workers are not necessarily aware of the nature and value of end-of-life services or how to access them. The strategy of specialist palliative care nurses assisting in other wards across the hospital is effective and could be extended. There is a need to make connections among health services to maximise their effectiveness through establishing a central point of contact for patients and health professionals. Other strategies include building the network of Aboriginal and CaLD supportive and palliative care workers and volunteers and establishing dedicated palliative care spaces, such as the palliative and supportive care unit at Mt Druitt, in all hospitals.

6: Increasing culturally safe end-of-life and bereavement services in the community

A need was identified for more formal services in the community that can support culturally appropriate end-of-life care. The suggestions fell into three main strategies. First, increasing the coverage of end-of-life and bereavement by existing organisations that support Aboriginal and CaLD communities. For example, Multicultural Health and the seven local community health centres across the LHD. Second, increasing the cultural sensitivity of end-of-life and bereavement services, including through cultural awareness training and recruitment of staff from diverse backgrounds for the in-home palliative care service as well as bereavement services and hospital-based services. Third, creating new end-of-life and bereavement services in the community which could be staffed by people from local cultures. For example, multiple dedicated palliative and supportive care spaces in the community, such as in aged care facilities; and appropriate informal spaces for bereavement support, such as in local community centres which could provide basic support but have connections to bereavement services and culturally specific supportive and palliative care workers.

Recommendations

The research findings provide clear community-led evidence of what is needed to secure culturally safe end-of-life care and foundational here, is the need for trusted therapeutic relationships within a framework of continuity of care. We make the following recommendations (here, in brief and detailed fully in the Report below) to incorporate these findings into policy development, service models and service delivery across formal, clinical and community settings. Together, these recommendations support services to deliver continuity of care and case management that supports relational trust between service providers, patients and their families.

1: More culturally specific supportive and palliative care workers

Expanding on the successful implementation of the dedicated Aboriginal Supportive and Palliative Care Worker role, we recommend the appointment of more culturally specific supportive and palliative care workers sufficient to cover at least the most populous migrant cultures within the Local Health District.

2: Establish a palliative and end-of-life resource centre

We recommend establishing a centralised point of contact that would be a Health Department unit attached to Supportive and Palliative Care which would bridge the silos within Health and also link to community health services such as Silverchain and GPs. Patients and families would have a single contact point for all their end-of-life and bereavement needs, and health professionals could track the service history of their clients.

3: Extend the role of volunteers

We recommend extending the role of volunteers in each hospital, including a manager to coordinate and supervise a large group of CaLD palliative care volunteers. Volunteers should be trained to extend their support into the bereavement period.

4: Utilise existing educational programs and organisations

We recommend utilising existing educational programs and organisations to provide more educational and awareness raising programs for health workers, for communities and for carers.

5: Develop culturally appropriate end-of-life communications

We recommend the dissemination of relevant print and electronic media contain culturally appropriate language and images. This material must be developed with community groups to ensure cultural sensitivity.

6: Expand suitable spaces for palliative care

We recommend (1) dedicated palliative care spaces in all hospitals that invite trust and comfort for diverse cultural groups (this may include artwork, spaces for large gatherings, prayer rooms, kitchens for preparing food, viewing rooms, and outside spaces for gatherings and rituals); (2) hospice type accommodation away from hospitals with palliative care support; and (3) day clinics in accessible community places (such as large medical centres).

7: Increase bereavement support

We recommend more bereavement counsellors with understanding of culturally diverse needs; and the establishment of bereavement drop-in centres located in current community facilities.

8: Take a public health approach to create compassionate communities

We recommend taking a public health approach to end-of-life and bereavement to support capacity building in the community for people to support each other in their end-of-life journeys whether as patients, carers, or other friends and family. This includes knowledge of how to find additional help when it is needed.

These practical and achievable recommendations, discussed more fully in the report, aim to ‘move beyond conversations to see actual change happen’ and in doing so, underscore the crucial importance of direct consultation with communities.





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