

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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WESTERN SYDNEY
UNIVERSITY



Health
Western Sydney
Local Health District

ACKNOWLEDGEMENT OF COUNTRY

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

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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We warmly acknowledge and sincerely thank our Western Sydney Local Health District Advisory Board and research partners who collaborated, supported and inspired us throughout the three years of research undertaken for the project and without whom the research would not have been possible. The Board was insightfully led by Dr Sally Greenaway (Director, Supportive and Palliative Medicine) alongside Monika Latanik (Multicultural Health Services Manager), Belinda Cashman (Director, Aboriginal Health Services), Nicole Winters (Senior Aboriginal Education Officer, Palliative Care), and Dr Kristin Bindley (former Bereavement Counsellor and Clinical Lead, Supportive and Palliative Care). We have learned much from the collaboration and are indebted to you all for your leadership and commitment to culturally safe end-of-life and bereavement services.

We also warmly acknowledge and sincerely thank our former colleagues from the Western Sydney University Caring at End-of-Life Research Program who provided invaluable contributions at various stages of this project: Dr Alison Rahn, Senior Research Officer who sadly passed in 2020 was instrumental to the organisation and initial stage of the research; Dr Jody Thomson who seamlessly carried forward as Senior Research Officer provided vital momentum to the mid-stages; and Ms Helen Psychogios, long term Research Assistant for the Caring at End-of-Life Research Program who was a force of efficiency and organisation on the project before a career change in 2022. Finally, and importantly, we acknowledge the key role of Professor Debbie Horsfall, retired Lead of the Caring at End-of-Life Research Program who was instrumental in the planning and early stages of this research and whose internationally recognised scholarship and leadership in caring at end-of-life research provided the foundations and ongoing inspiration for our collaboration with WSLHD.

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Finally, we thank all those who have contributed to the research project including those who have made this report possible - Bronny Carroll and, similarly, the team at Transcription Australia for transcription of recorded interviews and focus groups; Eva Melham and the Western Sydney Local Health District Translation Service for translations; and Ally Mosher for the report design.

Rosemary Leonard, Joy Paton, Peta Hinton

Western Sydney University

Foreword

Dying is a universal human experience, occurring in a particular social and cultural context, and deeply embedded in the fabric of our lives, whoever we are. The care that we want for ourselves and those we love in the last months, weeks and days of life will be informed by our culture of origin and the traditions old and new that support us and add meaning to this most challenging of times. This is an important consideration when delivering care for people in the last year of life in a health district like Western Sydney with its wealth of culturally and linguistically diverse (CaLD) communities speaking over one hundred languages. Here also, living on the unceded Aboriginal land of the Darug nation is one of the largest urbanised Aboriginal communities in the country.

What we now call 'Palliative Care' or 'Supportive, Palliative and End of Life Care' is a development in Western Health care that pushes back against the medical model of seeing the problem as a failing organ in a dying body. Palliative care is about delivering holistic care, attending to the physical, emotional, social, psychological, and spiritual well-being of the person and their family in the last phase of their life, in their particular social and cultural context and with reference to what matters to them. This care does not hasten death – and indeed people will at times live longer and certainly better when receiving Supportive and Palliative Care. This care is precious, sacred, privileged, and ancient, having been done in community since the dawn of time. In the Western world however, such care is now usually delivered within a health system that remains culturally unsafe for some people. My colleagues and I in the Supportive and Palliative Care Service in Western Sydney Local Health District (WSLHD) have long been aware of this challenge – despite our LHD's long and proud tradition of delivering otherwise excellent (albeit resource constrained) palliative care both in the acute hospitals and in community.

In the last few years, the NSW Ministry of Health has delivered very welcome enhancement funding to improve end of life and palliative care in a range of settings across the state. We are thankful for the recognition of the importance of this area of care and that we were able to use 'flexible project funding' to undertake research to explore how to better meet the palliative and end of life care needs of our diverse community. We were fortunate in partnering with the team from Western Sydney University's End of Life Research Program led initially by Professor Debbie Horsfall, then Professor Rosemary Leonard to undertake an important research piece exploring the end of life care needs of Aboriginal and Culturally and Linguistically Diverse groups in our community.

This work, the summation of which is delivered in this report, will be critical in informing how we deliver care. It is of note that despite the differences within and between CaLD communities, there are shared core needs: for trusted therapeutic relationships and continuity of care, for timely culturally appropriate information and for hospital and care environments that cater for family and community and rituals of importance. The acknowledgement by some of the project's participants of the difficulty of discussing death and planning for it when death is a taboo subject provides a helpful basis for an ongoing conversation with these communities. Indeed, the insights and findings here have already led to adaption of our models of care in all settings and informed the design of both the new Auburn Hospital Palliative Care Unit and the recommissioned Westmead Hospital Acute Supportive and Palliative Care Unit set to open in 2026.

On behalf of the dedicated and talented multidisciplinary team of clinicians and support staff that are the WSLHD Supportive and Palliative Care Service, I wish to extend our heartfelt thanks to the WSU End-of-Life research team for their knowledge, skills and excellent work, and their dedication and commitment to this project despite the challenges intrinsic to the nature of the research and despite the interruptions of the COVID-19 pandemic. I also thank them for their kind tolerance of the vagaries of working with time poor clinicians! It has been a privilege and pleasure to work with you all. I wish to thank the Ministry of Health for supporting this work: and in particular the knowledgeable, committed, and hardworking ministry team of policy advisers who support all of the Palliative Care Services across NSW. I am particularly grateful to the WSLHD Chief Executive Mr Graeme Loy and the leadership teams in Aboriginal Health, Multicultural Health and Integrated and Community Health for supporting this project, and the talented WSLHD staff from both these services and my own team who generously worked with the WSU team in addition to their many usual commitments. In particular I wish to thank Monika Latanik and the cultural advisers from Multicultural Health Services and Belinda Cashman from Aboriginal Health. I also wish to thank and note the critical contributions made by Ms Nicole Winters our Senior Aboriginal Education Officer (Palliative Care), and Dr Kristin Bindley our Bereavement Service Lead during this time.

Lastly, and most importantly I wish to thank the members of our Aboriginal and Arabic, Hindi and Mandarin speaking communities for their generosity and trust in sharing their experiences, and their insights around how to best care for people during the last year of life, at the end of life, and beyond when supporting grieving families. This work will lead to more culturally safe care for your communities and indeed others as we extend our work to consider the best ways to care for all our people here in WSLHD.

The Yolngu-Matha people of Northeast Arnhem land have the word 'Ganma' to describe a special place in the river where fresh water meets the sea water, giving rise to unique new life in the local ecosystem — different to what is up or down stream. This 'coming together' of two differing life forces creating a third has been applied as a metaphor to the coming together of ways of thinking and learning, as exemplified by the Batchelor Institute in the Northern Territory with its philosophy of 'Both Ways Learning'.¹

1 Chirgwin, S.K., & Huijser, H. (2015). Cultural Variance, Critical Thinking, and Indigenous Knowledges: Exploring a Both-Ways Approach. In Davies, M., & Barnett, R. (Eds) *The Palgrave Handbook of Critical Thinking in Higher Education*. Palgrave Macmillan, New York. https://doi.org/10.1057/9781137378057_21

What we hope to achieve with this work is indeed a ‘coming together’ of bodies of knowledge and customs of care, continuing a ‘both ways learning’ relationship with our communities. This report is a tangible and valuable first step in what will be an ongoing journey together with the people we are privileged to serve, as we strive to deliver the best of care for those approaching the end of their lives.

Finally, I wish to dedicate this work with great respect on behalf of our team in WSLHD Supportive and Palliative Care to all those people and families we have cared for over the years, who trusted us and from whom we have learned so much. You remain our inspiration and continue to give meaning to our work. In the ancient Darug language:

NGALAWAN “They live, they remain”.



*The logo of the WSLHD Supportive and Palliative Care Service
Aboriginal Health workers, painted by Uncle Greg Simms,
Uncle Wes Marne, and Jie Pittman*



Sally Greenaway

Director of Supportive and Palliative Care
Western Sydney Local Health District

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.



ملخص تنفيذي

لمحة عامة

يقدم هذا التقرير الذي يحمل عنوان "ما يهم في النهاية" (<http://doi.org/10.26183/cnxj-nw28>) تحليلاً لآراء شريحة من السكان بشأن احتياجات مرحلة نهاية الحياة لدى الأشخاص الذين يعانون من مرض عضال يحد من الحياة ويحتضرون بسببه، ممن ينتمون إلى المجتمعات المتنوعة ثقافياً ولغوياً ومجتمعات السكان الأصليين في غرب سيدني. ويرمي هذا البحث الذي مولته دائرة الصحة في ولاية نيو ساوث ويلز إلى التفاعل بشكل مباشر مع أفراد تلك المجتمعات وبالتالي إفساح المجال أمام أولئك المهمشين أو المستضعفين أو المحرومين منهم للتعبير عن آرائهم وأقوالهم. كما وركز البحث على فهم الاحتياجات الثقافية والطرائق التي يمكن من خلالها تقديم الرعاية في مرحلة نهاية الحياة إلى أفراد مجتمعات السكان الأصليين والجاليات الناطقة باللغات العربية والهندية والصينية (الماندريين) بشكل يراعي الخصائص الثقافية لأفراد تلك المجتمعات والجاليات ويحترمها. وبناءً على النتائج التي توصل إليها البحث، يقدم التقرير توصيات واضحة وقابلة للتطبيق تتعلق بأنظمة الخدمات بغية تحسين دعم الأشخاص الذين هم في مرحلة نهاية الحياة بالإضافة إلى مقدمي الرعاية لهم ومجتمعاتهم أيضاً. وعلى الرغم من أن نطاق البحث كان مقتصرًا على منطقة غرب سيدني، إلا أن النتائج التي خلص إليها تتعدى بكثير تلك المنطقة، إذ يمكن أن تسهم بشكل كبير في نماذج الرعاية التي تحترم ثقافات المجتمعات الأخرى التي تسكن في المناطق الحضرية في أستراليا.

كان البحث يرمي أساساً إلى فهم احتياجات أفراد المجتمعات المتنوعة من خدمات مرحلة نهاية الحياة التي تقدمها المنطقة الصحية المحلية في غرب سيدني (WSH)، (LD) والأمور التي يمكن القيام بها لتصبح هذه الخدمات آمنة ثقافياً، ويشمل ذلك الدفاع عن حق المريض في أن يختار الموت في فراشه، إذا رغب في ذلك، ومساندته للقيام بذلك. وقد رمت أسئلة الدراسة المحددة إلى فهم النواحي الثقافية المتعلقة بمرحلة نهاية الحياة، بما في ذلك المواساة عند وقوع الفاجعة، والمعلومات المتعلقة بالموت، والأمور الناجحة عملياً التي تتبعها المجتمعات، ووسائل الدعم والخدمات التي وجدها أفراد المجتمعات ذات نفع وجدوى، ووسائل الدعم والخدمات الأخرى التي يحتاجها أفراد تلك المجتمعات ومن هي أفضل جهة تقدمها، والطرق التي يجب بموجبها أن تتغير وسائل الدعم والخدمات الحالية لتصبح ملائمة ثقافياً للمجتمعات المعنية. وقد أجرى البحث أعضاء برنامج البحث في تقديم الرعاية في مرحلة نهاية الحياة في جامعة غرب سيدني بدعم من اللجنة الاستشارية التابعة للمنطقة الصحية المحلية في غرب سيدني التي يقودها ممثلين عن «خدمة الرعاية الداعمة والتلطيفية» وعن «مركز صحة السكان الأصليين» وعن «خدمة صحة الجاليات متعددة الثقافات». وكجزء من تصميم هذا البحث، تم إجراء مشاورات مع مستشارين ثقافيين من مجتمعات محلية.

وقد أشرك القائمون على البحث متخصصين في الرعاية الصحية وأفراد من المجتمع في تصميم شامل ومتعدد المناهج يهدف إلى جمع بيانات كمية ونوعية على حد سواء لتحليلها. يُلخص الجدول رقم 1 مناهج جمع البيانات ومعلومات المشاركين:

الجدول رقم 1 تصميم الدراسة

مقابلات مع أصحاب خبرة ومعرفة رئيسيين	مقابلات نوعية منظمة ومسجلة مع متخصصين في الرعاية الصحية يعملون ضمن الرعاية الداعمة أو العامة أو التلطيفية في مرحلة نهاية الحياة ضمن منطقة الخدمة الطبية التابعة للمنطقة الصحية المحلية في غرب سيدني وفي المراكز المعنية التي تقدم خدمات المواساة عند وقوع الفاجعة.
استطلاع رأي عبر الإنترنت عن المعلومات المتعلقة بالموت (Death Literacy Index (DLI))	استطلاع رأي عبر الإنترنت يستخدم المنهج الكمي للبالغين من أفراد مجتمعات السكان الأصليين ومن خلفيات ناطقة باللغات العربية والهندية والصينية (الماندريين) ممن يسكنون في منطقة الخدمة الطبية التابعة للمنطقة الصحية المحلية في غرب سيدني. وقد تُرجم استطلاع الرأي هذا للمشاركين الناطقين بهذه اللغات الذين تمكنوا من الإجابة على الأسئلة بلغتهم أو باللغة الإنكليزية.
مجموعات تركيز لجمع المعلومات من أفراد المجتمع	مناقشات وجهاً لوجه، وشبه منظمة ومسجلة مع البالغين من أفراد مجتمعات السكان الأصليين ومن خلفيات ناطقة باللغات العربية والهندية والصينية (الماندريين)، ممن لديهم تجارب في رعاية مريض في مرحلة نهاية الحياة، ومن الذين يسكنون في منطقة الخدمة الطبية التابعة للمنطقة الصحية المحلية في غرب سيدني. وقد تم توفير موظفي الدعم للسكان الأصليين ومترجمين فوريين لمساعدة الأشخاص المشاركين في مجموعات التركيز المعنية.
مقابلات فوتو فويس	مقابلات فوتو فويس شبه منظمة ومسجلة مع البالغين من أفراد المجتمع الذين لديهم تجارب سابقة لا تقل عن ستة أشهر في رعاية مريض في مرحلة نهاية الحياة ممن يسكنون في منطقة الخدمة الطبية التابعة للمنطقة الصحية المحلية في غرب سيدني. وقد أجريت المقابلات عبر الإنترنت مع أحد الباحثين الناطقين بالإنكليزية، وقد أعطي المشاركون فرصة أن يحضر شخصاً ثنائي اللغة لدعمه إذا دعت الحاجة.

وبعد الانتهاء من مرحلة جمع البيانات وتحليلها، عُقدت منتديات عامة في المجتمع لعرض نتائج الدراسة المبدئية. وعليه، أتاحت الفرصة لأفراد المجتمع لإبداء آرائهم وملاحظاتهم، ولتقديم مقترحات إضافية للنظر في الاحتياجات الثقافية في مرحلة نهاية الحياة. ويحدد الجدول رقم 2 المواضيع الرئيسية ونتائج الدراسة:

الجدول رقم 2 المواضيع الرئيسية

1 - إن الممارسات والأعراف الثقافية من الأمور المهمة في مرحلة نهاية الحياة وفي المواساة عند وقوع الفاجعة.	2 - إن العلاقة المبنية على الثقة أمر جوهري.
3 - استحداث طرائق يمكن لأبناء المجتمع من خلالها تقديم مساهماتهم بشأن الرعاية المناسبة ثقافياً لمجتمعاتهم.	4 - زيادة المعرفة بخدمات مرحلة نهاية الحياة.
5 - الاستفادة قدر المستطاع من الخدمات التي تقدمها المستشفيات.	6 - زيادة عدد الخدمات المناسبة ثقافياً في مرحلة نهاية الحياة وخدمات المواساة عند وقوع الفاجعة في المجتمع.

وفيما يلي شرح مقتضب للعناوين الرئيسية بعنوان «النتائج الرئيسية»، وقد تم شرحها بالتفصيل في قسم «النتائج والمناقشة» من هذا التقرير الذي يوثق احتياجات مرحلة نهاية الحياة التي حددها كل من أفراد مجتمعات السكان الأصليين ومن خلفيات ناطقة باللغات العربية والهندية والصينية (الماندرين) في المنطقة الصحية المحلية في غرب سيدني ومتخصصين في الرعاية الصحية العاملين في مرحلة نهاية الحياة.

النتائج الرئيسية

1 - إن الممارسات والأعراف الثقافية من الأمور المهمة في مرحلة نهاية الحياة وفي المواساة عند وقوع الفاجعة.

كانت الممارسات والأعراف الثقافية، بالنسبة لجميع المجموعات الثقافية الأربعة، التي تتعلق بمرحلة نهاية الحياة مهمة لتوفير الطمأنينة والسلام للأشخاص الذين يحضرون ولأسرهم وأصدقائهم أيضاً. فقد ينجم عن عدم تلبية متطلباتهم الروحية أو الدينية معاناة مستمرة ومضاعفات ترتبط بأسى فاجعة الأسرة والمجتمع. إلا أن تنوع المعتقدات والممارسات بين شتى المجتمعات الثقافية وتباينها ضمن المجتمع الواحد هو الآخر أمر لا يقل أهمية عما سبق ذكره. فعلى سبيل المثال، قد تختلف أسباب إيمان بعض المشاركين من أي من المجموعات الأربع بالعقيدة المسيحية، إما لدوافع شخصية، أو بسبب خلفياتهم العائلية. كما وبلغنا المشاركون عن اختلافات بين الأجيال من ناحية الرغبة في الرعاية واتباع الطقوس التقليدية. وكشف استطلاع الرأي عبر الإنترنت عن المعلومات المتعلقة بالموت (DLI) عن أن عدد السنوات التي قضاها الناس في أستراليا كان من أهم العوامل الديموغرافية للتنبؤ بمدى معرفة الناس بالمعلومات المتعلقة بالموت، وهو مؤشر أكثر أهمية من خلفيتهم الثقافية. إن التنوع في الممارسات الثقافية من ناحية، والاختلافات في المعلومات المتعلقة بالموت من ناحية أخرى، يشير إلى عدم وجود «طريقة سهلة» لتحديد احتياجات الأشخاص في مرحلة نهاية الحياة. وهذا يستدعي زيادة الوعي حول بعض العادات الثقافية المتنوعة وفهم القيم التي تركز عليها هذه العادات وذلك لزيادة قدرة المتخصصين في الرعاية الصحية على التعاون مع المرضى وأسرهم من أجل توفير رعاية مركزة مناسبة ثقافياً تتحاشى افتراض أي مسار سوف تسلكه مرحلة نهاية الحياة ورحلة المواساة عند وقوع الفاجعة.

2 - إن العلاقة المبنية على الثقة أمر جوهري.

كان فحوى ما قاله لنا المشاركون هو «إن الثقة أمر جوهري». وقد شددت الحاجة إلى بناء علاقات تتسم بالثقة على المواضيع الأخرى التي جاءت في نتائج الدراسة. وإن انعدام الثقة يعني أن الناس لن يتحدثوا عن مواضيع حساسة مثل الموت والاحتضار، ولن يستمعوا إلى الخدمات المتاحة لهم، كما أنهم لن يحاولوا الحصول على تلك الخدمات إذا لم يكونوا متأكدين من أنها ستلبي احتياجاتهم. إن الثقة كانت من الأمور المهمة خصوصاً في الاستشارات التي تتعلق بالمواساة عند وقوع الفاجعة حيث كان الناس يعانون من مشاعر الأسى. فضلاً عن أن قدرة أفراد المجتمعات على بناء الثقة بالخدمات الحالية تتأثر تأثراً بالغاً بمشاكل أنظمة الرعاية المتعلقة بتوقف الخدمات. وكانت الحاجة إلى البحث عن خدمات في نظام صحي مجهول يضم العديد من الأنظمة والخدمات والوظائف المتوقفة عن العمل، مدعاة للحزن والإحباط. ولكن لم يكن هناك الوقت الكافي أو الفرص المناسبة لبناء علاقات تشوبها الثقة. وبناءً عليه فإن انتظام الرعاية الطبية والرعاية الداعمة والاعتناء على رؤية طاقم الرعاية الصحية والرعاية الداعمة، عندما يكون المرء في أشد مراحل ضعفه، على أنها أمر في غاية الأهمية. فقد طلب من المرضى وعائلاتهم تكرار قصتهم عدة مرات لموظفي الصحة المختلفين في أقسام مختلفة من النظام الصحي. وكانت النقاط الرئيسية التي تتعلق بتوقف العمل ضمن نظام مرحلة نهاية الحياة والتي تم تحديدها هي: (1) فصل الأطباء في العيادات الخاصة (G.P.s) عن نظام المستشفيات، (2) والاستعانة بمقدمي رعاية تلطيفية خارجيين في المنزل، (3) وفصل الخدمات الطبية عن خدمات الحزن والمواساة عند وقوع الفاجعة، و (4) وفصل الخدمات الصحية الرسمية عن المنظمات غير الحكومية والدينية وغيرها من المنظمات التي تقدم الدعم في المجتمع.

3 - استحداث طرائق يمكن لأبناء المجتمع من خلالها تقديم مساهماتهم بشأن الرعاية المناسبة ثقافياً لمجتمعاتهم.

إن الأمور التي تقف حاجزاً أمام تقديم الدعم في مرحلة نهاية الحياة والمواساة عند وقوع الفاجعة مذكورة في الموضوع رقم 1 وتتعلق بالحاجة إلى احترام الاختلافات الثقافية للممارسات والأعراف في مرحلة نهاية الحياة؛ أما الموضوع رقم 2 فيتناول صعوبات بناء الثقة في مختلف أقسام النظام الصحي المنعزلة. وتبين جميع هذه المواضيع الصعوبات التي يواجهها السكان الأصليون والأشخاص الذين ينتمون إلى مجتمعات متنوعة ثقافياً ولغوياً في الحصول على المساعدة التي يحتاجونها. إذ قد يصعب عليهم إبداء رغبتهم في الحصول على المساعدة أو معرفة ممن يطلبونها أو طريقة طلبها. أما الموضوع رقم 3 فيتناول المنظمات والبرامج والجهات الخدمية والشبكات غير الرسمية غير التابعة لدائرة الصحة في نيو ساوث ويلز، والطرق التي يمكن من خلالها ربط هذه الجهات بخدمات مرحلة نهاية الحياة وخدمات المواساة عند وقوع الفاجعة. وقد اقترح المشاركون سبلاً لربط هذه الجهات بخدمات مرحلة نهاية الحياة وخدمات المواساة عند وقوع الفاجعة تتمثل فيما يلي: ١- توسيع نطاق الدعم المجتمعي وربط الجهات بعضها ببعض، ٢- زيادة الوعي لدى السكان الأصليين وأفراد المجتمعات المتنوعة ثقافياً ولغوياً حول مجموعة الخيارات المتاحة لهم، ٣- تعيين موظفي اتصال محدّدين يمكن للمرضى وأسرهم ومقدمي الرعاية لهم اللجوء إليهم للمساعدة في الاستجابة لمرحلة نهاية الحياة والتخطيط لها.

4 - زيادة المعرفة بخدمات مرحلة نهاية الحياة

يتجنب الكثيرون التحدث عن مرحلة نهاية الحياة لأسباب متعددة منها التشبث بالأمل أو الخشية من استحضر الموت أو لأنهم ببساطة يتضايقون من الحديث عن هذا الموضوع. إن تدني المعرفة الصحية لدى المرء وعدم فهمه لوظائف الجسم أو تعرضه للضغوطات أو شعوره بضعفه، كلها عوامل يمكن أن تحول دون إلمامه بخدمات مرحلة نهاية الحياة وفهمه لها. فمن دون فهم ماهية الخدمات ووظائفها، يمكن أن يفوت الفرد المساعدة التي يحتاج إليها في مرحلة نهاية الحياة. ويمكن أن تكون هناك عقبات أخرى تعزى إلى الاختلافات اللغوية والثقافية وعدم الإلمام بالنظام الصحي. وقد أفصح المشاركون عن أن بعض المفاهيم مثل «الرعاية التلطيفية» و«الإرشاد» و«التطوع الرسمي» و«الخرف» غير مألوفة لدى العديد من السكان الأصليين وأفراد المجتمعات المتنوعة ثقافياً. لذا، يستدعي هذا الأمر فهم هذه العقبات بحذر من أجل تقديم اقتراحات في نطاق إمكانية توفير الخدمات في قسم ما أو تحسينها للحصول على دعم يراعي خصائص المجتمعات الثقافية لأولئك الذين هم في مرحلة نهاية الحياة وأسرهم ومقدمي الرعاية الآخرين.

5 - الاستفادة قدر المستطاع من الخدمات التي تقدمها المستشفيات

كثيراً ما يلجأ الأشخاص إلى خدمات الرعاية التلطيفية بعد «فوات الأوان». ولذا، إن تقديم رعاية داعمة وتلطيفية مبكرة للمرضى وأسرهم من شأنه أن يحدّ من دخولهم إلى المستشفى بشكل طارئ أو غير مخطط له مسبقاً عبر تشجيعهم على الاستفادة من مسارات الرعاية التي تعكس حالة الفرد فتلبي احتياجاته وتناسب ظروفه الاجتماعية. إلا أنه وبسبب الأقسام المنعزلة في نظام الرعاية الصحية (راجع الموضوع رقم 2)، فإن أعضاء الطاقم الصحي لا يدركون بالضرورة طبيعة خدمات مرحلة نهاية الحياة وقيمتها أو طريقة الحصول عليها. وتعد استراتيجية ممرض الرعاية التلطيفية المتخصص الذي يقمّ المساعدة في أقسام المستشفى الأخرى فعالة ويمكن توسيعها. ويستدعي هذا الأمر ربط الخدمات الصحية ببعضها البعض لتصبح أكثر فعالية وذلك عبر إنشاء نقطة اتصال مركزية للمرضى وأفراد الطاقم الصحي. كما وتشمل الاستراتيجيات الأخرى بناء شبكة من الموظفين والمتطوعين الداعمين من السكان الأصليين ومن أفراد المجتمعات المتنوعة ثقافياً ولغوياً في مجال الرعاية الداعمة والتلطيفية، وإنشاء مساحات في جميع المستشفيات مخصصة للرعاية التلطيفية مثل وحدة الرعاية التلطيفية والداعمة في مستشفى ماونت درويت (Mount Druitt).

6 - زيادة عدد الخدمات المناسبة ثقافياً في مرحلة نهاية الحياة وخدمات المواساة عند وقوع الفاجعة في المجتمع

لقد خلصت النتائج إلى وجود حاجة لمزيد من الخدمات الرسمية في المجتمع التي يمكن أن تدعم الرعاية المناسبة ثقافياً في مرحلة نهاية الحياة. وتنقسم الاقتراحات إلى ثلاث استراتيجيات رئيسية هي كالاتي: أولاً، أن تقوم المنظمات الحالية التي تقدم الدعم لمجتمعات السكان الأصليين والمجتمعات المتنوعة ثقافياً ولغوياً بزيادة رقعة خدمات مرحلة نهاية الحياة والمواساة عند وقوع الفاجعة، على سبيل المثال «خدمة صحة الجاليات متعددة الثقافات» والمراكز الصحية المجتمعية المحلية السبعة في المنطقة الصحية المحلية. ثانياً، زيادة مراعاة الخصائص الثقافية ضمن خدمات مرحلة نهاية الحياة والمواساة عند وقوع الفاجعة وذلك من خلال إقامة دورات تدريبية لنشر التوعية الثقافية وتوظيف طاقم موظفين من خلفيات متنوعة لخدمة الرعاية التلطيفية في المنزل بالإضافة إلى خدمات المواساة عند وقوع الفاجعة والخدمات المتوفرة في المستشفيات. ثالثاً، إنشاء خدمات مرحلة نهاية الحياة والمواساة عند وقوع الفاجعة في المجتمع حيث يتم توظيف أشخاص من الثقافات المحلية لإنشاء خدمات متعددة مخصصة للرعاية التلطيفية والداعمة في المجتمع، كما هو الحال في مرافق رعاية المسنين، والخدمات غير الرسمية المناسبة لدعم المواساة عند وقوع الفاجعة، كما هو الحال في مراكز المجتمع المحلي التي يمكن أن توفر الدعم الأساسي، ولكن لديها اتصالات بخدمات المواساة عند وقوع الفاجعة والعاملين في مجال الرعاية الداعمة والتلطيفية المخصصة لمجتمع ثقافي معين.

التوصيات

توفر نتائج البحث دليلاً واضحاً بقيادة المجتمع على ما هو مطلوب لتأمين رعاية آمنة ثقافياً في نهاية الحياة، والأساسي هنا هو الحاجة إلى علاقات علاجية موثوقة في إطار استمرارية الرعاية. نحن نقدم التوصيات التالية (هنا، باختصار ومفصلة بالكامل في التقرير أدناه) لدمج هذه النتائج في تطوير السياسات ونماذج الخدمة وتقديم الخدمات عبر الإعدادات الرسمية والسريية والمجتمعية. تدعم هذه التوصيات معاً الخدمات لتوفير استمرارية الرعاية وإدارة الحالات التي تدعم الثقة العلاقية بين مقدمي الخدمة والمرضى وأسرهم.

1 - زيادة العاملين في مجال الرعاية الداعمة والتلطيفية من الناحية الثقافية

تبعاً لنجاح تعيين موظف الرعاية الداعمة والتلطيفية المخصص للسكان الأصليين، نوصي بتعيين عدد أكبر من موظفي الرعاية الداعمة والتلطيفية من الذين ينتمون إلى مجتمعات ثقافية محددة يكفي على الأقل لتلبية احتياجات مجتمعات المهاجرين الأكثر اكتظاظاً بالسكان ضمن المنطقة الصحية المحلية.

2 - إنشاء مركز موارد تلطيفية ونهاية الحياة

نوصي بإنشاء نقطة اتصال مركزية تكون عبارة عن وحدة تابعة لدائرة الصحة مرتبطة بالرعاية الداعمة والتلطيفية من شأنها أن تربط دوائر النظام الصحي بعضها ببعض وترتبط أيضاً بمنظمات الخدمات الصحية المجتمعية مثل (Silverchain) وعيادات الأطباء العاميين. وبالتالي سيكون لدى المرضى وعائلاتهم نقطة اتصال واحدة لجميع احتياجاتهم المتعلقة بمرحلة نهاية الحياة والمواساة عند وقوع الفاجعة، ويمكن لأفراد الطاقم الصحي تتبع تاريخ الخدمة لعملائهم.

3 - توسيع دور المتطوعين

نوصي بتوسيع دور المتطوعين في كل مستشفى، بما في ذلك استحداث وظيفة مدير للتنسيق والإشراف على مجموعة كبيرة من متطوعي الرعاية التلطيفية الذين ينتمون إلى مجتمعات متنوعة ثقافياً ولغوياً. كما وينبغي تدريب المتطوعين لكي تشمل خدمات الدعم التي يقدمونها فترة المواساة عند وقوع الفاجعة.

4 - الاستفادة من البرامج والمنظمات التعليمية الحالية

نوصي باستخدام البرامج والمنظمات التعليمية الحالية لتوفير المزيد من البرامج التثقيفية والتوعية للعاملين في مجال الصحة ولأفراد المجتمع ومقدمي الرعاية.

5 - تطوير اتصالات مناسبة ثقافياً في مرحلة نهاية الحياة

نوصي بنشر المواد المطبوعة والإلكترونية المناسبة التي تتضمن لغة وصوراً تناسب ثقافة المجتمع المعني، ويجب إشراك مجموعات مجتمعية عند وضع هذه المواد لضمان مراعاة الخصائص الثقافية.

6 - توسيع رقعة الأماكن المناسبة للرعاية التلطيفية

نوصي بـ (1) تخصيص أماكن للرعاية التلطيفية في جميع المستشفيات تبعث على الثقة والراحة في أفراد المجموعات الثقافية المتنوعة (وقد يشمل ذلك الأعمال الفنية، وأماكن للتجمعات الكبيرة، وغرف الصلاة، ومطابخ لإعداد الطعام، وغرف المشاهدة، والمساحات الخارجية للتجمعات والطقوس)؛ (2) إنشاء أماكن للسكن تقدم رعاية طبية بعيداً عن المستشفيات وتتضمن خدمات دعم الرعاية التلطيفية؛ و (3) عيادات نهائية في أماكن مجتمعية يسهل الوصول إليها (مثل المراكز الطبية الكبيرة).

7 - زيادة دعم المخصص للمواساة عند وقوع الفاجعة

نوصي بزيادة عدد المرشدين فيما يتعلق بالمواساة عند وقوع الفاجعة ممن لديهم فهم للاحتياجات المتنوعة ثقافياً، وإنشاء مراكز لخدمات المواساة عند وقوع الفاجعة في المرافق المجتمعية الحالية.

8 - اتباع نهج الصحة العامة لإنشاء مجتمعات رحيمة

نوصي باتباع نهج الصحة العامة في التعامل مع مرحلة نهاية الحياة وفترة المواساة عند وقوع الفاجعة لدعم بناء قدرات الناس في المجتمع فيتمسك بهم دعم بعضهم البعض في رحلة نهاية الحياة سواء أكانوا مرضى أم مقدمي رعاية أم أصدقاء أم أفراد آخرين من العائلة، ويتضمن ذلك معرفة كيفية العثور على مساعدة إضافية عند الحاجة إليها.

تهدف هذه التوصيات العملية والقابلة للتطبيق التي تمت مناقشتها بشكل أكثر تفصيلاً في التقرير أدناه، إلى «الانتقال من مرحلة الحوار إلى مرحلة التنفيذ وذلك لكي نشهد حدوث تغيير فعلي»، ومن خلال القيام بذلك، تؤكد الأهمية الحاسمة للتشاور المباشر مع المجتمعات.

कार्यकारी सारांश

संक्षिप्त विवरण

पश्चिमी सडिनी में सांस्कृतिक और भाषाई रूप से विविध और ऐबओरीजनल समुदायों में जीवन को सीमति करने वाली बीमारी के साथ सक्रिय रूप से रह रहे और मृत्यु का सामना करने वाले लोगों के लिए What Matters in the End (आखिर में क्या मायने रखता है) (<http://doi.org/10.26183/cnxj-nw28>), नामक इस रपिर्त में, जनसंख्या-आधारित जीवन-के-अंत की आवश्यकताओं के विश्लेषण का एक विवरण दिया गया है। न्यू साउथ वेल्ज़ स्वास्थ्य मंत्रालय द्वारा वित्त पोषित इस अध्ययन की संरचना, समुदायों के साथ सीधे जुड़ने के लिए की गई थी, जो उन लोगों को एक आवाज़ देने का काम करता है जो हाशिये पर हैं, किसी अतिसंवेदनशील या प्रतिकूल परिस्थिति में हैं। यह सांस्कृतिक आवश्यकताओं को समझने में और इस पर ध्यान केंद्रित करती है कि ऐबओरीजनल समुदाय के लोगों और अरबी, ह्रिदी और मंदारनि भाषी पृष्ठभूमि के लोगों के लिए, कनि-कनि तरीकों से जीवन के अंत की देखभाल को सांस्कृतिक दृष्टि से सुरक्षित रूप में प्रदान किया जा सकता है। अनुसंधान से उत्पन्न नषिकर्षों के आधार पर, रपिर्त सेवा प्रणालियों के लिए स्पष्ट और साध्य सफ़ािशि करती है जिसे जीवन के अंत का सामना कर रहे लोग, और उनके देखभालकर्ताओं और उनके समुदायों को बेहतर सहारा दिया जा सके। हालाँकि यह शोध पश्चिमी सडिनी पर केंद्रित था, लेकिन इसके परिणाम बहुत व्यापक हैं, जसिमें ऑस्ट्रेलिया के शहरी क्षेत्रों में रहने वाले अन्य समुदायों की देखभाल के सांस्कृतिक रूप से सचेत मॉडलों में महत्वपूर्ण योगदान देने की क्षमता है।

शोध का प्राथमिक उद्देश्य यह समझना था कि विविध समुदायों को वेस्टर्न सडिनी लोकल हेल्थ डिस्ट्रिक्ट की जीवन-के-अंत की सेवाओं से क्या-क्या आवश्यकताएँ हैं, और इन सेवाओं को सांस्कृतिक रूप से सुरक्षित बनाने के लिए क्या किया जा सकता है। इसमें यह शामिल है कि यदि कोई चाहता है कि उसकी मृत्यु घर पर ही हो, तो इस बात में उनकी वकालत करना और उनका समर्थन करना। इन उद्देश्यों की प्राप्ति को ऐसे केंद्रित शोध प्रश्नों द्वारा सुगम बनाया गया था, जो जीवन-के-अंत समय के सांस्कृतिक पहलुओं को समझने की कोशिश करते हैं, जनिमें शामिल है शोक अवस्था; उनकी मृत्यु साक्षरता (अपनी मृत्यु से संबंधित सोचे-समझे फैसले लेने की क्षमता) किस हद तक वकिसति है; समुदायों के पास ऐसा क्या है जो पहले से ही उनके लिए सही रहा है; सहायता और सेवाएँ जनिहें समुदायों ने उपयोगी पाया है; लोगों को अन्य कनि सहायताओं या सेवाओं की आवश्यकता है और उन्हें प्रदान करने के लिए कौन सर्वोत्तम परिस्थिति में है; और कैसे मौजूदा सेवाओं और सहायताओं को बदला जाए जसिसे वे सांस्कृतिक रूप से उपयुक्त बन जाएँ। शोध को वेस्टर्न सडिनी यूनिवर्सिटी के केयरिंग एट एंड-ऑफ-लाइफ़ रसिर्च प्रोग्राम द्वारा संचालित और WSLHD के सलाहकार पैनल के सुझावों की सहायता से किया गया जसिमें सहायक और उपशामक देखभाल (Supportive and Palliative Care), ऐबओरीजनल स्वास्थ्य और बहुसांस्कृतिक स्वास्थ्य (Multicultural Health) के प्रतिनिधियों ने नेतृत्व किया। अनुसंधान के डिज़ाइन के रूप में स्थानीय समुदायों के अलग-अलग सांस्कृतिक सलाहकारों के साथ भी परामर्श किया गया।

एक व्यापक, बहु-वधिक डिज़ाइन में अनुसंधान ने स्वास्थ्य देखभाल पेशेवरों और समुदाय के सदस्यों को भी शामिल किया जसिसे विश्लेषण के लिए गुणात्मक और मात्रात्मक दोनों तरह का डेटा प्राप्त किया गया। तालिका 1 डेटा संग्रह के तरीकों और प्रतिभागियों के प्रोफाइल का सारांश प्रस्तुत करती है:

तालिका नंबर एक अध्ययन की संरचना

जानकारी देने वाले प्रमुख लोगों के साथ साक्षात्कार	WSLHD कैचमेंट क्षेत्र और संबंधित शोक-अवस्था सहायता सेवाओं में काम करने वाले सहायक दल कर्मी, साधारण डॉक्टर या उपशामक, जीवन-के-अंत समय की देखभाल प्रदान करने वाले स्वास्थ्य पेशेवरों के साथ संरचित और रिकॉर्ड किए गए गुणात्मक साक्षात्कार।
मृत्यु साक्षरता सूचकांक (Death Literacy Index: DLI) ऑनलाइन सर्वेक्षण	WSLHD कैचमेंट क्षेत्र में रहने वाले ऐबओरीजनल, अरबी, मंदारनि, या ह्रिदी सांस्कृतिक/भाषाई पृष्ठभूमि के वयस्क समुदाय के सदस्यों का मात्रात्मक ऑनलाइन सर्वेक्षण। अरबी, मंदारनि और ह्रिदी भाषी उत्तरदाताओं के लिए सर्वेक्षण का उनकी भाषा में अनुवाद किया गया, जो अपनी भाषा या अंग्रेज़ी में प्रश्नों का उत्तर देने का विकल्प चुन सकते थे।
फ़ोकस ग्रुप (जानकारी सत्र)	जीवन के अंत समय की देखभाल का अनुभव रखने वाले और WSLHD कैचमेंट क्षेत्र में रहने वाले ऐबओरीजनल, अरबी, मंदारनि, या ह्रिदी सांस्कृतिक/भाषाई पृष्ठभूमि वाले वयस्क समुदाय के सदस्यों के साथ आमने-सामने, अर्ध-संरचित, रिकॉर्ड की गई चर्चाएँ। भागीदारी में सहायता के लिए संबंधित फोकस ग्रुप में ऐबओरीजनल सहायता कर्मी और द्विभाषी दुभाषि उपलब्ध थे।
फोटोवॉइस साक्षात्कार	जीवन के अंत समय की देखभाल का पछिले छह महीने से अधिक का अनुभव रखने वाले और WSLHD जलगरहण क्षेत्र (कैचमेंट क्षेत्र) में रहने वाले समुदाय के वयस्क सदस्यों के साथ अर्ध-संरचित और रिकॉर्ड किए गए फोटोवॉइस साक्षात्कार। अंग्रेज़ी बोलने वाले शोधकर्ता के साथ किए जाने वाले ऑनलाइन साक्षात्कार और यदि आवश्यकता हो तो किसी नामांकित द्विभाषी सहायता व्यक्ती को उपस्थित होने का विकल्प दिया जाता है।

डेटा संग्रह का चरण और डेटा का विश्लेषण पूरा हो जाने के बाद, अंतरिम नषिकर्षों को प्रस्तुत करने के लिए समुदाय में सार्वजनिक जनसभाएँ आयोजित की गईं। इस प्रक्रिया ने समुदाय के सदस्यों को शोध नषिकर्षों पर टपिपणी करने और जीवन के अंत के समय की सांस्कृतिक आवश्यकताओं को संबोधित करने और उनके बारे में सुझाव देने का अवसर प्रदान किया। अनुसंधान डेटा से प्राप्त प्रमुख प्रासंगिक वषियों और/या मुद्दों का उल्लेख तालिका 2 में किया गया है:

तालिका 2 प्रमुख वषिय

1. सांस्कृतिक तौर-तरीके और प्रथाएँ जीवन के अंत और शोक-अवस्था देखभाल के पहलूओं का एक महत्वपूर्ण अंग हैं।	2. एक दूसरे पर भरोसा होना एक मूलभूत चीज़ है
3. सांस्कृतिक रूप से उचित देखभाल प्राप्त के लिए समुदायों को सुझाव व्यक्त करने के तरीके	4. जीवन के अंत की सेवाओं के बारे में ज्ञान को बढ़ाना
5. अस्पताल-आधारित सेवाओं का अधिकतम लाभ उठाना	6. सांस्कृतिक रूप से उपयुक्त जीवन के अंत के समय की और शोक-अवस्था सेवाओं को समुदाय में बढ़ावा देना

इन वषियों पर नीचे 'मुख्य नषिकर्ष' के अंतर्गत (संक्षेप में) चर्चा की गई है। इनके बारे में वसितृत जानकारी, इस रपिर्त के 'नषिकर्ष और चर्चा' खंड में दी गई है, जो आद्वितीय समुदाय और WSLHD के भीतर अरबी, ह्रिदी और मंदारनि भाषी पृष्ठभूमि के लोगों के साथ-साथ, जीवन के अंत समय से संबंधित कार्य करने वाले स्वास्थ्य पेशेवरों द्वारा पहचानी गई जीवन के अंत की आवश्यकताओं का दस्तावेज़ीकरण करते हैं।

मुख्य नषिकर्ष

1: सांस्कृतिक तौर-तरीके और प्रथाएं, जीवन के अंत और शोक-अवस्था देखभाल के पहलुओं का एक महत्वपूर्ण अंग है।

इन चारों सांस्कृतिक समूहों में, जीवन के अंत से संबंधित सांस्कृतिक तौर-तरीके और प्रथाएं, मृत्यु का सामना कर रहे लोगों के साथ-साथ उनके परिवारजनों और दोस्तों के लिए सुकून और शांति प्रदान करने के लिए महत्वपूर्ण थे। यदि आध्यात्मिक या धार्मिक ज़रूरतों की पूर्ति नहीं होती है, तो इसके परिणामस्वरूप, शोक-अवस्था से जुड़े परिवार और समुदाय को शोक प्रक्रिया के साथ-साथ नरितर अत्यंत पीड़ा और जटिलताओं का सामना करना पड़ सकता है। हालाँकि, विभिन्न संस्कृतियों की विविध मान्यताएँ और प्रथाएँ हैं और संस्कृतियों के बीच की भिन्नताएँ भी उतनी ही महत्वपूर्ण थीं। उदाहरण के लिए, ऐसा हो सकता है कि चारों समूहों में से किसी एक के लोग, व्यक्तिगत रूचि या पारिवारिक पृष्ठभूमि के कारण ईसाई धर्म में आस्था रखते हों। देखभाल करने की इच्छा होने और पारंपरिक रीति-रिवाज़ों का पालन करने के प्रति पीढ़ीगत अंतर बताए गए। मृत्यु साक्षरता सूचकांक (डेथ लटिरेसी इंडेक्स) (DLI) सर्वेक्षण ने दिखाया कि लोगों की मृत्यु साक्षरता का अनुमान लगाने के लिए सबसे महत्वपूर्ण कारक यह था कि उनको ऑस्ट्रेलिया में रहते कितने वर्ष हो गए हैं, यह कारक उनकी सांस्कृतिक पृष्ठभूमि के कारक से भी अधिक महत्वपूर्ण संकेतक था। एक ओर सांस्कृतिक प्रथाओं में होने वाली विविधता, और दूसरी ओर मृत्यु साक्षरता में होने वाले अंतर का मतलब यह है कि लोगों की जीवन के अंत की आवश्यकताओं की पहचान करने के लिए कोई 'आसान नुस्खे' नहीं हैं। रोगियों और परिवारों के साथ काम करने की स्वास्थ्य पेशेवरों की क्षमता को अधिकतम करने के लिए प्रथाओं की विविधता के बारे में जागरूकता और उन प्रथाओं को रेखांकित करने वाले मूल्यों की सराहना किया जाना आवश्यक है, ताकि सांस्कृतिक रूप से उचित रोगी-केंद्रित देखभाल प्रदान की जा सके, जो जीवन के अंत और शोक अवस्था की यात्रा के रास्ते के बारे में कोई धारणा बनाने से परहेज़ करे।

2: एक दूसरे पर भरोसा होना एक मूलभूत चीज़ है

हमारे प्रतिभागियों का संदेश यह था कि भरोसा होना अति-आवश्यक है। विश्वास के रश्मि बनाने की आवश्यकता ने नषिकर्षों के अन्य विषयों को रेखांकित किया। भरोसे के बिना लोग मृत्यु और मरने जैसे संवेदनशील विषयों पर बात नहीं करेंगे; उपलब्ध सेवाओं के बारे में संदेश नहीं सुनेंगे; और अगर उन्हें भरोसा नहीं होगा कि उनकी आवश्यकताएँ पूरी की जाएंगी, तो वे सेवाओं का उपयोग नहीं करेंगे। भरोसा विशेष रूप से शोक-अवस्था से जुड़े परामर्श के लिए महत्वपूर्ण था, जहाँ लोग पहले से ही अपने शोक से जूझ रहे थे। मौजूदा सेवाओं के भीतर विश्वसनीय संबंध बनाने की क्षमता, देखभाल मिलाने में होने वाले अंतराल से संबंधित प्रणालीगत मुद्दों की वजह से बहुत अधिक प्रभावित हुई थी। एक दूसरे से जुड़ा बहुत सारी प्रणालियाँ, सेवाओं और कर्मचारियों के साथ-साथ, एक अज्ञात स्वास्थ्य प्रणाली में अपना काम निकलवाने की आवश्यकता परेशान और नरितर करने वाली थी। विश्वसनीय रश्मि वकिसति करने के लिए पर्याप्त समय या अवसर नहीं था। जब लोग सबसे अधिक आघात योग्य परिस्थिति में होते हैं, तो चिकित्सा और सहायक देखभाल कर्मचारियों के एक-से और जाने-पहचाने चहरो का होना महत्वपूर्ण समझा गया। हालाँकि, मरीज़ों और उनके परिवारों को प्रणाली के विभिन्न हिस्सों में विभिन्न स्वास्थ्य कर्मचारियों के सामने अपनी कहानी कई बार दोहरानी पड़ती थी। जीवन के अंत की प्रणाली में जिन प्रमुख कमियों की पहचान की गई उनमें शामिल थे: (1) नज़ी प्रैक्टिस (जी.पी.) करने वाले डॉक्टरों का अस्पताल प्रणाली से अलग होना; (2) घर में प्रदान की जाने वाली उपशामक देखभाल का किसी नज़ी प्रदाता को सौंप दिया जाना; (3) चिकित्सा सेवाओं को दुःख और शोक-अवस्था सेवाओं से अलग करना; और (4) समुदाय में सहारा देने वाले गैर सरकारी संगठनों, धार्मिक और अन्य संगठनों से औपचारिक स्वास्थ्य सेवाओं का अलग होना।

3: सांस्कृतिक रूप से उचित देखभाल प्राप्त के लिए समुदायों को सुझाव व्यक्त करने के तरीके

थीम 1 में जीवन के अंत (EoL) और शोक-अवस्था संबंधी सहायता की एक अच्छी प्रणाली के रास्ते की बाधाएँ, जीवन के अंत की सांस्कृतिक विभिन्नताओं और प्रथाओं के सम्मान के संबंध में दर्शाई गई हैं और थीम 2 दर्शाती है कि स्वास्थ्य प्रणाली के विभिन्न विभागों के बीच विश्वसनीय संबंध बनाने में क्या कठिनाइयाँ प्रस्तुत होती हैं। एक साथ ये उन कठिनाइयों को दर्शाती हैं जिनका सामना ऐबओरीजिनल और सांस्कृतिक और भाषाई रूप से विविध (CaLD) लोगों को उस सहायता को प्राप्त करने में करना पड़ता है, जिसकी उन्हें आवश्यकता हो सकती है। मदद मांगने का मन होना और यह जानना कि मदद के लिए किससे पूछना है, या कैसे पूछना है, चुनौतीपूर्ण हो सकता है। थीम 3 उन संगठनों, कार्यक्रमों, सेवाओं और अनौपचारिक नेटवर्कों को संबोधित करती है जो पहले से ही न्यू साउथ वेल्स स्वास्थ्य विभाग के बाहर मौजूद हैं और कनि तरीकों से वे EoL और शोक-अवस्था से संबंधित सेवाओं से जुड़ सकती हैं। उत्तर देने वालों ने सुझाव दिया कि इन सेवाओं से जुड़ने में आने वाली बाधाओं को नमि द्वारा संबोधित किया जा सकता है: (1) समुदाय-संबंधित सहायता का वसितार और समूहों के बीच तालमेल स्थापति करना; (2) सहायता के उपलब्ध वकिलों के बारे में ऐबओरीजिनल और सांस्कृतिक रूप से विभिन्न समुदायों के बीच जागरूकता पैदा करना; और (3) विशिष्ट सामुदायिक संपर्क व्यक्तियों का मौजूद होना जो परिवारों और रोगियों और उनकी देखभाल करने वालों के लिए, जीवन की अंतिम यात्रा पर सवाल का जवाब देने और मार्गनिर्देशन करने में उनकी मदद कर सके।

4: जीवन के अंत की सेवाओं के बारे में ज्ञान को बढ़ाना

बहुत से लोग जीवन के अंत के बारे में बात नहीं करना चाहते हैं, चाहे वह आशा पर टिके रहने की वजह से हो, मौत को बुलाने से बचने की चाहत हो, या सरि इसलए कि इस विषय से व असहज होते हों। स्वास्थ्य साक्षरता और शारीरिक कार्यों की समझ का कम होना, तनावग्रस्त होना, या असुरक्षित महसूस करना ऐसे सभी कारक हैं जो लोगों में जीवन के अंत की सेवाओं के ज्ञान या समझ में बाधा उत्पन्न कर सकते हैं। हालाँकि, यह समझें बिना कि सेवाएँ क्या हैं और वे क्या करती हैं, लोग जीवन के अंत समय की ऐसी सहायता से चूक सकते हैं जिसकी उन्हें आवश्यकता है। भाषाई अंतर, सांस्कृतिक अंतर और स्वास्थ्य प्रणाली से अपरचितता के कारण और भी बाधाएँ उत्पन्न हो सकती हैं। कई सांस्कृतिक रूप से विविध और ऐबओरीजिनल लोगों ने 'उपशामक देखभाल', 'परामर्श', 'औपचारिक स्वयंसेवा' और 'मनोभ्रंश (Dementia/डमिशिया)' जैसे विषयों से अपने आप को अपरचित पाया। जीवन के अंतिम पड़ाव पर पहुंच चुके लोगों, उनके परिवार वालों और अन्य देखभालकर्ताओं को सांस्कृतिक रूप से संवेदनशील सहायता प्रदान करने के लिए सेवाएँ कहाँ लागू की जा सकती हैं, या कहाँ उनमें सुधार किया जा सकता है, इस पर सुझाव देने के लिए इन बाधाओं को संवेदनशील रूप से समझने की आवश्यकता है।

5: अस्पताल-आधारित सेवाओं का अधिकतम लाभ उठाना

जब 'बहुत देर हो चुकी होती है' तो लोग अक्सर उपशामक देखभाल (palliative care) की ओर देखते हैं। ऐसी देखभाल को प्राप्त करने के लिए प्रोत्साहित करने से, जो किसी व्यक्ति की परिस्थिति, आवश्यकताओं और सामाजिक परिस्थितियों के अनुकूल होती है, और शुरुआत से ही रोगियों और उनके परिवारों को सहायक और उपशामक देखभाल का परिचय प्रदान करने से, अनयोजित या आपातकालीन भर्तियों की घटनाएँ कम हो जाती हैं। हालाँकि, स्वास्थ्य देखभाल प्रणाली में असंबद्धताओं के कारण (थीम 2), स्वास्थ्य कार्यक्रमों को जीवन के अंत की सेवाओं की प्रकृति और उनके मूल्य या फरि इस बारे में जानकारी नहीं होती है कि उन तक पहुँचने के क्या-क्या तरीके हैं। विशिष्ट उपशामक देखभाल नर्सों द्वारा अस्पताल के अन्य वार्डों में सहायता करने की रणनीति प्रभावी है और इसे और बढ़ाया जा सकता है। रोगियों और स्वास्थ्य पेशेवरों के लिए संपर्क का एक केंद्रीय बटु स्थापति करके उनकी प्रभावशीलता को अधिकतम प्रभावी करने के लिए स्वास्थ्य सेवाओं के बीच सह-संबंध बनाने की आवश्यकता है। अन्य रणनीतियों में शामिल हैं ऐबओरीजिनल और CaLD सहायक और उपशामक देखभाल कार्यक्रमों और स्वयंसेवकों का एक नेटवर्क तैयार करना और सभी अस्पतालों में माउंट ड्रिड्ट की 'उपशामक और सहायक देखभाल इकाई' जैसे समर्पित उपशामक देखभाल स्थानों की स्थापना करना।

6: सांस्कृतिक रूप से उपयुक्त जीवन के अंत के समय की और शोक-अवस्था सेवाओं को समुदाय में बढ़ावा देना

समुदाय में ऐसी औपचारिक सेवाओं को बढ़ावा देने की आवश्यकता की पहचान की गई जो जीवन के अंत समय की ऐसी देखभाल का समर्थन करती हो, जो सांस्कृतिक रूप से उपयुक्त होती है। सुझाव तीन मुख्य रणनीतियों में वर्गीकृत किए गए। सबसे पहले, ऐबओरीजिनल और CaLD (सांस्कृतिक और भाषाई रूप से विविध) समुदायों को सहायता देने वाले मौजूदा संगठनों द्वारा जीवन के अंत समय और शोक-अवस्था से जुड़ी सेवाओं की कवरेज (क्षेत्र) को बढ़ाना। उदाहरण के लिए, Multicultural Health (बहुसांस्कृतिक स्वास्थ्य) और LHD (लोकल हेल्थ डिसट्रिक्ट) के कुल सात स्थानीय सामुदायिक स्वास्थ्य केंद्र। दूसरा, EoL (जीवन के अंत) और शोक-अवस्था संबंधी सेवाओं की सांस्कृतिक संवेदनशीलता को बढ़ाना, जिनमें शामिल हैं सांस्कृतिक जागरूकता प्रशिक्षण देना और घरेलू उपशामक देखभाल सेवा समेत शोक-अवस्था संबंधी सेवाओं और अस्पताल-आधारित सेवाओं के लिए विविध पृष्ठभूमि से कर्मचारियों की भर्ती करना। तीसरा, समुदाय में नई EoL

और शोक-अवस्था संबंधी सेवाओं का निर्माण करना जिसमें स्थानीय संस्कृतियों के लोगों को नयिकृत किया जाए। उदाहरण के लिए, समुदाय में बहुत सारे समर्पित उपशामक और देखभाल-सहायक स्थान, जैसे कि वृद्ध देखभाल सुविधाओं में; और शोक-अवस्था संबंधी सहायता के लिए उपयुक्त अनौपचारिक स्थान, जैसे कि स्थानीय सामुदायिक केंद्रों में, जो बुनियादी सहायता प्रदान कर सकें लेकिन उनका जुड़ाव शोक-अवस्था संबंधी सेवाओं और सांस्कृतिक रूप से विशिष्ट सहायक और उपशामक देखभाल कार्यकर्ताओं के साथ भी हो।

सफ़िराशि

शोध के निष्कर्ष स्पष्ट समुदाय-आधारित साक्ष्य प्रदान करते हैं कि सांस्कृतिक रूप से सुरक्षित जीवन के अंत की देखभाल को सुरक्षित करने के लिए क्या आवश्यक है और यहां मूलभूत देखभाल की नरितरता के ढांचे के भीतर विश्वसनीय चकितिसीय संबंधों की आवश्यकता है। हम इन निष्कर्षों को औपचारिक, नैदानिक और सामुदायिक सेटगिंस में नीति विकास, सेवा मॉडल और सेवा वरितरण में शामिल करने के लिए नमिनलखित सफिराशि करते हैं (यहां, नीचे दी गई रपिर्ट में संक्षेप में और पूरी तरह से वसितृत)। साथ में, ये सफिराशि देखभाल और केस प्रबंधन की नरितरता प्रदान करने के लिए सेवाओं का समर्थन करती हैं जो सेवा प्रदाताओं, रोगियों और उनके परिवारों के बीच संबंधपरक विश्वास का समर्थन करती हैं।

1: और अधिक सांस्कृतिक रूप से विशिष्ट सहायक और उपशामक देखभाल कार्यकर्ता

एक समर्पित Aboriginal Supportive and Palliative Care Worker (ऐबओरीजनल सहायक और उपशामक देखभाल कार्यकर्ता) की भूमिका के सफल कार्यान्वयन का वसितार करते हुए, हम सफिराशि करते हैं कि स्थानीय स्वास्थ्य जलि में कम से कम सबसे अधिक आबादी वाली प्रवासी संस्कृतियों को कवर करने के लिए पर्याप्त मात्रा में, और भी ज़्यादा सांस्कृतिक रूप से विशिष्ट सहायक और उपशामक देखभाल कार्यकर्ताओं की नयिकृत की जाए।

2: एक प्रशामक और जीवन समाप्ति संसाधन केंद्र स्थापित करें

हम सफिराशि करते हैं कि एक मुख्य संपर्क व्यक्ती की स्थापना की जाए, जो सहायता और उपशामक देखभाल से जुड़ी स्वास्थ्य वभिग की एक इकाई होगी, जो अलग-थलग स्वास्थ्य वभिगों के बीच एक कड़ी का काम करेगी और सलिवरचेन और जी.पी. जैसी सामुदायिक स्वास्थ्य सेवाओं से भी जुड़ी होगी। मरीजों और परिवारों के पास उनकी सभी EoL और शोक-अवस्था से जुड़ी आवश्यकताओं के लिए एक ही संपर्क बढि होगा, और स्वास्थ्य पेशेवर अपने ग्राहकों को मली सेवाओं का इतहास देख पाएंगे।

3: स्वयंसेवकों की भूमिका का वसितार करना

हम सफिराशि करते हैं कि प्रत्येक अस्पताल में स्वयंसेवकों की भूमिका बढाई जाए, जिसमें एक प्रबंधन की स्थापना भी शामिल है जो सांस्कृतिक और भाषाई रूप से वविधि उपशामक देखभाल स्वयंसेवकों के एक बड़े समूह का समन्वय करे और उन पर नज़र रख सके। स्वयंसेवकों को प्रशिक्षित किया जाना चाहिए कि शोक-अवस्था की अवधि में अपना सहयोग और भी अधिक बढा सके।

4: मौजूदा शैक्षिक कार्यक्रमों और संगठनों का उपयोग करना

हम सफिराशि करते हैं कि स्वास्थ्य कार्यकर्ताओं, समुदायों और देखभालकर्ताओं में शक्ति और जागरूकता को बढावा देने वाले कार्यक्रम प्रदान करने के लिए मौजूदा शैक्षिक कार्यक्रमों और संगठनों का उपयोग किया जाए।

5: जीवन के अंत समय में सांस्कृतिक रूप से उपयुक्त संचार का निर्माण करना

हम सफिराशि करते हैं कि प्रासंगिक प्रटि और इलेक्ट्रॉनिक मीडिया के प्रसार में सांस्कृतिक रूप से उपयुक्त भाषा और चर्ित्र शामिल हों। सांस्कृतिक संवेदनशीलता को सुनिश्चित करने के लिए इस सामग्री को सामुदायिक समूहों के साथ मल कर वकिसति किया जाना चाहिए।

6: उपशामक देखभाल के लिए उपयुक्त स्थानों का वसितार करना

हम सफिराशि करते हैं कि (1) सभी अस्पतालों में समर्पित उपशामक देखभाल स्थानों का होना जो वविधि सांस्कृतिक समूहों में विश्वास और आराम ले कर आएँ (इनमें कलाकृत, बड़ी सभाओं के लिए स्थानों का उपलब्ध होना, प्रार्थना कक्ष, भोजन तैयार करने के लिए रसोई, चलचर्ित्र के कमरे और सभाओं और रीत-रिवाजों के लिए बाहरी स्थान); (2) उपशामक देखभाल सहायता से लैस, अस्पतालों से दूर बनाए गए घर जैसे आवास स्थान; और (3) सुलभ सामुदायिक स्थानों (जैसे बड़े चकितिसा केंद्र) में डे क्लीनिक का होना।

7: शोक-अवस्था संबंधी सहायता को बढाना

हम सफिराशि करते हैं कि सांस्कृतिक रूप से वविधि आवश्यकताओं की समझ रखने वाले और अधिक शोक परामर्शदाता उपलब्ध हों; और वर्तमान सामुदायिक सुविधाओं में शोक अवस्था 'ड्रॉप-इन' केंद्रों की स्थापना की जाए।

8: एक करुणामय समुदाय बनाने के लिए सार्वजनिक स्वास्थ्य दृष्टिकोण अपनाना

हम सफिराशि करते हैं कि जीवन के अंत और शोक-अवस्था के लिए सार्वजनिक स्वास्थ्य दृष्टिकोण अपनाया जाए, ताकि समुदाय की क्षमता निर्माण में सहयोग मल सके जिससे कि लोग, जीवन के अंत की यात्रा में एक-दूसरे को सहारा दे सकें, फरि चाहे वे रोगी के रूप में हों, देखभालकर्ता, या अन्य मर्ति और परिवार जन के रूप में। इसमें इस बात का ज्ञान भी शामिल है कि आवश्यकता पड़ने पर अतरिक्ित सहायता कैसे प्राप्त करनी है।

नीचे दी गई रपिर्ट में और भी अच्छी तरह से चर्चा की गई इन व्यावहारिक और साध्य सफिराशियों का उद्देश्य है 'वास्तविक परिवर्तन होता देखने के लिए बातचीत से आगे बढना' और ऐसा करने में, समुदायों के साथ किए जाने वाले सीधे परामर्श के महत्वपूर्ण महत्व को रेखांकित करना।

摘要

概述

这份题为《最终什么才重要》的报告 (<https://doi.org/10.26183/cnxj-nw28>) 详细介绍了在西悉尼文化和语言多元化群体和原住民社区中, 对患有生命受限疾病并积极生活和濒临死亡的人的临终关怀需求进行的基于人口的分析。这项研究由新南威尔士州卫生部 (NSW Ministry of Health) 资助, 旨在直接与社区互动, 让那些处于边缘化、弱势和处境不利的人士发出自己的声音。它侧重于了解文化需求, 以及如何以顾及文化需要的方式向原住民社区以及阿拉伯语、印地语和普通话背景的人士提供临终关怀。本报告根据研究结果为服务系统提出了明确和可实现的建议, 以更好地支持正接受临终关怀的人及其照顾者和社区成员。虽然这项研究以西悉尼地区为研究重点, 但其影响却要广泛得多, 有可能为对生活在澳大利亚城市地区的其他社区提供顾及文化需要的关怀模式做出重大贡献。

本研究的主要目的是了解不同社区对西悉尼地方卫生区 (WSLHD) 所提供的临终关怀服务有什么需求, 以及可以怎么做使这些服务在文化上顾及服务使用者的感受和需求。这包括倡导和支持选择在家渡过最后日子的人。重点研究问题有助于实现这些目标, 这些问题旨在了解与临终关怀有关的文化因素, 包括丧亲之痛、死亡知识 (death literacy) 的认识程度、该社区都有哪些已经证明为有效的服务、有哪些人们认为有帮助的支持和服务、还需要哪些支持或服务以及谁最适合提供这些支持或服务、现有的服务和支持需要怎样改变以便在文化上更适合服务使用者的需求。该研究由西悉尼大学的临终关怀研究计划 (Western Sydney University’s Caring at End-of-Life Research Program) 进行, 并得到了由支持和善终照顾机构 (Supportive and Palliative Care)、原住民健康局 (Aboriginal Health) 和多元文化健康局 (Multicultural Health) 等机构代表共同组成的西悉尼地方卫生区咨询小组的意见支持。作为研究设计的一部分, 还与当地社区的文化顾问进行了咨询。

本研究项目让医疗护理专业人员和社区成员参与了一项全面及多方法的设计, 收集了定性和定量数据进行分析。表1总结了数据收集方法和参与者概况:

表 1. 研究设计

与主要参与者进行访谈	对在西悉尼地方卫生区辖区内从事临终关怀工作的支持性、一般性和专责善终照顾的医疗护理人员进行结构化和录音记录的定性访谈。
死亡知识指数 (Death Literacy Index, 简称 DLI) 在线问卷调查	对居住在西悉尼地方卫生区辖区内的原住民、阿拉伯语、普通话或印地语文化/语言背景的成年社区成员进行定量在线问卷调查。该问卷调查被翻译成阿拉伯语、普通话和印地语, 说这些语言的受访者可以选择用自己的语言或英语填写问卷调查表。
焦点小组	与来自原住民、阿拉伯语、普通话或印地语文化/语言背景的成年社区成员进行面对面、半结构化及录音记录的讨论; 这些成员具有临终关怀的经验, 并生活在西悉尼地方卫生区的辖区内。焦点小组有原住民支持工作者和双语口译员在场协助。
照片讲述 (Photovoice) 访谈	对超过六个月前曾有临终关怀经验并居住在西悉尼地方卫生区的辖区内的个别成年社区成员进行半结构化和录音记录的语音采访。受访者与讲英语的研究人员进行在线访谈, 若有需要, 受访者可以与一名双语支持者一起参加访谈。

在完成数据收集和数据分析后, 研究团队在社区中举办了公开论坛, 介绍中期研究结果。这一过程使社区成员有机会对研究结果发表意见, 并为应对临终关怀方面的文化需求提出进一步的建议。表2列出了从研究数据中提炼出的关键主题和/或问题:

表 2. 关键主题

1. 文化习俗和仪式是临终关怀和丧亲关怀的重要方面	2. 相互信任是基础
3. 容许社区以不同的方式就顾及文化需要的关怀服务提供意见	4. 积累与临终关怀服务相关的知识
5. 充分利用基于医院的服务	6. 在社区中增加顾及文化需要的临终支持服务和丧亲支持服务

这些主题将在“主要调查结果”标题下进行简要讨论。本报告在“调查结果和讨论”标题下对这些主题进行了详细的说明。报告的该部分记录了由原住民社区和西悉尼地方卫生区辖区内阿拉伯语、印地语和普通话背景的人士以及在临终关怀领域工作的医疗护理专业人员所阐述有关临终关怀的需要。

主要调查结果

1: 文化习俗和仪式是临终关怀和丧亲关怀的重要方面

参与研究项目的四个文化群体均将与临终有关的文化习俗和仪式视为非常重要;这些文化习俗和仪式向临终的患者和亲友提供安慰,并使他们感到内心平静。如果精神或宗教需求未获满足,失去亲者的家人和其他社区人士可能因此而长期感到悲痛,丧亲者也可能在悲伤期间面临其他问题。然而,各个文化之间存在不同的信仰和习俗,文化内部的差异也同样重要。例如,参与研究项目的四个文化群体均有人可能因为个人兴趣或家庭背景的缘故而信仰基督教。研究报告显示,在照顾和遵循传统仪式的意愿方面存在着代际差异。死亡知识指数(DLI)调查显示,人们在澳大利亚居住的年数是预测人们死亡知识指数最重要的人口统计指标,并且是比他们的文化背景更重要的指标。一方面是文化习俗的多样性,另一方面是死亡知识的差异性,这意味着在确定人们临终关怀需求方面没有“简单的方法”。需要了解文化习俗的多样性并理解其背后的价值观,才能最大限度地提高医疗专业人员与患者及其家属合作的能力,以提供顾及临终患者文化需要和以患者为中心的关怀服务,并应避免对患者的临终经历和患者家属丧亲的经历做出假设。

2: 相互信任是基础

研究参与者向我们表达的信息是:信任至关重要。建立信任关系的必要性凸显了调查结果中的其他主题。没有信任,人们就不会愿意谈论临终和死亡等敏感话题;就不会了解到有关可用的服务信息;如果他们不相信自己的需求能获得满足,就不会使用所提供的服务。丧亲的人已经极为悲痛,因此信任对于丧亲咨询服务来说尤为重要。在现有的服务中建立信任关系的能力受到与护理中断有关的系统性问题的严重影响。在一个未知的医疗系统中,必须与众多互不关联的系统、服务和工作人员打交道,这让人感到痛苦和无力。没有足够的时间或机会来发展信任关系。当人们处于最脆弱的时候,固定的医疗护理人员和他们熟悉的面孔被认为是至关重要的。然而,患者和家属往往需要多次向医疗系统中不同机构的不同医疗人员重复说明他们的情况。研究发现,临终关怀系统中存在的主要服务不连续性有:(1)私人执业的全科医生(GP)与医院系统彼此分离;(2)将居家的善终照顾服务外包给私人服务提供者;(3)医疗服务与悲伤和丧亲支持服务彼此分离;以及(4)正规医疗护理服务与民间机构、宗教组织和其他在社区中提供支持的组织彼此分离。

3: 容许社区以不同的方式就顾及文化需要的关怀服务提供意见

主题1(需要尊重临终关怀习俗和仪式中的文化差异)和主题2(在医疗系统里多个独立运作的机构中建立信任关系的困难)都介绍了要获得良好临终关怀和丧亲支持所面临的障碍。它们共同显示了原住民以及文化和语言多样化背景(CaLD)人士在获得他们可能需要的支持方面所面临的困难。愿意寻求帮助,并知道向谁求助或如何寻求帮助,这些可能具有挑战性。主题3涉及新南威尔士州卫生部以外已经存在的组织、计划、服务和非正式网络,以及它们可以与临终关怀和丧亲支持服务联系起来的方式。受访者建议,可以通过以下方式解决与这些服务建立联系的障碍:(1)扩大和建立与社区相关的支持网络;(2)提高原住民和文化多样性社区对现有支持选项的意识;(3)有特定的社区联系人,可以帮助患者、其照顾者和家属应对患者临终的过程。

4: 积累与临终关怀服务相关的知识

许多人不谈论与临终有关的事,无论是因为抱有希望,避免召唤死亡,还是仅仅因为对这个话题感到不舒服。健康知识不足、对身体机能的理解不足、压力大或感到脆弱都可能进一步阻碍人们对临终服务的了解或理解。然而,如果不知道有什么服务以及服务的作用是什么,人们就可能会错过他们所需的临终关怀帮助。语言差异、文化差异和对医疗系统的不熟悉可能会造成进一步的障碍。研究结果显示,许多文化多样化和原住民人士对于“善终照顾”、“心理辅导”、“正式志愿服务”和“失智症”等概念并不熟悉。有必要敏感地了解这些障碍,以便建议可以在哪里引入服务或改进服务,为临终者、他们的家属和其他护理人员提供具有文化敏感性的支持。

5: 充分利用基于医院的服务

人们经常在“为时已晚”时才接受善终照顾。较早向患者和家属介绍善终照顾和支持服务,通过鼓励采取反映个人病情、需求和社交情况的护理途径,减少意外或紧急入院的发生。然而,由于医疗系统中各单位往往独立运作(主题2),医疗工作者不一定了解临终服务的性质和价值,也不一定知道如何获得这些服务。由专门从事善终照顾的护士在医院其他病房提供协助是个有效的策略,可以推广。有必要在医疗服务之间建立联系,通过为患者和医疗专业人员建立一个中央联络点,最大限度地提高医疗服务的效率。其他策略包括建立原住民和文化及语言多样化人士支持和善终照顾工作者与志愿者网络,并在所有医院建立善终照顾专责单位,如Mt Druitt医院的善终照顾和支持性护理单位。

6: 在社区中增加顾及文化需要的临终服务和丧亲支持服务

研究发现需要在社区中提供更多顾及文化需要的正式临终关怀服务。这些建议分为三个主要策略。首先,增加目前向原住民及文化和语言多样化人士提供临终支持服务和丧亲支持服务的覆盖面。例如,多元文化健康局(Multicultural Health)和地方卫生区辖区内的七个当地社区卫生中心。其次,提高临终支持服务和丧亲支持服务的文化敏感度,包括通过进行文化意识培训和聘请来自不同背景的工作人员提供居家善终照顾服务、丧亲支持服务和基于医院的服务。第三,在社区中成立新的临终关怀服务和丧亲支持服务机构,服务可由来自当地文化背景的工作人员提供。例如,在老年护理院等社区的机构中成立多个专门提供善终支持和丧亲支持服务的场所;以及例如在当地社区中心等适当的非正式场所提供丧亲支持服务,这些中心可以提供基本支持,并且与丧亲支持服务以及适合特定文化背景人士的善终照顾支持工作者有联系。

建议

研究结果提供了以社区为主导的明确证据,证明需要什么来确保文化安全的临终关怀,而这里的基础是需要在连续性护理的框架内建立值得信赖的治疗关系。我们提出以下建议(在此简要介绍,并在下面的报告中详细说明),将这些发现纳入正式、临床和社区环境中的政策制定、服务模式和服务提供中。这些建议共同支持服务提供连续性护理和病例管理,从而支持服务提供者、患者及其家人之间的关系信任。

1: 应有更多向特定文化背景人士提供善终照顾的工作者

专门向原住民提供支持和善终照顾的工作者计划已推行得很成功。我们建议在这个基础上任命更多向特定文化背景人士提供善终照顾的工作者,至少足以覆盖地方卫生区内人口最多的移民群体。

2: 建立姑息治疗和临终资源中心

我们建议设立一个中央联络点,该联络点将会是附属于支持和善终照顾机构下的一个医疗单位。中央联络点将会起到为各个独立运作的医疗卫生单位搭建桥梁的功能,并同时与社区医疗服务(如Silverchain善终照顾服务和全科医生等)建立联系。患者和家属将有一个单一的联络点来满足他们所有的临终支持和丧亲支持需求,而医疗专业人员也可以跟踪其客户使用该服务的历史。

3: 扩大志愿者的作用

我们建议扩大每家医院志愿者的作用,包括指定一名管理人来协调和管理人数众多的文化和语言多样化善终照顾支持志愿者团队。应培训志愿者,使他们能将提供的支持服务从临终支持扩展到丧亲支持。

4: 利用现有的教育计划和机构

我们建议利用现有的教育计划和机构,为医疗工作者、社区和照顾者提供更多的教育计划和提高意识的计划。

5: 就临终议题进行沟通方面发展文化适当的沟通方式

我们建议传播相关的印刷和电子媒体,包含文化适当语言和图像。这种材料必须与社区团体一起制作,以确保其文化敏感性。

6: 扩大合适的空间用以提供善终照顾

我们建议(1)在所有医院设立能让不同的文化群体感到安慰并有助于建立他们的信任感的善终照顾专用空间(可包括艺术品、大型聚会空间、祈祷室、准备食物的厨房、观景室以及进行聚会或仪式的室外空间);(2)在医院以外提供善终支持服务的临终关怀式住宿;以及(3)在容易出入的无障碍社区场所(如大型医疗中心)设立日间诊所。

7: 增加丧亲支持

我们建议应有更多了解不同文化需求的丧亲辅导员;以及在现有社区设施内设立服务使用者无需事先预约的丧亲支持服务中心。

8: 从公共卫生的角度创建富有同情心的社区

我们建议对善终和丧亲采取公共卫生的方法,以提高社区提供支持的能力,使人们在临终旅程中相互支持,无论是作为患者、照顾者或是其亲友。这包括知道如何在有需要时寻求额外帮助。

我们将在下面的报告中对这些实用且可实现的建议做更全面的讨论。这些建议旨在“将讨论转变成实际行动”,并借此强调直接与社区进行咨询的至关重要性。

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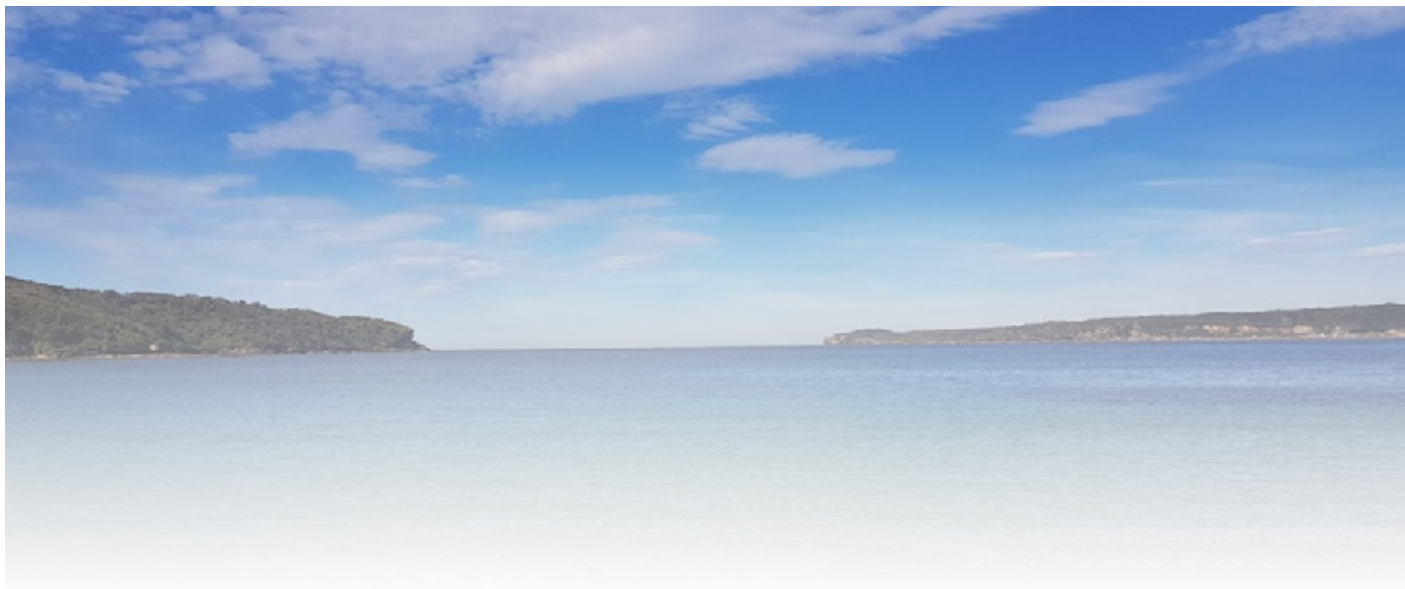
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List of Abbreviations

ACP	Advance Care Planning
ALO	Aboriginal Liaison Officer
ASPCW	Aboriginal Specialist and Palliative Care Worker
A&TSI	Aboriginal and Torres Strait Islander
CaLD	Culturally and Linguistically Diverse
CNC	Clinical Nurse Consultant
DLI	Death Literacy Index
FG	Focus Group (group participants from Aboriginal, Arabic, Hindi, or Mandarin cultural backgrounds)
KI	Key Informant
LGA	Local Government Area
LHD	Local Health District
NAIDOC	National Aboriginal & Torres Strait Islanders' Day Observance Committee
NPCS	National Palliative Care Standards
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCU	Palliative Care Unit
PEPA	Program of Experience in the Palliative Approach
PICAC	Partners in Culturally Appropriate Care
PICF	Participant Information and Consent Form
PV	Photovoice (individual participants from Aboriginal, Arabic, Hindi, or Mandarin cultural backgrounds)
SII	Social Impact Investment
SPC	Supportive and Palliative Care
WSLHD	Western Sydney Local Health District
WSPHN	Western Sydney Primary Health Network
WSU	Western Sydney University



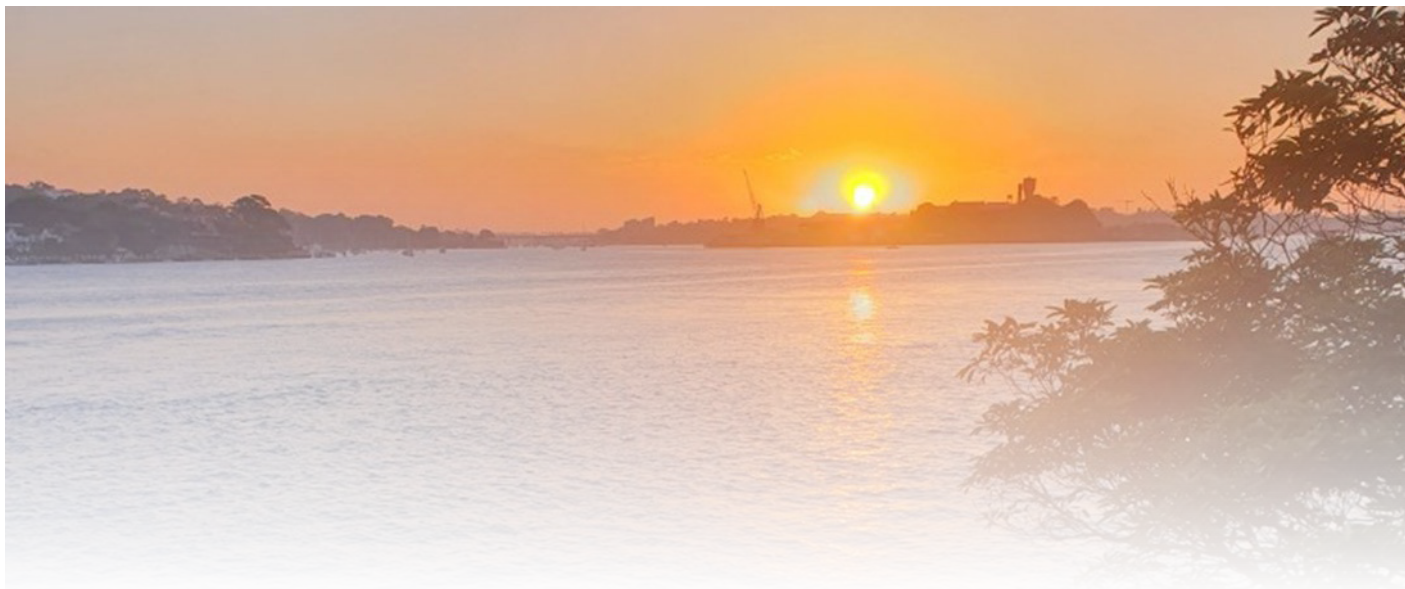
Introduction

This report, *What Matters in the End*, is the culmination of a three-year multi-method and multi-disciplinary research initiative investigating the end-of-life needs of culturally diverse people living in Western Sydney. The project, formally titled *Understanding the End-of-Life Needs of CaLD and Aboriginal Communities in Western Sydney Local Health District (2020-2022)*, was funded by the NSW Ministry of Health and administered by Western Sydney Local Health District (WSLHD). The research began in late 2019 when representatives from WSLHD Supportive and Palliative Care, Bereavement Support, Aboriginal Health, and Multicultural Health, came together as an Advisory Board for research to be conducted by Western Sydney University's Caring at End-of-Life Research Program. The researchers and Advisory Board collaborated to create an ethical research design with clear research goals and relevant research questions to achieve them. The specific aim of the research was to conduct a palliative care and bereavement needs analysis to understand (1) the end-of-life needs of Aboriginal² and Culturally and Linguistically Diverse (CaLD) communities and (2) how services need to adapt to deliver safe and culturally appropriate end-of-life and bereavement care.

In WSLHD, supportive and palliative care and bereavement services are provided by a committed team of medical and acute care specialists and supported by a dedicated team of 'generalist palliative care' professionals (Quill et al., 2013; Firth, 2013; Murray et al., 2004) who may have palliative care experience and be specialists in their own discipline. A large team of trained palliative care volunteers also support service delivery. Supportive care includes primary care clinicians (GPs), social and other allied health workers, pharmacists, pastoral or spiritual care, bereavement counselling and trained volunteers, who work across settings that include acute hospitals, primary care, community and in-home services. However, individuals and families from Aboriginal and CaLD communities face significant challenges in accessing services and communicating their supportive and palliative care needs, including the choice to be cared for at home. With a complex network of practitioners, services, and delivery pathways, the aim of the research was to hear directly from communities about their needs and to implement change to provide services within WSLHD that are culturally safe for people who are nearing the end of their lives and the family and friends who care for them.

The research investigated palliative care and bereavement needs in four of the largest cultural groups within WSLHD to find out what is needed in the service system and wider community to support culturally diverse people and their families at end-of-life. We worked with people from Aboriginal communities, and people from Arabic, Mandarin and Hindi-speaking backgrounds; as well as healthcare professionals in the end-of-life space who had experience working with diverse communities (some were members of the specific communities). Multiple methods of data collection were used for the research, including an online death literacy survey, community focus groups, key informant interviews and photovoice interviews. *What Matters in the End* provides details of the research design and findings as well as a comprehensive set of recommendations for the delivery of culturally appropriate and safe end-of-life care. The companion report, *Stories of Care at End-of-Life*, presents findings from the project's photovoice component and includes the stories and photographs of people who had direct personal experience of caring at end-of-life. Collectively, the community voices contributing to this research have shown that both particular cultural norms as well as individual preferences from those within cultural communities need to be simultaneously addressed if end-of-life care is to be inclusive and holistic, as suggested in the National Palliative Care Standards for Australia (PCA 2018).

2 With the greatest respect, First Nations people are mainly referred to as *Aboriginal* in this report as no research participants identified as Torres Strait Islander.



Background

Palliative Care in Australia

Palliative Care is care for people who have a life limiting illness, as well as their families. It is care that aims to improve quality of life by meeting the physical, emotional, psychosocial, and spiritual needs of the patient in a way that is congruent with their care preferences. Care in the early stage of disease trajectory or during treatment of symptoms associated with complications is sometimes called 'supportive' care. Supportive and palliative care will predominantly be directed at living well in the last months, sometimes years, of life. Helping to prepare the person and their family for the person's last weeks and days of life ('end-of-life' phase), as well as their death, is also part of palliative care. It aims for comfort and dignity in death, supported by high quality care (Palliative Care Australia, 2023). The *National Palliative Care Strategy* (PCA, 2018) states that high quality evidence-based palliative care should be accessible to all Australians. However, many populations are currently under-served, including Aboriginal and culturally and linguistically diverse (CaLD) Australians (DoH, 2018). Further, there is no nationally consistent collection and reporting of palliative care data (Productivity Commission, 2017; CoA, 2012). This prevents adequate monitoring and evaluation of services.

In their National Palliative Care Standards (NPCS) review, Palliative Care Australia (PCA, 2018, p.5) "clearly articulate and promote a vision for compassion and appropriate palliative care". They outline core values and standards for *specialist* palliative care service providers who have expert skills, competencies, experience and training in palliative care. The PCA standards of care involve ethically and culturally responsive medical interventions, service coordination and a philosophy of patient and family-centred care. However, and critically, it is care that promotes compassion, dignity, and respect, including the "provision of psychological and spiritual support to reduce suffering and distress related to feelings of helplessness, remorse, loss, anxiety and loneliness as people and their families face mortality" (PCA, 2018, p.1). The NPCS advocates that:

Specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning. This includes, but is not limited to, Aboriginal and Torres Strait Islanders, asylum seekers, people who have experienced torture and trauma, people who are experiencing homelessness; people living with mental illness, intellectual disabilities or dementia; paediatric populations or people from ethnically and culturally diverse backgrounds (PCA, 2018, p.23).

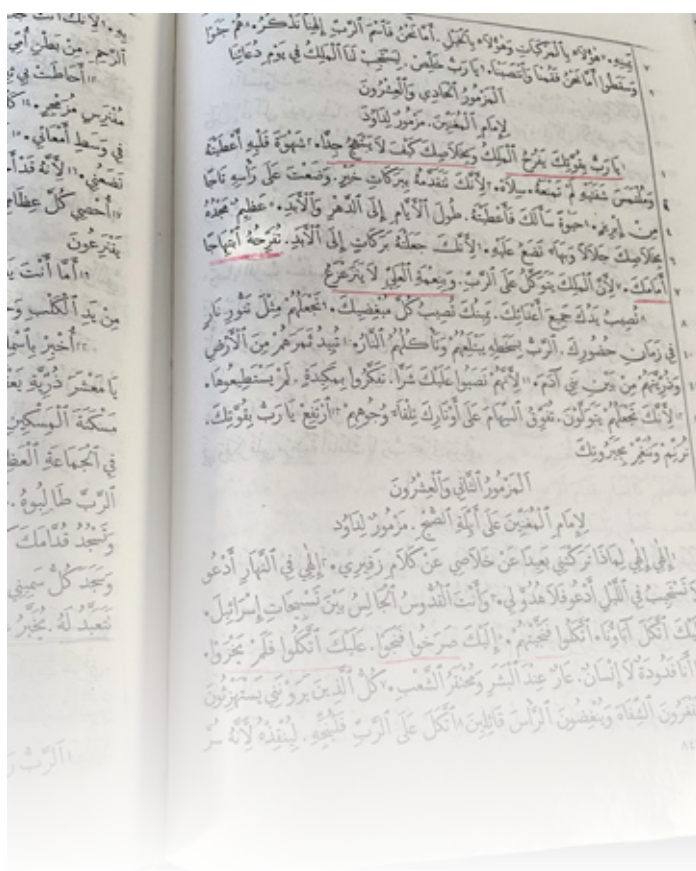
The NPCS argues for an inclusive and holistic approach, acknowledging that "providing quality palliative care relies upon a committed team of professionals and volunteers who assist the person, their family and carers" (PCA, 2018, p.4). Whether specialist or supportive care, a person, family and community-centred approach is shaped by, and responds to, community values and priorities to support the physical, emotional, spiritual or social aspects of death, dying and bereavement. Following the NPCS guidelines, this report understands the delivery of effective palliative care as "a collaboration of three types of providers – specialist palliative care providers, non-specialist palliative care providers and support care providers (including assistants in nursing, healthcare workers, volunteers, non-clinical therapists and family members)" (PCA, 2018, p.13). Within WSLHD, the supportive and palliative care ethos and structure works to follow these NPCS requirements, and to recognise the impact and implications of culture and ethnicity in the end-of-life space. Culture directly shapes the way patients and their families might approach life limiting illness and end-of-life care and caring which has significant quality and safety service implications for the providers of supportive palliative and end-of-life care for multicultural populations. Internationally, concerns have been raised about the palliative care needs of migrants with key considerations including how medical staff can best communicate about the disease and prognosis, the treatment choices made and the care goals and preferences during the end-of-life phase, including death rituals and observances (McDermott et al., 2018; Nelson et al., 2021). There is particular concern about the marginalisation of people with limited English in migrant communities (Barwise et al., 2023; Six et al., 2020)

As a result of the higher mortality rates of Indigenous Australians (Brooke, 2011; Maddocks & Rayner, 2003), Aboriginal and Torres Strait Islander peoples experience more death and bereavement in their lifetimes relative to the general population (Anderson & Devitt, 2004; Askew et al., 2019). Despite this, many Indigenous peoples have little knowledge of palliative care services (Dembinsky, 2014; McGrath, 2006; 2010; McGrath & Patton, 2007; Shahid et al., 2019; Yates, 2006) and wish to know more (Costigan, 2018). The historical backdrop of dispossession, racism and systemic discrimination has created a climate of mistrust of government services, and this continues to limit access to health services and palliative care services, in particular (Awofeso, 2011; Australian Healthcare Associates, 2019; McGrath, 2000; Maddocks & Rayner, 2003). Additional barriers to accessing general practice-based palliative care include referral issues, shame, fear, limited knowledge and issues of eligibility for non-cancer clients (Sullivan et al., 2003). There is some evidence of a misconception among Aboriginal peoples that palliative care relates only to the last few days of life (Shahid et al., 2013) or that the purpose of pain relief is to hasten death, as a form of euthanasia (McGrath, 2006). Indigenous Australians thereby tend to present for palliative care services in hospital emergency departments at the acute stage (AIHW, 2019a). Their rate of palliative care-related hospitalisations in Australian public hospitals is almost double that of the general population (AIHW, 2019a), while at the same time Indigenous Australians account for only 1.3% of palliative care-related presentations to general practitioners (AIHW, 2019b). There is an evident need for directed and engaged communication about life limiting illness and end-of-life care with both the Aboriginal and CaLD communities within WSLHD.

Western Sydney Local Health District

The Western Sydney Local Health District (WSLHD) is a large, rapidly growing region with a highly diverse population and incorporates areas with high levels of relative socioeconomic disadvantage (ABS, 2018).³ Public transport and other infrastructure have not kept pace with rapid growth (Hurni, 2006). The current census data (ABS, 2021), shows that over one million people (1,1080,820) live in the WSLHD and almost 58.3% are non-English speakers at home. Compared with most LHDs in Australia, WSLHD has a relatively high number of Aboriginal and Torres Strait Islander (A&TSI) people (16,614),⁴ who make up 1.5% of its total population. One of the most noticeable features of the Indigenous demographic is that relatively few reach old age with only 1.7% over 75 years whereas the proportion for the general population is 7.5% (ABS, 2022). Far from homogenous, Australia's Aboriginal peoples comprise diverse language and culture groups, many of whom have been displaced from their communities on Country, with some acculturated to urban life (Anderson & Devitt, 2004). The scant palliative care/end-of-life literature pertaining to Aboriginal peoples has tended to be Australia-wide or geographically focused on the Top End of Australia (Australian Healthcare Associates, 2019). Research into urban populations is lacking (Australian Healthcare Associates, 2019). Consequently, it cannot be assumed that the existing evidence is applicable to urban contexts such as Western Sydney. Furthermore, most of the literature simply raises awareness rather than exploring culturally specific models of service delivery (Brooke, 2011).

People who have migrated from China, India, the Middle East and Africa are significant communities in WSLHD which vary in terms of language, culture, religion and traditions. National and international evidence suggests that these CaLD groups generally receive sub-standard palliative care due to communication barriers (Broom et al., 2013). Furthermore, cultural influences play a part in their attitudes to end-of-life services, although acculturation to Western life has occurred (Bosma et al., 2010; Bowman & Singer, 2001; Elkan et al., 2007; Lui et al., 2009). Within WSLHD the three most populace CaLD groups are people from Mandarin (6.5%), Hindi (3.5%), and Arabic (5.3%) speaking backgrounds, making up 15.3% of the WSLHD population (ABS, 2021). Australian palliative care research demonstrates that meeting the palliative care needs of CaLD communities requires sensitivity to cultural and linguistic specificities together with a "multi-stakeholder understanding of the CaLD experience that moves beyond cultural stereotyping" (Broom et al., 2013, p.1043). The needs of individuals and families at end-of-life in this region may therefore be characterized by both heterogeneity and complexity. To date, no data has been collected on the end-of-life practices and service needs specific to Western Sydney's diverse population, indicating an immediate need for the provision of targeted, culturally safe end-of-life services within the Western Sydney Local Health District.



3 See Appendix 1 for an overview of WSLHD.

4 The highest number live in Blacktown LGA (see Appendix 1).

WSLHD Palliative Care and Bereavement Services

Hospital based services: In WSLHD, acute palliative care is provided by two major public hospitals (Westmead, Blacktown) and two specialist Palliative Care Units (PCU) located in Mt Druitt and Auburn Hospitals. The WSLHD has a range of supportive and palliative care (SPC) and end-of-life care services. Inpatient and 'outpatient' or ambulatory palliative care and end-of-life care services are provided by a multidisciplinary team of physicians, senior nurses, and allied health staff from physical and physical health disciplines as well as a trained volunteer service and pastoral care services. The service provides an extensive consultation resource to the two teaching hospitals and regional hospitals as well as inpatient care.⁵ Clinical nurse specialists work throughout the LHD in its various community health services supporting community nurses to deliver supportive and palliative care to a range of clients and their families. These roles are supported by the SPC and other specialist physicians, and the patients' general practitioners. WSLHD recognises the importance of ascertaining Aboriginal and multicultural community needs for end-of-life services and awareness-building. The WSLHD health service workforce including the district wide SPC team is culturally diverse by virtue of the nature of the district and the LHD has appointed a Senior Aboriginal Worker in Supportive and Palliative Care in addition to the extant Aboriginal Liaison Officer (ALO) support systems in hospitals to support Aboriginal patients and families with a life limiting illness.

In-home palliative care: Unlike other NSW LHDs, referrals to in-home palliative care for adults⁶ in WSLHD are outsourced to the Silverchain Group under a seven-year, Social Impact Investment (SII) contract. Created in 2017 between the NSW Government (Health Administration Corporation) and Silverchain, the SII model for community palliative care was the first of its kind in the Australian health sector and established Silverchain as the sole provider of such services for WSLHD (Paxon Group, 2020, p.9). Patients and families are cared for in the case management organisation of the WSLHD supportive and palliative care (SPC) model and then transferred to the Silverchain service, with its different model of care for end-of-life when the prognosis is short (approximately three months). The interruption to end-of-life care implied in this service delivery framework adds to the potential complication of how to access care. Previous work demonstrating the diversity of care providers in other settings has been shown to provide challenges for people facing end-of-life and their families in understanding which services exist and how to access them (Leonard & Johansson, 2008). The task becomes even more difficult for people without English language proficiency or familiarity with Australia's medical systems.

Bereavement Support: At the commencement of data collection, bereavement support was provided by a single bereavement counsellor for WSLHD. The position was attached to the Mt Druitt Palliative Care Unit (PCU) to support carers and families after the death of their loved ones. Silverchain has limited bereavement follow-up for the families of their clients, usually by telephone. Their social workers may continue to support families with complex needs for a period before transferring their bereavement care to the LHD. Bereavement is a natural extension of the palliative care journey and, as with end-of-life care, bereavement needs differ with levels of social disadvantage and also across Aboriginal and CaLD communities. Some research has focused on bereaved carers' experiences of specialist palliative care in the WSLHD (Bindley et al., 2018). Further, vulnerably positioned carers might encounter difficulties that heighten their precariousness in bereavement (Bindley et al., 2021). However, in looking at the experiences of grief and specific bereavement needs within WSLHD, the needs for those from diverse cultural backgrounds still need to be accounted for.

Social disadvantage has a significant impact on the ability to access bereavement services and end-of-life needs for families and communities. Social disadvantage is prevalent in some areas of WSLHD which has a large refugee population and covers local government areas (LGAs) with marked socio-economic differences (Appendix 1). Private services such as home nursing services, death doulas, funeral celebrants, psychologists, and counsellors are available in WSLHD but are likely to be too costly. If people have access to Medicare, they can receive a referral from a GP for six sessions with a psychologist with a possible four additional sessions. However, for migrants and refugees, visa status can significantly negatively impact access to medical, end-of-life, and bereavement services. They may not be eligible to access Medicare, but the full cost of medical treatment is beyond the budget of almost all families. Problems accessing Medicare arise if migrants are not yet permanent residents – bearing in mind that the process of being approved for residency can involve a long wait. Applicants for residency need to stay in Australia for four years on valid visa before applying then wait about one year for processing⁷ but there are often delays. Recently visa processing times have doubled, and some skilled Chinese migrants have been waiting up to three years to have their Australian permanent residency approved.⁸ People who have a work visa, or family member who is an Australian or New Zealand citizen or and Australian permanent resident can access Medicare while their application is being reviewed but people on parent visas are excluded unless Australia has a Reciprocal Health Care Agreement with the country they came from.⁹

5 In the near future the LHD will have two subacute palliative care inpatient units and a new Specialist Acute Supportive Palliative Care Unit at Westmead Hospital, its quaternary referral facility.

6 For children and adolescents, in-home care remains coordinated by community nurses. PCA notes that children and adolescents are likely to have longer and more illness trajectories than those of adults generating particular needs for palliative care (PCA, 2018), which highlights service gap that potentially compromises continuity and coordination of care for young adults.

7 <https://immi.homeaffairs.gov.au/visas/getting-a-visa/visa-processing-times>.

8 <https://www.abc.net.au/news/2022-01-01/189-and-190-visas-applicants-long-wait-permanent-residency/100725088>

9 <https://www.servicesaustralia.gov.au/enrolling-medicare-if-youre-australian-permanent-resident?context=60092>



Research Design and Methods

Ethics and Consultation

Consultation with community members and leaders was a critical part of designing ethical research for this project which aimed to understand the palliative and bereavement needs of Aboriginal and culturally and linguistically diverse (CaLD) communities in Western Sydney Local Health District (WSLHD). The cultural advisors and WSLHD Advisory Board provided invaluable knowledge for the research team, supporting development of a study that was culturally appropriate and effective. The design and conduct of the research were also informed by the literature on researching with vulnerable and marginalized groups (Paton et al., 2018; CoA, 2018; AAG, 2017; AIATSIS, 2012) which highlights the ethical considerations needed to avoid replicating past injustices. The concept of 'Dadirri', a methodology of deep listening that assumes an equality and reciprocity between the researcher and the communities being researched, also inspired the design and conduct of the research, allowing for cultural sensitivities to come through in the research process (Stronach & Adair, 2014; West et al., 2012).¹⁰ This is especially important in research with Indigenous and migrant communities who have often been subjected to disrespectful and exploitative practices in research including a lack of significant benefit for those being researched (Martin & Mirraboopa, 2003; Clark-Kazak, 2021).

From a position of cultural humility (Loue, 2022; Foronda et al., 2016; Yeager & Bauer-Wu, 2013) and respectful practices which focused on listening and supporting people to participate, the voice of participants was at the centre of the project, giving those who are normally powerless an equal and important voice in the research process. These valuable perspectives have, in turn, helped to inform policy and system change recommendations that can enable culturally safe and appropriate services for people from different cultural backgrounds and those who care for them at end-of-life. However, in acknowledging people are the 'experts' on their own experience, affording epistemic privilege has meant more than hearing their voices as expert research 'subjects' (Paton et al., 2018). We have sought to foster a relationship of equality and genuine participation as co-researchers and co-designers. The exchange of knowledge amongst the research team members and between researchers and participants has ensured that the research goals would be achieved in ways that were simultaneously culturally sensitive.

The University research team worked with WSLHD partners to hear from the community about their culturally specific end-of-life and bereavement needs. The WSLHD Advisory Board, consisting of representatives of Supportive and Palliative Care, Bereavement Support, Aboriginal Health, and Multicultural Health, collaborated with the researchers to set clear research goals and to ensure relevance of the research questions designed to achieve them. Similarly, input from Multicultural Health and Aboriginal Health representatives ensured our means for collection of data were culturally safe and appropriate. The research design and process were also informed by input from 20 cultural advisors who represented all four groups participating in the research (see Appendix 4). This input came via informal phone consultations with community members who work with one or more of the four cultural/linguistic groups (and who may or may not be from that cultural/linguistic group) living in the WSLHD catchment area.¹¹

Ethics approval for this research was granted by:

- Western Sydney University Ref: H13743
- Aboriginal Health & Medical Research Council of NSW Ref: 1657/20)
- Western Sydney LHD Ref: 6530 – 2020/ETH00559

¹⁰ As it is described by Stronach & Adair (2014, p.122), "[t]he word *Dadirri* belongs to the language of the Ngangikurungkur people of the Daly River area of the Northern Territory and means 'listening to one another', but listening in contemplative/reciprocal relationships".

¹¹ See Appendix 4 for breakdown of the roles/communities represented by the cultural advisors.

Effects of COVID-19 on the Research: COVID-19 had a significant impact on the people and communities involved in the research. The effects of the virus were severe in areas of WSLHD and considerable efforts were channelled into managing the crisis and encouraging vaccine uptake in areas where there was uncertainty among cultural communities. NSW restrictions on the number of visitors and volunteers in hospitals affected patients and families and this was particularly acute in the area of palliative care. Transitioning in and out of lockdown delayed the start of fieldwork and impacted recruitment due to the sensitive nature of the research, time constraints and cultural preferences of the communities engaged for face-to-face interaction. Understandably, community members were reluctant to discuss death and dying in the midst of a global pandemic. This was intensified for CaLD communities where families live overseas; for example, the Hindi-speaking community which experienced severe social impacts caused by the COVID-19 outbreak in India. Additional ethics approvals were required to accommodate variations to data collection processes, with most interviews conducted online and the community focus groups held in person between periods of lockdown. Collaboration between the research team, the WSLHD advisory partners and the cultural advisors was also affected due to lockdowns in Western Sydney. During these times there was a focus on *preventing* death by getting communities vaccinated, and where end-of-life care became more focused on shock, social isolation, unanticipated death and intensive medical care interventions.

Research Aims and Questions

This study had two overarching aims. First, to understand the culturally specific end-of-life and bereavement needs of the Aboriginal community and the Arabic, Hindi and Mandarin-speaking background communities in Western Sydney Local Health District. Second, to learn how services need to adapt to deliver culturally appropriate and safe end-of-life care and bereavement support. These aims were supported by the following research questions:

1. How do Aboriginal and CaLD communities experience death, dying, caring and bereavement?
2. How might these communities differ in their death literacy and what are the demographic and life experiences that contribute to those differences?
3. What do these communities already have that works?
4. What supports and services have they found useful, or believe could be useful, and how is this different to what is already available?
5. What other support or services do they need and who is best suited to provide this support and/or services?
6. In what ways do existing services and supports need to change in order to be culturally appropriate?

The mixed methods design for this study used an online quantitative death literacy survey (Leonard et al., 2021), key informant qualitative interviews, culture-based community focus groups, and individual photovoice interviews (Wang & Burris 1997). In all, 306 participants across the cultural/linguistic communities and health services within WSLHD (and other LHDs as relevant to bereavement service engagement) took part in this research. Data collection spanned a one-and-a-half-year period from October 2020 to October 2021 and from February to June 2022. Community Forums for discussion of interim findings were held in the final months of 2022. Fieldwork was conducted by Chief Investigators (CI) Debbie Horsfall, Rosemary Leonard and Joy Paton, together with Senior Research Associates (SRA) Jody Thomson and Peta Hinton and Research Associate (RA) Helen Psychogios. A breakdown of participation by cultural group, gender and data collection method is detailed in Table 3.

Snapshot of Participants

Table 3. Distribution of participants by cultural group, gender and method

Participants	Aboriginal	Arabic	Hindi	Mandarin	Other	Total
Key Informants	2	5	7	4	27	45
(Gender)	(1F 1M)	(2F 3M)	(6F 1M)	(2F 2M)	(25F 2M)	(36F 9M)
DLI Survey	24	36	60	83		203
(Gender)	(21F 3M)	(22F 13M 1NA)	(32F 27M 1NA)	(62F 21M)		(137F 64M 2NA)
Focus Groups	10	13	10	10		43
(Gender)	(7F 3M)	(9F 4M)	(4F 6M)	(5F 5M)		(25F 18M)
Photovoice	4	4	3	4		15
(Gender)	(4F)	(4F)	(2F 1M)	(3F 1M)		(13F 2M)
Total	40	58	80	101	27	306
(Gender)	(33F 7M)	(37F 20M)	(44F 35M)	(72F 29M)	(25F 2M)	(211F 93M 2NA)

Death Literacy Survey

Death literacy is defined as “a set of knowledge and skills that make it possible to...understand and act upon end-of-life and death care options” (Noonan et al., 2016, p. 31; Leonard et al., 2020). The Death Literacy Index (DLI) measures *knowledge, skills, experiential learning and social action*, which reflect people’s capacity to access, understand, and make informed choices about end-of-life care options (Leonard et al., 2021). People and communities with high levels of death literacy have context specific knowledge about death systems and the ability to put that knowledge into practice (Leonard et al., 2021). For this project, the DLI was administered as an online survey.

Participants: Respondents numbered 203 across the four communities (see Table 3 above) with the highest participation rate from the Arabic speaking community. Recruitment and support for completing the survey were undertaken by health educators during business hours with the result that 40% of respondents were over 65 years of age.

Recruitment: Recruitment was primarily conducted by members of the WSLHD Aboriginal Health Unit and Multicultural Health Education teams, who approached their contacts within the community, along with the community members in the WSLHD health education programs. The survey was also promoted through electronic flyers forwarded to health professionals and community workers to circulate amongst their networks. Paper flyers and posters were distributed to 42 general practices and medical centres, and five community centres throughout the WSLHD catchment area.

Process: The survey was accessed online through the WSLHD website (the URL was displayed on flyers with a QR code linking people’s smart phones to the webpage). The survey was available in English, Arabic, Hindi and Mandarin languages (see Appendix 3).¹² The introductory page informed respondents their participation was anonymous and outlined the research aims along with what was involved in completing the survey. To gain a broad overview of each target group, data were gathered about death, dying, caring at end-of-life, and associated services. Participants were asked questions about their knowledge and experience of end-of-life, including giving emotional support to a caregiver and preparations such as a funeral or will. Implied consent was received as respondents proceeded through to the survey. The survey tool was released in February 2021 and remained live online for a total of eight months, longer than initially planned due to slower than expected uptake, likely due to the impact of the COVID-19 pandemic.

Key Informant Interviews

Information from key professionals in the end-of-life space offered important insights into the spectrum of end-of-life and bereavement care and opportunities to understand and develop culturally appropriate services. The professional roles of key informants included: hospital palliative care staff and managers; occupational therapists; general practice doctors and their information provider network; Aboriginal health workers; integrated community health workers; health educators for the multicultural community and transcultural educators for health workers; health interpreters; in-home palliative care workers and social workers; funeral directors; death doulas; and grief and bereavement counsellors.

Participants: Participants comprised healthcare workers within supportive, generalist or palliative end-of-life care who worked within the Western Sydney Local Health District (WSLHD) catchment area, as well as other adult people working in end-of-life related services. Forty-nine key informant interviews were held with 45 interviewees (repeat interviews were held with some end-of-life informants also holding relevant bereavement expertise). Eighteen were from an Aboriginal, Arabic, Hindi or Mandarin cultural/linguistic background (see Table 3 above).

Recruitment: Key informants were recruited for their expertise through, or on recommendation from, the WSLHD Advisory Board, Multicultural Health Education Officers, and suggestions from other interviewees. They were contacted by email. After reviewing the initial interviews, specific informants were sought to fill the identified gaps (e.g. general practitioners, community-based services).

Process: Participants were provided with Participant Information and Consent Forms (PICF). Following receipt of signed consent, interviews (of up to 2 hours) were held online. They were conducted in English and the audio recordings fully transcribed. Participants were first asked to describe their roles and experiences working with the target communities. Prompt questions were used to elicit insights on the traditions and beliefs of the communities and the extent to which death, dying, caring and bereavement might be experienced differently to the majority population (see Appendix 2). Participants were invited to describe and comment on the existing services and supports available and to identify potential improvements, along with any recommendations for new services or supports.

Community Focus Groups

Culture/language-based focus groups with community members (see Kruger & Casey, 2015) were an effective way to understand cultural differences at end-of-life. They also provided a space to identify possible strategies and barriers or opportunities to developing culturally sensitive end-of-life and bereavement services. The data were collected between February and May 2021.

12 Hindi and Mandarin recruiters found it more suitable to provide paper copies of the survey to their participant groups, while the Aboriginal recruiter found it more effective to sit alongside participants to help them complete the survey on an iPad. Of the 203 survey respondents, 83% of Arabic speakers completed the survey in Arabic, 4% of Hindi speakers completed it in Hindi, and 96% of Mandarin speakers completed it in Mandarin.

Participants: Adult community members from an Aboriginal, Arabic, Mandarin, or Hindi cultural/linguistic background with end-of-life caring experience and living in the Western Sydney Local Health District (WSLHD) catchment area. Participants had cared for someone at the end-of-life but with a limitation of more than six months prior to the research to protect their emotional safety. There was a combination of English speaking and language only participants, with interpreters present and Multicultural Health co-facilitators from the same language groups. The number of participants in each group ranged from ten to thirteen (see Table 3 above). Participants in the three CaLD focus groups were community members who attended the WSLHD-led health education groups. Participants in the Aboriginal focus group were active members of the Aboriginal community and Aboriginal healthcare workers.

Recruitment: Flyers (digital and printed) were offered in four languages (English, Mandarin, Arabic and Hindi). Digital flyers were made available for community leaders/representatives to distribute using their email lists. Interested individuals were screened and those meeting the inclusion criteria were sent a Participant Information & Consent Form (PICF) and provided with details of the focus group (including date, time, location). WSLHD Aboriginal Health Unit and Multicultural Health education teams provided participants with an in-depth explanation of the project (in their preferred language) and assurance their participation would be voluntary and anonymous.

Process: Separate two-hour focus groups were conducted face-to-face at a convenient community centre with each of the four cultural/linguistic groups. The focus groups were facilitated by a researcher alongside co-facilitators from Aboriginal Health or Multicultural Health who shared the cultural background of the participants. After an in-depth explanation of the project aims and what participation would involve, PICFs in the preferred language were distributed. Following initial verbal consent, written consent was obtained, and again clarified before commencement of the focus groups, allowing regular opportunities to review consent by means of the Process Consent Method (e.g., Dewing, 2008).

The Arabic and Mandarin focus groups were both conducted in Arabic or Mandarin languages and led by a bilingual Multicultural Health Project Officer. A State accredited translator was also present to help translate the discussion to the researcher. The Hindi focus group, which included people who speak Punjabi, was conducted in English, as the majority of participants spoke and/or understood English. The Multicultural Health co-facilitator translated for a small group of participants who were not able to express their contributions in English. The groups began with personal introductions for all participants and facilitators including, if they wished, their caring at end-of-life experience and interest in coming to the group. All focus groups were audio-recorded and transcribed verbatim. The Research Assistant managed the consent forms, recording and note taking. The Arabic and Mandarin focus group recordings were sent to a translator to transcribe into English, and then sent to the bi-lingual co-facilitators to check content and accuracy. Feedback was obtained from all co-facilitators. At the end of the research analysis, all participants were invited to one of three public forums to discuss the results.

Material: Speaking about personal end-of-life experiences is a delicate matter for most of the communities, so focus groups were designed to address the subject of death indirectly. A written hypothetical vignette about a person not known to the participants was presented and they were invited to build upon that story through a series of prompting questions relating to the scenario (see Appendix 2). The vignette and prompt questions were designed to address the research aims and were prepared in collaboration with the Advisory Board.¹³ Professional translations of the vignettes were checked by the Multicultural Health co-facilitators to ensure integrity of meaning. The Aboriginal advisors chose to use the prompt questions without a vignette to elicit discussion of participants' past experiences. Along with providing a gentle way to lead into the discussion, the vignette and prompt questions proved useful to keep the conversation topic centred on end-of-life and the aims of the project.

Photovoice Participant Interviews

We used photovoice (Wang & Burris, 1997) to learn more about what works (or not) in the health service system and wider community to support people caring for someone at the end-of-life. Photovoice is a helpful method in sensitive enquiry (Paton et al., 2018) because visual material such as photographs helps enter research conversations that might otherwise be difficult due to the personal nature of the subject matter. Working with participants' own photographs provides opportunities for their collaborative contribution to knowledge. The amplification of (often marginalised) personal experience in photovoice aims to create social or policy change through the public dissemination of visual and narrative material. In this project, photovoice participants were invited to be part of a report and community book that would also serve as a resource for their cultural communities (see *Stories of Care at End-of-Life*, <https://doi.org/10.26183/w66h-qn16>).

Participants: Adult community members from an Aboriginal (4), Arabic (4), Hindi (3) or Mandarin (4) cultural/linguistic background living in the WSLHD catchment area. Participants had cared for someone at the end-of-life but with a limitation of more than six months prior to the research to protect their emotional safety. The majority spoke and understood English with bi-lingual Multicultural Health Project Officers assisting as needed.

Recruitment: Recruitment was initially conducted through the online death literacy survey, which invited respondents to leave contact details if they had an interest in participating in the photovoice process. Further recruitment was conducted by word of mouth and distribution of electronic and print flyers in English, Mandarin, Arabic and Hindi. These were circulated through partner networks alongside digital campaigns on the Western Sydney University Facebook page and online local newspapers. Interested

13 The CaLD advisors agreed vignettes would be an effective tool for their communities to approach the discussion.

individuals were screened and those meeting the inclusion criteria were sent the Participant Information & Consent Form (PICF). WSLHD Aboriginal Health Unit and Multicultural Health education teams provided participants with an in-depth explanation of the project (in their preferred language) and assurance their participation would be voluntary and anonymous.

Process: We modified the use of photovoice to meet the aims and goals of the research within a context where community lockdowns prevented us from meeting people face-to-face. People were contacted by phone or email to discuss the photovoice process in more detail and those agreeing to participate were sent, by post or email, the project documents and consent form. Once signed, consent forms were returned, participants used their own cameras or devices to take photographs that represented what was helpful or meaningful to them during the period of caring for someone at end-of-life. Over a period of two or three weeks, participants were contacted by a researcher to see how they were going with the 'photo assignment' and to offer support if needed. Sometimes taking the photographs was challenging so we suggested that people could also bring existing photographs to the interviews.

Semi-structured interviews of up to two hours were held with individual participants and took place online. All 15 interviews were conducted by a researcher speaking English with a Multicultural Health Project Officer attending some interviews to assist with translation as needed. The discussions focused on participant experiences of care prompted by the photographs and guided by a series of questions based on the project information previously given to participants. This process enabled us to understand what was helpful and supportive (or not) in the participant's caring journey from *their* point of view. Participants were then invited to choose photographs for inclusion in the community book and to add anything further they wanted to be reflected in their one-page story. With permission, the individual interviews were recorded and later transcribed, providing the basis for data analysis and also the community book narratives, which were developed in collaboration with each participant, using their own words.

Data Analysis

Quantitative data analysis: Descriptive statistics were generated from the quantitative data obtained through the Death Literacy Index (DLI) online survey and these were further analysed using IBM SPSS Statistical Package. Scores for the total DLI and its subscales were calculated on scales from 1 to 10 where 10 would indicate a very high level of death literacy (Leonard et.al., 2021). The research question on demographic differences and differences in life experience was addressed through a series of linear models with (1) sociocultural group and the demographic variables as the predictor variables and the DLI as the dependent variable; (2) Analyses of variance with sociocultural group as the predictor variables and the Actions and attitude scales as dependent variables; (3) Linear models with sociocultural group and the Actions and attitude scales as the predictor variables and the DLI and each of its subscales as dependent variables.

Qualitative data analysis: Analysis of the qualitative data followed the principles of thematic analysis (Braun & Clarke, 2006, 2021). The de-identified key informant interviews were analysed as one data set, and the four focus groups were analysed individually. Each de-identified transcript was analysed independently by at least two members of the research team. Analysing the transcripts was an interpretative, qualitative and data-driven inductive process that focused on emergent themes as well as the specific research questions. Transcripts were analysed thematically (Braun & Clarke, 2006, 2021; Crowe, Inder & Porter, 2015) by the research team to identify common and recurring themes, similarities and points of difference among the cultural groups. Quotes were identified which helped to illustrate the themes. These themes were further co-analysed in consultation with community leaders and the WSLHD Advisory Board to identify the thematic priorities from a cultural perspective. Edited stories for the community book were co-written by a researcher and each individual photovoice participant following a process of data distillation from the transcribed photovoice interviews.





Findings and Discussion

This section is in two parts. The first details the results from the death literacy survey. The second details key thematic findings emerging from the qualitative data collected from key informant interviews (KI), community focus groups (FG) and photovoice interviews (PV). In keeping with ethical and collaborative research practices, the thematic findings prioritise participants' own words by extensive use of verbatim quotes (*italicised*).

Death literacy survey results

The death literacy online survey was completed by 203 people. This WSLHD community sample consisted of 83 Mandarin speakers, 60 Hindi speakers, 36 Arabic speakers, and 24 Aboriginal respondents (see Appendix 3 for a more detailed analysis and relevant tables). Overall, they had a Death Literacy Index (DLI) score of 5.5/10 but to make sense of this score we need to compare it to other groups of respondents. One type of comparison group are representative population samples taken from panels where the respondents are paid to do a set number of surveys, so they do not need to be attracted to a particular topic. The other type are the community samples which tend to attract people interested in the topic who therefore have higher death literacy. It is not surprising therefore that the WSLHD community sample had significantly higher DLI score than the National representative sample. It also had higher scores on all the subscales.

To make the comparison more relevant, a subsample of the National population survey that consisted of people from the four cultural groups of interest was examined. This subsample had a significantly lower DLI score than the overall National population, and much lower DLI than the WSLHD community sample. Other relevant comparisons are with community samples. The most relevant was the South Western Sydney (SWS) Public Health Network sample because it is an area which also has a great deal of cultural diversity and a low socio-economic profile. The overall DLI score for the WSLHD and the SWSPHN were very similar. There was variation in the subscales where the WSLHD sample had higher scores for Factual Knowledge and Accessing Help but lower scores for Experiential Knowledge and Practical Knowledge. Using these comparisons, we conclude that consistent with other community samples, our WSLHD sample has higher scores than if we had been able to obtain a representative sample of the four cultural groups in this geographical area.

Demographic differences among the four cultural groups

There were differences among the four Cultural Groups on the DLI, with Aboriginal respondents having significantly higher scores followed by Mandarin Speakers, Hindi Speakers and then Arabic Speakers. This pattern held for all the subscales with the exceptions of the Experiential Knowledge Scale where there were no differences among the groups and the Community Scale for which Arabic speakers had higher scores than Hindi speakers.

A range of other demographic variables were examined to understand these differences. In the 2019 National survey (see Leonard et al., 2020, p.10), Age and related variables such as being retired or widowed; Having children; plus Belief in an after-life or Religious or spiritual background, were all related to the DLI. In the present WSLHD survey, these demographic variables differed among the four Cultural Groups but did not explain their differences in DLI score. Other variables were also examined such as Gender, Having a disability or long-term health condition, Having adult dependents, Having someone to call on for help and likewise None of these explained the differences in DLI scores amongst the four groups.

There were four variables that did seem to make a difference to DLI scores among the groups:

- Being in the workforce was associated with higher DLI score, in particular Arabic speakers who were not in the workforce had much lower DLI scores than other groups.
- Having a tertiary education was associated with higher DLI score, especially for Aboriginal respondents, but not for Hindi speaking respondents.
- Speaking English at home was associated with higher DLI score, especially for Arabic speaking respondents, but not for Mandarin speaking respondents.
- Number of years in Australia had the strongest association with higher DLI score, especially for Arabic speaking respondents, but not for those Mandarin speaking respondents who had been here for over 15 years.

Because the demographic variables that related to the DLI are not independent of each other (e.g., people who speak English at home are likely to have lived here longer), it made sense to analyse them together to see if some variables are more dominant and account for the variation in the others.

Bringing together all the Demographic variables that related to DLI individually, we found that only Cultural Group and Years in Australia were significant predictors of DLI score. Years in Australia was clearly the most dominant predictor of DLI which suggests that a key factor for acquiring death literacy is being familiar with Australian culture and systems. However, the demographic variables did not account for much of the variation in DLI score. Altogether, they only accounted for 20% so it was important to look at other factors in people's life experiences.

Variables related to end-of-life

Attitudes and actions at end-of-life scales: The survey also collected data on a number of end-of-life experiences that could help develop death literacy. The nine measures were:

1. Discussing of death and dying
2. Providing emotional support to a carer
3. Being present at the time of death
4. Feeling supported around a recent death
5. Experience caring at end-of-life
6. Cultural experience related to death and dying
7. Providing practical support to a carer
8. Planning for end-of-life
9. Avoiding death and dying

All were strongly related to DLI score (in the order they are listed) except for Avoiding death and dying which had a weak negative relationship.

Working or volunteering in end-of-life: Formal experiences with end-of-life work and volunteering have been found to be strong predictors of DLI score in the National and community surveys. The WSLHD sample also had strong relationships for working or formal training, but volunteering was not important in explaining DLI score after considering differences among the cultural groups. Formal volunteering is a Western concept which is often not easily translated so this might account for the difference between these results and those of other surveys.

Predicting death literacy: As with the demographic variables, the end-of-life variables are not independent of each other, so it made sense to analyse them together to see if some variables are more dominant and account for the variation in the others. Cultural group and Years in Australia were included in the analysis to see if the end-of-life variables accounted for the differences in DLI score for the four Cultural Groups and Years in Australia.

Being Present at the time of death Scale and the Discussions of death and dying scale were the strongest predictors followed by having Worked Trained or Volunteered at end-of-life. Years in Australia was significant so there were differences in DLI that could not be accounted for by their personal experiences of end-of-life. Caring at end-of-life was also significant but the variation in Cultural group and the other six end-of-life scales was absorbed by these five variables. Overall, the end-of-life variables together with Years in Australia accounted for 46% of the variation in DLI score.

Concluding comments

Consistent with other community samples, our WSLHD sample has higher scores than if we had been able to obtain a representative sample of the four cultural groups in this geographical area. There were differences among the four cultural groups on the DLI with Aboriginal respondents having significantly higher scores followed by Mandarin Speakers, Hindi Speakers and then Arabic Speakers. These differences reflected differences in how long respondents had been in Australia. The fact that Years in Australia was clearly the most dominant demographic predictor of DLI score suggests that a key factor for acquiring death literacy is being familiar with Australian culture and end-of-life systems. The power of discussions of death and dying to develop death literacy is particularly important given that everyone can be part of such conversations whereas not everyone has the opportunity to be present at the time of a death, provide care for someone at end-of-life, or other end-of-life experiences which improve death literacy.



Key Thematic Findings

The key themes and/or issues identified in the research data and discussed below are: (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; and (6) Increasing culturally safe end-of-life and bereavement services for the community. These themes document 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. Together, these thematic findings build a comprehensive understanding of community-based needs around end-of-life care and, in turn, inform recommendations for the delivery of culturally safe palliative and supportive care and bereavement services.

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

Cultural practices and rituals related to end-of-life are important for providing comfort and peace for people who are dying, as well as their family and friends. Our participants from Aboriginal communities and Arabic, Hindi and Mandarin speaking backgrounds reported diverse practices that were important to them. For example, prayers and verses from the Qur'an may be recited by the Arabic community; chanting, prayer, incense, and various rituals form part of the end-of-life practices for the Hindi community; and some in the Aboriginal community choose to perform smoking ceremonies and other traditional rituals. Although Mandarin speakers from mainland China often do not have a formal religion, they can have beliefs about the spirit world and significant cultural practices to prepare the person who is dying.

After death, burial is important for Aboriginal and Islamic people, whereas cremation is important for people of the Hindu faith. Practices related to paying respects to the dying person or bereaved family also vary. Having extended family present at time of death is important for people from a Mandarin background while for Hindi-speaking background, the dying person should never be left alone. These and similar practices are important to beliefs about ensuring the soul or spirit goes peacefully to the afterlife. If spiritual or religious needs remain unmet, ongoing suffering and complications with the grieving process may result for the bereaved family and community (see below, *Differences in response to bereavement*).

Variations of tradition and practice within cultures are equally important. People from any of the four cultural groups might have a Christian faith due to personal interest or their family background. Aboriginal people might have a Christian faith due to displacement from traditional lands onto Missions or the inter-generational impact of the Stolen Generations. Within all demographic groups there are sub-groups and individual choices about how to follow the end-of-life journey. For example, in the Aboriginal focus group, participants talked about the need to be able to adapt end-of-life care practices because there are diverse Aboriginal nations within WSLHD: *This is Aboriginal health policy from Aboriginal people – grassroots ... So it's being able to make it work, building the shoe to fit for Western Sydney because there's so many nations. This is their home now. This is their community* (Aboriginal FG).

With generational differences, younger generations of diverse communities are generally more comfortable with Western culture, although it also *[d]epends on... how they are being raised, whether they have a strong cultural influence or not* (Multicultural health worker KI). Another dimension, revealed in the quantitative analysis, was how long people have been in Australia but again this varied with personal experience: *people who have been here for some time, they are quite familiar with the system [but] ...because we get involved with looking after refugees and asylum seekers, those are a very challenging group ... They don't know the system ... Not only psychosocial issues – physical and psychological issues* (Hindi GP KI).

The diversity of beliefs and practices between and within cultures means there are no easy recipes for identifying the end-of-life needs of people from Aboriginal and culturally and linguistically diverse (CaLD) communities. However, adopting a position of cultural humility is a way forward for service provider staff to address diversity and the attendant power imbalances often present in the context of cultural needs at end-of-life. The concept of cultural humility suggests supportive interactions are based on attributes of openness and reflexive self-awareness (Foronda et al., 2016; Yeager & Bauer-Wu, 2013) where people are asked about their cultural needs rather than having these assumed or ignored. Its practice is “relationship-based” in contrast to the presumptions of ‘knowledge’ embedded in the “models of cultural competence” shaping much diversity training (Loue 2022, p.105). Cultural humility offers a way to move beyond “cultural stereotyping and predicting need” (Broom et al 2013, p.1043) toward creating respectful, inclusive environments with “optimal care” (Foronda et al., 2016, p.210).

Building awareness of some of the diversity of practices in Aboriginal and CaLD communities along with appreciation of the values that underpin those practices can alert health workers to avoid making assumptions about the path that the end-of-life and bereavement journey needs to follow. Beginning with the acknowledgement that dying is a socially significant event, other dimensions of this theme discussed below include cultural beliefs about religion and spirituality and the diversity of beliefs within culture; cultural differences in decision-making; getting support within the community; inter-generational differences in norms of care; differences in response to bereavement; choosing where to be cared for at end-of-life; and funerary practices. The theme concludes with a summary of some of the challenges for health care providers which will be addressed in other themes.

Dying as a socially significant event

A cultural need for all the communities in this study is that people should not be alone when death comes. Extended families or kinship groups might be present in large numbers as death approaches, and for some, after their loved one has died. For the Aboriginal community, visitation is a sign of respect. Similarly, for Hindi-speaking background, the dying person should not be left alone at any time and this was reinforced with an example shared in the focus group whereby a roster was prepared for someone who was a stranger just visiting Sydney. In the Arabic focus group, participants expressed that: *visiting the patient is remuneration, reward, and mercy ... and forgiveness* (Arabic FG). All groups expressed concern when visiting times were limited, for example the Mandarin group noted: *...ideally, [hospitals] could give the family more time to be with the patient ... Like you can't say ok you can spend time together, but it's 8 o'clock now time to go. And if the patient really wants to have someone to talk to and yet there is nobody around to talk to, that's just a terrible feeling, it's just a lonely feeling* (Mandarin FG). Relatedly, the importance of being with the dying person as close to death as possible is seen as critical from a traditional cultural perspective: *family should be allowed to visit at any time, so that the patient may leave this world peacefully* (Mandarin FG).

Cultural beliefs about religion and spirituality

Valuing, understanding and facilitating diverse cultural, religious and spiritual needs at end-of-life is significant and part of holistic care for Aboriginal and culturally diverse communities: *I know we're trying to be client centred, but if you don't have any awareness of the spiritual cultural needs it can be difficult to...match the needs of the client [and] family* (Occupational therapist KI): *...your pain is always greater if you're in kind of spiritual, psychological distress – I mean we know that ... If people are in pain, we can't manage their pain just with medication if they have psycho-social existential distress. And if you're far away from family that you're very connected with, that's going to contribute* (Volunteer network KI).

While some families may not have religious affiliations, for others, religion or spirituality can anchor them emotionally and shape their understanding of life and death:

...that has to do with their faith, their spirituality. I think if you look at Hindu [people] ... they seem more at ease and whether that is because of their beliefs. Also...Aboriginal [people] they have [the] Dreamtime, that spirituality as well. They know that they will be going back to Country. I mean as much as none of us want to die or we don't like death or dying but it seems to be about their cultural beliefs, I think that has a lot to do with it (Palliative care nursing manager KI).

Diversity of spiritual beliefs within culture: Respect for spiritual needs involves asking, not assuming or generalising: *it's again checking in...because everyone can do things slightly differently and doesn't mean they're from the same community that they do things the same way* (Occupational therapist KI). For example, although Mandarin speakers from mainland China often do not have a formal religion, they can have beliefs about the spirit world and significant practices to prepare the person who is dying, while others have converted to Christianity:

...these groups of people are having beliefs. Other than that, majority don't believe anything...Not everyone believes in the afterlife...That's why they cry because they think 'that's it'...and then they don't understand why people celebrate...even when I first came to Australia, I didn't understand why people laugh in the funeral or laughed at stories about interesting things in their life. And I have so many friends ask me, 'How come they laugh in the funeral?' 'You shouldn't laugh. Why you laugh? You should be crying all the time'. Because they don't believe there is another stage (Multicultural health worker KI).

Cultural differences in decision-making

Decision-making in Aboriginal and many culturally diverse communities is embedded in collective processes and therefore a different approach to decision making is required of health practitioners. In Western medicine patient autonomy is one of the major ethical principles underpinning current palliative care. This mandates the disclosure of diagnosis and prognosis to patients, obtain-

ing informed consent and “truth telling” by providers (Green et al., 2018, p.1420). In palliative care in Australia, obtaining informed consent from a patient for an operation or procedure is an essential ethical requirement and is usually a routine and rapid process. However, conversations around informed consent are often individualistic (Green et al., 2018).

Cultural beliefs and practices add a layer of complexity to the process of obtaining consent, where rules about who should make decisions in the family need to be considered. Australian palliative care researchers have noted the Western concept of individualism runs counter to other cultural perspectives which “may eschew individual autonomy in favour of the ‘family unit’” (Green et al., 2018, p.1420). Such expectations need to be acknowledged by medical teams seeking consent directly from the patient: *It’s collective from the whole family (his wife, children, and brothers). It takes into account mainly the person’s faith that they lived by, as well as their inherited norms and practices in their surrounding social environment (Arabic FG); A lot of people from CaLD come from a collective family structure. The Indigenous population, the Islamic population, they tend to be very collective in their decision making. So, when the doctors are getting in to consult with the patient expecting an autonomous decision, it doesn’t sit right for them within their normal family structure (CNC community health KI); no one took that initiative to learn about the family dynamics. For us, family is really important. Each of us has a specific role and responsibility. When we make any decision in the family, it involves the entire family - Uncles and Aunts, too - making that decision together, especially the big decisions (Hindi PV).*

Moreover, the family unit is an extended family structure that may be widely inclusive, and not necessarily blood related. Therefore, a patient might not feel able to make particular decisions. Effective communication may involve identifying a family spokesperson, respecting shared decision making and conducting family conferences: *it is communication within that kind of space, with extended families, and extended church goes and extended community that is always very, very difficult ... I think the close family input, family meeting has to be the way to go (CNC community health KI).* In some cases, there can be debate within the family about who makes the decisions: *in the Hindi families ... I do see quite a lot of ‘argy bargy’ within a family unit sometimes where say the wife might want to be the primary carer for the husband but the more educated or the more well to do person in the family might want to take over (CNC palliative care KI).*

There is also the (concerning) possibility that the patient is not giving willing informed consent. Mandarin speaking elders were reported as deferring to their sons who were often more fluent in English but did not confer with their parents. It was also reported that Hindi speaking widows can believe themselves to be of such low worth that they would not be deciding on the basis of their own best interests (Hindi woman community leader KI).

Differences are also evident around decisions to utilise strong medical interventions and life support systems. For Arabic-speaking participants, such interventions were an important sign of respect and affection: *we say that Allah the almighty, might grant him life again. So they wait. Patience, for the end of a human being’s life is better. They shouldn’t rush the decision (Arabic FG).* Mandarin-speaking participants stated their community had shifted toward focusing on a peaceful death: *in the past people thought we needed to let the person hang on to their last breath, that it was filial on the part of the children to see to that. Now, our thinking is changing, people now would like the person to go peacefully, to have peace in their final leg of the journey (Mandarin FG).*

Hindi-speaking participants indicated there is no particular cultural pressure to keep the patient alive as long as possible, but rather, a decision about turning off life support would be made jointly between the family and doctors. It is important to build into existing practices a cultural awareness and sensitivity around these diverse decision-making processes so that perceived delays in consent and other decisions are not seen by health workers and medical staff as ‘disruptive’ to existing hospital timetables. Rather, they help to inform how certain processes may be undertaken.

Getting support within the community

The importance of community is central in the end-of-life experiences of Aboriginal and culturally diverse communities. For migrants, families may be overseas, and in the Aboriginal community many people have come from Country and may have less support locally. End-of-life is a time when the sense of isolation from family or kinship networks can be exacerbated and ideally people can turn to their community for support. Indeed, support from friends can be as central as support from family at that time (Leonard et al., 2018).

Community support can come in many forms. For example, by cooking or bringing food, offering comfort and conversation, or providing transport where needed. Within Arabic speaking communities, community support and responsibilities in providing moral, emotional, and financial help were described by participants, and the importance of friends, neighbours and faith were also underlined: *when you have friends, if someone dies, they stand by the family as siblings, even if they can’t help financially, the moral support is very, very important (Arabic FG); the emotional support is there... even the neighbours and people in the area ... you also receive visits from the clergy, and they work on the faith side...as a community we want to help other people. It shows a beautiful thing about our community (Arabic FG).*

The Hindi focus group gave examples of supporting neighbours who did not have family nearby, and as mentioned above, visiting a stranger in hospital. In the Mandarin group, a health educator gave an example of how a young man supporting a wife, two children and four parents needed help for the family when he was severely injured. A friend set up a WeChat group and he was able to obtain extensive advice from the health educator and practical help from the community. A connection was noted between psychological or practical assistance and physical wellbeing in relation to the maintenance of hope: *[a visit] might make her well because she will feel better. She might become better without a treatment. If she sees someone, her friend or anyone that cares for her, she will feel psychologically better (Arabic FG).*

However, there were differences expressed in relation to 'community support' within the Arabic group:

If there was a death in the family, we gather as an Arabic community. We are an emotional community. We gather and every person will be saying I will do this, and I will do that. And they leave the family in their sorrows. They organise everything, they call the funeral companies, they call the mosque, and they do everything. All what the family of the deceased need to do is to physically attend the funeral. This is something nice we have in our community. I heard here someone saying there's no help. I think there is help in the case of death (Arabic FG).

In contrast:

I've been here for four years in Australia, and I feel that there's no social solidarity in the community. They are all busy at work, occupied with the family and focused on themselves. As Syrians, until now I don't know if we have a community. Unfortunately, unfortunately, we brought our problems here with us ... There's no affection, no spiritual life, for me it's nothing. It's nil (Arabic FG).

These divergent experiences indicate the risk of cultural assumptions and reinforce the need for developing awareness and practicing humility in diverse cultural contexts.

Inter-generational differences in norms of care

Inter-generational differences in the norms of care can cause disquiet regarding appropriate care for those with a life limiting illness or who are ageing alongside the need to seek support from outside the family. Younger generations are generally more comfortable with Western culture and in the Mandarin speaking community this was noted as a growing issue amongst older people. Many Mandarin speakers have only one child (due to Chinese government policy) which limits family capacity to care. In the Hindi speaking community younger generations can experience a kind of 'liminal space' between family traditions on the one hand and the reality of contemporary Australian culture on the other: *it is about how we manage the expectations of our parents because these young Indians believe they are between – they are the betwixt and between, because they have to pretend that they're still obeying their elders, their parents, but they are with the current Gen Y or millennials* (Indian counsellor in Asian cultural organisation KI).

In the past, and currently when the family of origin is a strong factor in cultural identity and practices, children would administer care for their parents. Whereas the inter-generational differences for those living in Western Sydney and Australia commonly mean that children are more willing to place their parents in nursing homes and similar facilities to receive the care they need as they age. *A lot of our older people are getting to that age, going to a nursing home because their children are no longer able to look after them* (Multicultural health worker KI). However, even in cases where a doctor directs that a parent enter into aged care, the family can still experience shame and guilt: *In our culture, it's quite taboo for a family member to go to an aged care facility. It's almost like we can't care for our own... And there are family members back home that don't know that my granddad was in aged care because we can't share that. It's quite shameful... especially for my mum, she felt very ashamed* (Hindi PV). Similarly: *he should have still stayed with us. That's my regret...I blame myself – not blame, but I could have taken a year's leave from work and then looked after him rather than sending him there...He didn't complain but I still have this guilt* (Hindi PV).

Facilities for the aged can be difficult with unsuitable food and language barriers: *every time we went and saw our granddad, we would pack some food from home, take it and put it in the fridge there and ask the nurses to warm it up for the following day ... We just knew they weren't...they weren't culturally sensitive* (Hindi PV). One participant reported the loneliness his father experienced because he had a strong accent and lack of a suitable place to pray (Hindi PV). For these reasons, and where possible, members of CaLD communities seek out care spaces that are culturally appropriate and can cater for their language needs: *so, if they go to nursing home, they got language barrier – that's the first thing, they can't talk. And the food!... So a lot of people ask me, Chinese-speaking nursing home because number one is the language, number two is the food* (Multicultural health worker KI)

Choosing where to be cared for at end-of-life

Although every family or relational situation is different in caring capacities and cultural needs, the Aboriginal community in general prefer to be cared for at home and to access palliative services as needed for pain relief, with the option to die in the hospital: *...he would go home for a day or two to be with his family and get them to take his medication and when he got a bit too much for him or too much for them, he used to say, 'Take me back to the hospital'...and they kept his room there and stuff for him* (Aboriginal FG). Misgivings around hospital care can play a part in the decision about where to die: *I've got doubts around health and care in hospitals and things like that – caring for our mob. Even though we had to put my mum in a nursing home, most of the time people stayed at home and died* (Aboriginal FG).

For the Hindi and Mandarin-speaking communities, a decision for the patient to die at home should be up to the patient and respected by the family and services can come to the home to keep the patient comfortable. Several focus group participants had not known about palliative care at home and were



pleasantly surprised to find this was available. For the Mandarin community, though, choosing to die in palliative care spaces was singled out as a preferred option: *I think for our generation, we wish to stay in the hospital. If you're at home, there's nobody around to look after you. Also, we too see being in the hospital as being more compatible with our wish* (Mandarin FG).

However, choices can be limited by a person's family connections and how many people they can draw on to help them (Palliative home care KI). In the case where family connections are limited, community support becomes all the more important:

Hospitals are so intimidating when you don't speak English maybe or if you haven't got your family there ... or if you can't see your parish or burn your incense or play the music you need to or chant or do whatever is culturally appropriate ... but for a lot of people there just isn't that family support, so having particular groups that can access these people from the outside that already exist in the community (Palliative home care KI).

In many cases people cannot choose to be cared for or to die at home because the level of community and family support needed is not available. Those who may have large families overseas yet very few relatives living in Australia are more likely to die within the palliative care unit: *with some of our Indian patients — they have a big family but they only have very few people who are here ... they might have a community around them but they're not going to help them at this stage of their dying or their life. So they generally die with us because they don't have that support* (CNC palliative care KI).

Differences in response to bereavement

As with end-of-life care, bereavement support is generally expected to be provided by family members and other members of the community. Having a large family means there is, potentially, a lot of support available in bereavement. However, as already noted, many migrants and Aboriginal people may not have extensive family nearby. We should therefore not discount the impacts of isolation and changing traditions on people's ability to obtain support. Further, making the assumption that family is the first place to go for bereavement support might overlook the existing social and community support relationships available to those from CaLD and Aboriginal backgrounds.

Both family and community can provide culturally appropriate bereavement support. For example, in the Hindi speaking community, *whenever there is death or sickness in the family...instead of going to a psychiatrist or somebody, people come and talk and spend time with them...Those people in the community need to be supported by people they know and...who know their culture...that would help* (Hindi health educator KI). The use of counsellors is not always relevant to the cultural norms of bereavement:

...cause once you mention this concept [grief and loss counselling] to someone from a refugee or multicultural community, they will just ponder a bit and [say], "Okay, what are you talking about? There's the grief and loss, we experience grief this way, the way we understand and how we experience it." So, they're not gonna see it from the same angle as we see it. They will see it from their own angle (Multicultural and refugee health worker KI).

There are also differences with regard to the culturally appropriate time for grieving. For example, after 40 days, people from Muslim traditions would be expected to stop grieving and 'move on with life'. Such cultural conventions mean that information about bereavement support may not feel relevant after certain time periods:

...about the 49 days, we'd tell ourselves on that day that it's over...it's just a token to comfort oneself. It's a legacy practice or a relic, it's meant to symbolize one's sorrow and missing of their loved one...It's more that you spend 49 days to memorize someone, to remember someone...After the 49 days, the person departs to be on their way to Heaven (Mandarin FG).

Complex grief: People from Aboriginal and CaLD communities have often experienced multiple stressors, including trauma, that may increase their risk of severe or complex grief, which is more than a 'prolonged grief disorder'.¹⁴ The development of complex grief can be tied to individual experience and background as well as cultural practices or expectations (Calvary Care, n.d.). It interrupts daily life and can leave someone feeling 'stuck' in their grieving process. Consistent with existing literature (e.g., Mayland et al., 2021; Calvary Care, n.d.), our data show risk of complex or complicated grief is often related to social isolation following the loss of a loved one: *I wish I have anyone [from] my family – my sister, my brother – just to tap on my shoulder when I cried, but this is the life here. I felt at that time that I need somebody just to listen to me. I felt I want just to talk and somebody just to listen* (Arabic PV). Carers may experience a significant change in identity after their loss or be left in a precarious situation due to traditional gender roles or financial challenges. Complex grief may also develop when feelings of guilt arise due to a dissonance with cultural expectations. When someone cannot accomplish certain end-of-life tasks set by their culture, they may not be able to integrate their grief into daily life.

The potential issues are more difficult for people who are refugees and have lost everything or for people with temporary visas who cannot visit home. These are *the communities we work with where grief...literally hangs onto the hems of their clothes* (Multicultural health specialist KI):

...for these specific cultural groups, the biggest difference in my experience I think has been lack of support that are here and readily available, because if your whole family is overseas, then that can create, added complexities. I've worked with a lot of people who have been here and not wanting to die here, and so I think one of the other issues is becoming dredged in tasks that are priorities and not having the space to process (Social worker KI)

14 See <https://www.psychiatry.org/patients-families/prolonged-grief-disorder>

Multiple other factors can potentially contribute to complex grief. These include the affordability of funeral and other costs (see below *Funeral rituals and practices*); the expectation that certain cultural practices or tasks are being fulfilled that might take away from the time spent with a loved one who is dying; or the strict need to attend to certain cultural rituals related to the passing of a loved one that may delay the ability to grieve. Additional risk factors are the mental health issues that can be prevalent within some communities (refugee and Aboriginal communities) and, relatedly, separation from cultural practices and rituals that might otherwise be available: *...living in Australia as a minority ethnic group would be a risk factor in and of itself, and not seeing yourself represented in life or in everyday life or in media and supports as well, like this bereavement service, for example... your culture being represented, not having that in and of itself is a risk factor* (Bereavement counsellor KI).

What happens in hospitals can also play a role in complex or complicated grief. Our data shows the experience of service providers is positive for some people: *the hospital, the nurses were beautiful. They offered their condolences. They didn't tell us to go 'cos we were taking up the waiting room...and we were taking up the corridor. They allowed us to gather for that time* (Arabic PV). However, for others, it is less positive, especially when 'normal' hospital processes do not align with cultural traditions:

Until today I get nightmares and dreams...one thing that always still bothers me, that in hospital at the very end after he passed, they put him into the hospital clothes. In Chinese cultural traditions, when the body's still really warm, we need to put on the formal best clothes for them to go. They didn't give us the opportunity to do all of that. No-one asked, no-one helped, no-one gave the opportunity to do it... And this picture [is] still in front of my head all the time until now. I can always see that bared, damaged back of my husband and I feel so sorry, so bad that he didn't have the clothes on (Mandarin PV).

Not being able to perform cultural rituals at death can be very distressing, even harmful and *it's important] to know that this is something [that] requires...better understanding by the health workers or by the system, which can be improved...and to be cautious about the cultural awareness in [that] kind of area* (Multicultural health worker KI). Furthermore, the usual definitions of complex grief may not be easy to define or apply in these contexts. For example, culturally normative expressions of grief, such as expressive outpourings in mourning particular to Arabic speaking communities, are *misunderstood* as a form of complex grief. It is therefore crucial that health staff, including social workers and counsellors, are informed about cultural differences in bereavement, otherwise the experiences of complex grief in and amongst Aboriginal and CaLD communities may not be reported or fully understood.

Funeral rituals and practices

Our data revealed the importance for people of being able to follow their traditional funeral rituals and practices to provide peace to the bereaved and prepare the soul of the person who has died: *we have a cultural temple...here. They support us. Bhajan is like when everyone sings together (to) try to move away from their grief...You can do some rituals for the dead person. So, it is just a mental peace that at least that dead person is in heaven or wherever and their soul is free* (Hindi PV). *In the Hindu culture actually, it's being burned, and the ashes has been taken to the riverside...the whole soul is washed in water and so the person will be clear from the sin* (Hindi FG).

Hindi focus group participants also reported good support from their community for the funeral, with money collected at the temple to help the family with the costs. However, Aboriginal and Arabic people are committed to burial rather than cremation and the cost of burial raises the issue of 'funeral poverty'. For Aboriginal people, funeral funds may be contributed by the Aboriginal Land Council if people have an Aboriginality Certificate and the family is known to the Council, and by other organisations such as Anglicare. However, these contributions may often fall short of what is needed. An Aboriginal participant asked: *why [do] black fellas have to pay to get buried back on their own country?* (Aboriginal FG). It was also noted that in some cases a body may be laying in a morgue for an extended period of time waiting for the funds to be raised for a funeral (Aboriginal FG).

The cost of the funeral for members of the Aboriginal community also has the potential to impact the bereavement experiences of those who have lost their loved one. Without organised financial support or access to that support in the instance that someone has not been a paid carer, for example, the lack of affordability of the funeral may mean that some people don't have the time to grieve:

I'm gonna say to you the biggest problem... is the cost of the funeral. People are absolutely shocked at how hard it is to be able to get that sort of money so quickly...The Land Council is supposed to give a thousand dollars, but then they put up all these barriers to how you can get that money. And if you weren't a paid carer for that person, then you don't get anything for Centrelink...They don't even have time to grieve when they've got to try and bury them. They can't afford it. (Community nurse for Aboriginal people KI)

Further, the ability to die on or return the body to Country was raised as a difficult challenge by participants: *for instance, if that person wanted to go home to where they come from, how does it all work? Who works with that? Who does all that?* (Aboriginal FG). Some saw this as practically and financially complex, and generally at the expense of the family.

Funeral poverty also emerges as an issue for the Arabic-speaking community in WSLHD. Access to high-quality, free public health and palliative care services is not necessarily available in the Arabic speaking countries and depends on the family's ability to pay. Low-income Arabic families living in Western Sydney face additional threats to their socio-cultural dignity regarding funeral poverty, which has led to advocacy around this issue. The psychological, financial and emotional burden of funeral costs in Australia were discussed in relation to family shame and psychological troubles: *it's a shame to ask for it. It's a shame, it's not nice to ask for it. How can a man ask someone for money to bury his dead? What happens to his personality, his self-respect, and the respect of the dead?*

For us, respecting the dead is an obligation (Arabic FG). One focus group participant suggested a government loan scheme whereby people could pay off their burial expenses gradually.

Concluding comments

This brief glimpse at some of the cultural differences among and within the Aboriginal and CaLD communities in this research highlights the need for cultural humility and frames some of the challenges in providing good patient and family-centred end-of-life and bereavement care:

Recognising the diversity within culture: Our participants reminded us of the diversity of people who identify as Aboriginal or who come from the same language group. For example, participants from Hindi speaking background identified a number of key dimensions - north vs south India; Hindu, Sikh, Muslim; new migrant vs established; older vs younger generations; women vs men. Therefore, the first challenge is to avoid making assumptions. Learning something about another culture helps us to be aware of our own values, including the culture of our health system. Indeed, accommodating cultural needs can sometimes run counter to current biomedical conceptions of best practice (Leonard et al., 2023). Cultural awareness means being alerted to potential issues and asking appropriate questions from a position of cultural humility.

Reaching out to people in their grief and bereavement: The usual assumption is that most people work through their grief and bereavement perhaps with the support of family and friends. Religious and cultural practices can also bring comfort. At other times, counselling with a suitably trained person is helpful in supporting people through the process: *having someone to talk to...maybe that's my best experience – talking to someone that wasn't family about losing her or potentially losing her at the time* (Arabic PV). However, counselling is not a relevant concept in all cultures and its principles may be contrary to some traditions or values, such as keeping one's problems private, just within the family. Further, as previously mentioned, Aboriginal and CaLD people have often experienced multiple stressors, including trauma, which increases their risk of severe or complex grief. Reaching out to people who might well be struggling requires both sensitivity to cultural needs alongside safely communicating information about service availability: *no support services were made available to help Mum with coping, or to help her process everything going on...we weren't advised of services available to us, such as a bereavement counsellor* (Hindi PV).

Cultural sensitivity in family meetings: Cultural differences suggest that cultural sensitivity is needed when meeting the family to discuss care options. Some considerations include: who attends, recognising any important relationship differences, differences in the time to understand and process the decisions, not assuming families and carers know the support available, being conscious of potential financial burdens, and not under or overrating the role of community. In recognising that decisions which run contrary to deeply held religious or cultural practices cannot be made lightly and can cause long term distress, we need to remind ourselves that communication is a two-way process which requires listening with humility.

In the following themes we explore the implications of these challenges as well as potential responses to help to create a more supportive environment for carers and families and assist a warmer transition between services and from caring to grieving.



Theme 2: Relational trust is fundamental

The clear message from our research participants is that trust is essential. The need to build relationships of trust underscored all the other themes in the findings. Without trust people would not talk about sensitive topics such as death and dying, whether it be from holding on to hope, wanting to avoid summoning death, or just being uncomfortable with the topic. However, this means people would not hear messages about the available services and would not access these services if they could not trust that their specific needs would be addressed. Trust is particularly important for bereavement counselling where people are already struggling with their grief. Furthermore, the necessity to navigate an unknown health system with a multitude of disconnected systems, services, and staff can be distressing and disempowering and in no way provides time or opportunity to develop trusted relationships. Once within the system, the fragmented structure undermines continuity of care.

Trust is needed to overcome barriers to conversations about death and dying

Talking about death is difficult in any language. For the CaLD communities living in WSLHD, the willingness to talk directly about death generally relates to people's cultural or spiritual background and beliefs, how long they have lived in Australia, and whether they are first or subsequent generations. We found that in CaLD and Aboriginal communities, and particularly for older or more traditional CaLD generations, people are often reluctant to talk about death and dying, especially where speaking about death may be seen as a 'taboo' subject. For example, in the Arabic speaking community families may try to protect or shield relatives who are dying by avoiding talk of death: *In Arabic culture – no, they do not talk about it...It is like karma. If you talk about death, it is karma... People do not want to talk about it: "Oh, it is bad karma! If you talk about it will happen". So, just put it aside and just do not even mention it. That is part of the culture* (Arabic health educator KI).

In the Hindi speaking community, particularly for the elderly, preparing them sensitively and well in advance was seen as critical, because *people hesitate to talk about death and sickness, because they're too scared. They know it, but they don't want to face it ...there are a lot of issues, the mobility, language, cultural issues, financial issues, and more than that, the emotional and social issues are the big ones* (Hindi health educator KI). For the Aboriginal community, talking about death is *a conversation that we try to stay away from unless we really have to have it* (Aboriginal drug & alcohol worker KI). In Mandarin culture, it is privacy that is emphasised: *the culture and idea, for thousands of years passed on, for the Chinese is privacy. Don't bother other people. It's my own suffering* (Mandarin FG).

Non-disclosure of someone's diagnosis or prognosis, or perhaps the full details of the prognosis, can also be related to people's reluctance to talk about death and dying. For some, not wanting to know is not denial, but simply a way to cope *when families are relying on hope culturally as well, you are not allowed to give up at any stage because you have to hold on to...miracles* (Palliative home care KI).

Communicating through a single, family spokesperson can help to avoid family members hearing contradictory messages about the patient's condition or treatment. However, the complexity of using family or community members as interpreters is reported in the literature (e.g., Butow et al., 2011; Silva et al., 2016). In this research, using interpreters was generally seen as advantageous, yet at the same, posed risks if people want to maintain privacy: *...some of the things [they] want to ask [their] doctor, [they] can't say in front of [their] son because it's a very personal issue* (Multicultural health worker KI); or if conversations are mediated or 'culturally adapted':

Family acting as interpreters can be protective of the patient and filter the information provided by medical staff. [However], they may be reluctant to let them know [what] is actually happening, fearing that they 'give up'...we found a couple of them over the years wouldn't tell the patient – the doctor would say something and then [they] would not interpret that correctly... So the doctor said something, the interpreter said something to the patient and then the daughter said, 'That's not what he said' (CNC palliative care KI).

A reluctance to talk about death and dying poses difficulties for effective communication with patients and families about specialist and supportive palliative care services. Relationships of trust create spaces to have these difficult conversations in ways that are respectful to people's specific individual or cultural beliefs. Further, trust is generated when services "acknowledge the importance of learning from each patient and family member what the illness, health care, dying and death means to them (and, by extension, their culture), reflecting on how their culture might interact with the health care system" (Chan et al., 2009, p.120).

Building trust in government services

On a broad level, the Australian government's treatment of Aboriginal people and migrants, especially refugees, is not a record that engenders trust. Furthermore, refugees and migrants often come from places where government cannot be trusted. In social contexts where there is little trust in government services and the fairness of law, it makes sense for people to rely on trusted relationships or a chain of trusted relationships. Trust needs to be proactively developed over time:

To develop trust, health workers need to walk with them for a while not just provide information. Health workers need to check in with their clients not just go in with a set spiel so they need to research how to approach that conversation and what they can do with the person and what they might offer or not offer that isn't going to offend them and disconnect them (Social worker KI).

Trust requires a strong relationship with people who can guide patients and their families and help them understand the strengths and limitations of the services on offer. However, while barriers to trust can be well entrenched, these also emerge through the Australian health, palliative care, and bereavement support systems which have a multitude of disconnected systems, services, and staff. This disconnected system inhibits the development of trusted relationships and the continuity of care so central to culturally safe service provision.

Bridging the health system 'silos' for continuity of care

Overwhelmingly, end-of-life and palliative care services were seen by the informants from medical and specialist supportive care as comprehensive yet highly fragmented. The presence of systemic issues related to *discontinuity* of care was one of the most striking themes that emerged from the data and had a critical impact on the ability of patients and families to build trusted relationships within the existing palliative and supportive care services. The continuity in care should also extend to bereavement support so that families, and others who are grieving, are better positioned to access relevant services.

Palliative Care Australia (2018) states that quality palliative care for all individuals occurs when strong networks exist between providers, including specialist, generalist and community services.¹⁵ Continuity of care depends on building and maintaining ongoing relationships between providers, patients, families and communities in order to provide quality supportive care for families from diagnosis, through treatment and into palliative care and bereavement. Continuity of care and relational trust at this vulnerable time is easily broken when patients are transferred from one service to another.

Navigating the health system for people with a life limiting illness can be a significant challenge. Although some research participants stated that care coordination on the whole *actually works quite well* (CNC palliative care KI), the data revealed communities were not always aware of, and had minimal contact with, available services through the end-of-life journey. There was a lack of timely and appropriate referrals from diagnosis to bereavement, and often because *conversations are just not started early enough to say it is a life limiting illness* (CNC community health KI).

Because of the fragmentation of services and the likelihood many patients do not receive timely advice, it is necessary to facilitate the coordination of care, system navigation and maintenance of communication. At present this relies on the individual initiative and commitment of social workers and other allied health workers, service managers, GPs, Aboriginal and pastoral care workers, and community nurses. A health system should not be relying on individual initiative and commitment. While such navigation has been an essential part of the Senior Aboriginal Supportive and Palliative Care Worker role since that position was implemented in 2020, culturally specific supportive and palliative care workers are needed for other cultural groups (this is discussed further below in *Culturally specific supportive and palliative care workers* and also in Theme 5).

Discontinuities in care

The research has found a series of major discontinuities in care that affect the end-of-life journey for Aboriginal and CaLD people, and likely also for the broader population. The five major discontinuities identified are the separation of supportive and palliative medicine from curative medicine; the separation of doctors in private practice (GPs) from the hospital system; the outsourcing of palliative care in the home to a private provider; the separation of medical services from grief and bereavement services; and, finally, the separation of formal health services from NGOs, religious, and other organisations providing support in the community.

The separation of supportive and palliative medicine from curative medicine: Discontinuities among medical specialisations and their separation from supportive and palliative medicine means that patients can be transferred within the hospital multiple times. When people are at their most vulnerable, patients and families need consistency and familiar faces amongst medical and supportive care staff rather than having to repeat their story to many different doctors and nurses: *One woman told me about 17 services she had been to. There's no wraparound shop. And when you're flung from one service to the other, mate, I would run away after the fifth service* (Indian counsellor in Asian community organisation KI). Further, *I would like to have good continuity of care from the time people are referred into the service to the time they die and even after they've died...We had one patient who ended up dying here but the husband said there was 16 different clinicians...so they're telling that story 16 different times* (Palliative care nursing manager KI). This problem is further discussed in the *Importance of early referral to a Palliative and Supportive Care Service* in Theme 5.

The separation of doctors in private practice (GPs) from the hospital system: General practitioners (GPs) are often the first point of contact for those diagnosed with a life limiting illness. GPs can have a significant role in how a patient and family first encounter the diagnosis as well as the next steps — the referral pathway for treatment, palliative care and potentially bereavement support. The separation of GP services from public health services can be a major source of confusion and distress especially when patients have a strong relationship of trust with their GP but then find that their GP is not well informed about their time in hospital or the services they are receiving at home. Further some GPs may be hesitant to refer patients to palliative care or may have limited awareness of care options and referral pathways. Some suggestions for increasing the interconnections are discussed in Theme 6.

The outsourcing of palliative care in the home to a private provider: The separation of in-home palliative care from hospital-based care prompted the most comments and concern from research participants. As described in the Background section under *WSLHD Palliative Care and Bereavement Services*, Silverchain is a privately run service. It provides a community palliative service with home

¹⁵ <https://palliativecare.org.au/about-pca>

visits from nurses and, as needed, doctors, along with 24 hour support from nursing staff in the last months of life. There is a great need for palliative care in the home and GPs are able to refer their patients to this service, which, unlike other LHDs, is the sole provider of the community palliative care service for WSLHD (Paxon Group, 2020, p.10). While appreciation for the service was evident on the one hand, this outsourcing arrangement was also identified as a key factor in creating barriers to the continuity of care for families and communities. At a personal level, the severing of care relationships built into the model has an impact on patients and families at a time when they are extremely vulnerable and need continuity of care:

I don't think you can run a service where you give all that support for a reasonable period of time and make the connections with family and then at the time when they need you most, you say, 'No, look I'm sorry I have to say goodbye', and you hand [them] to another service...it just breaks that connection, and these people are very, very vulnerable (Community nurse for Aboriginal people KI).

The continuity of care relationships was seen to be of particular importance to Aboriginal and CaLD communities where relational trust takes time to develop: *if you are from a background where you might be concerned about how you will be treated respectfully, and suddenly you're being asked to change and you don't know who's going to be coming in the home and understanding of the situation, I think that would be quite traumatic actually (Occupational therapist KI).* Further, *the problem is that we've got these two services, and if I had a life limiting illness, I wouldn't want lots of different people coming in...you build a rapport with the community nurse who may have been coming for six months, or more, and then suddenly you come into palliative care... (Occupational therapist KI).*

The separation of medical services from grief and bereavement services: At the commencement of this research there was one bereavement counsellor for people whose family member had been a patient in the palliative care unit, and no other free services. People can obtain a GP referral to a psychologist for a series of counselling sessions but there is a cost involved and limit on the number of sessions (six, at time of data collection), which might be insufficient to meet needs. Aboriginal and CaLD people who have experienced multiple life stressors due to discrimination, economic hardship, and culture shock, are at risk of complex or complicated grief (as discussed under *Differences in response to bereavement* in Theme 1): *often when you have not grieved the first stress, or the first trauma, or the first grief, it goes underground. That's why I keep using the word subterranean...They don't even want to approach it because "if I unravel this thread, what rest will appear?" (Indian counsellor and community leader KI).* Additional effort and sensitivity are needed to help people at this time, especially when the concept of counselling is unfamiliar or a cultural reticence to talk about death is present. Again, relationships of trust are key to reaching out to bereaved people. Some practical strategies are discussed in *Connecting to bereavement services* in Theme 6.

The separation between formal health services and organisations providing support in the community: A compassionate communities framework (Kellehear, 2013) aims to dissolve the barriers between formal health services and NGOs, religious, and other organisations providing support in the community. This aims for a whole of community approach to death and dying within which formal health services are just one part. A compassionate community creates a safe space for people to ask for, and offer support for, end-of-life and bereavement. It moves from trust in specific individuals to trust in people generally. Practical strategies are discussed in a number of sections in the report, particularly under *Need for a centralised information hub* (Theme 5), *Building bereavement care capacity with community input* (Theme 6), and *Advance Care Planning* (Theme 4).

Collectively, these discontinuities in care reflect the fragmented structure of health services. Unsurprisingly, participants in the research stressed the need to make *the system... work in a more cohesive, coordinated patient-centred way* (Primary health worker KI). This is absolutely fundamental for delivering culturally safe end-of-life and bereavement services where ongoing trusted relationships have been identified as central.



Culturally specific supportive and palliative care workers

As discussed above in *Bridging the health system silos for continuity of care*, the fragmentation of services requires extensive system navigation. Although this is an essential part of a dedicated WSLHD role for the Aboriginal community, elsewhere navigation relies on the initiative of a diverse array of committed professionals throughout the health services network (e.g., social workers, allied health workers, service managers, GPs, Aboriginal and pastoral care workers, community nurses). This adhocery in system navigation is countered to a minimal extent by death doulas who are hired by those who can afford a private service. Culturally specific supportive and palliative care workers, along the lines of the dedicated Senior Aboriginal Worker in Supportive and Palliative Care, are needed for other cultural groups: *there should be somebody there to make that contact...someone with compassion, wisdom and experience who understands the transition to the end of life, to support the person, as well as the family* (Aboriginal PV).

Informants for this research consistently spoke about the value of the dedicated Aboriginal Worker role in Supportive and Palliative Care. This position was established in 2020 to provide culturally appropriate and coordinated support for the Aboriginal community in WSLHD. It works alongside a Chronic and Complex Community Nurse and hospital-based Aboriginal Liaison Officers (ALOs). The Senior Aboriginal Worker in Supportive and Palliative Care bridges the silos in end-of-life services. It connects with the Aboriginal community identifying patient and family needs, providing education and reassurance, intervening when care is inadequate or culturally insensitive and mediating disagreements.

The role has made a huge difference because she's absolutely the link to our services...[she] has come in seamlessly and her role and her ability, because she's got more time to do home visits and liaise with the community (Occupational therapist KI). *Just the fact that she is available and comes around very quickly to support the nurse and the family. Even just to be able to speak to her about helpings us, get the family members in, get the [Nursing Unit Manager] involved, too...just having that understanding, communication, getting the family involved ... That has proven very, very useful* (CNC palliative care KI). Having someone of the same cultural background is central to the success of the role: *...having an Aboriginal worker available because that honestly is the key ... I get on well with the clients you know, but when I go in with the Aboriginal worker, they go, 'Oh'! It's just so different. I can't even describe it...it's magical* (Community nurse for Aboriginal people KI).

Patients and families have time to develop a trusting relationship with the person in the Senior Aboriginal Supportive & Palliative Care Worker role as they walk with them through all aspects of their end-of-life journey. The consistent help and support provided can deepen trust:

[she] had been there...basically the whole time. It was just like another family member was there really. The nurses, they're doing their nursing part...whereas just having [her] there for that support, I think it would have been very different if we didn't have her. You just feel you're not doing it alone...it's just nice to know that you've got somebody there on your side... [she] brought herself into our family – she was there (Aboriginal PV).

The success of this role depends on relationships with specialist, supportive palliative care and outreach services, and maintaining consistent and timely contact with families. Most heavily, it relies on the drive and commitment of the Senior Aboriginal Supportive & Palliative Care Worker, resulting in a centralised, well-informed, and coordinated referral hub. The effectiveness of the position and the increasing demands of the role led to its establishment as Senior Aboriginal Education Officer (Palliative Care) in 2022 and at the time of writing this report, a second position has been established for recruitment.

The need for similar positions for the major CaLD groups in WSLHD is a strong finding from this research: *at any one time we have at least five different nationalities that we are navigating - their care, their support, who do we get in to help them to understand what is going on?* (CNC palliative care KI). At a minimum, having multicultural workers in hospitals to provide cultural support and who know the services available and are conversant with referral pathways and service providers from the point of diagnosis through to bereavement. Similarly, a dedicated community contact or liaison person/worker who has an embedded understanding of cultural differences and needs could assist with navigating the complexities of the palliative healthcare and bereavement systems and facilitate community liaison in-language:

...they don't know you and they feel hesitant to share those things, but if you work along with people who are, even if they don't personally know us, but they know and say 'hang on, you understand, you were born there' and then it becomes a connection thing ... they work alongside of organisation which is community based who has the trust of the people and understand the system. Use them, share resources with them; they have volunteers to help you who can speak the language, instead of using other people from the translation and all that (Hindi health educator KI)

Culturally specific education and liaison workers in the palliative care sector, particularly for people without family in Australia, was a key need expressed in focus groups: *instead of...the social workers there in the hospitals – so in this regard ... language from that particular country would be helpful* (Hindi FG).

...people when they come here they don't know the system when they go into hospital. They're needing a counsellor or a social worker ... if there is no-one in the community here and the person is all by himself and he dies, what sort of support is available? ... information on some of the support services and how to access those support services would be helpful (Hindi FG).

[being a migrant myself gives me] a better understanding of the issues that multicultural communities and refugee communities face whether it's on a social aspect or emotional side of their lives or their support needs, and also being able to liaise

better with community organisations, partners, colleagues to support those community members (Multicultural and refugee health worker KI).

Research participants identified the need for linguistically or culturally specific *hospital-based* workers to act as ‘way finders’ to guide patients and liaise with hospital staff:

So, what do we do for our patients to feel like they are connecting with some of their own, background, their own culture? To understand their way of life?...You can go to [Multicultural Health] and they will know what is available for their community. But, in the hospital we don't have it. It doesn't have to be medical, no. Just a contact person like [the Aboriginal palliative care worker] (CNC palliative care KI).

At each WSLHD hospital: *we need an Arabic, Chinese, and Indian multicultural worker based in the hospital. To understand...to be aware of the services available in the community (CNC palliative care KI).* Existing services can offer a path forward in making these deliberate connections in end-of-life care, but so far this has not stretched across services where the cultural and linguistic needs of patients and carers remain relevant.

Dedicated group of health workers: The care co-ordination and maintenance of a community network is critical, but the breadth of services provided by the Senior Aboriginal Supportive & Palliative Care Worker was unsustainable in the long term and, as discussed above, two dedicated roles are now in place (although one is yet to be filled at the time of writing). An extension of the idea of the culturally specific supportive and palliative care worker is to have a small group of staff who would have a continuous relationship with the patient and family. Wherever possible at least one of these staff would have a similar cultural background to the client. The small group could include an appropriate nurse and a care navigator to help address the difficulties that people experience in navigating referral pathways and the coordination of care. These groups could be formed within each hospital (see also *Need for a centralised information hub* in Theme 5): *if you had a team of a [supportive and palliative care worker], a [chronic and complex nurse] and a social worker. I think you need teams of the three – and a team of that three here, at Blacktown and at Auburn. And those teams would be able to come together with network meetings to support each other (Aboriginal drug and alcohol worker KI).*

Concluding comments

While no metric exists to evaluate the importance of spending time to build relational trust and rapport, the work of building trust is fundamental for the CaLD and Aboriginal communities involved in our research. The need for more sensitive communication by medical staff is particularly important for CaLD or new migrant families who may have high expectations of Western medicine and are not anticipating dire news. Families may need preparation before delivering a prognosis and assurances that the comfort of their loved one is the priority of supportive care.

In the context of this research, relationship building is about demonstrating respect for cultural needs, customs and beliefs, and the development of trust: *it's about being present (CNC palliative care KI);... allowing them to get to know you,... and one day they will ask you those difficult questions, and they will trust you (Palliative care nursing manager KI).* Rapport develops not from the performance of transactional care, but over time through attentive and respectful listening which then translates into positive and culturally safe care experiences for patients and families: *It's never about what we think they need, it's about offering what they would like and what's available (Palliative care nursing manager KI).* Further:

...the consultants from Western Sydney...always talk about building rapport - 'if this person trusts you, they will do what you advise' ...How do you really let somebody tell you? How do you really listen to what they want? How do you still explain to them their options, the risks of all the choices and all that stuff to get them to understand and make a choice - and then you need to respect their choice? I don't quite know how you do it other than that's a very individual thing that comes with experience (Palliative home care KI).

The *National Palliative Care Standards (PCA, 2018)* identify a palliative care philosophy that is culturally sensitive, person and family-centred with the capacity to meet the physical, cultural, spiritual and psychosocial needs of individuals, families and communities. However, it is clear from our research findings that culturally sensitive, person and family-centred care cannot be delivered without trusted relationships. As Broom et al., (2013, p.1043) noted a decade ago, we need to move “beyond cultural stereotyping and predicting need”, toward an understanding that end-of-life needs are based on the establishment of relational trust and cultural safety with individual patients and families. This takes time and a commitment to developing cultural humility (Foronda, et al., 2016; Yeager & Bauer-Wu, 2013).

Our findings revealed a number of practical ways in which trust can be fostered. Taking the time needed to establish trust is a priority, but not one that is necessarily easy in pressured work environments. However, spending time observing, listening, and asking questions in a gentle, non-judgemental way, rather than arriving at someone's home with a checklist at the ready, is a good way to start. Similarly, GPs and consultants or medical services could deploy extended consultation times to convey a trusting presence and as the basis for longer-term trusted relationships. It is also important that services reflect the diversity of their communities. Having someone present from the same cultural background can help to build trust. The need for such diversity in bereavement counselling services and having an Aboriginal worker to accompany health and care staff, at least to the initial meeting, were two specific needs for building trust identified in this research. Visual symbols and messages in multiple languages can also help to develop trust by sending the message that Aboriginal and CaLD people are welcome.

Overall, the key elements in developing trust revolve around having a single person who could guide people through the whole end-of-life process; respectful interpersonal interactions; recognition that people might have specific needs; the presence of workers or community members from similar cultural backgrounds; and physical environments with appropriate cultural symbols and facilities. Fostering trusted relationships can also be supported by structural innovations such as the establishment of culturally specific supportive and palliative care workers; a dedicated group of care workers for each patient; and developing community support activities. The development of trusting relationships is fundamental for good end-of-life care and is therefore also relevant in other Themes discussed in this report.



Theme 3: Ways to provide community input for culturally appropriate care

Our research findings show a clear need for community input on the end-of-life and bereavement services that are relevant to them. Barriers to good end-of-life care and bereavement support were presented in Themes 1 and 2, which showed the difficulties faced by CaLD and Aboriginal 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 shifts attention to the informal networks, organisations, programs, and services that already exist outside NSW Health to consider ways in which the barriers to accessing support could be addressed through extending and networking community-related support; building awareness amongst Aboriginal and CaLD communities on the range of support options available; and using a community of practice model (Smith, 2003; Delgado, 2021) to combine the resources of existing organisations to address appropriate end-of-life and bereavement care.

Informal networks

In Australia, the average length of community-based palliative care is significant. Previous research has identified that out of 119 days of care, 117 days were typically provided by family, friends, neighbours, and community members (Rumbold, 2010). An important aspect of being cared for at home is the patient's sense of control:

Because our clients have lost control and the only control that they have are the choices they have left available to them. They can't control the diagnosis. They can't control the medical system a lot of the time. But when they're at home in their own place they can have some control on their circumstances. And I see that as really important and a huge relief in the people who loved the person who's die (Palliative home care KI).

The participants suggested that in Aboriginal and most migrant communities, cultural values strongly supported the norm of family and community caring: *in our culture, it's quite taboo for a family member to go to an aged care facility. It's almost like we can't care for our own...especially for my mum, she felt very ashamed (Hindi PV).* The Aboriginal focus group reported a struggle to take people home: *it's one of the most stressful times in our lives as you know...to stand there and to say to this Western white system – to say 'We don't want to die your way. We want to go home'. We want to take them back to their house (Aboriginal FG).*

The Arabic focus group also talked about the support from family, friends and community for end-of-life care: *all of the family comes to participate and surround, and from the community, friends and the social circle. I mean you get a huge amount of food during such days, you wonder what to do with it all...and they stop their work to be there, to make it easier* (Arabic FG). However, they reported that the dying person should go to hospital to relieve the burden on the family, not just for the caring but for the community attention too: *because the family living in the same house, the visitors, and the neighbours, they get very, very, tired. First taking care of the sick person, welcoming visitors, and hosting people require a lot of work and effort* (Arabic FG). In contrast, the Mandarin focus group reported people prefer to be cared for in hospital: *living here [in Australia], if we get to the end of our lives and the hospital can care for us, we'd be very grateful* (Mandarin FG).

Previous research by the Caring at End-Of-Life Research Program (e.g., Horsfall et al., 2015) supported the feasibility and value of end-of-life caring at home but it identified four requirements for a good experience for the dying person and carers. There needs to be a principal carer or carers who are committed to care at home, but they need to be supported by a network of more peripheral carers who provide a range of practical and emotional support to the dying person and carer. People in this caring network assist only to the extent that is comfortable and easily managed within their current life commitments. The network relieves the central carers of chores such as house and garden maintenance, transport for patient carers and family, pet care, etc., and gives emotional support. It is protection against carer burn-out. The network benefits by learning how end-of-life caring at home can be managed if they ever need to take on a more central caring role. A valuable person in the network was a coordinator to organise the others and ensure tasks are covered and to keep everyone informed. Without such a person, the principal carer needs to cover all the organising and communicating. Another invaluable person to include in the caring network, if possible, is a person familiar with the health system and local community services so the dying person can be supported through training for the carers, in-home nursing, equipment, palliative care, and other services as needed.

The Hindi focus group gave an example of a happy experience of caring at home by the parents of a teenager with involvement of wider family and friends: *they keep him at home. Whatever he likes to go, whatever he eats, everything they provide and make him happy. They have sisters – some birthday or function or something, they invited all the close family and friends, and they celebrated a big party like that. He really enjoyed and everything* (Hindi FG). In the Arabic focus group, they were quite clear about the need to organise support for others – not just family: *We can provide moral support, we visit her, we tell her beautiful stories, we give her hope in life and if we can, help her financially. I can make her food. I can agree with my friends, create a group and tell them her story. We divide responsibilities among each other, and we won't leave her* (Arabic FG).

Given the extensive nature of caring in the home, it is important to reach out to carers and ensure they are well supported. Already there are signs of good community support. However, there are added difficulties when discussions of death, dying and bereavement are not culturally acceptable and safe trusting relationships are essential (Theme 2). For example, the fostering of specific social media and face-to-face community groups was suggested by the Mandarin speaking focus group. Ultimately a compassionate communities model (first mentioned in Theme 2), which argues that end-of-life is everybody's business, would embed such support in everyday practice.

Working with existing organisations

Culturally appropriate support is provided to a certain extent through formal connections between health units and existing community organisations and programs.

Formal links between health and community organisations: There are a number of community-based multicultural and refugee programs that provide culturally sensitive support for CaLD communities. New migrants and the older generations in the CaLD communities are served by organisations such as SydWest Multicultural Services.¹⁶ This organisation has a close relationship with Multicultural Health (Theme 5) who link with their social groups. For the Mandarin and Cantonese speaking communities this can also involve tapping into large support groups in the community, such as *the Mandarin speaking group, the Cantonese speaking group, also the Hills Women's group. In that group – the Mandarin group has 600 members* (Multicultural health worker KI).

Another important community-based organisation reported by respondents is the Western Sydney Primary Health Network (WSPHN) formerly Wentwest which is located in the Westmead Hospital Precinct and largely funded by the Federal Government's National Public Health Network scheme. It has a *community stakeholder engagement program* that actively works to connect community and health (Primary health worker KI). Part of their service support involves understanding where barriers *within the services in terms of how we perform the service exist* (Primary health worker KI). To this end WSPHN has *a number of groups, meetings with community leaders, had consumers involved as well, Multicultural health, Councils and so on* (Primary health worker KI).

Community organisations supporting carers: There are organisations which contribute by supporting carers and older people such as the Cancer Council which has groups for carers and *they can also access through the Cancer Council some counselling for bereavement support, as well, from their counselling service* (Social worker KI). Council on the Aged (COTA)¹⁷ has a peer support program which includes CaLD peer supporters and a webinar, 'Ageing as an Aboriginal and Torres Strait islander person'. Carers NSW¹⁸ have Fact Sheets related to Palliative Care and bereavement in English, Chinese, Arabic, Hindi and Greek and a podcast series in English,

16 See <https://www.sydwestms.org.au>

17 <https://www.cotansw.com.au/get-involved/events/event/2023-webinar-program/>

18 <https://www.carersnsw.org.au/about-caring/who-are-carers/diverse-carers/in-our-own-voices>

Chinese, Arabic, and Hindi. The National Aboriginal and Torres Strait Islander Catholic Council provide palliative care packages for Aboriginal people.¹⁹

Initiatives by individual health workers: Working with existing community networks was also considered to be an important opportunity space for WSLHD in drawing CaLD and Aboriginal carers, families, and patients towards the existing services that would be most culturally supportive. To this extent, some social workers and others within the services space have made individual inroads into connecting with existing support networks via community-based organisations:

...the Community Resource Network...I found myself a Pacific Islander contact, an Arabic community contact, and I'm looking to speak with someone next week about if there's a Turkish contact. They're just a forum that's come together as community workers that Blacktown Council identified this need for community networking...the main point about the forum is to educate each other about what's around in our local community (Social worker KI).

Building bereavement care capacity with community input: Mostly people work through their grief, often with the support of their family and friends. Community rituals and practices also have an important role (as discussed in *Differences in responses to bereavement*, Theme 1):

A part of me thinks that, for example, the Islamic world have more support in bereavement because they have specific cultural practices that on certain days they have to come back together again and they have timespans and their grieving is obvious at certain times, mostly, not everyone, and especially not if you're a secretive refugee and trying not to be seen or heard. But I think when you're part of a subculture, even if you're Christian or you have people around you, that feel a sense of responsibility to support you through hardship and challenge, and I think that offers a resource that someone who doesn't have that community...So I think someone who potentially does go to the mosque or has their family that goes to the mosque has a better grief resource network than someone who doesn't... (Palliative home care KI)

When people are struggling with their grief they may need specialist help. However, respondents reported there was very little uptake of this support by some communities, evidently due to not knowing about referral pathways to specialist grief support. Awareness raising around bereavement support for CaLD and Aboriginal communities is therefore a critical focus for WSLHD. Having culturally appropriate bereavement supports available through existing services, as well as building familiarity with these services, becomes a high priority, and especially in curtailing the likelihood of complex grief. Community, therefore, can play an integral role in building awareness of the grief and bereavement services that are available and how the bereaved might be supported through counselling and other methods. They can also assist with recommendations to counselling services by someone within the community who has some experience or familiarity with the services.

For the Aboriginal community, Red Dust Healing is a specific cultural healing program. It is written from an Indigenous perspective and targeted at Indigenous men, women and families to address family and community violence, suicide, rejection, addictions, identity and culture, grief and loss and mental health issues. The program encompasses visual holistic learning modules, linking Indigenous and non-Indigenous cultures.²⁰ Also, Tribal Warrior provide mentoring, education, cultural activities and training which can address cultural sensitivities around death and dying.²¹

With faith being central to the lives of many CaLD communities in Western Sydney, there are valuable opportunities for bridging the gap between communities and supportive and palliative care and bereavement services. Ways of making these services culturally appropriate, better known, and accessible to communities include working with community leaders, especially religious leaders, as well as funeral directors, through a compassionate communities approach (Kellehear, 2013; Horsfall, 2018; Horsfall et al., 2020). Enlisting religious leaders and others, such as funeral directors, can help with building an understanding within the community of the bereavement services available: *changes within the community members, that changes the understanding of grief and loss, changes the mentality...so leaders also play a big role. And then it just spreads out to the community members in an informal way (Multicultural and refugee health worker KI); If I start off from a community perspective [it] is involving religious leaders and funeral homes...even if it's a funeral director in particular locations, like Western Sydney (Multicultural health worker KI).* Hindi focus group participants reported that they can follow their traditional funeral practices with suitable priests in the local area: *we have a freedom, and to have the rituals actually, and the burial. So, we have our own way and up to now no-one has objected (Hindi FG).*

Engaging community leaders to promote Advance Care Planning: Leaders could also promote Advance Care Planning (ACP),²² which can make a difference for the experiences of the bereaved when patient wishes are understood and agreed upon. To this end, a key suggestion was made to *[go] back into the community and [talk] to religious leaders about how do we engage with people about this?* (Bereavement social worker KI). Training community leaders in ACP was seen as an integral step in building awareness and knowledge within communities in more informal community spaces: *Having community leaders themselves trained in things like that, in Advanced Care Planning ... and getting them to be the advocates of actually educating communities. So it becomes like a team work...so you slowly build the community's capacity to engage as an equal partner with a system (Multicultural health educator KI).* However, we note that ACP is a particular instrument of the medical establishment and perhaps not appropriate for diverse

19 <https://natsicc.org.au/>

20 www.thereddust.com/

21 <https://tribalwarrior.org/contact/>

22 <https://www.health.nsw.gov.au/patients/acp/Pages/default.aspx>

cultures. Training others in the ways of the health system should not be assumed as the ideal. Rather, as equal partners with the health system, communities could consider adapting the tool to be more appropriate for their culture.

Communities of practice for end-of-life and bereavement

The communities of practice model (Smith, 2003; Delgado, 2021) not only provides supportive care but also a positive sharing of wisdom and experience amongst those directly involved in delivering to the needs of carers, patients, and the bereaved. This extends into suggestions for how in-language opportunities for those who are first encountering the palliative care and bereavement space in WSLHD might be more supported in culturally appropriate ways.

One suggestion, consistent with growing a community of practice, was the team approach where teams form across the silos and into the community services to include the provider of palliative care in the home. Yet it was understood that the important part is to find out who are the key people who need to come from the community. Such teams were seen as essential for both Aboriginal and migrant communities and could involve face-to-face meetings in which *pathways of care would be developed and good systems discussed together* (Social worker KI).

Networking across organisations was also seen as a critical approach in building awareness, knowledge, and understanding of bereavement and counselling supports, and an opportunity to build support for bereavement needs. At the same time, it can also build capacity for CaLD healthcare workers to understand how these might work in culturally (and spiritually) different ways. One strategy was to make use of existing forums and meetings:

probably with networking, that would be your best option, 'cause having networking is one of the key activities that I always find effective to deliver a message or advertise for an activity. But a number of forums, network, meetings, bi-monthly meetings that are going on, either with at least here with us, with the Councils, depending on [the] area (Multicultural and refugee health worker KI).

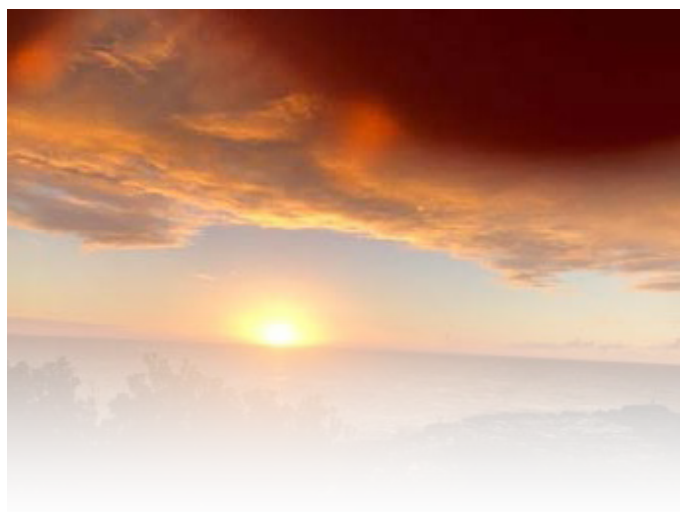
More specifically, inter-agency meetings gave opportunities for shared learning about end-of-life care and bereavement. Blacktown City Council supported several relevant interagency meetings which could provide venues for shared learning. For example:

we have the monthly Blacktown-Mandurah interagency meeting with SydWest. We have our Refugee Health Coalition bi-monthly with at least up to 20-25 attendees each time... here's the asylum-seekers' interagency meetings, there's the Council's meetings, there's disability forums...and there's the Blacktown Council's Community Resource Network Meeting (Multicultural and refugee health worker KI).

Clearly there is wide scope to build on existing organisational and community connections to develop cultural skills and sensitivity alongside awareness of end-of-life and bereavement needs within WSLHD. Each Council area can have its own set of meetings but learning across the WSLHD would maximise the diversity of input into a community of practice.

Concluding comments

Support networks for end-of-life care can be developed around existing relationships in the community and there are many ways this can happen. Our previous research has shown many implementable and outstanding examples of caring networks (Horsfall 2018; Horsfall et al., 2015; Leonard et al., 2015). However, they worked best with network coordination and some connection to health services, which can be challenging for people from Aboriginal and migrant backgrounds. It must be remembered that informal networks manage most of the end-of-life care in communities which already have a wide range of potentially supportive organisations and active community leaders. These community organisations might already, or could be mobilised to, provide suitable support along the end-of-life and bereavement journey. Depending on their current focus, they might need to develop further cultural sensitivity or end-of-life and bereavement competence through interconnections with other organisations and cultural groups.



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

Our findings show there is a need to build knowledge in the community about end-of-life services. This flows from the absence of trust and fragmented nature of the service system addressed in Theme 2, both of which serve as barriers to accessing and negotiating relevant services. For the general population, factors such as levels of health literacy, being stressed, or feeling vulnerable, can also hinder people's understanding of, and engagement with, end-of-life services. However, for culturally diverse communities, there are further considerations of culture and language that bring complexity to the knowledge space around end-of-life. For example, people may not have language equivalents for words such as 'palliative care' or 'counselling', and they may be unfamiliar with the health system. Without knowledge of the services available and what these services might do, people can miss out on the end-of-life help they need. Understanding the obstacles to knowledge about end-of-life services can drive suggestions for where services can be introduced or improved to provide culturally sensitive support for those with a life limiting illness as well as their carers and families.

Key terms such as 'palliative care' and 'counselling'

Regardless of cultural background, people who have not had contact with palliative and supportive care or bereavement counselling will not be familiar with these services and may not know of their potential benefits. Even where English is a first language, people are often unfamiliar with health jargon or may be unable to take in information when they have received bad or unexpected news: *some people come to us not even knowing what palliative care is and for me that conversation should have happened in the consult office with the palliative care staff specialist...and sometimes...they're listening, but they're not hearing it, not taking it in* (Palliative care nursing manager KI). For Aboriginal and CaLD communities there can be additional difficulties, especially relating to language: *the Aboriginal community, in particular here, don't cope very well with the word 'palliative' ... the word palliative just frightens people...[it's] almost like a four-letter word – they really worry about it* (Community nurse for Aboriginal people KI).

Some key words, such as 'terminal' or 'palliative' may not directly or clearly translate from English, while other words have no direct equivalent. For example, counselling as practiced in Australia is a Western concept which makes assumptions about people's understanding of the world: *I'm yet to see one [understanding of bereavement] that isn't coming out from a Western nation. So that in itself is limiting... We don't know other theories or approaches...non-Western people's existential or spiritual experiences after someone, their special person's died* (Grief and bereavement social worker KI). Furthermore, in theories of counselling, *they even have what's called the sense of agency. [But if] somebody says, "Thank you for your goodwill, but you must understand that my problems, they were in the stars on the day of my birth." What can we do?* (Cultural mental health educator KI).

When there is no equivalent system of palliative care in their country of origin, palliative care may not be something that is fully understood or seen as culturally relevant for families who are dealing with end-of-life needs and potential opportunities for care. In many traditions, people are cared for at home, which is both a family responsibility and cultural obligation, whereas *sending a parent to palliative care is like abandoning them, because it is an obligation to the children and the family to look after the person until they pass away* (Multicultural health worker KI).

Services like palliative care are not an easy fit for many of the Aboriginal and CaLD families facing end-of-life options within the current Australian and WSLHD context. Some people believe that palliative care is only for the last days of life, so the mention of 'palliative' is distressing. For others, palliative indicates that the doctors are 'giving up', and the belief that Western medicine is infallible causes shock and anger when it is seen to 'fail' their loved one: *it's a mystery how pain that started in his ears within three months became a problem with his kidneys, and the doctors didn't know what the issue was? Impossible!* (Arabic FG).

However, in the Mandarin focus group it was acknowledged that while previous generations would want people to *hold on to their last breath*, they were now more positive about palliative care: *when we talk about palliative care or 'end-nearing care', we can say it's about 'end-nearing happiness'. In fact, there are two types, the first type is about relieving one's physical pain and suffering; the second type has to do with emotions* (Mandarin FG).

Elsewhere, it was suggested that taking things slowly can open up the space for talking about culturally difficult topics such as dementia and death: *it's a very sensitive issue. Dementia, we don't want to hear about dementia, now they talk - same with this [death]. So just slowly you can do it* (Hindi health educator KI). Again, this demonstrates the value of trusted relationships. Here, it is a path to learning about the terminology and benefitting from services for end-of-life. Similarly, without knowledge of the help provided by palliative care and bereavement counselling, families of those with a life limiting illness face challenges in gaining the necessary information to guide them and their loved one on the end-of-life journey: *I didn't even realise that there [were] so [many] resources out there and so I did it all on my own ... I just wish I had known [about] all that support out there which would have helped when I was going through a lot of stuff with my mum* (Hindi FG).

Formal records and legal requirements

The end-of-life journey involves engaging with a range of formal processes which can be challenging for anyone. Some are legal requirements while others are not compulsory but can be helpful. Advanced care directives and advance care planning provide an important opportunity for starting conversations around end-of-life. Having an Advance Care Plan (ACP) in hand can make things easier for the family and others who are making decisions for someone with a life limiting illness. However, building awareness and having conversations around such plans requires some knowledge of the process of dying which can present as a challenge for some communities. For example, an ACP might be deemed unnecessary for patients from a traditional Islamic background where the faith

system may guide their response: *sometimes they surrender to God, so they will turn around and they'll go "Oh, it is in Allah's hands" or "it is in God's hands"* (CNC community health KI).

However, our Western plan [is] to have everyone over 65 to have their ACP uploaded on medical records so we know what they want, but in reality that's not happening. So, going back into the community and talking to religious leaders about how...we engage with people about this [is needed] (Grief and bereavement social worker KI). Similarly, the paperwork upon the loss of a loved one can be overwhelming. Cultural expectations about who should be handling the task might not be realistic if that family member does not have sufficient background knowledge. We cover some suggestions to address the need to deal with these systems below.



Culturally safe language

When talking about death and dying, euphemisms abound (Jamet, 2010). However, these may not always be appropriate for linguistically and spiritually diverse communities, so it is important to use words that are culturally sensitive. Phrases such as 'advanced illness' or 'life limiting illness' instead of end-of-life care were suggested by participants in this research, together with an emphasis on using 'supportive', rather than 'palliative' care. Some Aboriginal respondents preferred the term 'end-of-life care' to palliative care and also reported that Sorry Business (see SWSPHN, n.d.) was a term that was recognised and widely used in Aboriginal communities: *end-of-life sounds more appropriate than the word palliative. I didn't know what the word meant...That's actually where the Sorry Business starts* (Aboriginal FG).

In communities with collective traditions, culturally appropriate and effective communication may involve identifying a family spokesperson to facilitate conversations and liaise with medical staff or support services. On the other hand, some health professionals argued that not speaking directly, clearly and consistently can result in miscommunication, confusion and a sense of false hope for the family: *when I'm talking to people I don't like to fluff about because people tend to understand the word dying. 'Passing away' is not something that I'm a fan of because it's not a true reflection of what is actually happening* (Palliative care nursing manager KI). However, with such direct communication there is also a risk that people do not absorb the information because they are in shock. Taking the time to ascertain if people have specific cultural or religious beliefs and the language that is safe for them is important in these contexts so that communications can be effective.

Bereavement counselling

As noted above, people are not always aware of the counselling services available to them and in some cultural contexts, there is no equivalent word for the term 'counselling'. Just as with supportive and palliative care services, it is important to have timely and informative discussions around what bereavement support involves and whether it is culturally appropriate. The unavailability of language-based resources impacts the visibility of existing bereavement services and, in turn, people's capacity, or willingness, to access such services. Further, people are less likely to seek bereavement support if they believe a counsellor who does not speak their language will not understand them well enough.

Silverchain social workers provide bereavement follow-up, but they often do not have the time due to heavy caseloads:

Ideally, as a social worker, we'd like to take every client because how do you know whether someone needs grief and loss support just by their social circumstances? ...Unfortunately, we don't have capacity to take on a referral for every client that comes into Silverchain. I have a client load of about 50. So, to stay on top of all of that is stretching it. It's tough (Palliative home care KI) .

When people's grief is protracted or becomes complex or otherwise beyond the scope of Silverchain's bereavement capacities, the service will try to find appropriate counsellors: *we will refer to [WSLHD] bereavement service...otherwise, with Mandarin-speaking, I ring up Parramatta Chinese Multicultural Centre...'can you recommend a counselling service in Mandarin?'* (Palliative home care KI). Having dedicated bereavement services for specific language groups is also important for culturally specific bereavement referrals, ensuring the cross-service, community, and agency coordination of bereavement needs is in place. This could also help to overcome some of the challenges in using interpreters in the counselling space (as discussed further below):

...a bereavement service just for certain language group...would be the dream really because, yes, we could work with interpreters but it's not just the same especially in the counselling space...someone from their own community being able to connect with them through that bereavement and hold that space for them would be so invaluable (Palliative care bereavement counsellor KI).

Suggestions for expanding knowledge about end-of-life services

Without relevant knowledge, patients and families are unable to access the assistance and end-of-life services that are offered. Ensuring information is available and accessible is crucial, especially at an early stage when there is time for relationships of trust to develop that would support patients and families through the last months of life as well as during bereavement. Our research findings identified a variety of ways that patients, carers, families, and communities could be provided with relevant information to grow their knowledge of end-of-life services. These strategies include the holding of public events, using culturally appropriate language in conversations and discussions, deploying interpreters, employing culturally and linguistically diverse (CaLD) staff, and providing culturally targeted written information, for example, *A Journey into Sorry Business* (SWSPHN, n.d.).

Public events: Australian and international initiatives such as Dying to Talk,²³ Dying to Know Day²⁴ and Compassionate Communities²⁵ recognise that talking about death is a social priority and promoting early discussions before end-of-life care is needed. Taking a direct approach by tapping into existing community programs such as Dying to Know Day can make the conversations appear more normal, less taboo or shocking. Yet people who are uncomfortable with discussing death and dying (be that due to personal reasons or cultural traditions) are unlikely to attend events where death is the focus. They might, though, attend events where the emphasis is on caring for the frail and elderly or the treatment of a specific disease, for example. Here it may be possible to approach the subject indirectly by integrating information about support services for end-of-life into such events. However, whether a direct or indirect approach is taken to communication, information and education about end-of-life, the language that is used in these conversations needs to be culturally sensitive and have the capacity to acknowledge alternative values and beliefs.

The role of formal interpreters: Interpreters are an obvious service for conveying language-based information that supports CaLD patients and families to understand the end-of-life services available. Effective, clear, and accurate translation conveys not only words but *meaning* (Butow et al., 2012 & 2013; Norris et al., 2005). Currently, the Health Care Interpreter Service (HCIS) is the major provider of trained interpreters in Western Sydney and other LHDs. They are available at all hours either on-site or via telephone. Accredited interpreters are available in over 120 languages and dialects and are “competent in the use of medical terminology and bound by a professional Code of Ethics”.²⁶ However, there are a range of considerations and potential challenges in utilising interpreters for conversations related to end-of-life or bereavement.

There is still a need for developing a trusting relationship, as identified in Theme 2. Trust is particularly relevant in the context of using interpreters sourced from a formal service. Being able to have access to the same interpreter each time is advantageous but would be difficult to organise because doctors and interpreters both have busy schedules. Continuity allows people to develop rapport and build relationships, which is crucial to ensuring honest information and a willingness to accurately translate difficult conversations or bad news. However, trust can be challenging to develop at times; for example, when patients hold concerns that information might not be confidential in a small cultural community.

Language specificities and cultural norms for talking about death and dying are still relevant in this context, too. There may be difficulties translating key words, phrases, or practices when there is no equivalent in the patient's language or culture of origin. Interpreters may sometimes be aware of the person's culture and associated beliefs and will be reluctant to translate verbatim: *one interpreter... said 'I am not going to translate – You are in a palliative care unit to die - No!' (CNC community health KI).* This also highlights the need to build in sufficient time to brief interpreters beforehand: *I explain very quickly in those few seconds you have before the client is on the phone that I will be talking about death and dying and I can debrief with the interpreter later if they would like that. But it does get tricky cause you're [working with] a culture, cultural [belief] (Palliative home care KI).*

On the other hand, the cultural role played by Interpreters was seen to be an important mediator in communicating about death and dying: *I also have a cultural role as well because culture plays an important role in health. So, if there is a misunderstanding due to a cultural difference, I sometimes find that I have to interfere to explain the cultural issue, and this can be done during briefing, debriefing, or during a session itself (Health care interpreter KI).* Yet this can introduce a bit of a dilemma in some instances: *usually we are only interpreting the information of what both parties said. Except for the specific cultural-related information, we are not allowed to get our personal opinions involved, although sometimes it is difficult to distinguish between these (Health care interpreter KI).*

There is limited availability of interpreters especially for some cultural groups. Interpreters tend to be available in large health facilities and are less likely to be easily accessed in services outside NSW Health. In particular, bereavement services are usually located away from these large facilities. Despite the year-round, twenty-four-hour presence of the HCIS, our findings indicate that even

23 See: <http://dyingtotalk.org.au/>

24 See: <https://www.thegroundswellproject.com/dying-to-know-day>

25 See: <http://www.compassionatecommunities.net.au/>

26 <https://www.wslhd.health.nsw.gov.au/Health-Care-Interpreter-Service->

within large hospital facilities there are concerns about the timely availability of interpreters with effective booking and pre-briefing procedures.

Using telephone interpreters has the advantage of being able to access interstate interpreters, which increases availability and may allay concerns about privacy held by some patients or clients of the interpreter service: *in that case the confidentiality is kept* (Multicultural health worker KI). However, telephone-based translation can be problematic for difficult conversations where visible non-verbal cues are lost as a means for indicating that meaning, not just the words, is understood. Furthermore, *often, to get to a phone interpreter, you have to wait...[and] they are coming in blind and that can be very challenging* (CNC community health KI).

In the bereavement space, having counselling in a person's own language is beneficial but not widely available. Working with interpreting services on very sensitive matters can be fraught. The presence of a third party makes it very difficult to connect with someone more deeply on the level that is needed for bereavement counselling. It impacts the flow of discussion and ability to communicate deep feelings of grief: *...an interpreter is obviously quite helpful, but it does make things more – there's another step involved...the communication – it doesn't flow quite as smoothly as if you're talking to someone in your own language...* (Palliative care social worker KI).

Counsellors and health staff might expect interpreters to directly translate their words. However, as mentioned above, in different language and cultural contexts, ideas do not always translate. A literal translation could have a very different meaning to that which is intended by the counsellor or client: *sometimes, if there is no equivalent, we have to paraphrase. We double-check with the healthcare provider and we say, "We don't have an equivalent. Is it okay if I say this?" and they say yes or no* (Health care interpreter KI). Often, interpreters need to explain the significance of the specific cultural-related information. For example, why a family might feel they need to feed the patient when medically, this is inappropriate. Given that health staff hold uncertainties about translation at times, it may be useful to bring together interpreters and health staff so they can each learn about the respective roles and expectations.

Culturally targeted community information about end-of-life and bereavement services: Clear and accurate information is needed to facilitate engagement and uptake of available services and supports. Early introductions to end-of-life services for Aboriginal and CaLD communities will aid awareness of and familiarity with palliative care services. In turn, this may help to reduce emergency admissions related to end-of-life that occur because people have not known about or accessed the palliative care services available. Exploring ways to engage communities about end-of-life services in a way that is relevant and easily understood culturally is an important finding in this research pointing to the need for culturally accessible end-of-life resources. Culturally appropriate brochures and fact sheets give time to read and understand information about medical conditions and available services.

Booklets or other materials with important information about the palliative care process and what is possible within the particular palliative care unit (such as amenities for patients and visitors, or for cultural practices that might bring comfort) can help carers, extended families and friends know about how to support people in palliative care in hospital. Resources providing guidance for families and loved ones was suggested, so they could *collect up all the info they need at end-of-life – account numbers, wills, family history, person's end-of-life wishes, etc. This helps families be clear* (Death doula KI). At present a comprehensive package has been developed by the Aboriginal Health Hub in WSLHD that includes information to help plan ahead for the legal and practical steps involved when someone dies. These include making end-of-life medical wishes known when the patient can no longer provide consent on their own, assigning a guardian, considering a funeral fund, and assistance with writing wills in a way that is culturally appropriate for Aboriginal people.²⁷

A similar resource, in both online and printed forms, is needed for migrant communities. The material needs to be culturally sensitive in explaining any 'clashes' between migrants' traditional expectations and Australian customs and laws. Given that the cost of funerals, especially burials, was a major challenge raised in Theme 1, the booklet needs to include information on how to find out about the costs and potential sources of financial help. The information provided to different cultures will not be a simple translation of an English resource. The material needs to be visually appropriate and use culturally relevant language that is clear, concise and jargon-free. These resources could be usefully distributed to communities, including to GPs as they are well placed to introduce discussions about end-of-life, especially when they are from the same culture and have a developed relationship.

In addition to printed materials, or included by way of QR codes, an introduction to key physical spaces such as palliative care units or bereavement counselling services could be provided as virtual tours. However, whether printed, digital or virtual, the issues of trust and appropriate language still apply. Terminology needs to be explained in culturally appropriate ways, and the artwork and presentation of any brochure needs to speak to the relevant cultural group. Further, information materials should not assume a knowledge of the health system. People also need explanations about the structure of the system and potential services provided – public versus private services and hospital versus community services.

Our findings also identified concerns about printed brochures and other materials. They should not be the only source of information because people who are stressed or in shock are unlikely to be able to absorb written material. Further, there is the potential to discourage meaningful connections with patients if medical staff believe they *can now treat them just as a knee or a left foot because [they] know 'that' – [they've] got a bit of paper that's been translated into Hindi and [they] can just hand it out or get the Hindi care worker* (Palliative care and bereavement counsellor KI). Face-to-face opportunities to hear about end-of-life choices and have

27 Taking care of business: Planning ahead for Aboriginal people in NSW and Aboriginal Wills Handbook.

discussions about what is possible or practical are also important. This is a means to ensure that people have accurate information and that their questions and concerns are met. Crucially, the chance for in-person conversations allows widespread accessibility, as not all people will be able to engage with written or graphic materials. A tour of the specific palliative care unit and meeting teams of health staff may provide an important opportunity for in-person conversations and interactions with the family.

Any efforts to disseminate end-of-life information for Aboriginal and CaLD communities may face the challenge of talking about death and dying (as described in Theme 2). The WSLHD Multicultural Health team is an obvious resource for the distribution of end-of-life resources and for conducting relevant educational programs. This service already provides psychosocial health literacy education on medical system navigation and preventative health-related concerns. They provide support and language-based resources and assist people with CaLD backgrounds to navigate healthcare and hospital systems, including how these connect with community-based care. These services could be expanded to cover end-of-life information (see also Theme 6).

Our findings also highlight that expanding knowledge of end-of-life is a two-way process. A simultaneous exchange is possible between community leaders and health staff whereby community leaders bring knowledge for staff about culture in end-of-life care, and staff bring knowledge for community leaders about end-of-life/palliative options: *we're learning from them just as much as they're learning from us in regards to end-of-life care...we ask the people what is it that we need to do for them to make sure their care is culturally acceptable. So, we're [consulting] our patients for education* (Palliative care nursing manager KI).

Information and support for carers and families

Even when people use hospital and palliative care services, the majority of end-of-life caring occurs in the home, typically provided by family, friends, neighbours and community members (Rumbold, 2010). The need for educational opportunities and support for carers is therefore a high priority. Engaging with carers culturally, as part of an extended family and community, requires an understanding of the ways in which people might approach communication, expectations and familial obligations.

As noted in Theme 1 subsection on *Cultural differences in decision-making*, the 'collectivist' nature of some cultures means the community itself could be seen as an extended family and often there are cultural expectations around offering care or support. When people are being cared for at home *giving information over the phone is always an issue anyway. So, it is important to establish who is the first person for most of these large families, who is the person to whom we can deliver, and how much information are we allowed to give them* (CNC community health KI).

Although there can be strong cultural expectations that family will provide the care, this may not easily be fulfilled. In Theme 1 under *Inter-generational differences in norms of care*, we discussed post-migration generations and noted they may not maintain traditional cultural norms and expectations which impacts willingness to care or follow traditional rituals: *migration has changed a lot of traditions...that children should...take care of their parents...this is not as strong as before* (Mandarin PV). Similarly, family or kinship networks may not be close by when the family networks of people who have migrated are overseas: *with some of our Indian patients – mostly they do die with us because they have a big family but they only have very few people who are here...they might have a community around them but they're not going to help them at this stage of their dying or their life* (CNC palliative care KI).

The range of cultural circumstances within which end-of-life carers might be located is complex. There may be strong support from close family; or from extended family or kinship networks; or from community through, for example, religious or spiritual affiliations or cultural expectations. Conversely, cultural expectations around care may not be easily fulfilled. Service use needs to be sensitively encouraged because a culture might dictate the level of family caring and a family that cannot care might experience shame (as discussed in Theme 1). In these varied circumstances, it is necessary to appropriately resource carers and families in ways that are culturally safe and avoid making assumptions about the end-of-life caring journey or how care and bereavement might be experienced.

Concluding comments

Theme 4 has identified the need for expanding knowledge of end-of-life and bereavement services across both communities and service organisations and has explored some of the cultural considerations in doing so. It has also identified a range of practical supports for implementation that will aide in caring at home. The suggestions explored in this theme all need to take into account cultural safety. We cannot assume that people from any culture who are unwell, stressed, unfamiliar with the health system and its attendant language/jargon, will immediately understand distressing information or the complexity of health services. Expanding knowledge and facilitating access to end-of-life services through public events, the use of culturally appropriate language, employing culturally and linguistically diverse (CaLD) staff, and wider access to interpreters are all important strategies. However, investment in the training of health staff is also needed to secure better mutual understandings of how staff, patients, and interpreters can work together in culturally safe ways that can be flexible to the individual needs of a patient and family. Relatedly, we now turn to hospital-based services and a consideration of how to 'make the most' of these.



Theme 5: Making the most of hospital-based services

Our hospitals house huge repositories of infrastructure, knowledge and skills which can greatly benefit people at end-of-life, as well as their families and carers. Although at the time of commencing this research only one hospital in the LHD (Mt Druitt) had a dedicated palliative care unit, Westmead hospital had some palliative care beds and services. Beyond dedicated palliative care, hospitals have interpreters, social workers, grief and bereavement counsellors, volunteer programs, occupational therapists and equipment, and community outreach nurses, all of whom can provide valuable support. More specifically for Aboriginal and CaLD communities, there are Aboriginal Liaison Officers (ALOs) and staff from diverse cultural backgrounds.

However, hospitals can also be experienced as large and impersonal, with a maze of seemingly disconnected functions. People at end-of-life and their carers can feel alienated and confused, especially if they need to access a range of services, and it might seem impossible to develop the relationships of trust that they value (Theme 2). Also, hospitals are often stressed for resources and this stress can be passed on to patients: *transport's probably the biggest issue. There's a lot of negotiation there because it's so slack... We had an Aboriginal lady who wanted to go home...and we waited a number of hours. She ended up dying in the ambulance on the way home* (Community Nurse for Aboriginal people). Knowing more about end-of-life services (Theme 4) does not negate the difficulties people might experience in the hospital environment. In this current theme, we examine the need to make connections within hospital-based services to maximise their effectiveness as well as the need for hospitals to provide palliative care spaces that invite trust and comfort.

Excellent medical treatment but concerns about cultural safety

We start by acknowledging that the research participants expressed a great appreciation of the medical services they receive: *it was very good medical care everywhere in the hospital* (Hindi PV); *My experience is that all the doctors and the nursing staff were wonderful, nice people* (Mandarin FG). Some participants contrasted this with the treatment in their country of origin, for example: *in many places villagers [in China] can't even afford to see doctors* (Mandarin FG). However, migrants may not be likely to complain about the hospital: *the other thing to be aware of is that a lot of those cultures will be – I don't know if it's grateful...they're not going to ask for more because they're getting all this wonderful medical care* (Volunteer network KI). Further discussion revealed an element of distress:

It was just not very understanding in terms of clinicians not being very empathetic, or culturally appropriate, or sensitive with the way they interacted with my family and in understanding our roles in our family, the roles and responsibilities each of us play in my granddad's life, and that was really important for us...no one [tried] to learn about the family dynamics (Hindi PV).

We recognise that cultural sensitivity is not straight forward. Medical staff might believe they are being helpful but still cause distress. For example, some doctors have directed that patients should be put in a nursing home, believing that by making this directive they are relieving the family of any guilt associated with putting their parent in aged care. However, our data show where this experience was reported, the interviewees expressed shame that their parent was in a nursing home because culturally, it is *quite taboo* (Hindi PV). Another participant explained the regret and guilt he has experienced even though his parent *was okay there...he didn't complain. But I still have this guilt* (Hindi PV). The community and the extended family back in their country of origin do not necessarily know that doctors made the directive and may assume the family are not fulfilling their duties.

It is important to recognise that with cultural expectations, people might think that they need to act differently but they can still experience emotions associated with contradicting deeply held cultural values. The question arises as to whether the doctors were helpful. What else might they have done? A discussion with the family would implicate the family in the decision and perhaps trigger more guilt. Could sufficient support have been provided in the home, possibly with the Hospital in the Home model?²⁸ Could the family have been given more time and support to fully discuss the options? What risk is the patient prepared to take to stay at home? Sometimes, people feel less guilt when they know they have fully investigated all the alternatives.

28 https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2018_020.pdf

The examples above also raise questions about cultural sensitivity training. The doctors had some cultural awareness because they were trying to relieve the family of the guilt of the decision, but the strategy was not effective. We would suggest that training is helpful to raise awareness of possible sensitivities and challenge one's own assumptions, but, as discussed in Theme 1, it cannot provide a set of simple rules in the tradition of 'cultural competence' that has become influential in contemporary diversity training (Loue, 2022). A trusted relationship (Theme 2) and time to understand and process the options (Theme 4) are essential to reduce distress. Staff such as culturally specific supportive and palliative care workers are probably better placed to assist the patient and family to make care decisions than medical staff who are already under pressure.

Cultural awareness training about Aboriginal culture is mandatory but not for migrant cultures. Even the mandatory training was not seen as sufficient: *people just basically let the videos play while they do whatever else* (Aboriginal drug and alcohol worker KI):

It needs to be face-to-face ... and they need to make a little bit more interactive. There's a lot of games that you can play with its roles reversed...I think they need some understanding about Aboriginal people and trauma, loss and grief. They do that and they'll get the insight of how they can best work with the family and the individual (Aboriginal drug and alcohol worker KI).

As well as promoting the principles of cultural humility (Foronda et al., 2016; Yeager & Bauer-Wu, 2013), an immediate strategy for increasing cultural awareness and developing cultural sensitivity is the promotion of existing training programs such as those provided by Partners in Culturally Appropriate Care (PICAC).²⁹ The PICAC program is a national initiative which aims to improve service providers cultural inclusivity. It provides training to service providers and is building a collaboration with the Program of Experience in the Palliative Approach (PEPA).³⁰ PICAC audiences include allied health teams, doctors, (general) managers, and frontline workers mainly in the residential aged care facilities.

Importance of early referral to a palliative and supportive care service

Even within hospitals, patients might not be referred to palliative and supportive care in time for that unit to provide good care and reduce suffering: *conversations are just not started early enough to say it is a life limiting illness* (CNC community health KI). *We get referrals sometime way too late. It is horrible for everybody. It is hard for us to play catch up. It is hard for the patient by this point, who has suffered so much, they just give up, they do not even want to think of anything because they suffered so much* (Palliative care nurse KI).

Two main reasons for untimely referrals were identified in the data. First, the failure of medical staff to recognise that a person is approaching end-of-life which was associated with a general attitude that sees death as a treatment failure: *we spend a lot of time educating doctors to try and see death as normal, because is part of a normal aspect of life. Again, that is another important aspect of culture...Death is not a failure, bad death is a failure* (CNC community health KI); *A patient was dying in the acute neuro-gastro ward and the team leader came up to me and said 'This patient has to go! We do not do dying on this ward'. I was so shocked!* (CNC palliative care KI). Second, the absence of knowledge or understanding of the role of palliative and supportive care due, at least in part, to the silos within the hospital system: *it really is about ensuring that our providers have that ability to navigate and have that understanding of everything that is out there* (Primary health worker KI).

It is also important to introduce patients to the palliative and supportive care service at an early stage to decrease potential shock: *[let them know] 'this is who we are, this is what we do, you don't need us now, but we are there when you do'...just so it's not a shock... 'omg, I need palliative care'* (Palliative care nursing manager KI). Our data on the importance of having early conversations about palliative care options is consistent with international research which demonstrates that early access to palliative care can avoid futile therapies, prolong life in some patient communities and significantly reduce hospital costs (e.g., Haun et al., 2017; Howie et al., 2013; Greer et al., 2012; Gade et al., 2008). Providing patients and families with an early introduction to supportive and medical services reduces the occurrence of unplanned or emergency admissions by encouraging uptake of care pathways that reflect the individual's condition, needs and social circumstance.

Promoting early referral to palliative care services

Initial palliative care referrals may come from hospital emergency or specialist departments, NGOs, allied health, community, family or pastoral services, or primary care physicians. However, due to the silos in the health care system, health workers are not necessarily aware of the nature and value of supportive and palliative care services or how to access them. Health workers could also benefit from the suggestions made in Theme 4, but some further, more specific, initiatives were reported to address this problem within hospitals. The Senior Aboriginal Supportive & Palliative Care Worker already moves around the hospitals visiting all the Aboriginal patients who might be approaching end-of-life. In the process she promotes awareness of end-of-life care and in particular the needs of Aboriginal patients. Also, because the LHD recognised the problem of poor end-of-life care outside palliative care units a specialist palliative care nurse now visits the wards to identify people at end-of-life and helps provide good care:

...we have started using the Comfort Observation and Symptom Assessment (COSA) that is designed by the CEC (Clinical Excellence Commission)... [we] identify a deteriorating patient, or a dying patient, and implement this... [nurses] have to

29 <https://www.health.gov.au/our-work/partners-in-culturally-appropriate-care-picac>

30 <https://pepaeducation.com/>

check on the patient every 4 hours and assess their symptoms and [do the COSA] checks...as part of their 4-hourly obs... (Specialist palliative care nurse KI).

In turn, this extra help gives nurses and their managers outside palliative care an insight into palliative care services and relevant contacts to more readily make referrals. Awareness could also be extended using training options such as those provided by PEPA. In particular, PEPA support short-term placements of medical staff in palliative care units so they can learn firsthand about palliative care services.

Making the most of palliative care volunteers

Volunteers are a major asset, whether part of a formal volunteering program or an informal volunteer network. This is especially the case when they come from diverse backgrounds with diverse and rare languages. Volunteers can develop relationships of trust with patients and families and work across the silos within and beyond the hospital. WSLHD employs one full time manager to coordinate and supervise a large group of CaLD palliative care volunteers. These specially trained volunteers visit people who are palliative in hospital and in their homes (although, unsurprisingly, the service was significantly disrupted during the COVID-19 pandemic). Same-language volunteers can spend time with people and provide respite for carers and, most importantly, they provide culturally nuanced social interaction: *[volunteers] come to it with quite a sense of responsibility for their community...if they meet anyone from their cultur[e] you know – it does touch them more* (Volunteer network KI).

Relationships with same-culture volunteers provide people at end-of-life and their families with reliability and predictability, with care from someone who is sensitive to community and cultural needs: *[a volunteer's] husband cooked [the patient] a certain food from where he was from in India – cooked him this special dish and took it on Sunday to the hospital...so special* (Volunteer network KI). Volunteers can bridge the needs of patients when family members are not available: *having somebody non-clinical that they trust in the hospital is really important...at Westmead, there's a large number of patients who don't have very many families here... Having developed a rapport with the volunteer...[provides] that level of relief that there's someone else [as] backup when you have so few family members here* (Volunteer network KI).

Patients can be referred to volunteers by medical staff, and are a highly valued and important cultural, social and emotional resource, particularly for people disconnected from their families who may live overseas: *I think that separation of families at that point in your life, having non-clinical people who are there really as other humans, is huge* (Volunteer network KI). Further training for volunteers about the services available and referrals to social work and occupational therapy would enhance the role of volunteers as part of the supportive care team: *the doctors value the fact that if I can say, 'Well a volunteer can sit with them'. If [the patient is] really distraught in the evenings, I'll ask a volunteer to especially come and sit with that person...it can be quite individualised...and they do, the staff do ask* (Volunteer network KI). Recruiting palliative care volunteers into grief and bereavement support would also help to provide cultural, social and emotional support:

...they've come to volunteer to give back. So, they have an experience of a bereavement...It was always in my head after I set up the service to get palliative care volunteers into bereavement volunteer support. Because they may already have made links or because of...an interest in bereavement from their own experience in supporting people (Volunteer network KI).

Informal volunteers from diverse cultural backgrounds: In addition to the formal program of volunteers from diverse cultural backgrounds, existing health staff can also provide useful assistance as informal volunteers. Bilingual medical staff are an important resource, such as *a resident [doctor] who does speak another language... because if we get a patient in from that language, you know we have direct communication with them* (CNC palliative care KI). Same-culture nursing staff are also an advantage and can be reassuring for families, helping them to understand the processes and options for pain relief. Similarly, in bereavement support *having that understanding of the language around which foods or names of practices (e.g., thaali) can be very helpful for working in the bereavement space. Having in-language services for these specific cultural needs can be very effective* (Multicultural health worker KI). Maintaining a register of informal volunteers such as health staff who are willing to help with the support of people from their language or culture would be a useful step and could be part of the 'information hub' discussed below.

Need for a centralised information hub

The idea of a centralised information hub is one suggested solution to the silos in the care system introduced in Theme 2: *one woman told me about seventeen services she had been to. There's no wraparound shop. And when you're flung from one service to the other, mate, I would run away after the fifth service* (Hindi counsellor KI).

Such a service could be administered in the hospital where it could be a point of information and connection for staff. For example, in Theme 2 there was a suggestion that the culturally specific supportive and palliative care role was too great for one person and would benefit from a small group which could include an appropriate nurse, social worker and, ideally a staff member or volunteer from the same language group as the patient. This three-person team could be coordinated in the hub and would have a continuous relationship with the patient and carers. Staff involved in the care of a patient would know when the patient has died thereby providing an opportunity to process the end of their relationship. The hub could also keep a record of bilingual staff who were willing to be contacted to support people from their shared cultural background. This would be particularly important for dialects or languages that are less common and especially for patients who do not appear to have much support from family or friends.

The hub would also assist patients and families to be connected to all their needs. A dedicated phone number and email address would provide the means to access all support including critical and complex support, home care, palliative care at home, occupational therapy support and equipment, community and family support, appropriate funeral celebrants, and the family's need for grief and bereavement support. A centralised hub of this kind would also provide an integrated system whereby the home-based palliative care service and other home care services would be well connected with hospital palliative care, outpatient and other services. Patients would be tracked by the same system as they move in and out of hospital and after the death. Through the information system, for example, a hospital occupational therapist would know that the correct equipment was delivered to a patient, and a hospital social worker could find out about the home care support a person has received. The essential role here is to bridge the discontinuity between hospital and home-based services.

Managing and maintaining a network of relationships beyond the hospital with a variety of stakeholders would also be possible. For example, with volunteers, community and spiritual leaders, psychosocial support groups, bilingual GPs and pharmacists, government agencies such as My Aged Care,³¹ and interpreters. Hospital staff would call the hub if, for example, a patient was distressed and needed counselling or spiritual support. At a broader level it could facilitate a community of practice. Such a community would include health staff, community services, and service users who meet together to talk about the end-of-life services and systems, identify gaps and potential improvements we will discuss these connections between hospital and community services further in Theme 6.

Dedicated culturally and linguistically diverse (CaLD) palliative care workers

As discussed in Theme 2, the development of an Aboriginal supportive and palliative care position to provide culturally appropriate and coordinated support for the Aboriginal community in WSLHD has been an outstanding success and provides a model from which CaLD communities could benefit. A key function of the Aboriginal role is supporting end-of-life patients and their families, facilitating communication, and providing education. Having someone of the same cultural background is central to the success of the role. Patients and families have time to develop a trusting relationship with the person as they journey together through all aspects of the end-of-life journey.

The need for similar positions for the major CaLD groups in WSLHD is a strong finding from this research with people from multiple different cultural communities needing care and support at end-of-life and *help...to understand what is going on* (CNC palliative care KI). Dedicated CaLD supportive and palliative care workers would bridge the silos in end-of-life services, providing cultural support and guidance for navigating the complexities of the palliative healthcare and bereavement systems from the point of diagnosis through to bereavement: *someone...to support the person, as well as the family* (Aboriginal PV). The CaLD roles would connect with the relevant cultural communities, identifying patient and family needs, providing education and reassurance, intervening when care is inadequate or culturally insensitive and mediating disagreements. They would liaise with interpreters where needed and assist patients and their families to understand the technical communications of doctors, as necessary.

Although there is ample evidence of the need for culturally and linguistically diverse (CaLD) workers in the end-of-life and bereavement spaces, it should not be assumed that having health workers from the same culture is necessarily a sufficient solution in and of itself. Families may make unreasonable demands of workers from their own community and, as discussed in relation to Interpreters in Theme 4, there may be complications of privacy and confidentiality if the worker is known to families or within the community: *some communities have that confidentiality issue...in a small community everyone knows everyone* (Multicultural health worker KI). Furthermore, intra-cultural sensitivity cannot be assumed: *some people say that all doctors who speak my language are terrible because they don't give us enough time – It's all 'business'* (Multicultural health worker KI). Nevertheless, employing supportive and palliative care workers with diverse language and cultural backgrounds is an important investment for meeting the end-of-life needs of diverse communities.

Dedicated palliative care spaces

Palliative care services focus on care rather than cure, which enables a holistic view of the patient's needs and those of the family and other carers. Such services work best in dedicated palliative care spaces which can provide culturally sensitive environments to accommodate the needs of the diverse communities within WSLHD. Indeed, having dedicated palliative care spaces that could be responsive to different cultural needs was a recurrent theme in our findings.

The Palliative Care Unit at Mt Druitt was found to be a place of flexibility for accommodating cultural needs. It includes an outside space which was greatly appreciated by the Aboriginal community: *we had guitars, didgeridoos, clap sticks. We did smoking [ceremonies]* (Aboriginal FG). The nature of 'space', both qualitatively and quantitatively, is central here. Across all cultural groups, the need for sufficient palliative care beds

31 See <https://www.myagedcare.gov.au/>.



alongside sufficient size of rooms to allow for family and friends to be near their loved one were both paramount: *we moved in – the whole tribe – well not the whole tribe – most of them...sisters, brothers, the rest of us that were left, his sons, his grandsons, we all literally moved into that room with him* (Aboriginal FG). *The idea is if the doctor feels the person is going to die, they inform the family straight away so the family can come and stay* (Mandarin FG).

However, size is not all that matters. Making people feel welcome and that their culture is respected is also important. Incorporating art and/or symbolic decoration conveys a sense of value, supporting cultural visibility and knowledge: *...make it more appropriate. Like doing the sandstone box, doing the Aboriginal artefacts in and around the environment instead of just one didgeridoo on the wall* (Aboriginal FG). Similarly, hospitals need to provide prayer and meditation rooms, well signposted in multiple languages, with stools, chairs, and prayer rugs for use by families and visitors. Further, allowing sufficient space for cultural practices for patients themselves or with their families and friends – areas or private rooms where they can decorate them appropriately, play their own music, chant, or say prayers: *he didn't have a proper place to pray...so that stopped him. Culturally...he felt...isolated* (Hindi PV).

Another common theme in our findings was the centrality of food to culture. Having a kitchen in which people were invited to bring and prepare appropriate food for the patient and family would be a further means of providing culturally appropriate space. In the Hindi focus group, they noted that food is symbolic as well as nutritious and pleasurable. The dying person will often crave the foods of their childhood and families and carers get comfort from being able to provide the dying person with that pleasure. It is not easy to bring hot food from a distance, but nevertheless visitors come with food: *well-wishers and the family members and relatives – if the patient is in a position to eat anything they definitely don't come empty handed...they come with food* (Hindi FG).

Locating a palliative care unit where it can have its own entrance is also potentially useful. It can be reassuring for people that they can come and go easily and allay fears that if you go into palliative care you never leave. Having an easy connection to outside areas is also facilitative of flexible use. For example, yarning circles for Aboriginal people, ceremonial circles for any cultural group, or simply an outside reflective or 'respite' space for patients or visitors: *a 'love heart' in a gumtree at palliative care. It was my happy place out in the courtyard. I used to go out there, I used to be upset then I'd turn and look at that love heart and I'd be like, 'OK I'm right again now. I can go back inside'* (Aboriginal PV).

Finally, having a viewing room in all hospitals could also contribute to culturally safe end-of-life experiences. For some cultures, it is necessary that someone stays with the body until it is buried or cremated and having a viewing room would facilitate this practice while also freeing up the hospital bed. A viewing room could also accommodate visits by family and friends coming from regional areas or interstate.



Concluding comments

Our public hospitals provide excellent medical treatment at little or no cost to the patient, which is essential in areas where people live with relative socioeconomic disadvantage. They also house excellent allied health and associated services. There are four main areas for improvement in meeting the end-of-life needs of Aboriginal and CaLD communities. First, increasing the cultural sensitivity and skills of staff through formal training programs such as those provided by PICAC. Ideally such training would be face-to-face and compulsory. Cultural sensitivity also grows through day-to-day interactions with the Senior Aboriginal Supportive & Palliative Care Worker and could be extended through employing supportive and palliative care workers from other relevant cultures in WSLHD. However, the role is demanding and there are many migrant communities with large populations in WSLHD so considerable investment would be needed to start to address their needs. Second, increasing hospital staff awareness of the role of supportive and palliative care which facilitates early referral to palliative care services. Formal training and placements in palliative care wards are provided by the *Program of Experience in the Palliative Approach* (PEPA). Informal avenues include day-to-day interactions with expert palliative care nurses who work with patients at end-of-life in any ward within the hospital and with any culture-specific supportive and palliative care workers.

The third main area for improvement relates to bridging the silos both within the hospital and beyond so that patients and their carers can develop trusting relationships and experience continuity of care. Strategies for this include having small teams to build trusting relationships with patients and families; extending the role of palliative care volunteers to be more aware of other allied health services and to continue to work with families in bereavement; and establishing a centralised information hub to enable all health staff, volunteers, home services, patients and carers to find the information they need to optimise care. And fourth, creating dedicated palliative care spaces which have the capacity and flexibility to address the needs of diverse cultural groups. Although calls for more support for CaLD and Aboriginal people might seem beyond the current resources of hospitals, it is important to remember that early palliative intervention reduces expensive emergency admissions. Given the expertise and resources concentrated in our public hospitals it seems worth the relatively small extra investment to make them work for the LHD's large multicultural population.

Theme 6: Increasing culturally appropriate end-of-life and bereavement services for the community

Our findings show that more formal services are needed in the community to support culturally appropriate end-of-life care; and that these services need to be robustly connected with the Aboriginal and CaLD communities who need them when people have a life limiting illness, are caring for someone at end-of-life or are experiencing grief and bereavement. Increasing the scope and reach of these more formal services can be a positive help, as can building on the cultural capacity of existing community-based care and developing connections and opportunities for more informal community-based supports. Three main strategies for this were identified in the data: increasing the coverage of end-of-life and bereavement care by existing organisations that support Aboriginal and CaLD communities; increasing the diversity and cultural sensitivity of existing end-of-life and bereavement services; and creating further end-of-life and bereavement services in the community staffed by people from specific cultures: *I would be thinking that those people who are very connected to their culture probably need to have an Aboriginal person who can help with their grief and loss, with counselling, with whatever is needed* (Community nurse for Aboriginal people KI). Below, we discuss a range of issues and suggestions that emerged in the data for expanding culturally safe end-of-life services.

Western Sydney community health centres

There are seven community health centres across WSLHD which “aim to improve the health and wellbeing of people living in Western Sydney by providing treatment and care in community settings, away from hospitals” (WSLHD, 2023).³² These services mainly focus on child and family health, violence prevention and response, and youth services. Currently end-of-life care and bereavement support have not been a specific focus.³³ However, community health centres across the LHD often have staff from local cultures and could extend their services to provide end-of-life and bereavement support. This has been reflected more broadly in the Multicultural Health coordination within WSLHD and could translate into the specific community health care spaces.

There is a need for services to work across each other so that those providing education and multicultural health assistance are also aware of the tranche of services relating to end-of-life that are available within the LHD and advise accordingly. Further there is a need for services to learn from communities. Having embedded services is an important mechanism for two-way transmission of information *for* the community and *from* the community, especially in terms of cultural knowledge. This was noted by Integrated and Community Health (WSLHD) during the COVID-19 pandemic but has enduring relevance in the context of end-of-life and bereavement: *we are trying to link into community, to sort of say teach us, tell us things, because we can get...information from our patient and the family, but I think, how can we educate ourselves as well. How can we reach out to the community in a time like this?* (Integrated and community health worker KI).

Community health centres to provide practical resources for carers: In Theme 4, we discussed the need for increasing knowledge of end-of-life services, including through printed and online material, and emphasised the need for this information to be culturally appropriate, not just a direct translation of English. This also applies to the more specific information required by carers. Our findings also highlight a diverse range of other ways in which end-of-life carers and families could be resourced and supported:

- Development of a palliative home care package – ‘Pall-Pack’ – based on the NSW Health Community Packages (ComPacks) which provide eligible patients with a short-term care package after hospital discharge:

...a palliative home care package in my view would identify that you are going to deteriorate and to stay at home, we need to put more into support around you bearing that in mind; and that would be extra personal care, a hand with the house, someone just to sit with you, someone to check in on you; it would be the same support that already exists just for a different target group (CNC community health KI).

- Information for carers showing practical help for patients, e.g., sponge baths; turning the patient; making beds more comfortable; and so on. This could include video tutorials (e.g., YouTube) in various languages for better care at home.
- Letting people know about social media supports such as the ‘Lotsa helping hands’ website where a downloadable App allows people to establish a ‘caring community’ and centralised place to coordinate support from family, friends, and community, especially if someone is dying at home.
- ‘Life alarms’ which can ring back to base or ring allocated numbers need to be made more user friendly for non-English speakers.

Cultural capacity and general practitioners (GPs)

Western Sydney has numerous bilingual GPs and yet barriers to their services still exist. In relation to the elderly, one key informant commented: *[a] lot of [people] complain about not getting enough GPs [who] speak their language. Because once you reach that age, for most of them English is a big issue* (Multicultural health worker KI). For CaLD communities, extended consultation times may be required to communicate effectively, particularly when interpreters are involved. Yet with an increasing number of services no longer bulk billing, this introduces an added cost to the patient.

Ongoing education for GPs that is specific to end-of-life and palliative care was identified as *a big gap* (Primary health worker KI) and further compromised for GPs under the time constraints of running small businesses with a high turnover of patients (acute during

32 See <https://www.wslhd.health.nsw.gov.au/Community-Health-Hospital#:~:text=Welcome%20to%20Community%20Health%20Services,community%20settings%2C%20away%20from%20hospitals.>

33 Although chronic health care support and palliative care is a key focus within some of these community-based health care spaces.

the COVID-19 pandemic). Potentially helpful strategies to bridge the GP knowledge gap include promoting the Advance Project;³⁴ increasing placements in palliative care units for GPs with PEPA (*Program of Experience in the Palliative Approach*); and engaging the Western Sydney Public Health Network to work with GPs in the region. Steps forward have already been made around improved communication lines between primary care and palliative professionals: *I don't know whether the education's getting better or we're getting out there more and explaining things a bit more. I know there's the online service now to help GPs and we've had a lot of GP forums where our doctors go out and discuss...I think that's helped a lot* (CNC palliative care KI).

It was noted that within the Arabic-speaking community, effective care coordination is compromised by a reliance on community nurses as liaison between primary, specialist care, and patients; and also by relying on GPs to do much of the social work in locating affordable or bulkbilling services: *90% of our time in general practice is social working* (Arabic GP KI). A centralised referral hub was suggested to address this: *somewhere where an intake person takes the information, then they engage [services for] the person... because in many cases when you call an organisation or even Public Health, they tell you the person who takes the intake is not here – only on Friday morning between 9 and 11 and here you are on Tuesday* (Arabic GP KI).

The appointment of liaison nurses or social workers attached to GP centres whose role is to advise on local community services was a further suggested strategy. There is also a clear need for well-funded primary care case conferences that result in timely service provision, because *if we don't do that, [the] patient will end in hospital for something we can deal with in the community ...and it costs a lot more* (Arabic GP KI). Similarly identified, was the need for funding for GPs to make home visits: *many, many big medical centres do not do home visits...because when you do home visits, you pay money from your own pocket* (Arabic GP KI). Home visits are a cultural need in many communities, but especially for older people who do not have English as a first language or have mobility issues or cultural constraints.

GP engagement has also been augmented with the use of technology that brings them into broader contact with existing community services. Western Sydney Primary Health Network (WSPHN) developed an App which links into the Clinical Management System. The App allows GPs to match individuals who are willing to identify as a refugee with relevant services and/or community groups that are added to the App as the PHN becomes aware of them: *you can have a patient...flagged and identified as...A&TSI, but there is nothing there for refugees...[the] App...allows practices to flag a patient if they are willing to be identified...as we become aware of different services [or]...community groups that might be available...they can proactively start to reach out to those individuals...* (Primary health worker KI).

Some GPs are able to participate in the *Closing the Gap* program which ensures people in the Aboriginal community with a health-care card receive cost-free medication from the Pharmaceutical Benefit Scheme (PBS). However, because the participating GPs are required to have training and receive accreditation, some patients might need to change doctors in order to receive the benefits and this undermines any trusted relationships which have been developed: *why can't all doctors do this? Why is it set up in such a way that it's so selective?* (Community nurse for Aboriginal people KI). Furthermore, it is reported as a time-consuming process for GPs to gain accreditation, but also one that may be inequitable between individual GPs and large medical practices: *[the GP said] 'I have to literally close my practice for three to four days to be able to do it and then I have to go through the accreditation process'. And he just said financially it wasn't viable...But the sad thing is...a big medical centre only has to send one person...for that training and everybody is covered* (Community nurse for Aboriginal people KI).

Cultural capacity in private palliative home care

As discussed in Theme 2, the Silverchain community palliative care service provides home nursing and a palliative care doctor but is disconnected from public health services, which creates problems for continuity of care. Considering culturally appropriate care, Silverchain has staff from a diversity of backgrounds but no guarantee that a client will see the same staff from day to day, so it may be difficult for clients to feel cultural safety. However, access to an in-home service when none had been available before is appreciated by some communities and thought to be *good, actually...[patients] are making use of it. Some of the services – they speak the language – so I mean that's pretty good actually. That's going very well...a lot of elderly patients I look after, they are happy with the way they are getting help from the government and the LHD* (Hindi GP KI).

Nevertheless, our data identified a number of issues with the model of in-home care provided by Silverchain, in particular, where the service is unable to address actual need. Beyond nurse home visits, there is no personal care or carer respite, although a care package from a separate provider can be arranged. GP coverage is weak, with only one doctor on weekend duty for all of Western Sydney: *the demand is huge...it's like everywhere, they need more staff ...I think they provide a good service...there are people there who really care about palliative care* (Occupational therapist KI). Nurse practitioners who are able to write prescriptions was suggested as an alternative: *a home-visiting doctor is absolutely important...or even having a nurse practitioner who could do that would be another probably good resource because getting doctors is really hard* (Community nurse for Aboriginal people KI).

According to an evaluation of Silverchain by the Paxon Group (2020), no staff respondents identified as Aboriginal or Torres Strait Islander. Our key informants from the area of supportive care noted the connection between the absence of staff and absence of clients: *I think that's important. But yeah, I just notice a lot of [Aboriginal people] are dying in hospital* (Community nurse for Aboriginal people KI). The Aboriginal community focus group participants were largely unaware of the services available through Silverchain: *for every Aboriginal client that comes on their books, they need to have an Aboriginal worker that goes in there and meets*

34 An Australian example of primary care resources and education to support GP practices to initiate palliative care and advance care planning conversations with patients is The Advance Project, see <https://www.theadvanceproject.com.au>. These evidence-based resources are available free of charge and online.

with the person and helps their staff to be culturally appropriate...you can still make mistakes and do it so innocently (Community nurse for Aboriginal people KI).

Silverchain indicated that while they have a comprehensive multicultural health representation, the opportunity to work with Aboriginal health workers or having Aboriginal community liaison engagement was a clear need: *it would be nice for the nurses to be able to access the Aboriginal health workers, because I find Aboriginal clients are less likely to have any kind of interventions even if they are for comfort...if an Aboriginal health worker were able to accompany them or, that could make services more accessible (Palliative home care KI).* Silverchain, as the sole provider of in-home palliative care services, relies on the WSLHD Senior Aboriginal Supportive & Palliative Care Worker to bridge cultural needs and this places additional demands on the public health role.

WSLHD Multicultural Health

The WSLHD Multicultural Health (MCH) team responds to community needs by providing psychosocial health literacy education on medical system navigation and preventative health-related concerns such as diabetes and cancer. The ethos of the Multicultural Health team is to work with communities to provide support and language-based resources. These assist people with CaLD backgrounds to navigate the healthcare and hospital systems, including how these connect with community-based care. With their staffing from diverse backgrounds and established connections to cultural communities, Multicultural Health has the capacity to deliver sessions in culturally sensitive ways, for example, avoiding the words death or dying when they are seen as 'inviting death' by some cultures (see also Theme 4).

The programs delivered by Multicultural Health are developed in response to requests from the community about the information they may be seeking and education about palliative care and end of life has not been 'on the radar' of MCH because: *...people, they never ask ...about end of life ... this is not something that people would like to talk about (Multicultural health worker KI).* Without such community support, dedicated sessions about death and dying may not be well attended, if at all. However, Multicultural Health is well placed to integrate information about end-of-life and bereavement resources and services into other (related) information sessions, such as those for caring or specific diseases or for Advance Care Planning (ACP).

Because of their strong connections to diverse communities, Multicultural Health would be an appropriate place to staff the culture-specific palliative and supportive care workers discussed in Theme 5. These CaLD workers, similar to the Aboriginal supportive and palliative care worker in the Aboriginal Health unit, could have an educational role developing resources and contributing to community sessions, as well as supporting end-of-life patients and their families. Relatedly, there is also a need to develop connective opportunities between MCH teams and supportive and palliative care staff and processes through interagency engagement and training: *...the knowledge of palliative care, multicultural health staff probably don't have that much. And the palliative care staff probably [don't] know too much about the community needs. So those kind of...interagency...that kind of training...[is needed] (Multicultural health worker KI).*

Dedicated palliative and supportive care spaces in the community

Our findings showed a need to provide alternative spaces for palliative and supportive care away from the hospital environment, especially when care cannot be provided in the home. Multiple dedicated palliative and supportive care spaces in the community could be more easily accessible to family and community members. In turn, these spaces could be more flexible in responding to cultural needs than hospitals. Hospices for longer stays would help to keep people out of emergency departments and busy wards with high bed turnover. These would also be suitable for people who might need extra support but do not qualify for entry to a palliative care unit in a hospital. They can be more flexible than hospitals around family and cultural needs.

There could also be spaces in the hospital or in medical centres in the community for non-acute patients needing day treatment; and respite places in the community for palliative care patients. The latter could possibly make use of a dedicated section of existing aged care facilities, although aged care facilities are not very inviting for young or middle-aged people at end-of-life. Further, appropriate informal community spaces, possibly in local community centres, are a way to provide basic support for bereavement. Where more comprehensive support is needed, these spaces would have connections to dedicated bereavement services and culturally specific supportive and palliative care workers.

Connecting to culturally appropriate bereavement services

Pathways to bereavement services are important for continuity of care in the end-of-life journey. Recognition that grief is present well before the loss of a loved one is a central part of end-of-life care and support. Our data highlight multiple considerations in relation to bereavement including the location and physical space of bereavement support, its timeliness, available approaches, cost, and crucially, the language and cultural barriers that make accessing bereavement support difficult: *...some community members may be worried about whether the service will be able to understand their particular needs if the counsellor may not speak their language. They probably worry that we will not speak their language and that they would see that [as a barrier] (Bereavement counsellor KI).*

The standard practice for follow up on contact after a person has died is very much impacted by funding and resources currently available to existing services both within and outside the palliative care space. Sending letters or text messages to ask how families are managing has been part of the traditional supportive care approach from social workers and counsellors. However, some of

these approaches, and opportunities to maintain a connection with the family or those close to the person who has died, have increasingly become a challenge due to higher workloads and constraints on funding:

We do have some bereavement follow up...but it's usually a phone call and then linking to another bereavement service... best practice would be a bereavement follow up call from us a few days after the death and then maybe a few weeks later, so that some of that situation can be captured more effectively than three days later [which is] still that shocked phase... (Social worker, palliative care KI).

At the same time, bereavement counsellors may be unaware of specific cultural requirements surrounding grief and mourning practices, which indicates a twofold need for both cultural sensitivity and consideration of resources: *I'm not familiar with any culturally specific services* (Social worker, palliative care KI). For bereavement support, having dedicated in-language counselling services is ideal, but there are relatively few specialist bereavement counsellors from diverse cultural backgrounds with the requisite language skills. There is a clear need for additional in-language services and counsellors to respond to community bereavement needs and to make these more accessible and cost-effective. Most counselling is provided as a private service which is too expensive for many people, especially for people living with relative socioeconomic disadvantage. A package of six sessions, available via a GP referral on a mental health care plan, is less expensive but this is rarely sufficient to meet the needs of people with complex grief (the practitioner can request additional sessions but only up to a maximum of ten for the year).

Access to an Aboriginal bereavement counsellor or similar professional for the Aboriginal community is needed to work alongside the Senior Aboriginal Supportive & Palliative Care Worker. The latter role does not formally extend to bereavement support, although the nature of the incumbent's relationship with clients means that she does provide compassionate support. Nevertheless, it is not a counselling role; rather the worker is well positioned to help her clients develop a trusting relationship with a counsellor when more help is needed. To this end, the Aboriginal palliative care worker regularly liaises with the WSLHD bereavement counselling service for Supportive and Palliative Care to ensure continuity where necessary.

Active recruitment for culturally diverse bereavement counsellors within the LHD is needed but developing the relevant expertise takes time and specialised training. People first need to become qualified in a relevant helping profession (e.g., psychology, social work, counselling); and then, because bereavement expertise is not a major part of their training, additional professional development is needed: *mental health workers, psychologists, psychiatrists, do not have specific training in bereavement counselling. In the APS [Australian Psychological Society] Sydney branch, 350 psychologists enrolled to learn about bereavement because it's not part of the curriculum* (Bereavement counsellor KI). Workers within WSLHD have sought to expand their training in various ways. For example, *when it comes to social work, I do my own training because it's my passion. Myself and one of the educators here, we've started up little grief and loss training sessions to go in induction, but it's not something that had already exist[ed] much to my horror* (Hindi psychologist KI).

In addition to developing expertise in grief and bereavement, existing experienced counsellors also need to be appropriately trained for cultural safety. Cultural sensitivity in the counselling context includes understanding ways of providing support that are not based on Western diagnostic systems. The main resource used in diagnosing disorders related to grief and bereavement is the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM). Although the DSM is often contested in the Western context, its use in some cultural contexts is highly problematic. For example, a key informant reported instances of migrants asking for advice from their elders in ways that would be considered signs of pathology in Australia: *they will meet the complete DSM diagnostic criteria for dependent personality disorder. In their community, they're considered a wonderful citizen, a family member with a great future* (Bereavement counsellor KI).

Across LHD services, there is a need to be responsive to different cultural needs and timeframes for grief and bereavement counselling. The issue of how and when to offer help with grieving at end-of-life is often difficult. It is hard to know when people will be open to reading letters or brochures or receiving phone calls, and for some CaLD communities there are specific timeframes around grieving that should be considered alongside 'practice as usual' (see *Differences in response to bereavement*, Theme 1). Having a culturally informed response that can be more comprehensive is needed within the existing supportive and palliative care space. However, there has been a move away from cultural assessment with the move to electronic medical record (EMR) databases such that cultural information is no longer available.

Appropriate and informal spaces for bereavement support

Location was also an important consideration when it comes to accessing bereavement services. Entering the space, or being proximal to the space, where they have lost a loved one may be too confronting for someone seeking bereavement support. Too much visibility can also be a problem if people do not want to be seen entering the bereavement service for fear of how they might be perceived by others within their community. Therefore, locating bereavement services in spaces that are not in the hospital, or are more 'unassuming', can be helpful: *...the flexibility in being able to provide a responsive service I think is really key. And it needs to not sit in the monolith on the hill. It needs to be in the community, it needs to be in the community hall* (Grief and bereavement social worker KI).

There is a need to extend existing bereavement services in the LHD, or to investigate more informal spaces where bereavement work can be done. Creating bereavement groups to share stories and to talk about loss is a potentially powerful alternative to existing models of counselling and bereavement support (Breen et al., 2022; Aoun, 2020) that could work well in some cultural contexts.

Above all, consulting with the communities to determine their needs is an important step: *...some community space with like – I'm just thinking for Aboriginal communities having something outdoors or it could be someone, like an elder running it, or something like that, really consulting them to see who would be best* (Bereavement counsellor palliative care KI).

Drop-in centres for people to go to when they are grieving that offer a non-judgmental and culturally safe space to talk about grief, or simply share stories could be based on successful models in other contexts: *it needs to be word of mouth and they need to be [non] judgmental...somewhere people can go – give them a cuppa...make people feel comfortable. ... [a place] the community knows about... and they know that they can go there if things are not going well... could be just that they're not coping* (Community nurse for Aboriginal people KI). Drawing on the UK model from St Christophers Hospice,³⁵ bereavement 'health points': *...[a place] where you could just come and have a bit of a check-in and have a chat about how you're coping with grief, and so it might be stationed for like a couple of hours at one afternoon and people would drop in and just have a cup of tea and have a little chat* (Bereavement counsellor palliative care KI).

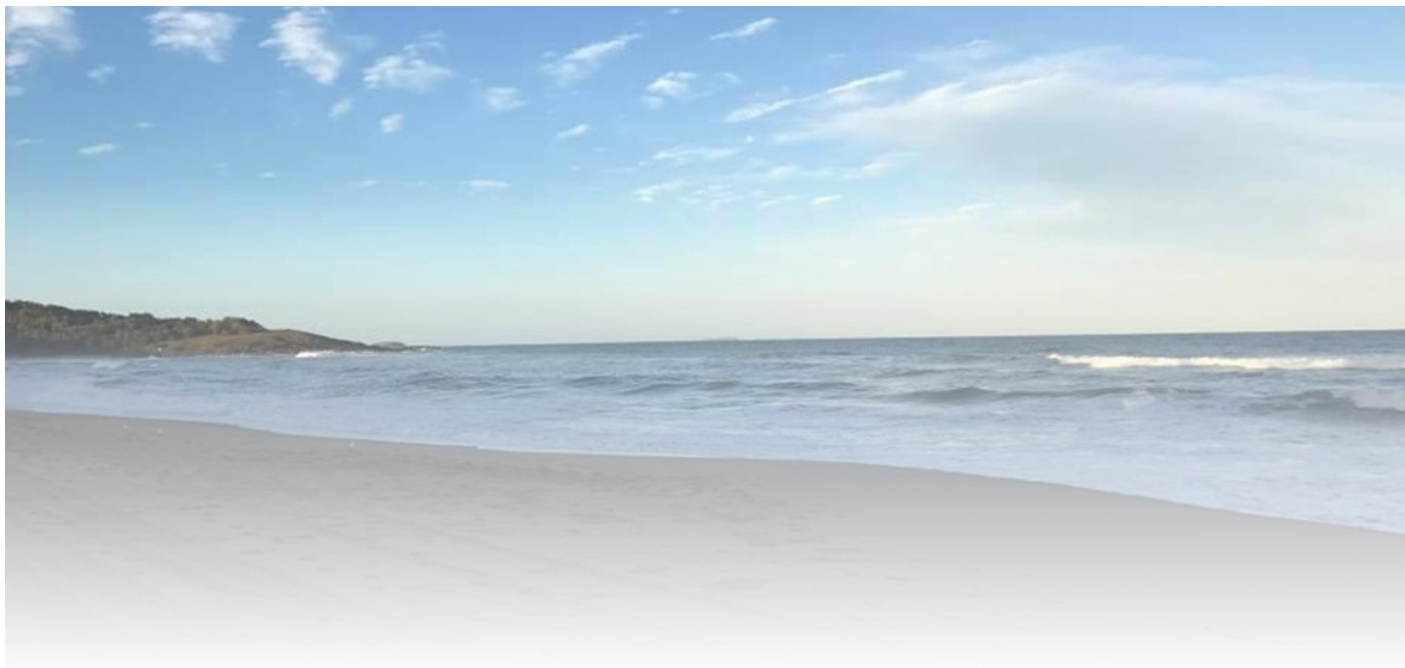
The one-on-one or group conversations made possible in 'drop-in' or 'health point' models could provide informal support that is potentially powerful in terms of culturally specific bereavement for Aboriginal and CaLD communities. This is especially the case in a context where formal culturally specific counselling might be challenging to resource. Multicultural Health could be an anchor for CaLD bereavement health points in community spaces. A key role for informal groups and drop-in centres would be connecting with a trained counsellor for people who may need specialised professional help. Ideally, centres would have access to counsellors on call and for no cost to the person in distress.

Concluding comments

Theme 6 identifies ways in which existing health services in the community could be adapted or extended to provide end-of-life or bereavement support for Aboriginal and CaLD communities. These services can capitalise on their visible presence and accessibility and are not as daunting as public hospitals. The adaptations or extensions involve increasing cultural capacity or increasing capacity in end-of-life or bereavement care; both in some cases. Services located within the community also have greater opportunity for two-way learning as service providers can absorb cultural perspectives while they provide their expertise. Community health centres, GP surgeries, Silverchain home-based palliative care, aged care facilities, Multicultural Health, bereavement support and counselling, and community centres more generally, are all potential sites for developing culturally focused end-of-life services. Bereavement support was also found to be an area that needs significant investment due to the lack of Aboriginal and CaLD counsellors, the expense of private services, and, as discussed in Theme 4, the need to expand knowledge of bereavement services and their availability to and within Aboriginal and CaLD communities. Extending current services is generally a more cost-efficient option than new services however any extension of services needs to be appropriately resourced.



35 See <https://www.stchristophers.org.uk/bereavement-help-points/>



Community Feedback from Public Forums

Following identification of interim research themes, three public feedback forums were held for the research participants and other interested members of the community or service provider areas. The forums, held in October and November 2022, provided an opportunity for the interim findings to be considered and to hear the attendees' thoughts about the priority suggestions for change around end-of-life services within WSLHD. Two forums were attended predominately by CaLD communities and, where needed, translators worked with forum participants to ensure they were able to engage with discussion activities and provide their feedback on content. A further forum was held for the Aboriginal community. People's motivations for participating in the forums were diverse, including wanting to learn more about end-of-life for themselves or others close to them, having a passion for the topic, or wanting to be heard.

The forums were facilitated by members of the WSLHD Advisory Board with input from the Western Sydney University research team. They were organised around a series of discussion activities based on themes and suggestions for change drawn from the interim findings. Each theme was presented along with a range of 'options' to meet the end-of-life 'need' indicated by the theme. In small groups, arranged as much as possible along the lines of language/cultural-based representation, people discussed the content and what they would like to prioritise for end-of-life services and supports. Attendees were also invited to add further suggestions. The discussion activities are listed below and include the strongest responses/priorities. We note there were diverse perspectives within CaLD groups across forums, but the details provided below present a synthesis that highlights the main community priorities.

Discussion Activity 1 – Finding health services for end-of-life: A range of suggestions were presented for how access to health services could be made clear and better available for those from Aboriginal and CaLD backgrounds. Participants were asked to discuss and rank these in their groups.

Having *culturally specific end-of-life workers* was a highly popular option across the forums, along with the suggestion for having *culturally aware workers* who are able to understand the more specific needs of carers and those experiencing end-of-life. The idea of having a *'Care Navigator' for each patient and family to access the help they need* was also supported by many, although not so popular for Mandarin-speaking attendees. Some Hindi-speaking attendees suggested a Care Navigator could also have some cultural, spiritual, and religious awareness. Also valued across the forums was the idea of having *help from the same health workers/ community carers each visit*, indicating that a continuity of care, and culturally specific care, was a felt priority in general and useful for finding and understanding health services for end-of-life.

Other suggestions from the research included: moving from 'patient as customer' to care for the whole family; all health and community services for one patient and family recorded in the same place; early referral to palliative and supportive care; a trained volunteer to support the patient and family throughout, including bereavement; and regular meetings of health and service providers and community. Although there was general support for these ideas they were not as high a priority.

Discussion Activity 2 – Reaching out to people in their bereavement: Although grief can be experienced at any point in the end-of-life journey, this activity focused on bereavement and how communities might feel best supported by WSLHD and community services following loss of a loved one. Four main suggestions were presented: people told about grief and bereavement support well before expected death; contact after death via personal letters, brochures in language, phone calls, invitation to an annual memorial, anniversary cards; contact from a familiar health worker or volunteer; and availability of informal community drop-in centres.

There was a mixed response across the forums, but one of the highest priorities was that *people are told about grief and bereavement support well before expected death*. This was especially relevant for the CaLD communities excepting those from Arabic speaking communities, where speaking about death before it happens may not be culturally appropriate. From the Aboriginal community, bereavement constitutes Sorry Business and it should be at the individual's choice as to how their status might be shared, and therefore how grief and bereavement support might follow.

Receiving *personal letters, brochures in language, phone calls, invitation to an annual memorial, anniversary cards* after death was favoured by attendees from Arabic speaking communities. Mandarin-speaking participants noted that doing this without knowledge of specific mourning periods could open feelings of sadness and loss. Bereavement follow-up could also acknowledge rituals after death that are important to those in the Aboriginal community. Suggestions included memorial services (at the palliative care space or independently), annual memorials and smoking ceremonies facilitated on Country and open to Aboriginal and non-Aboriginal peoples.

Having *contact from a familiar health worker or volunteer* was considered important by many, as a way of providing comfort and recognition of loss. The suggestion for *informal drop-in centres in the community* was appreciated by many Mandarin-speaking attendees and, along with Aboriginal participants, was viewed as an opportunity to find support but also access necessary health checks. Informal drop-in centres could also work well for those who feel isolated in their grief.

Discussion Activity 3 – Improving physical spaces for end-of-life care: This discussion focused on a number of explicit suggestions that were common across the four cultural groups participating in the research. These included: art and decoration to make people feel welcome; a place with its own entrance to easily come and go; access to outside areas; kitchen facilities for preparing appropriate food; private rooms to decorate and have rituals; sufficient space for large numbers of visitors; and viewing rooms to allow time to visit the deceased. Due to time constraints, the activity was included in only one forum, so the responses articulated below are from Aboriginal attendees. They provide clear priorities and suggestions for space in the palliative care environment.

Personalising rooms with paintings, artefacts, music and photos was valued, and *artwork* could be placed on the ceiling of the room, representing a legacy of those who have been through the dying process before. Also prioritised was the critical point (strongly reflected in the research) of being able to *accommodate large families* and provide spaces for their recess during the visiting and dying process. Another priority was having a *separate space for food preparation*, as this could both personalise the experience of being able to bring your own food, or simply offer refreshments. The idea of a *separate entrance* could include private access to the palliative care unit and a place to shower. Having *access to outside areas* was a clear priority and could include a space for quiet drumming, smoking ceremonies or yarning circles; and 'breathing space', an opportunity to be removed from the hospital setting momentarily. *Viewing rooms* should ensure that the person is not moved from where they have died. End-of-life care needs to include help with relevant paperwork and referral to appropriate support for broader needs relating to payments and housing.

Discussion Activity 4 – Learning about supportive and palliative care and bereavement services: This activity considered the means and methods through which community members might learn about supportive and palliative care and bereavement services in a culturally sensitive and accessible way. Suggestions presented included: events organized for the general public such as Dying to Know Day; culturally specific events possibly led by community leaders; culturally diverse community arts events; Multicultural Health or Aboriginal Health services workshops; through general workshops such as 'Advance Care Planning' or 'helping carers in the community'; brochures in language developed with communities for appropriate images and content; in person from any health professional who knows about these services; and only when the information is needed for someone close.

Overall, personal contact and trust was a priority source and opportunity for learning about available services, with people needing a connection with someone they can trust in order to learn about existing services. The most popular option was to learn about services *in person from a GP or someone people know well*. GPs tend to be the first point of contact in the end-of-life process and are ideal advisors if a trusting relationship already exists. However, GPs who are familiar with, or part of, the communities they work within may also avoid significant topics when these are also culturally sensitive. For some Aboriginal attendees, an Elder in the community could also be a strong source of knowledge for learning about services; or others such as a specialist or family GP, an Aboriginal Liaison Officer (ALO) from the hospital, a mentor in the community, or close family or friends.

Having *brochures in language* was considered a positive resource by many of the Mandarin-speaking participants as well as those from the Aboriginal community where such materials could be distributed through events, for example, NAIDOC week, or through different media formats. Hindi-speaking participants mentioned that health literacy and people's understanding of bereavement and palliative care should be properly considered in compiling and distributing such material, and again emphasised trust with the service, person, or provider. *Multicultural Health or Aboriginal Health Services workshops* were also considered an effective resource across forum participants. Hindi-speaking participants noted the importance of making use of existing community-based services and clubs for supporting learning about end-of-life, and relevant resources, supports and pathways. The strong community-based networks and spaces in communities could be well-utilised for such purposes.

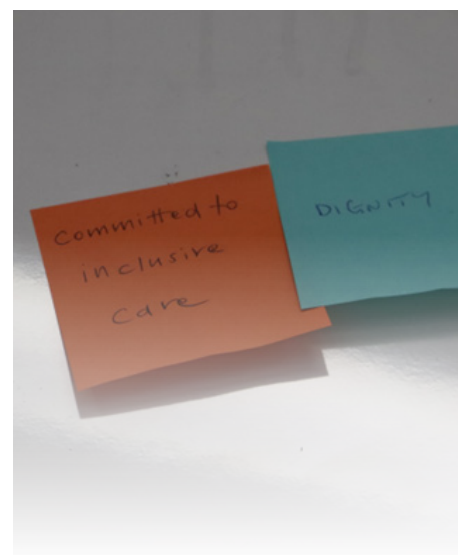
Discussion Activity 5 – Resources for communities: Options presented for consideration included two-way education of interpreters and service providers; culturally appropriate translations of information/brochures; compulsory cultural awareness training in all health services; consulting with communities on how to talk about end-of-life; and CaLD-friendly online systems.

The highest priority from attendees was *consulting with communities on how to talk about end-of-life*, reinforcing the importance of community consultation and input on how best to approach end-of-life support and literacy. Arabic-speaking participants noted this approach can help tailor training that responds to different communities' needs, preparing resources accordingly. Consultation is also important for identifying diversity within the community and learning about appropriate topics for conversation (for example, participants advised one does not talk about organ donation within Islamic communities). The Hindi-speaking participants suggested consultation could combine with short education sessions involving community educators. However, it was clearly communicated that not everyone is in agreement on this issue, and that certain generations will not talk about death.

The suggestion for having *compulsory cultural awareness training in all health services* was also very well supported. As one of the Hindi-speaking groups commented, 'cultural awareness is everyone's business!'. Support for this as a priority was also evident from Arabic and Mandarin-speaking attendees, with the latter noting that compulsory cultural awareness training can show respect to CaLD people. Further, it can deliver better patient care and support to the family; facilitate trust and rapport; and can make the delivery of bad news easier for families or those close to the person with a life limiting illness or entering palliative care. Compulsory awareness training can also intersect with *culturally appropriate information and brochures* provided to loved ones and carers; and likewise with *culturally appropriate online systems* for accessing information about end-of-life care, services, and next steps. Forum attendees suggested that cultural awareness training should not necessarily be located within the palliative care space itself but should extend across services that are relevant to end-of-life and communications.

Concluding comments

The feedback from these forums supported the research findings but added additional suggestions and insights into community priorities. Participants here, and in the research, have made extremely valuable contributions to our understanding of diverse communities' needs at end-of-life. They have underscored the importance of this research and the potential impact for their communities. Their desire to 'move beyond conversations to see actual change happen' is at the core of the recommendations made below.



Recommendations

The findings from this research provide clear community-led evidence of what is needed to secure culturally safe end-of-life care. Foundational here, is the acknowledgment that dying is a socially significant event and end-of-life care is a relational experience. These principles underpin the need for trusted therapeutic relationships in a framework of continuity of care. Health services need to strive to deliver continuity of care and case management to support trust within sustained therapeutic relationships between clinicians and patients and their families. Below we propose eight recommendations for incorporating these findings and principles into policy development, service models and service delivery across formal, clinical and community settings within WSLHD. Together, these recommendations support service providers and clinicians to deliver end-of-life and bereavement services that are embedded in trusted relationships, continuity of care and cultural safety.

Recommendation 1: More culturally specific supportive and palliative care workers

We recommend more culturally specific supportive and palliative care workers. The position of Senior Aboriginal Supportive & Palliative Care Worker was initiated during this project and feedback from the participants who knew about the position was extremely positive. It is widely recognised that that more positions are needed to help other cultural groups. A key role of the culture-specific workers is to bridge silos so people at end-of-life, their carers, and families all have the same contact throughout the end-of-life journey, regardless of their illness, the hospital department they are admitted to, the home care they are receiving, or their funeral or bereavement needs. We recommend that:

- More Supportive and Palliative Care workers be appointed to cover at least the most populous cultures in a region.
- The positions be defined in terms of language/cultural group and location (rather than disease type or Health Unit) so each culture-specific worker can become expert in the local services not only of NSW Health but also other government departments, religious and community organisations, and relevant businesses such as funeral directors.
- These positions should be able to advise where culturally inappropriate interactions occur in all health units within the hospital and in community services and tactfully show more appropriate styles of interaction.
- The job descriptions should be extended to include after death needs such as funeral requirements, guidance for Aboriginal people on returning to Country or CaLD people returning to country of origin, and bereavement follow-up.
- For Aboriginal patients it is important that the Aboriginal Liaison Officers connect with the Aboriginal Supportive and Palliative Care workers.

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

We recommend the WSLHD establish a dedicated unit to bridge the silos within hospitals and link hospital-based services with community health services such as home-based palliative care, GPs, and relevant community and cultural organisations. Patients and families would be connected to all their needs.

The palliative and end-of-life resource centre would:

- Be the place patients and carers can call for information about end-of-life services. It would be the one phone number that they need to access all support.
- Track patients and carers in the same records system as they move in and out of hospital and after the death. Thus, all the service providers for each client can know how care is progressing.
- Have the information to put together teams – e.g., social worker/community nurse/care navigator or culturally specific palliative care worker; ideally including someone (who might be a volunteer) of the same cultural/linguistic background as the patient. Hopefully patients and carers could get to know their small team well enough to develop a trusting relationship.
- Record language and cultural background if the patient wishes.
- Include bereavement follow up by a health worker with an existing relationship to check for extreme or complex grief.
- Maintain a data base of hospital staff and other health workers with particular language or cultural backgrounds who have said they are willing to help with cultural explanations or interpreting when the language is not covered by the interpreting service or interpreters are not available.
- Keep a list of community contacts (e.g., religious leaders, funeral directors, community groups/leaders, death doulas) by language and cultural group. Also, details of carer support organisations and services providing help with funeral costs. This would centralise existing contact lists.
- Be open to enquiries from GPs and other services.
- Create 'communities of practice'. The end-of-life resource centre could establish and facilitate groups of representatives of local services and community groups for ongoing improvement in end-of-life and bereavement support. They could work with communities to advocate for policy to mandate cultural responsiveness training or culturally responsive practice training in community settings, human service organisations, and general practices, especially those who work among multicultural and refugee communities.

Recommendation 3: Extend the role of volunteers

We recommend WSLHD employs one full-time manager in each hospital to coordinate and supervise a large group of culturally and linguistically diverse (CaLD) palliative care volunteers. They often develop relationships of trust with patients and families and work across the silos within and beyond the hospital. These volunteers could, with more training, extend their support into the bereavement period and alert counsellors to any concerns about extended or complex grief. However, some migrants do not understand the concept of trained and supervised volunteers and are therefore reticent to trust their help. Community awareness is therefore needed.

Recommendation 4: Utilise existing educational programs and organisations

We recommend culturally appropriate educational and awareness raising programs for health workers, for communities, and other programs specifically for carers:

For health professionals

Two types of information are needed for health workers: information about recognising and understanding end-of-life with information about relevant services; and information about the needs and services for Aboriginal and culturally and linguistically diverse (CaLD) communities. Ideally, they would then receive education about how these areas intersect.

There are several organisations that provide relevant education and we recommend liaising with the existing pool of expertise and resources rather than trying to introduce new programs. However, it needs to be clear whose responsibility it would be to liaise with these organisations and how staff might engage. For example, would cultural awareness training be mandatory like Indigenous awareness training? How could non-mandatory training be supported?

- Promotion of existing training programs e.g., Partners in Culturally Appropriate Care (PICAC). The PICAC program is a national initiative which aims to improve service providers culturally inclusivity. It provides training to service providers and is building a collaboration with *Program of Experience in the Palliative Approach* (PEPA). PICAC audiences include allied health teams, doctors, (general) managers, and frontline workers, mainly in the residential aged care facilities. PEPA provides education but also placements in PCUs.
- Transcultural Mental Health provide education for both professionals and communities. They offer education and training that aim to assist service providers to understand and address the mental health needs of CaLD populations. Education and training are tailored to fit the needs of staff in a range of settings including hospitals, and in the community and other relevant services. They have a large repository of information sheets in a wide range of languages, including the grief and loss needs of children.
- *Closing the Gap* is a Federal Government program providing subsidies on PBS medicines for Aboriginal or Torres Strait Islander people at risk of missing out on their medications. Those who would normally pay full price, receive PBS medicines at the concession price of \$7.30. Those with a concession card get them for free. However, they need to be registered by either a PBS prescriber or an Aboriginal or Torres Strait Islander Health Practitioner registered with both the Australian Health Practitioner Regulation Agency (AHPRA) and Medicare. All GPs need to be included in this program, perhaps with some professional development, so Aboriginal people do not need to find another doctor just to get the subsidy.
- Grief Australia provides a range of training for counsellors. This includes workshops, self-paced training, and customised training for organisations, as well as downloadable webinars (including Indigenous Healing, and Working with Migrants and Refugees Experiencing Grief).
- Western Sydney Public Health Network provides information to GPs and attends a number of cross-agency meetings that all provide opportunities for increasing awareness of cultural needs around end-of-life (for example, Blacktown-Mandurah and SydWest, Refugee Health Coalition, Asylum-seeker agencies, Blacktown Council's Community Resource Network, other local Councils, and Disability forums).

However, such formal workshops and training are not enough. There needs to be some follow-up to make sure the training is understood with cultural humility and translated into practice.

For communities

Multicultural Health already provide community health education in a number of languages spoken by local communities. Although end-of-life and bereavement are not popular topics, they could be included by extending current programs such as Advance Care Directives or Navigating the Health System.

- Among their services, Grief Australia has online fact sheets for those experiencing grief in many forms. However, none are focused specifically on the needs of Aboriginal or CaLD people. Fact sheets are only available in English, so a more diverse range of culturally engaging resources are needed.
- The Cancer Council has booklets, factsheets, and videos in eleven community languages and the phone number of an interpreting service. The sheets appear to be direct translations of the English versions with no culturally appropriate images. The factsheets for Aboriginal and Torres Strait islander people were developed in conjunction with an Indigenous Consultation Group and have appropriate images.
- For Aboriginal people Tribal Warrior can provide training.³⁶

36 <https://tribalwarrior.org/contact/>

For carers

- Carers NSW have Videos in English on Managing Feelings, Taking Care of yourself; Practical Tips for Carers; and Bereavement plus Fact Sheets related to Palliative Care and bereavement in English, Chinese, Arabic, Hindi and Greek,³⁷ and Podcast series in English, Chinese, Arabic and Hindi.³⁸
- COTA, Council on the Aged, has a Peer Support Program, which includes CaLD peer supporters, and a webinar series includes Ageing as an Aboriginal and Torres Strait islander person.³⁹
- Red Dust Healing can help support Aboriginal people with grief and bereavement.⁴⁰

Recommendation 5: Develop culturally appropriate end-of-life communications

We recommend working with communities to create culturally safe resources for communities, carers, and people at end-of-life. As described under Recommendation 4, there are numerous relevant fact sheets, brochures, and webinars available, some in multiple languages, but very few have been developed with a concern for how they might be received by Aboriginal or CaLD communities. Our findings suggest that these communications will not be effective without addressing culture. All communications need to be:

- Culturally safe in language and images (not just a translation of the English text).
- Acknowledging diversity within culture so they are not used as simple recipes.
- Available in varied places and times in hard copy and online because it is difficult to know when people are ready to absorb this information.
- Linked to more detailed information, videos, and books.

Collectively the resources need to:

- Provide information about hospital, wider health and community services, and private services.
- Address the whole end-of-life journey including bereavement.
- Be complemented with in-language broadcasts, Facebook, and other social media.

Given the need for trusted relationships in the end-of-life journey for patients and carers, this material is likely to be most effective when it is given by a service provider they already know and trust. We recommend that it is used as a supplement rather than a substitute for personal guidance.

Recommendation 6: Expand suitable spaces for palliative care

We recommend an expansion of the number of suitable spaces for palliative care. For care to be palliative it needs to reduce the stress for people at end-of-life, their carers and families. Respondents spoke positively of the dedicated PCU at Mt Druitt. However, in many cases hospitals can be alienating and uninviting places under any circumstances. Our results showed that CaLD and Aboriginal people were very uncomfortable engaging with end-of-life but also that palliative care units do have more flexibility to accommodate the comfort of their patients and needs of families and carers. Further, given the geographical spread of WSLHD, the hospitals are not easy to access to many people.

Recommendation 6a: In all hospitals there need to be dedicated palliative care spaces that invite trust and comfort for diverse cultural groups such as through artwork, spaces for large gatherings, no limits on visiting hours, a prayer room, a kitchen for preparing appropriate food, a viewing room where people can sit with the deceased, and outside space for Aboriginal gatherings and rituals.

Recommendation 6b: Hospice type accommodation away from the hospital could be more attractive to people at end-of-life and families. Increasingly people are staying at home until the very last phase of the end-of-life journey so many aged care facilities that cater for high needs clients have people who really need hospice or palliative care. Palliative care or hospice units in aged care facilities could address this problem and make palliative care more widely available at a variety of more convenient locations. Units in diverse locations could more easily have staff and facilities tailored to local populations. These units could have guidance and visiting specialist doctors from the hospital-based unit.

Recommendation 6c: Day clinics, probably established in larger medical centres, are another way that people can access palliative support away from the hospital and closer to their homes when hospital admission is not necessary.

Recommendation 7: Increase bereavement support

We recommend increasing the availability of low-cost bereavement support; both the number of counsellors available and the ease of accessing them. Many people have sufficient support from friends and family, but others do need expert help. The difficulty is reaching out to bereaved people to identify those who are not coping. Difficulties with grief are more likely to occur when there is a history of trauma which can re-emerge from another loss. Because many Aboriginal people and migrants have faced discrimination and abuse and many migrants, even those that are not refugees, have experienced conflict, these groups may be at greater risk of complex grief than the general population. Further, our results found that many CaLD people are not familiar with the concept of

37 <https://www.carersnsw.org.au/about-caring/who-are-carers/caring-for-someone-living-with-a-chronic-condition-or-terminal-illness>

38 <https://www.carersnsw.org.au/about-caring/who-are-carers/diverse-carers/in-our-own-voices>

39 <https://www.cotansw.com.au/get-involved/events/event/2023-webinar-program/>

40 www.thereddust.com/

counselling and therefore not likely to seek it out or follow-up on a recommendation. Also, respondents working within counselling services reported a lack of staff diversity and long waiting times for expert help. The cost of private counselling is also a barrier to many in Western Sydney.

Recommendation 7a: Employ more grief and bereavement counsellors with an understanding of culturally diverse needs. This is not an easy solution as there are too few counsellors with the necessary level of expertise in both complex grief and the needs of Aboriginal and migrant communities. Active recruiting of diverse students into the field is necessary but will take some years to address the community need. Training existing grief and bereavement counsellors in the needs of Aboriginal and migrant communities would be more direct. Creating government funded positions for grief counsellors with the requirement that they gain knowledge and skills in culturally diverse needs should be created. But the issues of understanding the nature of the service and trust would need to be addressed, so working closely with the culturally specific end-of-life workers and other community representatives would be necessary.

Recommendation 7b: Establish bereavement support drop-in centres which could be located in community spaces where people could come in just to talk and ‘have a cuppa’. Staff and volunteers from diverse backgrounds common to that local area would be trained to provide basic support but also to look out for signs that a person needs more expert help. They would then liaise with the culturally specific end-of-life workers and specialist grief and bereavement counsellors.

Recommendation 8: Take a public health approach to create compassionate communities

We recommend a public health approach to end-of-life and bereavement to build capacity 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.

- There are National and international days such as World Hospice and Palliative Care Day and Dying to Know Day when a wide variety of community events encourage people to talk about their experiences. But to date they have not had a clear CaLD or Aboriginal presence. Although many people from diverse cultures might avoid the topic, it would be possible to recruit small groups, perhaps from younger generations, and start to set some new cultural norms about talking about death and dying.
- Current diversity celebrations e.g., Harmony Day; NAIDOC week already exist and present opportunities for raising end-of-life awareness.
- Improving the Medicare model for bereavement and grief. The current model is described as prescriptive with insufficient (funded) sessions available (six sessions with a possible four additional ones) especially for addressing complex or complicated grief. We recommend more types of treatment codes to provide longer treatment and more flexibility.
- Increased expert training in bereavement. Although Recommendation 4 identified some current training opportunities, there is no tertiary education specifically in bereavement counselling. As a society we need to develop that expertise and have it widely available to help the many people with severe distress who need expert care and ensure that training addresses the needs of the complete diversity of our population

Concluding comments

These eight recommendation areas draw from a strong body of research and deliver informed and meaningful suggestions for culturally safe and engaging end-of-life care within WSLHD. They are practical and achievable and follow WSLHD’s palliative and supportive care commitment to ‘moving beyond conversations to see actual change happen’. Already, during the period of the research, additional staff appointments have been made in Aboriginal Supportive and Palliative Care and in Bereavement Counselling. The key findings of the research have pointed to a compassionate communities model that helps to orient the actions and strategies taken by services to break down the silos in existing palliative and bereavement care provisions. These strategies, in turn, can help to establish spaces of trust and standards of care that are culturally sensitive and appropriate, providing for better quality end-of-life care for patients, carers, and all. Recognising and investing in the cultural needs of diverse and marginalised communities is an important step towards minimising trauma and strengthening trust in the health system. It affirms the social and cultural, rather than medical, nature of death, dying, and bereavement which are, indeed, everybody’s business.



Conclusion

This three-year research project operationalised an innovative mixed-method design informed by the principles of cultural humility to understand the end-of-life and bereavement needs of Aboriginal and CaLD communities in Western Sydney. The research was designed to directly engage with these communities, giving voice to those who are often marginalised, vulnerable or disadvantaged, as well as service providers who bring direct knowledge and experience of working with communities. The research aimed to understand the different cultural needs relating to death and dying of Aboriginal and migrant populations in Western Sydney, and how end-of-life care can be provided in culturally safe ways which can, in turn, inform policies that shape palliative care and bereavement service delivery in WSLHD and beyond.

People from culturally diverse communities are among the most disadvantaged and marginalised in health systems and specific concerns about the palliative care needs of migrants and Indigenous peoples, stemming from the traditional Western origins of holistic palliative care, have been raised internationally (Nelson et al., 2021; Barwise et al., 2023). In Australia, national data indicates Aboriginal and CaLD Australians are underserved (Department of Health, 2018), yet there is insufficient data available to guide local state-based health districts in service delivery (Productivity Commission, 2017; Australian Healthcare Associates, 2019). To address this gap, the methodologies used in this research placed the voices of research participants at the centre of knowledge production. These voices included both service-users and service providers from the Aboriginal community and from Arabic, Hindi and Mandarin speaking backgrounds within WSLHD.

The death literacy survey provided some useful insights. The fact that Years in Australia was clearly the most dominant demographic predictor of the Death Literacy Index (DLI) score suggests that a key factor for acquiring death literacy is being familiar with Australian culture and end-of-life systems. Further, the power of discussions of death and dying to develop death literacy is particularly important given that everyone can be part of such conversations, whereas not everyone has the opportunity to have the end-of-life experiences which help to expand death literacy (such as being present at the time of a death or providing care for someone at end-of-life). However, the qualitative results showed that such conversations or discussions need to be held in culturally safe ways, ideally within a relationship of trust.

Our qualitative findings underscore the crucial importance of direct consultation with communities, engaging with cultural humility, and taking time for strong relationships of trust to develop. Participants with direct experience of caring at end-of-life as well as key informants working in the end-of-life space were asked about the cultural aspects of end-of-life and bereavement as well as the supports and services available and how these might need to change to be culturally appropriate. The research findings show that people have not only identified and communicated their diverse cultural needs at end-of-life but have also provided clear suggestions for improving the services that impact their experience with the health system and its 'silos', both those within hospitals and those which divide hospital care from community based services.

The participant's contributions, stories and insights provided rich data that has been distilled into six main themes. These show how important cultural practices and rituals are to people at end-of-life and that providing space for them is crucial to cultural safety in service contexts. So too, relational trust and the need for community input on the services that affect them. There is also a need for greater knowledge and understanding in the end-of-life space through two-way exchanges between communities and service providers. Finally, there are important ways that existing services, both within hospitals and out in the community, can facilitate cultural safety and ways of increasing the availability of culturally appropriate end-of-life and bereavement services in the community.

The findings of this research provide clear community-led evidence of what is needed to secure culturally safe end-of-life care. This gives rise to a number of key recommendations that are both practical and achievable, although also requiring a committed investment, both in terms of costs and planning for implementation. They provide a pathway for incorporating the findings into policy development, service models and service delivery across formal, clinical and community settings to support service providers and clinicians to deliver end-of-life and bereavement services that are embedded in trusted relationships, continuity of care and cultural safety. The recommendations include (1) creating positions for more culturally specific supportive and palliative care workers; (2) establishing a palliative and end-of-life resource centre; (3) extending the role of volunteers; (4) utilising existing educational programs and organisations; (5) developing culturally appropriate end-of-life communications; (6) expanding suitable spaces for palliative care; (7) increasing bereavement support; and (8) taking a public health approach to create compassionate communities.

This research supports what we know to be true from our own lives – that dying, death and being bereaved are not so much a series of medical processes and incidents but profound socially and culturally informed human experiences. Holistic care needs to reflect this complexity. It is incumbent upon all providers of palliative services, end-of-life care, and bereavement support to do so in partnership with their communities. This care needs to be delivered from a position of cultural humility and with a capacity for deep listening, alongside the preparedness for flexibility in delivery of safe and high-quality care so as to best meet the needs of each person as well as their family and carers.

Future directions

The findings and recommendations stemming from the service-user and service provider perspectives in this research project prompt clear areas of further investigation. The first emerges from the constraints of the current research which was limited to four cultural groups. Expanding the study to include other less populace cultural groups in WSLHD would expand the understanding of cultural needs and identify other areas where cultural safety could be integrated into service delivery. Second, the current research needs to be built into a comparative study in other LHDs and states, including with a focus on traditionally disadvantaged regional and remote areas, to explore if and how the findings of this study resonate nationally. A third, related, area for further inquiry is Voluntary Assisted Dying (VAD) and the understandings of this in cultural communities, in relation to palliative care, and what is needed to have a sense of safety in the health system with VAD available.



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Appendices

Appendix 1: WSLHD snapshot

Appendix 2: Interview, focus group, and photovoice schedules

- Key informant interview schedule: phase 1 - palliative care

- Key informant interview schedule: phase 2 – bereavement

- Focus group schedule – Aboriginal group

- Focus group schedule – CaLD groups

- Photovoice schedules – Aboriginal and CaLD participants

Appendix 3: Death literacy survey results summary

Appendix 4: Cultural advisors and knowledge holders

Available on request:

Participant information and consent forms for focus groups in English, Arabic, Hindi, and Mandarin

Participant information and consent forms for photovoice in English, Arabic, Hindi, and Mandarin

Participant information and consent forms for key informants in English

Recruitment flyer/s [English, also distributed in Arabic, Hindi, Mandarin]

Appendix 1: Snapshot of Western Sydney Local Health District (WSLHD)

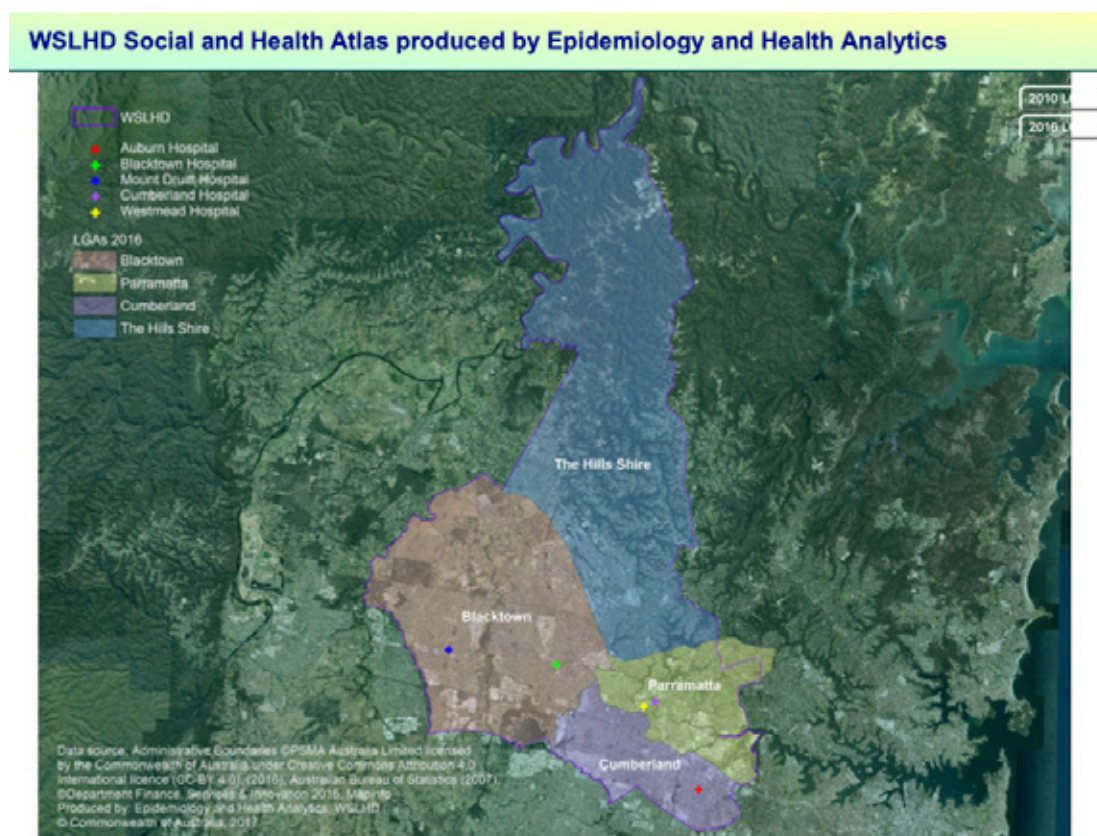


Figure A1.1 LGAs and hospitals in WSLHD

Source: www.wslhd.health.nsw.gov.au/SocialHealthAtlas/

Western Sydney Local Health District encompasses the Local Government Areas (LGAs) of the Hills Shire, Parramatta, Blacktown, and Cumberland (See Figure A1.1). The most recent population census (ABS, 2021) shows that 13.4% of the NSW residents live in WSLHD. It is a growing region and the proportion increased from 12.5% in 2016. Reflecting the inward migration to the region, the population has a lower median age (35 years) than the State (39 years). The Western Sydney region is one of the most culturally and linguistically diverse (CaLD) populations in Australia. Over 50% (51.5%) speak a language other than English at home, compared to the NSW average of 30% (ABS, 2021).

Table A1.1 shows marked socio-economic differences between more affluent areas such as the Hills Shire which have higher weekly household income and larger homes per person to more economically disadvantaged areas like Cumberland. Overall WSLHD has a lower weekly household income and higher density than the NSW averages.

Table A1.1 also shows other variations amongst the LGAs which reflect their cultural character:

- In The Hills Shire: After Australian or English, Chinese and Indian were the most common ancestries. Mandarin first; Hindi third; Arabic fifth most common language other than English spoken at home. This LGA had the highest household income, older residents (median 38 years), and relatively large homes averaging 3.8 bedrooms reflecting its largely established leafy suburban nature.
- In Parramatta LGA: Chinese was the most common ancestry then English Australian and Indian fourth. Other than English Mandarin was the most common language spoken at home: Hindi fourth and Arabic fifth. Parramatta is the most urban of the LGAs with the smallest homes averaging 2.7 bedrooms.
- In Blacktown LGA the third most common ancestry after Australian and English was Indian, and Hindi was the third most common language spoken at home with Arabic fifth and Mandarin eighth. Blacktown also has a relatively high proportion of Indigenous people, just slightly lower than the NSW percent.
- In Cumberland LGA the most common ancestries were Chinese, then Lebanese who are often Arabic speakers. Indian was fifth after Australian and English. Arabic was most common language other than English. Mandarin was second and Hindi eighth.

Table A1.1 Demographic statistics for LGAs and total WSLHD compared to the NSW population.

Location	The Hills		Parramatta		Blacktown		Cumberland		NSW		WSLHD	
	No	%	No	%	No	%	No	%	No	%	No	%
Population	192509		256729		396776		235439		8072163		1081453	
Indigenous	1207	0.6	2079	0.8	11812	3.0	1516	0.6	278043	3.4	16614	1.5
Median Age	38		35		34		34		39		35	
Female	97602	50.7	128108	49.9	198785	50.1	113952	48.4	4084514	50.6	538447	49.8
Ancestry												
Chinese	28141	14.7	57353	22.3	17664	4.5	29748	12.6	581641	7.2	132906	12.3
Indian	17432	9.1	28867	11.2	53712	13.5	20417	8.7	261103	3.2	120428	11.1
Lebanese	847	2.3	9091	3.5	5951	1.5	28014	11.9	177587	2.2	43903	4.1
Language at home												
Mandarin	15678	8.2	31823	12.4	7083	1.8	15777	6.7	270685	3.4	70361	6.5
Hindi	5418	2.8	9590	3.7	17429	4.4	5430	2.3	80051	1.0	37867	3.5
Arabic	3856	2.0	8311	3.2	11687	2.9	33264	14.1	227243	2.8	57118	5.3
Do not speak English at home	74379	38.8	144805	56.4	183558	46.3	154448	65.6	856911	29.5	557190	51.5
Medium household weekly income	2831		2051		2107		1678		1829		1764	
Av. bed-rooms per home	3.8		2.7		3.4		2.9		3.1		3.2	
Av. People per home	3.1		2.6		3.1		3.0		2.6		3.0	

Sources: 2021 Census data <https://abs.gov.au/census/find-census-data/quickstats/2021> and <https://profile.id.com.au/>

Appendix 2: Interview, focus group, and photovoice schedules

Interview schedules (key informants)

Key informant interview schedule (phase 1 – palliative care)

[Researchers] will conduct individual interviews with people holding expertise in palliative care and associated end-of-life services. Interviews will last for no more than 2 hours and will be held online via video conferencing, at a time convenient to the participant.

1. Introductions and consent process. Brief overview of the aims of the research and the purpose of the interviews. (5 minutes)
2. Can you briefly outline your experience and role working with CaLD or Aboriginal communities?
3. In your experience do these communities experience death, dying and caring differently to the majority population? (15 minutes)
4. In what ways is their experience different? (15 minutes)
5. What services and supports do you believe these communities find useful, and in what ways are they useful? (15 minutes)
6. What other support or services do they need and who is best suited to provide this support and/or services? (10 minutes)
7. In what ways do existing services and supports need to change in order to be more culturally safe and appropriate? (15 minutes)
8. What will it take for these changes to be achieved? (10 minutes)
9. Have you anything else you would like to say that would be helpful to this project? (10 minutes)
10. Outline of next steps in the research project. Thank you. (5 minutes)

Key informant interview schedule (phase 2 - bereavement)

[Researchers] from Western Sydney University will conduct individual interviews with people holding expertise in providing grief and bereavement support as part of palliative care and associated end-of-life services. Interviews will last for no more than 2 hours and will be held online.

1. Introductions and consent process. Brief overview of the aims of the research and the purpose of the interviews. (5 minutes)
2. Can you briefly outline your role and experience working with CaLD and/or Aboriginal communities? (5 minutes)
3. In your experience do these communities experience grief and bereavement differently to the majority population? (15 minutes)
4. In what ways are these experiences different? (15 minutes)
5. What are your observations of their experiences of more complex grief or bereavement? What contributes to this? (10 minutes)
6. In what ways do you understand people's confidence or even awareness of accessing grief and bereavement services [in these communities]? (5 minutes)
7. What services and supports do you believe these communities find useful, and in what ways are they useful? (10 minutes)
8. What other support or services do they need and who is best suited to provide this support and/or services? (10 minutes)
9. In what ways do existing services and supports need to change in order to be more culturally safe and appropriate? (20 minutes)
10. What will it take for these changes to be achieved? (10 minutes)
11. Is there anything you feel has been missed out in our discussion today, or anything else you would like to say that would be helpful to this project? (10 minutes)
12. Outline of next steps in the research project. Thank you. (5 minutes)

Focus group schedule – Aboriginal group



Dragonfly artwork by Leanne Tobin. Leanne's artwork reflects the vibrancy and transitional motions of the dragonflies as they move through their journey of life.

Yarning about end of life

Have you taken care of someone at the end of their life?

Would you like to share your experience, so that it may help our community?

1. What is your understanding of the term 'palliative care'?
2. In your culture is the place someone dies important — or less important than other rituals and customs?
3. If things got much worse and your friend did need to be admitted to hospital, are there any special customs or things that would help her or her family at this time?
4. Who might be involved in making decisions about her medical and supportive care, and about whether she needs to go to the hospital?
5. What kind of things would make being in hospital easier or better for her and her family/community?
6. What are your thoughts about prolonging life or stopping treatment?
7. What if she wanted to die at home?
8. What kind of help would be most important for her and her family?
9. Who might the family ask for help and support?
10. How important are religion and spirituality for your community at end of life?
11. Are there any special funeral rites or customs in your community?
12. What things might help or benefit the family afterwards?
13. What are the five most important things the medical and supportive care workers need to know about your cultural needs when someone in your community is dying?

If you have any questions after the discussion, please contact [Aboriginal Supportive & Palliative Care Worker]

Focus group schedule – CaLD groups

These questions can be used or adapted if people want to tell their own stories about caring and focus on the key things we want to know.

Vignette for Hindi, Arabic, and Mandarin-speaking focus groups:

We would like to imagine that you have been a long-time friend of a 61-year-old widow from your community, who lives with her daughter's family. Until recently she was very active in her community and worked as a schoolteacher. She had a heart operation eight years ago and has been receiving specialist treatment over the last ten years. But lately her condition has been getting worse. After a series of tests, she is told that her condition is extremely serious.

The aim of treatment now is to help her live as long and as comfortably as possible.

The specialist suggests that she goes to see the palliative care team at the local hospital for their help with things like pain, swelling, and indigestion.

Possible questions from the researchers:

1. What is your understanding of the term 'palliative care'?

Hospital care

2. If things got much worse and your friend did need to be admitted to hospital, are there any special customs or things that would help her or her family at this time?
3. What kind of things would make being in hospital easier or better for her and her family/community?
4. What are your thoughts about prolonging life or stopping treatment?

Dying at home

5. What if she wanted to die at home?
6. Who might be involved in making decisions about her medical and supportive care, and about whether she needs to stay in the hospital?
7. What kind of help would be most important for her and her family?
8. Who might the family ask for help and support?

Rituals and customs

9. In your culture is the place someone dies important — or less important than other rituals and customs?
10. How important are religion and spirituality for your community at end of life?
11. Are there any special funeral rites or customs in your community?
12. What things might help or benefit the family afterwards?

5 most important things

13. What are the five most important things the medical and supportive care workers need to know about your cultural needs when someone in your community is dying?

Photovoice schedules – Aboriginal and CaLD participants

In this project, we are interested in learning more about your experiences of care and caring at times of life limiting illness, death, dying and grief. In particular, what has been helpful or meaningful for you/your community and what services you have found useful or believe could be useful. As a photovoice participant, we invite you to take photos that represent this or are metaphors of this.

Telephone/email follow-up schedule:

The participants will have indicated at time of original consent whether they wish the follow up to be via telephone or email. Either way, the questions will be the same. This stage will be in a conversational style, in English. The [Research Assistant] will take field notes of the conversations:

1. Hellos and check in. How is it going?
2. Have you managed to take any photos? If yes: can you tell me what of and what that has been like? If no: have you some ideas about how you might start? Is there something you want to take a photo of but feel you can't? What needs to happen for you to get started?
3. Has it been easy for you/difficult? Tell me a bit more about that.
4. Do you think you have finished/nearly/soon? (Remind people of the process for returning the cameras and set date and place for 1:1 in-person interview).

1:1 in-person interview schedule: [NOTE: photovoice interviews were conducted online due to COVID-19]

The interviews will be conducted in English at a mutually convenient place. Interviews will last 2 hours and will be audio recorded and transcribed. They will be conducted by [a researcher].

Introductions. Renegotiating consent. Remind people it is a research project, check that they are still happy for the interview to be audio recorded. Remind them about how the photos could be used. Discuss the implications of any photos showing an identifiable person. Signing of 'use of photos' section in consent form, as applicable. Brief description of the purpose of the interview: to discuss the photos; to choose photos for the book; and to begin to develop the person's narrative/story.

Looking at the photos together over light refreshments. This stage also includes the throwing away of any photos people do not wish to be used in future.

People invited to talk about their photos. Use prompt questions for discussion, as needed:

1. What is your overall impression of the photos?
2. What stood out to you/interested you?
3. Do you think there are any connections/similarities between some of the photos?

4. What do you think the photos 'say' overall, about the needs of end of life care in your community?
5. What do they say about care/caring and about what is helpful or meaningful?
6. What do they tell us about the experience of death, dying and caring in your community and how people can be helped during these times?
7. Are there themes or an overall message?
8. What else would you like us to know about your photos?

4. Choose photos for book. Which (4) photos do you think you would like to use for the book? Which speak most clearly and powerfully about what you want to say/tell others?

5. Decide on process for written narrative. Now we need to think about writing a page or so which captures the things you want to say/your story. Shall we start doing this now? Do you want to think about it and get back to us with some ideas? Would you like us to write a draft and then send it to you?

6. To finish, agree on time frame for writing the story/narrative and clarify roles.

Note: the research questions below could be used as further prompts toward the end of the interview if needed/not already talked about - researcher to note if any such prompts are used.

1. How did you experience [name]'s final months?
2. What was the best experience you or [name] had during that time?
3. What traditions or cultural practices were important during [name]'s final months?
4. How was his/her place of death decided?
5. What health/support services were most important during [name]'s care?
6. What happened after [name]'s death?
7. What, if anything, would you change about [name]'s experience of dying?



Appendix 3: Death literacy survey results summary

In all, 203 people completed the Death Literacy Index (DLI) online survey. This WSLHD community sample consisted of 83 Mandarin speakers, 60 Hindi speakers, 36 Arabic speakers, and 24 Aboriginal respondents.

Overall means and confidence intervals for the DLI and subscales

The following two tables (A3.1 and A3.2) show the mean scores for the DLI and its subscales in comparison with other samples taken over the past four years. In the first table, WSLHD scores are compared to representative samples collected from panels consistent with the demographic profile of the four target populations. It shows that for almost all scales and subscales the community sample responding in WSLHD had higher scores than the representative samples from Brisbane South PHN, the National population, and those people from the cultures of interest who completed the National survey.

The WSLHD scores are significantly higher on almost all scales but this likely reflects the nature of the sampling process. The national representative samples are taken from panels where the respondents are paid to do a number of surveys, so they do not need to be attracted to a particular topic. In contrast the community surveys (in Table A3.2) tend to attract people interested in the topic who therefore have higher death literacy. It is interesting to note that the people from the four cultures of interest in the national sample had lower DLI scores than the general population. Brisbane South had higher scores which was mainly explained by having older respondents (a predictor of high death literacy).

Table A3.1 DLI and subscales for the WSLHD in comparison with the Australian population, subsample from the population for the 4 cultural groups, and Brisbane South population

DLI scales and subscales	WSLHD Mean (N=203)	Confidence Interval for WSLHD Lower bound	Confidence Interval for WSLHD Upper bound	2019 National mean (N=1200)	2019 National mean for the 4 cultural groups (N=145)	Brisbane South PHN population Mean (N=1200)
Factual knowledge	4.59	4.25	4.91	3.11^	2.48^	3.5^
Experiential knowing	6.52	6.21	6.83	5.93^	5.60^	6.0^
Practical	5.08	5.26	5.85	4.95^	4.12^	5.3
Talking support	6.06	5.69	6.39	5.53^	4.56^	5.9
Hands on care	5.57	4.74	5.41	4.37^	3.68^	4.6^
Community	5.50	5.17	5.82	4.36^	4.05^	4.7^
Accessing Help	5.81	5.46	6.19	4.21^	3.62^	4.4^
Community Groups	5.18	4.83	5.52	5.04	4.47^	4.9
DLI	5.54	5.33	5.79	4.70^	4.06^	4.9^

- Notes:
1. * Indicates community sample means that are statistically higher than the WSLHD sample
 2. ^ Indicates community sample means that are statistically lower than the WSLHD sample
 3. All scores ranged 0 to 10
 4. National figures are based on the 2019 DLI survey.
 5. In the WSLHD sample 30 respondents omitted answering an item of the DLI. Because they had answered almost all the questions it was reasonable to substitute their missing items with the mean for that item. In that way there were no missing values for the DLI and its subscales.

In the second Table WSLHD scores are compared to five other community samples. Three of these areas, Blue Mountains, Care Beyond Cure Tasmania and St Nicholas Hospice, had experienced compassionate communities interventions designed to increase death literacy so it is perhaps a tribute to those programs that they have higher DLI scores. South-West Sydney PHN (SWS PHN) was just beginning its intervention and like WSLHD, it has a high degree of cultural diversity. It has similar DLI scores to WSLHD.

Table A3.2 DLI and subscales for the WSLHD in comparison with community samples from SWS PHN, Brisbane South PHN, Blue Mountains, northern Tasmania, and St Nicholas Hospice UK

DLI scales and subscales	WSLHD Mean (N=203)	SWS PHN Mean (N=32)	Brisbane South PHN Mean (N=101)	Blue Mountains Mean (N=134)	St Nicholas Hospice, UK Mean (N= 106)	Care Beyond Cure, TAS Mean (N=121)
Factual knowledge	4.59	3.8^	5.7*	4.4	4.6	5.3*
Experiential knowing	6.52	7.2*	7.3*	7.7*	7.3*	7.4*
Practical	5.08	6.2*	6.5*	6.8*	6.7*	7.0*
Talking support	6.06	7.1*	7.3*	8.1*	7.5*	6.8*
Hands on care	5.57	5.2	5.8*	5.5*	5.8*	7.2*
Community	5.50	5.1	6.0*	5.9*	5.1	6.1*
Accessing Help	5.81	4.9^	6.1	6.0	5.0^	6.4*
Community Groups	5.18	5.3	5.9*	5.8*	5.1	5.7*
DLI	5.54	5.5	6.4*	6.2*	5.9*	6.5*

Notes: 1. * Indicates community sample means that are statistically higher than the WSLHD sample $p < .0005$

^ Indicates community sample means that are statistically lower than the WSLHD sample

2. All scores ranged 0 to 10

Demographic profiles of the four cultural groups

Table A3.3 shows that there were differences among the four cultural groups on the DLI with Aboriginal respondents having significantly higher scores followed by Mandarin speakers, Hindi speakers and then Arabic speakers. This pattern held for all the subscales with the exceptions of the experiential knowing scale where there were no differences among the groups and the Community scale for which Arabic speakers had higher scores than Hindi speakers.

Table A3.3 Mean scores for DLI and subscales for each cultural group

	Experiential	Factual ***	Practical ***	Talking support ***	Hands on Care ***	Community ***	Accessing help ***	Support groups ***	DLI ***
Arabic-speaking	6.40	3.53	4.95	5.30	4.60	5.16	5.13	5.19	5.01
Hindi-speaking	6.81	3.64	6.04	6.48	5.59	4.71	4.85	4.56	5.30
Mandarin-speaking	6.25	5.32	5.08	5.62	4.54	5.96	6.31	5.61	5.65
Aboriginal	6.94	5.60	7.05	7.73	6.38	6.36	7.54	5.18	6.59
Total	6.52	4.59	5.57	6.07	5.08	5.50	5.81	5.18	5.54

Notes: 1. *** $p > .0005$ indicates cultural groups are different from one another

2. All scores ranged 0 to 10

In the 2019 National survey, Age, and related variables such as being retired or widowed, having children, plus Belief in an after-life or Religious or spiritual background, were all related to the DLI. In the present WSLHD survey, these demographic variables differed among the four cultural groups. However, Cultural group was the key variable and other demographics were no longer significant when Cultural group was included in the analysis. The demographic variables which related to the DLI after Cultural group was included, were: Talking to their neighbours; Being in the workforce, Educational level, Speaking English at home and Years living in Australia.

Analysing the demographic variables together to predict DLI score

Because the demographic variables that related to the DLI are not independent of each other (e.g., people who speak English at home are likely to have lived here longer), it made sense to analyse them together to see if some variables are more dominant and account for the variance in the others. Because there were only 203 people in the sample, it was not possible to test all the interactions together so only those with p values of approximately .01 or below were chosen.

Bringing together all the demographic variables that related to DLI individually, we found that only Cultural group [$F(3,188) = 3.01$; $p = .031$], Years in Australia [$F(2,188) = 6.43$; $p = .002$], and their interaction [$F(4,188) = 2.62$; $p = .036$], were significant predictors of DLI score. Figure A3.1 shows the nature of the relationship more clearly. As expected, the Aboriginal people had been in Australia all their lives but there were significant differences among the other groups. 72% of Arabic, 42% Hindi and 8% Mandarin speakers had been here 5 years or fewer. 11% Arabic, 36% Hindi, and 40% Mandarin speakers had been here more than 15 years. Thus, in keeping with overall trends in Australian immigration, Arabic speaking respondents were most recent migrants and Mandarin speakers were the most long-standing [Chi sq (4) = 52.69; $p < .001$].

The number of years in Australia was the most powerful demographic variable for predicting DLI score [$F(2,193) = 6.82$; $p < .001$] plus there was a significant interaction (Figure A3.1) because Arabic speakers of long-standing residence had very high DLI scores, unlike those who were recent migrants. [$F(4,193) = 3.15$; $p = .016$]. Years in Australia was clearly the most dominant demographic predictor of DLI which suggests that a key factor for acquiring death literacy is being familiar with Australian culture and systems. Note: the result might have been overly influenced by the fact that all the Aboriginal respondents had been in Australia all their lives, but the same pattern of results was obtained when the Aboriginal group was omitted from the analysis.

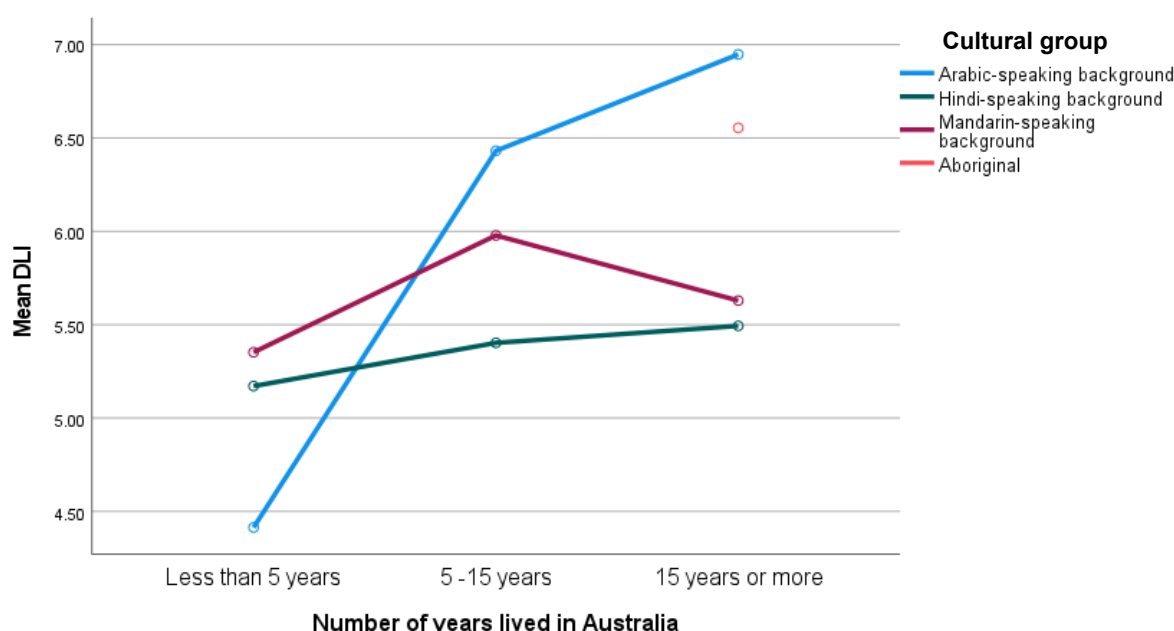


Figure A3.1: DLI Scores for each cultural group by Years in Australia

Variables related to end-of-life

The demographic variables did not account for much of the variance in DLI score. Even with all the variables in the model they accounted for less than 20% of the variance (Adjusted R Square = .191). However, the survey also collected data on a number of end-of-life experiences that could help develop death literacy (see Leonard et al 2021 report for details).

Attitudes and actions at end-of-life scales: Table A3.4 shows the means for each of these scales (scaled 1-10), compares them to the 2019 National sample, and shows their relationship to DLI score. All were strongly related to DLI score except for Avoiding death and dying which had a weaker negative relationship.

Table A3.4 Mean scores for attitudes and actions scales for the WSLHD sample and National population

	N	Mean	Std.	95% Confidence interval		2019 National sample	Correlation with DLI
				Lower	Upper		
Discussions of death and dying scale [^]	153	5.55	2.28	5.18	5.91	4.03***	.474**
Provided emotional support to a carer scale	171	7.49	3.84	6.90	8.07	5.85***	.402**
Being present at the time of death scale	173	5.58	4.07	4.97	6.19	3.67***	.385**
Felt supported around a recent death scale	160	6.03	2.21	5.67	6.38	5.93	.344*
Caring at end-of-life scale	173	4.87	4.38	4.22	5.53	2.86***	.319**
Cultural experience of death and dying scale	179	2.80	2.52	2.42	3.17	2.00***	.319**
Provided practical support to a carer scale	172	5.47	3.77	4.90	6.03	2.26***	.285**
Planning for end-of-life scale	174	2.18	3.52	1.66	2.71	2.49	.250**
Avoiding death and dying scale	177	4.67	2.27	4.33	5.00	4.40	-.193*

- Notes:
1. [^]Note in this survey there were 5 questions about discussions of death and dying whereas there were only 2 questions in the National survey.
 2. ***($p < .0005$) Indicates where means for WSLHD were significantly higher than those for the National sample.
**($p < .01$) *($p < .05$)

Working or volunteering in end-of-life: Formal experiences with end-of-life work and volunteering have been found to be strong predictors of DLI score in the National and community surveys. In this sample:

- The 35 respondents (17.2%) who had worked in end-of-life had higher DLI scores [$F(1,164) = 11.6$; $p < 0.001$]
- The 14 respondents (6.9%) had medical training as a doctor or nurse had higher DLI scores [$F(1,164) = 8.3$; $p = 0.004$]
- The 37 respondents (18.1%) had volunteered at end-of-life had higher DLI scores DLI [$F(1,164) = 3.9$; $p = 0.049$] but not when cultural group was taken into account. Formal volunteering is a Western concept which is often not easily translated so this might account for the difference between these results and those of other surveys.
- 62 respondents (30.4%) had either worked, trained or volunteered in end-of-life.
- Only four respondents were currently the main carer for someone who might die within 12 months

Analysing the end-of-life variables together to predict DLI score

As with the demographic variables, the end-of-life variables that related to the DLI are not independent of each other, so it made sense to analyse them together to see if some variables are more dominant and account for the variance in the others. Cultural group and Years in Australia were included in the analysis to see if the end-of-life variables accounted for the differences in DLI score for the four Cultural groups and Years in Australia.

The results showed that when Years in Australia was in the analysis, Cultural group was not significant and did not contribute to the variance in DLI. Nor was there a significant interaction effect between Cultural group and Years in Australia. So Cultural group was not included in the model below. Overall, the end-of-life variables together with Years in Australia accounted for 46% of the variance in DLI score.

Table A3.5 Years in Australia and end-of-life variables as predictors of DLI

Predictor variable	df	F
Being present at the time of death scale	1	14.63***
Discussions of death and dying scale	1	13.63***
Years in Australia	2	11.47***
Worked, trained or volunteered at end-of-life	1	7.61**
Caring at end-of-life scale	1	4.70*
Felt supported around a recent death scale	1	3.31
Cultural experience of death and dying scale	1	2.18
Provided emotional support to a carer scale	1	1.81
Provided practical support to a carer scale	1	0.19
Planning for end-of-life scale	1	0.05
Avoiding death and dying scale	1	0.05
Total	133	

Notes: 1. a R Squared = .496 (Adjusted R Squared = .446)
 ***($p < .0005$) **($p < .01$) *($p < .05$)

As shown in Table A3.5, Being present at the time of death scale and the Discussions of death and dying scale were the strongest predictors followed by having Worked, trained or volunteered at end-of-life. Years in Australia was also significant so there were differences in DLI that could not be accounted for by their personal experiences of end-of-life. Caring at end-of-life was also significant but the variance of the other six end-of-life scales was absorbed by these five variables.

The power of the discussions of death and dying to develop death literacy is particularly important given that everyone can be part of such conversations whereas not everyone has the opportunity to be present at the time of a death, provide care for someone at end-of-life, or other end-of-life experiences which improve death literacy. We conclude that there are differences in death literacy amongst cultures, but these differences are not intrinsic to the culture, but rather they relate to familiarity with the Australian health system.

Appendix 4: Cultural advisors and knowledge holders

Prior to commencement of the research, field notes were taken during informal interviews with a total of 20 cultural advisors, 11 of which were people from an Aboriginal, Arabic, Hindi, or Mandarin cultural/linguistic background. Professions amongst them varied and are displayed in Table A4.1 below.

The cultural advisors were mostly nominated by the WSLHD Advisory team and Key Informants, and also sourced through online searches the researchers conducted seeking community representatives throughout the LHD, and from the participants themselves making contact to express their interest in the project.

Some cultural Advisors worked or volunteered for WSLHD while others worked for small community organisations, were self-employed, or were from not-for-profit organisations such as Partners in Culturally Appropriate Care (PICAC), Palliative Care NSW, and Western Sydney University.

Table A4.1 Roles and cultural backgrounds of the cultural advisors

Role	Identified background	Frequency
Pastoral care volunteer	Arabic	1
Pastoral care volunteers	Hindi	2
Chaplain	Mandarin	1
Community development workers	Aboriginal	2
Funeral director	Mandarin	1
Funeral director	Aboriginal	1
Leader Hindi cancer support organisation	Hindi	1
Multicultural training, education and support	Hindi	1
Multicultural training, education and support	Arabic	1
Multicultural training, education and support	Other	2
Volunteer coordinators for palliative/ pastoral care	Other	2
Health consumer representatives	Other	2
Hospital social worker	Other	1
Death doula	Other	1
Policy officer palliative care	Other	1



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